

**The Benefits of a Person-centered Social Program for Community-dwelling People with
Dementia and Caregivers: An Interpretative Phenomenological Analysis**

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Abstract

This qualitative study aimed to explore the experience and impact of a person-centered, social program on community-dwelling people with dementia and their caregivers. I conducted semi-structured interviews with five dyads, each with a person with dementia and that person's caregiver, 7-8 months after the program ended to assess persistence of the program's impact. Interviews were analyzed using interpretative phenomenological analysis involving in-depth analysis of a small number of cases. Three themes emerged among people with dementia: 1) Participation in activities supporting self-identity; 2) The value of newly established intergenerational relationships; and 3) Empowerment and the student partner's attitude. These findings suggest taking part in a person-centered, social program promoted participation in activities supporting the self-identity of people with dementia and establishment of satisfying relationships with student partners. The student partner's attitude influenced the level of empowerment for the person with dementia in relation to participation in meaningful activities and relationships.

Three themes also emerged among caregivers: 1) Benefits of the program for caregivers; 2) Initial expectations and the later perspectives of caregivers about the program; and 3) Conflicting values and perspectives between caregivers and spouses. Benefits identified by caregivers included feeling enjoyment and satisfaction of their spouses with dementia from participation in the program; having a fun time with a friend or alone separate from the spouse; and a chance to socialize with a younger person while assuming a role as an older friend or parent. Participation in the program provided a sustained benefit to one couple in particular even 7 months after the program ended, by encouraging the caregiver to resume arranging activities the couple once enjoyed but now had difficulty pursuing. Conflicting perspectives noted between people with dementia and the caregivers illustrate needs and desires expressed by both people with dementia and their caregivers need to be considered when structuring social partner activities. These findings address a gap in the literature by documenting how a person-centered, social program benefits both community-dwelling people with dementia and their family

caregivers, with implications for providing insightful opportunities for social engagement as part of occupational therapy and other health care practices.

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General Summary

Person-centered care is an individualized and holistic approach to care addressing the whole person and considering that person's unique history, interests, preferences, needs, strengths, and abilities (Brooker & Woolley, 2007; Institute of Medicine, 2001; McCance, McCormack, & Dewing, 2011). Person-centered care is regarded as the gold standard for healthcare (Institute of Medicine, 2001). Much attention has been given to the person-centered approach in long term care settings and in caring for people in the later stages of dementia (Cohen-Mansfield, Libin, & Marx, 2007; van der Ploeg et al., 2013). By contrast, there is a lack of evidence illustrating the impact of a person-centered approach in social activity programs for people with earlier stages of dementia still living in the community. Chapter 1 is a research report accepted by the *American Journal of Alzheimer's Disease and Other Dementias* that emerged from a comprehensive review of prior qualitative studies describing perspectives of people with dementia regarding meaningful activities (Appendix 2). Chapter 2 is a systematic review submitted to *Activities, Adaptation, and Aging* in March, 2015 emerging from another comprehensive review of the literature (Appendix 3) in which benefits of individualized leisure and social activity interventions for people with dementia were described, with a discussion of how these interventions were individually tailored, and recommendations for intervention improvements and further studies. These two chapters provided a foundation for developing the focus of this dissertation research. Chapters 3 and 4 are a pair of research articles emerging from my dissertation research project that are being submitted for peer-reviewed publication. These articles report how a person-centered social program was experienced by community-dwelling people with dementia and their family caregivers, and the benefits experienced by these individuals. Findings of this dissertation research demonstrate how and why a person-centered, social program enriches lives of community-dwelling people with dementia and their family caregivers.

Chapter 1: Perspectives of People with Dementia about Meaningful Activities: A Synthesis

Abstract

Qualitative studies were synthesized to describe perspectives of people with dementia regarding meaningful activities. Themes of connectedness were identified using a meta-ethnography approach. The theme of being connected with self encompasses engagement for continuity, health promotion, and personal time. The theme of being connected with others includes being with others not to feel alone, doing an activity with others, and meaningful relationships. The theme of being connected with the environment encompasses being connected to one's familiar environment, community, and nature. This synthesis suggests that connectedness is an important motivation for engagement in daily activities. Findings indicate that identifying the underlying motivation for an individual with dementia to engage in different activities is important for matching a person with activities that will be satisfying. This review may inform the development of interventions for engaging people with dementia in meaningful, daily activities and creating connectedness to self, others and the environment.

Keywords: connectedness, dementia, engagement, meaningful activities, qualitative, synthesis

Introduction

Engagement in personally valued, meaningful activities is an important determinant of successful aging and quality of life in older adults.¹⁻³ People with dementia, however, often lack opportunities for such engagement to the extent they need and want. The most common unmet needs of people with dementia reported by themselves and their caregivers involve daytime activities, social company, and psychological distress.⁴⁻⁶ This can be due to decreased cognitive abilities, psychological and behavioral symptoms, deliberate social withdrawal outside of the home, perceived stigma (or self-stigma) of persons with dementia, and beliefs and strategies of those caring for persons with dementia (e.g., focusing on activities that help maintain current functional abilities without considering the individual's preference and value, de-emphasizing values and preference in daily activities of persons with dementia).⁶⁻⁹ People with dementia use professional supports for daytime activities and social company, but available services for daytime activities and social company may not be meaningful or valued by individuals with dementia or be matched to individuals' varied interests and abilities.^{4-6,10} Understanding perceptions of people with dementia on meaningful activities, thus, will help better develop activity programs that can fulfill psychosocial needs and maintain or improve quality of life of persons with dementia.

This paper aims to synthesize qualitative studies describing how people with dementia perceived meaningful activities. Specifically the intent is to understand the types of activities that are meaningful to people with dementia and the underlying motivations of people with dementia for engaging in these activities.

Methods

Search Strategy

To address the specific aims of this review paper, a search was conducted to identify articles on meaningful activities and dementia. Meaningful activities were defined as self-chosen activities derived from an individual's interests, preferences, values, motivations, pleasure, or sense of the importance of participating in certain activities.¹¹ The SPIDER (Sample, Phenomenon of Interest, Design, Evaluation,

and Research type) search strategy was used because of its suitability for identifying qualitative studies.¹² Electronic databases (including PubMed, CINAHL, and PsychINFO) were used to identify peer-reviewed journal articles, in English, published between January 1, 1990 and December 31, 2013. Initially, 796 articles were identified using the search terms listed in Table 1.

Inclusion Criteria

Once the initial search was completed, articles were selected for inclusion in the synthesis if they were qualitative studies or mixed method studies involving people with dementia living in the community or in residential care homes and included the views of people with dementia on meaningful activities. Studies had to use qualitative methods in collecting and analyzing data, and use qualitative interviews as the main method for data collection. Relevant qualitative journal articles were identified without limit to specific type of qualitative study, type of dementia, or age of persons with dementia. Titles and abstracts were reviewed for inclusion criteria. Articles were excluded from this review, if all participants in a study were not people with dementia and if studies did not have findings regarding people with dementia, daily activities and/or why they wanted to engage in these activities.

Quality Appraisal

The Critical Appraisal Skills Programme (CASP)¹³ was used for quality appraisal of included qualitative studies. CASP is a checklist that includes 10 questions assessing a study's rigor, credibility, and relevance. Studies were not excluded based on study quality so as not to miss potentially valuable findings, but we did want to identify the relatively poorer quality studies.¹⁴ We found no study with fewer than 7 points out of the 10 points (0= worst, 10= best) possible on the CASP checklist (Supplementary material A).

Analysis

Articles were analyzed using Noblit and Hare's meta-ethnographic approach¹⁵. Meta-ethnography is a widely used method for synthesizing multiple qualitative studies with diverse study designs.^{16,17} Meta-ethnography uses the authors' interpretations and explanations of their original qualitative studies as the

raw data for the synthesis in addition to the reported quotations of participants. In other words, the revealed themes, perspectives, or concepts from each qualitative study are selected as data for synthesis.¹⁸ This prevents misinterpretation of data from its' original collector and preserves the meaning of the original text.¹⁹

Noblit and Hare's meta-ethnographic approach¹⁵ outlines a series of specific steps that were followed in the present synthesis. While reading articles repeatedly, a list of relevant key metaphors (concepts, themes, perspectives, and phrases) was generated to describe the findings of each study. The researcher then compared metaphors of individual studies to one another (called 'reciprocal translations') and created working themes that emerged from the key metaphors. The researcher reviewed the themes that emerged to create new overarching themes that meaningfully integrated and interpreted related concepts. A second researcher checked if themes and subthemes fit well with the original data.

Results

Description of Studies

Among the initially identified 796 articles, a total of 717 articles were excluded based on title and abstract. Further 45 articles were excluded after reading full-text articles. The most frequent reason for excluding studies (97.77%) was that the data did not include perspective of people with dementia about meaningful activities.²⁰ Other less frequent reasons for excluding studies were: participants included older adults without dementia²¹; the paper was a review paper²²; or data were not collected through interviews.²³

A total of 34 studies met the inclusion criteria previously described. Characteristics of each study are outlined in supplementary materials A (a shorter version) and B. It is likely that our findings are typical of people with dementia because they were derived from 34 studies involving participants with varied characteristics. For example, participants in the studies included those living in the community (25 studies) and those in residential care homes (13 studies), and had varied stages and types of dementia and marital status. The included studies also varied in national origin, coming from the UK (13), Canada (4),

USA (3), Australia (3), Sweden (3), Norway (2), Netherlands (2), New Zealand (1), Belgium (1), Israel (1), and Hong Kong (1), and race and ethnicity, involving groups who were Jewish, Black, South Asian, and British Asian. The themes and subthemes developed based on 34 studies' findings capture common but broad perspectives of people with dementia on meaningful activities.

Description of Themes

Analyses revealed that being connected is an important motivation for people with dementia to engage in activities. Three primary themes regarding connection were identified. Persons with dementia were connected or wanted to be connected to self (theme 1), to others (theme 2), and to the environment (theme 3) through engagement in the individual's meaningful activities. In order to fully describe these broad themes, each was further conceptualized in terms of subthemes that captured distinct approaches to connectedness. Each of these primary themes is further described by three subthemes. Some subthemes occurred less than the others because the former was more narrowly defined than the latter (e.g., subtheme 1a vs. subtheme 1c). Table 2 describes definitions of themes and subthemes with one quote that represents each subtheme as an example. More examples of quotes from original studies supporting each subtheme are included in supplementary material C.

Theme 1: Being connected to self.

Subtheme 1a: Engagement for continuity. Community-dwelling people with early and middle stages of dementia had a significant desire for continuing engagement in typical everyday activities that they had done before the dementia to maintain some level of continuity with their previous lifestyle, long-held beliefs, and values.²⁴⁻³⁴ For example, staying interesting was a value for one woman with dementia who kept watching television programs of interest to her, reading books, and meeting friends to maintain her value of being an interesting person.²⁸ Two of the male subjects had past lifestyles of hard work and valued achievement through hard work.³⁰ Having no activity that required hard work to achieve a goal caused these men to feel empty and uncomfortable. They therefore tried to continue engaging in daily activities, including work-related activities, to maintain their identities.

Activities supporting each individual's habits, routines, and roles were meaningful because people with dementia could engage in these daily activities as much as possible, feel a sense of normality, and maintain their preferred lifestyle.^{27-29,31,33,35} Remaining involved in work-related activities and household chores helped some people with dementia maintain a sense of role identity; one as a previous choral conductor, another as a helpful husband for his wife with a disability, and a third as a good father for his children.²⁹ Helping others was another important way of maintaining continuity of lifestyle to one person with dementia related to his previous occupational role as a teacher.²⁵

Continuing engagement in cultural and spiritual activities helped people with dementia maintain their culture and long-held faiths. Community-dwelling older adults with early stage dementia valued cultural activities related to traditions, local history, folk music, and their own life histories.³⁶ Some people with dementia continued participating in spiritual activities by engaging in personal practices at home (e.g., prayer, reading the Bible), attending church, playing roles and helping others in church, and by being informed of events within the wider spiritual communities.³⁷⁻⁴⁰ They were strongly motivated to engage in these spiritual activities because of their sense of identity and continuity in faith, and the fellowship with and support from other members in the spiritual community.

Subtheme 1b: Strategic participation in activities for one's own health benefits. Community-dwelling people with dementia found enjoyment, satisfaction, and distraction from other worries by engaging in leisure activities, such as gardening, going for walks, music activities, and communal activities.^{29,35,41} Listening to music and singing were identified as common past and current leisure activities, and these activities were not too demanding to do, so people with dementia could actively engage in these activities with pleasure and without thinking about dementia.^{32,39,42,43} Music-related activities were also enjoyed by people with dementia because of positive benefits to their mood and concentration by soothing and uplifting their spirits and expressing themselves non-verbally.^{44,45} Background music also promoted participation in routine activities by making activities more enjoyable.⁴⁵

Engaging in intellectual, physical, and leisure activities (e.g., reading, doing crossword puzzles, and going out for daily walks) was meaningful to community-dwelling people with dementia because they believed that these activities would improve memory and restore their abilities.^{28,32,35,41} Some women with dementia, for example, watched television believing this would help maintain an active mind.³³ Intellectual activities, however, were avoided or abandoned if the people with dementia regarded that activity as too demanding.^{27,35} Keeping an active mind, being physically active, and maintaining health and well-being were of great value to people with dementia, who strategically participated in such activities to produce a sense of improved well-being.^{26-28,41} Older people with early stage dementia engaged in leisure activities and organized programs to keep busy and occupied and thus to reduce loneliness and get some distractions from social isolation.^{33,46}

Being or feeling useful helps older adults with dementia feel valuable to others and provides a sense of self-worth.^{32,47} Some community-dwelling people with dementia maintained feeling valued and a sense of purpose by doing household chores for their busy children.^{33,47} Finding new ways of feeling useful was meaningful to community-dwelling people with early stage dementia. One new way was participating in Alzheimer's research, which provided them with an opportunity to reflect on their experiences and feel useful through the interview process.^{31,48} Residents with dementia in care homes also expressed frustration and a need for feeling useful.^{49,50} The search by residents for active engagement in useful activities helped them feel more satisfied with living in care homes.⁴⁹

Reviewing past experiences and one's life was pleasurable to residents with dementia living in care homes because engaging in this activity recovered their sense of identity by compensating for their current losses.⁴⁹ Talking about past activities, experiences, and interests associated with one's social and occupational roles were enjoyed and meaningful to people with dementia as an expression of their identity.^{27,44} Looking back over pleasurable memories was a way for an individual with early stage dementia to enjoy being alone and not to feel lonely.⁴⁶

Subtheme 1c: Engagement for personal time and rest. People with dementia considered having time alone⁴⁴ and rest⁵¹ meaningful to them. Walking outdoors by oneself was one activity that provided relaxation and a low level of social stress.^{29,52} Having quiet meals alone was a way of connecting with self by allowing time for being with one's own thoughts.⁵³ Being in a private space alone and engaging in activities in the private space provided people with dementia with feelings of freedom, peace, and enjoyment.^{27,34}

Theme 2: Being connected to others.

Subtheme 2a: Being with others not to be/feel alone. Having company was meaningful to people with dementia to avoid being or feeling alone. Attending day care centers with highly satisfying levels of human contact was enjoyable to community-dwelling people with dementia.²⁴ Having social contact also was significantly important to residents with dementia regardless of their stages of dementia.^{42,44} Residents with middle and late stages of dementia in care homes expressed fear of being alone and loneliness due to a socially isolated life at care homes.⁴⁹ Those living alone listened to the radio and watched television in order not to feel alone and to feel a sense of connection to others by having virtual company.⁵⁴

Subtheme 2b: Doing an activity with others. Doing things together with others in a day care center promoted a sense of belonging and motivation for engagement in activities.²⁹ Working together in the garden was a meaningful activity to a man with dementia and his family because of a sense of shared identity as the family who worked hard together with partnership to overcome any challenge.³⁰ Some community-dwelling people with dementia regarded 'doing things together with my partner' as an activity that positively affected their quality of life (p. 542).³⁹ Residents with dementia in care homes were motivated to participate in group activities (e.g., newspaper-reading, gymnastics) offered in care homes because of a sense of belonging by doing things together with others.⁵¹ The residents found more enjoyment in some group activities matched with their abilities and interests so that they could participate equally with others. Activities involving music, such as singing together and dancing, involved and

encouraged social interaction by being physically and emotionally close with others.⁴⁵ Engagement in cultural activities with others who shared local life experiences also facilitated their feelings of belonging by culture not by dementia itself.³⁶

Talking to or sharing with others was a meaningful activity for people with dementia, and the personality and attitude of the person they talked to made a difference as to whether they felt at ease and connected to others.²⁶ Talking and sharing with similar people, in terms of dementia or unrelated to dementia (e.g., attending a women's group), helped people with early stage dementia normalize difficulties, learn different ways of coping from others, and not to feel alone.³¹ Talking to and about family gave residents feelings of being connected to their families by reminding residents with dementia of past memories and proving their existence outside of care homes.^{44,50} Couples reminisced together about their shared history, especially positive memories, to maintain their shared sense of identity and couplehood and to offset their current difficult situations.⁵⁵ Looking at personally significant items (e.g., family photographs, cushions made by a family member) and talking about related stories helped people with dementia maintain feelings of connection with family as well as connection with themselves.²⁷ Listening to music also helped people with dementia recall past memories and thus encouraged meaningful conversations with others by talking about their past experiences.⁴⁵

Subtheme 2c: Meaningful relationships. Older people with dementia who lived in either the community or long term care desired maintenance of meaningful relationships, and a loss of key relationships was a source of loneliness.^{39,42,46} Some older residents with dementia felt hurt and sad when their family did not visit the homes and care for them as much as the people with dementia expected and as they had done for their families in earlier years.⁵⁰ Understanding and accepting that family members could not visit the home often helped residents with dementia maintain positive relationships with family members and a sense of acceptance by family even if the family visits were fewer than they wished.⁴⁹ Some people with dementia desired to maintain positive meaningful relationships by receiving support and love from their family, and by being respected for their remaining abilities, their autonomy, and their

continued usefulness.²⁶ Participating in weekly get-togethers at a local café was a meaningful family ritual for one man with dementia and his family.³⁰ He did not actively engage in conversations, but he valued maintaining relationships with families and felt a sense of belonging. Some couples maintained their relationships and couplehood by trying to be active and sociable together, for instance, going out for Sunday lunch and doing crosswords together.⁵⁵

Theme 3: Being connected to environment.

Subtheme 3a: Being connected to one's own home and familiar environment. People with dementia want to stay in their homes because of feelings of peace and comfort at home where their life histories and memories are embedded.^{41,54} Moving to a nursing home can be a significant threat to people who have a strong tie to home and value independent living. Engagement in safety maintenance activities by using a checking strategy, paying extra attention, and avoiding any activity that is beyond their current abilities were important for people with dementia living alone to stay at home and not move to a nursing home.⁵⁴ Being in familiar environments promoted a sense of coherence for people with dementia and these feelings supported participation in activities, including taking walks, shopping, and using public transportation in the familiar environment where they had grown up.²⁷ Being in the familiar environment with personal things like photographs, furniture, plants, decorations and other memorabilia, supports a continuation of self and provides the person with dementia with feelings of being at home.⁵⁶

Subtheme 3b: Being connected to community. Some older people living alone may feel confined at home as they lose the ability to drive and do not have close social contacts they can socialize with frequently.⁵⁴ Looking out through a window at home was a way they could feel connected to their communities. One woman with dementia living alone found enjoyment in being out in the community when she went out for groceries by seeing other people and feeling good in the fresh air. Being involved in the things around self and being interested in what is happening in the world were important for quality of life in both community-dwelling older people and nursing home residents with dementia.³⁹

Participating in activities that give an atmosphere of community (e.g., parties, barbecues and celebrations of national events) was valued.⁵⁶

Subtheme 3c: Being connected to nature. Being in nature and the enjoyment and positive feelings derived from it were strong motivations for daily walks in community-dwelling men with early stage dementia.⁵² Pleasure from being connected to nature strengthened their value of staying physically active by making a routine of daily walks. The men and their wives used adaptive strategies for the men to continue engaging in outdoor walks themselves in order to compensate for their reduced ability due to dementia and to feel secure while walking. Being outdoors and gardening were important to residents with middle stage dementia because of the stimulation and pleasure nature provides (p. 567).⁴² Outside activities such as walking were not allowed in some care homes because of safety issues, and residents with dementia expressed how much they enjoyed participating in these activities in the past.⁵⁰

Theme Interactions

In addition to identifying unique themes, meta-ethnography also requires that interactions among themes be considered. Our analysis indicates that motivation for activities in a number of subthemes also fulfilled the activity needs described under other subthemes (see Figure 1). For example, engagement for continuity facilitated maintaining meaningful relationships and being connected to the community. Families or friends helped people with dementia continue engaging in activities matched with lifestyles, life-long beliefs, values, and interests. For example, a wife left a note with instructions and schedules for her husband with dementia every morning to help him plan his day, engage in work-related activities, go out on errands, and go to church with his son.²⁹ These supports from his wife promoted not only continuing engagement but also a sense of connection to his wife and the community. Going to church also facilitated a sense of belonging to the spiritual community and meaningful relationships from church members as well as maintenance of spiritual identity and faiths.³⁸ Engagement for continuity was strengthened while doing an activity with others, being connected to familiar environments, and being connected to natural environments. Working together in the garden allowed a man with dementia and his

family to maintain a sense of shared identity³⁰, and reminiscing shared histories together promoted maintenance of their shared sense of identity and couplehood.⁵⁵ Being in familiar environments supported continuing engagement in daily activities and a continuation of self-identity.^{27,56} Enjoyment from being in nature facilitated continuing engagement of staying physically active by making daily walks a routine.⁵²

Discussion

The purpose of the present synthesis was to integrate the findings of qualitative studies on meaningful activities from the perspective of people with dementia. Our focus was on identifying the activities that are meaningful to people with dementia and the reasons that they want to engage in these activities. We found that being connected is a strong motivation for engaging in activities and engagement in meaningful activities helps the person with dementia to be connected. The findings indicate that being connected in personally meaningful ways promotes a sense of belonging along with physical, mental, and emotional health, self and social identity, independence, interdependence, and life satisfaction in people with dementia. Individual differences in ways of being connected depended on values, beliefs, interests, culture, living environment, and previous lifestyles and roles. The common meaning and motivation for engagement, however, was to be connected to self, others, and environment. In addition to these findings about the importance of connectedness, findings from the studies synthesized here also highlight the importance of understanding each individual's motivation for participating in a given activity. Different individuals may engage in the same activity, but for different reasons or to meet different needs. Watching TV, for example, was meaningful to maintain the value of being an interesting person²⁸, maintaining an active mind³³, or not feeling alone.⁵⁴ Conversely, individuals may engage in activities that are very different on the surface, but that are motivated by a desire to meet the same need. For example, sharing a meal and gardening activities may both meet the need of being connected with one's spouse. Thus, the critical aspects of activity are that it is personally meaningful to the individual with dementia, and that it meets their individual need. When there are mis-matches between the meaning of an activity for a person with dementia and a caregiver's perception about the meaning of that activity,

frustration and conflict may occur. For example, family caregivers and staff valued social activities organized by care homes more than contact with family, whereas individuals with dementia often most highly valued contact with family.⁴⁴ Family caregivers also had little awareness that reminiscence activity and music activity were important to their relatives with dementia⁴⁴, and reported difficulty in finding meaningful activities for their loved ones.⁵² Similar mis-matches may be present between people with dementia and paid caregivers. In one study, being useful and maintaining religious faith was reported by people with dementia as being important for their quality of life, but was not mentioned as important to their care recipients by professional caregivers.³⁹ These findings underscore the importance of identifying the nature and scope of meaningful activities from the perspective of people with dementia when providing person-centered care.

Understanding why the person with dementia wants to engage in a particular activity is important for caregivers and health professionals to be able to support the connectedness of people with dementia. As dementia progresses, the individual may not be able to engage in his or her valued, meaningful activity even by using compensation strategies or adaptive tools or equipment. In that case, an alternative activity could be substituted that is matched with the value or need embedded in the previous activity. Without understanding why the particular activity was important to the person with dementia, the proposed alternative activity may not be successful. One man with dementia, for instance, liked cycling because of being connected to nature. After moving to a long-term care setting, the staff knew he liked cycling and assumed that he enjoyed physical activity. They asked him to ride the indoor bicycle without knowing why he liked cycling, and he is unlikely to enjoy or want to engage in cycling when the activity is disconnected from nature. In this case, he may enjoy walking in the garden more than riding the indoor bicycle.

The cycling example just described illustrates why health professionals and caregivers should make an effort to understand the underlying meaning of engagement in activity and help the person with dementia express and engage in activities matched with their psychosocial needs, especially as dementia

progresses. An awareness of connectedness as an important motivation for engagement, and of the variety of ways of being connected, will facilitate development of better interventions and care for people with dementia. Further studies are needed to identify how best to tailor interventions to meet an individual's need and desire to be connected to self, others, and environment to assure psychosocial well-being and quality of life in people with dementia.

And finally, our findings are consistent with earlier work by Register and Herman, who theorized that six interrelated processes of being connected (metaphysically connected, spiritually connected, biologically connected, connected to others, environmentally connected, and connected to society) were critical to quality of life for the elderly (p. 344).⁵⁸ In an evaluation of this theory in a qualitative study of community-dwelling older adults, Register and Scharer reported four processes involved with being connected in older adults, including (a) having something to do, (b) having relationships, (c) having a stake in the future, and (d) having a sense of continuity (p. 471).⁵⁹ Together with the present study, these findings suggest that being connected to self, others, and environments is an important motivation for engagement in personally meaningful activities for both healthy older adults and adults with dementia. Especially, helping persons with dementia feel a sense of continuity through engagement in personally meaningful activities should be encouraged to caregivers who may increasingly de-emphasize values and preferences of persons with dementia in daily activities.⁹

The present study has several strengths including the use of a meta-ethnography approach in synthesizing qualitative studies and involvement of participants with varied characteristics. The present study included multiple qualitative studies with diverse study designs and participants with varied characteristics while preventing misinterpretation of data from its' original collector and preserving the meaning of the original text. A limitation of the present study is that only one researcher reviewed the literature and determined the eligibility of the searched studies for inclusion. Although over 700 studies were searched by the first author, the absence of another independent researcher in this process might have helped to identify additional relevant studies.

Conclusion

The aim of the synthesis of qualitative studies reported here was to identify the meanings of engagement in daily activities based on perspectives of people with dementia. Our analysis indicates that persons with dementia want to engage in personally meaningful activities to be connected with self, with others, and with the environment. These findings support the premise that being connected is an important motivation for engagement in daily activities, and underscore the importance of understanding this underlying motivation for designing person-centered activities to achieve connectedness and meet the psychosocial needs of persons with dementia. Caregivers should help persons with dementia continue engagement in personally meaningful activities, by better understanding the person's want and need for engagement in activities and identifying varied ways of being connected in a personally meaningful way. Future studies are needed to identify if interventions tailored to meet an individual's need for being connected to self, others, and environment affect psychosocial well-being and quality of life of people with dementia. These interventions may benefit people with dementia better than interventions that only emphasize increasing activity level and stimulation.

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Tables & Figures

Table 1

Search Terms Used in Databases

SPIDER Tool	Search Terms
S (Sample)	dement* OR Alzheimer*
P of I (Phenomenon of Interest)	‘meaningful activit*’ OR ‘daytime activit*’ OR ‘daily activit*’ OR engagement OR occupation* OR ‘quality of life’ OR activit* OR meaning* OR valu*
D (Design)	interview* OR ‘focus group*’ OR survey* OR questionnaire* OR ‘case stud*’
E (Evaluation)	view* OR experienc* OR opinion* OR perspective* OR belie* OR feel*
R (Research type)	qualitative OR ‘mixed method*’ OR ethnograph* OR phenomenology OR ‘grounded theor*’

Table 2

Definitions of Themes and Subthemes

Themes	Subthemes
Theme 1. Being connected to self	Subtheme 1a. Engagement for continuity ²⁴⁻⁴⁰
Preference for or engagement in activities to preserve their individual identity and their health	Engaging in long-held habits, routines, local traditions, and leisure or work-related activities to maintain previous life-style, long-held beliefs, faiths, values, interests, identity, and culture E.g., <i>'Although I am very forgetful now, I try to keep my usual routine, do exercise and read newspapers.'</i> (p.596) ²⁶
	Subtheme 1b. Strategic participation in activities for health benefits ^{26-29,31-33,35,39,41-50}
	Engaging in activities to have enjoyment, satisfaction, and distractions from worries, improve and maintain health and well-being, feel useful, and recover a sense of identity E.g., <i>'I read a magazine and it [the worry] disappears.'</i> (p. 73) ³⁵
	Subtheme 1c. Engagement for personal time and rest ^{27,29,34,44,51-53}
	Engaging in activities by oneself to relax with freedom and peace, and without interruptions from others E.g., <i>'Every day I look forward to going for walks...I don't have to do anything. I just walk. I go places by myself and I can enjoy it without having to talk about it...'</i> (p. 388) ²⁹
Theme 2. Being connected to others	Subtheme 2a. Being with others not to be/feel alone ^{24,42,44,49,54}
Preference for or	Having company or social contacts not to be/feel alone E.g., <i>'I hate having nobody here . . . I'd like to know where they all are.'</i> (p.566) ⁴²

engagement in activities to feel part of a larger social context

Subtheme 2b. Doing an activity with others^{26,27,29-31,36,39,44,45,50,51,53,55}

Participating in social activities to have social interactions and enjoyment, maintain shared identity and quality of life, promote relationships, and cope with difficulties

E.g., ‘... Then they [staff] collect us [me]! I think it is boring too, to lie down, and then you lie there... it is much better to be with the others and doing something... Talking to each other, at least...’ (p. 101)⁵¹

Subtheme 2c. Meaningful relationships^{26,30,39,42,46,49,50,55}

Establishing and maintaining meaningful relations with others (e.g., family, friends, neighbors, other residents, staff, and health professionals) to overcome loneliness, and feel a sense of acceptance and companionship

E.g., ‘My life is lonely...very lonely. My daughter doesn’t come to see me; none of my children come to see me. Sometimes I would like to talk to one or other of them.’ (p. 1447)⁴⁶

Theme 3. Being connected to environment

Subtheme 3a. Being connected to one’s own home and familiar environment^{27,41,54,56}

Preference for or engagement in

Being connected to one’s own home and personal items that give feelings of peace and comfort, help coping and maintaining identity, and facilitate participation in activities

activities to maintain the connection to the physical environment

E.g., ‘I don’t want to do anything wrong . . . I don’t want to make any big mistakes or anything . . . [friend’s name] made mistakes and then they would put her in the old people’s home.’ (p. 274)⁵⁴

Subtheme 3b. Being connected to community^{39,54,56}

Being connected to a community that helps overcome loneliness, gives a sense of belonging, and promotes quality of life

E.g., *'I've been involved in the church all my life. It's just a part of me.'* (p. 591)³⁷

Subtheme 3c. Being connected to nature^{42,50,52,57}

Being connected to nature in a way that gives enjoyment, pleasure, and stimulation and promotes participation in activities

E.g., *'Being homely means being able to look out the window and liking what you're looking at ... Just normal things around you like a garden and animals, that's what I see as homely.'* (p. 2616)⁵⁶

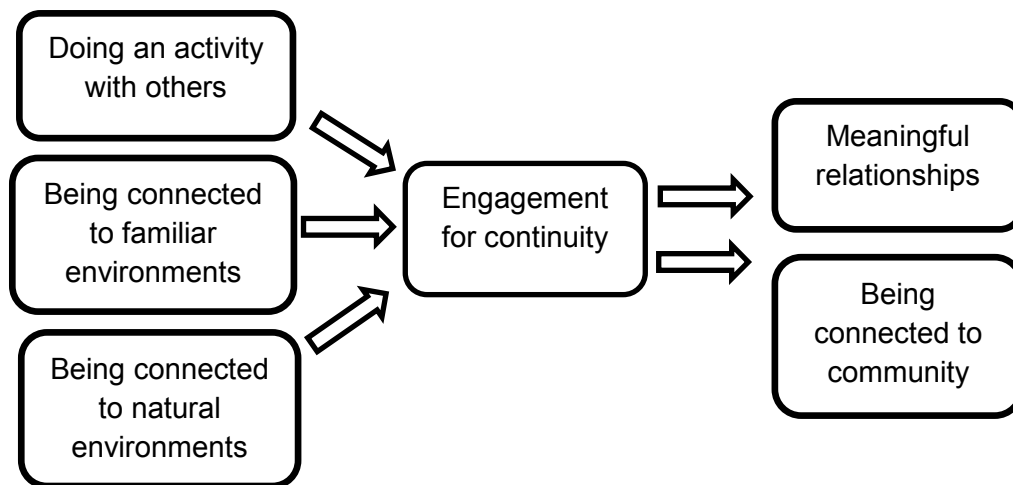


Figure 1. Theme Interactions. This figure illustrates interactions among themes.

Supplementary Material

A. Characteristics of Included Studies (a shorter version)

Authors	Stages of Dementia	Community-dwelling or/and Residential	Score on the CASP Checklist
Aggarwal et al. (2003) ²⁴	Varied (not specified)	Community-dwelling and residential	7
Menne et al. (2002) ²⁵	Early to middle	Community-dwelling	9
Mok et al. (2007) ²⁶	Early	Community-dwelling	10
Öhman & Nygård (2005) ²⁷	Early to middle	Community-dwelling	10
Phinney (1998) ²⁸	Early to middle	Community-dwelling	10
Phinney et al. (2007) ²⁹	Early to middle	Community-dwelling	10
Phinney et al. (2013) ³⁰	Early	Community-dwelling	10
Preston et al. (2007) ³¹	Early	Community-dwelling	9
Smith et al. (2005) ³²	Early to late	Community-dwelling	10
Van Dijkhuizen et al. (2006) ³³	Early	Community-dwelling	10
van Zadelhoff et al. (2011) ³⁴	Middle to Late	Residential	10
Nygård & Öhman (2002) ³⁵	Early	Community-dwelling	9
Brataas et al. (2010) ³⁶	Early	Community-dwelling	10
Beuscher & Grando (2009) ³⁷	Early	Community-dwelling	10
Dalby et al. (2012) ³⁸	Early to Middle	Community-dwelling	10
Dröes et al. (2006) ³⁹	Early to late	Community-dwelling and residential	7
Lawrence et al. (2011) ⁴⁰	Early to Late	Community-dwelling	10
Gilmour & Huntington (2005) ⁴¹	Not addressed	Community-dwelling	10
Cahill & Diaz-Ponce (2011) ⁴²	Early to Late	Residential	10
Cohen-Mansfield et al. (2000) ⁴³	Early to late	Residential	8
Harmer & Orrell (2008) ⁴⁴	Early to late	Residential	9
Sixsmith & Gibson (2007) ⁴⁵	Early to late	Community-dwelling and residential	7
Moyle et al. (2011a) ⁴⁶	Early	Community-dwelling and residential	10
Steeman et al. (2007) ⁴⁷	Early	Community-dwelling	10

Clare (2003) ⁴⁸	Early	Community-dwelling	10
Clare et al. (2008) ⁴⁹	Middle to late	Residential	10
Moyle et al. (2011b) ⁵⁰	Not addressed	Residential	10
Holthe et al. (2007) ⁵¹	Middle	Residential	10
Cedervall& Aberg (2010) ⁵²	Early	Community-dwelling	10
Keller et al. (2010) ⁵³	Early to middle	Community-dwelling	10
de Witt et al. (2009) ⁵⁴	Early to middle	Community-dwelling	10
Molyneaux et al. (2012) ⁵⁵	Varied (not specified)	Community-dwelling	10
Edvardsson et al. (2010) ⁵⁶	Not addressed	Residential	9
Gibson et al. (2007) ⁵⁷	Early to late	Community-dwelling and residential	8

B. Characteristics of Included Studies

Authors	Aims	Design/ data collection method/analysis method	Characteristics of the participants
Aggarwal et al. (2003) ²⁴	-To explore how people with dementia and their relatives experience dementia and to examine how they perceive and receive care provision, by directly eliciting their views, experiences, feelings and needs	-No mention about specific design -Semi-structured interviews and observations of daily activities -No mention about specific data analysis approach	- Twenty-seven people with dementia from residential (n=17) and day care settings (n=10), London, UK <ul style="list-style-type: none"> • Jewish origin • Various stages of dementia
Menne et al. (2002) ²⁵	-To explore the experience of dementia from the perspective of the person with early stages of dementia	-No mention about specific design -Individual interviews -Constant comparative analysis	-Six community-dwelling people with early stage dementia who attended an early stage dementia support group, Illinois, USA <ul style="list-style-type: none"> • 3 males, 3 females • A mean age of 72 years (range: 57-88 years) • Caucasian (n=5) and African American (n=1) • AD (n=4), mild cognitive impairment without dementia (n=1), frontotemporal dementia (n=1), • Mild dementia (n=4), moderate dementia (n=1), mild cognitive impairment without dementia (n=1) • Married (n=5), Widowed (n=1)
Mok et al. (2007) ²⁶	-To describe the lived experiences of Chinese people with early stage dementia and their ways of coping with the illness	-Phenomenology -Interviews & observations during the interview -Phenomenological data analysis	-Fifteen community-dwelling Chinese people with early stage dementia living in Hong Kong <ul style="list-style-type: none"> • 4 males, 11 females • Age range of 56 to 80 years: 56-59 years (n=2), 60-69 years (n=4), 70-79 years (n=4), 80 years (n=5) • Living at home with family members (n=15) • Married(n=6), widowed (n=8), and divorced (n=1) • Relationship with caregiver: daughter (n=9), daughter & daughter-in-law (n=1),

			daughter-in-law (n=1), son (n=1), husband (n=1), wife (n=1), sister (n=1)
Öhman & Nygård (2005) ²⁷	-To uncover and describe the meanings and motives for engagement in self-chosen daily life activities among community-dwelling people with AD	-Exploratory qualitative study -Interviews & observations of daily activities -Qualitative comparative and interpretative methods	-Six community-dwelling people living at home, Sweden <ul style="list-style-type: none"> • 3 males, 3 females • Age range of 65 to 80 years • Early to middle stages of AD • Married (n=3), widowed (n=2), and divorced (n=1)
Phinney (1998) ²⁸	-To understand the experience of living with dementia from the perspective of people with AD	-Qualitative descriptive study -Semi-structured Interviews of people with dementia and three spouses & observations of daily activities -Thematic analysis	-Five community-dwelling people, San Francisco, CA, USA <ul style="list-style-type: none"> • 1 male, 4 females • Age range of 75 to 89 years • Early to middle stages of AD • Living in their own homes (n=4) & living in a seniors' residence (n=1)
Phinney et al. (2007) ²⁹	-To explore how people with mild to moderate dementia perceive and understand meaningful activity in the context of their everyday lives	-Naturalistic design -In-depth conversational interviews & observations of daily activities -IPA	-Eight community-dwelling people living at home with at least one family member, Vancouver, Canada <ul style="list-style-type: none"> • 4 males, 4 females • Age range of 64 to 88 years • Early to middle stages of AD • European descent and born in the United States
Phinney et al. (2013) ³⁰	-To explore how men and their families experience changing patterns of everyday activity in the initial months after a diagnosis of dementia	-Phenomenology -Individual, dyadic, and group interviews & observations of engagement in routine activities -IPA	-Two men with early stage AD and members of their families (n=7), Canada <ul style="list-style-type: none"> • 80 year old male with AD and his wife; 74 year old male with AD, his common-law partner, and three daughters • Being diagnosed with AD within the previous 6 months • Living with their spouses
Preston et al. (2007) ³¹	-To develop a comprehensive understanding of the range of coping methods and strategies used by people with mild dementia	-Phenomenology -Semi-structured Interviews & observations during the interview -IPA	- Twelve community-dwelling people with early stage dementia, UK <ul style="list-style-type: none"> • 7 males, 5 females • A mean age of 71.1 years (range : 58 to 81 years) • White ethnic origin (11 British, 1 European had lived in England for 20 years) • AD (n=9), vascular dementia (n=3)

			<ul style="list-style-type: none"> • Living at home with their spouse (n=9) or alone (n=2), and living in supported accommodation (n=1)
Smith et al. (2005) ³²	- To develop a conceptual framework of health-related quality of life in dementia from the perspective of people with dementia and their caregivers and to examine differences in the reports of the health-related quality of life	-No mention about specific design -Individual interviews -Content analysis	- Nineteen people with dementia from local secondary care services in London, UK <ul style="list-style-type: none"> • 4 males, 15 females • Age range of 69 to 85 years • Stages of dementia: Early or early/middle (n=8), middle (n=7), middle/late or late (n=4) • Living at home (n=18) • Having a main family carer (n=16): spouse (n=14), other close relatives (n=2)
Van Dijkhuizen et al. (2006) ³³	-To capture a subjective account of women's experiences of early stage AD and how the subjects managed memory difficulties	-Phenomenology -Semi-structured Interviews -IPA	-Nine community-dwelling women with early stage AD, London and Essex, UK <ul style="list-style-type: none"> • Age range of 70 to 86 years (a mean of 77.89 years) • MMSE scores ranged from 20 to 29 (a mean of 23.11) • White (n=9) • Born in UK (n=7), Ireland (n=1), Southern Europe (n=1) • Widowed (n=6): living alone (n=2), living with daughters (n=2), living with her granddaughter (n=1), living with her son (n=1); living with husband (n=2); unmarried and living with her male partner (n=1)
van Zadelhoff et al. (2011) ³⁴	-To investigate experiences of residents, their family caregivers and nursing staff in group living homes for people with dementia and their perception of the care process	-Naturalistic design -Semi-structured Interviews and observations during daily life, care and activities in both homes -Inductive analysis	-Five residents with dementia of two group living units, in an urban area in the southern Netherlands <ul style="list-style-type: none"> • Age range of 68 to 93 years • Middle to late stages of dementia (MMSE scores ranged from 0 to 14, with a mean of 10)
Nygård& Öhman (2002) ³⁵	-To uncover and describe how people with dementia respond to and manage difficulties and change they experience in	-Phenomenology -Interviews & observations of daily activities -Phenomenological approach	-Seven people with early stage AD living in their own homes, Stockholm, Sweden <ul style="list-style-type: none"> • 4 males, 3 females • A mean age of 71 years (range: 62 to 78 years)

	everyday activities		<ul style="list-style-type: none"> Married (n=4), divorced (n=1), and widowed (n=2)
Brataas et al. (2010) ³⁶	- To explore whether and how person-centered and collaborative client day care programs gave meaning to the everyday lives of persons with early stage dementia	-Narrative qualitative design -Narrative interviews -Narrative content analysis	-Nine community-dwelling Norwegian people who participated in person-centered and collaborative day care program activities, once a week for seven weeks, Central Norway <ul style="list-style-type: none"> 2 males , 7 females A mean age of 82 years (range 77-88) Early stage dementia No mention about specific types of dementia but exclusion of frontal lobe dementia
Beuscher & Grando (2009) ³⁷	-To explore how people with early stage AD use their spirituality to cope with their disease, what spiritual practices support this process, and how AD has affected their spirituality or spiritual practices	-Ethnography -Semi-structured Interviews, observations of home environments, and observations during interviews -Content analysis & Constant comparison	-Fifteen community-dwelling people with early stage AD, Arkansas, USA <ul style="list-style-type: none"> 7 males , 8 females A mean age of 78.67 years (range 67-91) Caucasian (n=9), Black (n=6) Living alone (n=5), living with spouse (n=8), living with adult children (n=2) Christian religious affiliation (n=15)
Dalby et al. (2012) ³⁸	-To build an understanding of how people's experience of spirituality, religion, or faith is influenced by dementia, and to understand how the spiritual aspects of their lives affect the experience of dementia	-Phenomenology -Semi-structured interviews -IPA	-Six people with early to middle stages of dementia living in England, UK <ul style="list-style-type: none"> 5 females, 1 male Age range: 70-74 years (n=2), 75-79 years (n=3), 90-94 years (n=1) Ethnicity: White British (n=5), British Asian/Indian (n=1) AD (n=3), vascular dementia or a mixed diagnosis (n=3) Main spiritual/religious belief: Christianity (n=4), belief systems linked to eastern philosophies (n=2): follows teachings of an Indian Guru; spiritual (esoteric) healing Living alone at home (n=3), living with a husband at home (n=1), living semi-independently in warden-assisted accommodation (n=1), living in a care home because of physical needs (n=1) Professional backgrounds (n=6)

			<ul style="list-style-type: none"> Length of time since diagnosis ranged from 3 months to 2 years
Dröes et al. (2006) ³⁹	-To explore what people with dementia, living in the community and in nursing homes, and their caregivers consider important for the quality of life in dementia	- Exploratory qualitative study -Interviews, focus groups, literature study -Constant comparison derived from the grounded theory	-A total of 106 community-dwelling people with dementia, the Netherlands <ul style="list-style-type: none"> Mostly in the age range between 70 and 80 Early to late stages of dementia Recruited from 10 meeting centers in the Netherlands -A total of 37 nursing home residents with dementia, the Netherlands <ul style="list-style-type: none"> 11 males, 26 females Age range of 69-98 years Early to late stages of dementia Recruited from four wards in three nursing homes in Netherlands
Lawrence et al. (2011) ⁴⁰	-To examine attitudes, experiences, and beliefs of people with dementia within the 3 largest ethnic groups in the United Kingdom	-Grounded theory -Individual interviews -Constant comparative analysis derived from the grounded theory	-Thirty community-dwelling people with dementia living in London, UK - <i>Black Caribbean (n=11)</i> <ul style="list-style-type: none"> 3 males and 8 females Place of birth: Jamaica (n=10), Trinidad (n=1) Age range of 67-87 years (mean=76 years) Stages: Early (n=6), middle (n=3), late (n=2) Single (n=1), married (n=3), divorced (n=2), widowed (n=5) Living alone (n=4), with spouse (n=1), with family (n=4), in sheltered accommodation (n=2) - <i>South Asian (n=9)</i> <ul style="list-style-type: none"> 5 males and 4 females Place of birth: India (n=8), Kenya (n=1) Age range of 65-87 years (mean=77 years) Stages: Early (n=4), middle (n=2), late (n=3) Married (n=7), widowed (n=2) Living with spouse (n=4), with family (n=4), in sheltered accommodation (n=1) - <i>White British (n=10)</i> <ul style="list-style-type: none"> 5 males and 5 females Place of birth: England (n=10)

			<ul style="list-style-type: none"> • Age range of 72-96 years (mean=82 years) • Stages: Early (n=3), middle (n=4), late (n=3) • Married (n=7), widowed (n=3) • Living alone (n=1), with spouse (n=7), with family (n=1), in sheltered accommodation (n=1)
Gilmour & Huntington (2005) ⁴¹	-To explore explicitly the everyday experience of people with dementia	-No mention about specific design -Semi-structured interviews -Thematic analysis	-Nine community-dwelling people with dementia, New Zealand <ul style="list-style-type: none"> • 5 males, 4 females • Age range of 56 to 79 years • AD, multi-infarct or frontal lobe dementia • The time from diagnosis ranged from 1 to 8 years • Living with partners (n=8), living alone (n=1) • No mention about stages of dementia • All used Alzheimer's Society services
Cahill & Diaz-Ponce (2011) ⁴²	-To elicit people's own subjective views and individual accounts about their quality of life in general and in relation to their lives in nursing homes	- Descriptive/exploratory qualitative design -Semi-structured interviews -Thematic analysis	-Sixty-one people with dementia living in three nursing homes, Dublin, Ireland, UK <ul style="list-style-type: none"> • 13 males, 48 females • A mean age of 85.3 years (range 62-100) • Stages: Early (n=13), middle (n=20), late (n=28) • Married (n=6), single(n=16), separated (n=2), and widowed (n=37)
Cohen-Mansfield et al. (2000) ⁴³	-To explore past roles, the degree to which those roles are maintained in the present, and strategies for bolstering the sense of self-identity from the perspectives of residents with dementia, family members, and nursing staff members	-No mention about specific design -Structured interviews -No mention about specific data analysis approach	-Thirty-eight residents of two nursing homes in Israel <ul style="list-style-type: none"> • 9 males, 29 females • A mean age of 79.4 years (range 56-89 years) • AD (48%), vascular dementia (17%), dementia with Parkinson's (7%), unknown (10%), other (17%) • Early to late stages of dementia (a mean score of MMSE: 8.7; range: 0-22) • Place of birth: Eastern Europe (64%), Central/Western Europe (4%), Israel (7%), Asia/Africa

			<p>(7%)</p> <ul style="list-style-type: none"> Widowed (71%), married (21%), divorced (8%)
Harmer & Orrell (2008) ⁴⁴	-To explore the concept of meaningful activity for people with dementia living in care homes, from the perspectives of staff, family caregivers and residents themselves	-Focus group design -Focus groups -Thematic content analysis	-Seventeen people with dementia living in care homes, London, UK <ul style="list-style-type: none"> 5 males, 12 females A mean age of 85.6 years (range 72-99 years) Early to late stages of dementia Married (n=3), single(n=4), widowed (n=10) White British (n=14), Irish (n=2), black Caribbean (n=1)
Sixsmith & Gibson (2007) ⁴⁵	-To explore: (a) the meaning and importance of music in everyday life; (b) the benefits derived from participation in music-related activities; (c) and the problems of engaging with music	-No mention about specific design -Interviews & observations during the interview -No mention about specific data analysis method	-Twenty-six people living in England, UK <ul style="list-style-type: none"> 8 males, 18 females Age range of 62 to 96 years Early to late stages Living at home (n=18) and living in residential care (n=8) Three regions of England (Merseyside=8, Northamptonshire=8, South Yorkshire=10)
Moyle et al. (2011a) ⁴⁶	-To explore and describe loneliness from the perspective of people with early stage dementia and their family caregivers	- Descriptive/exploratory qualitative design -Semi-structured Interviews -Thematic analysis	-Seventy people with early stage dementia living in community or long term care, South East Queensland, Australia <ul style="list-style-type: none"> Age range of 66 to 97 years Female (n=70.2%) Living in community (n=10), LTC (n=60)
Steeman et al. (2007) ⁴⁷	-To explore what it means for elderly people to live with early stage dementia	-Exploratory qualitative study -Interviews with the person with dementia and family member(s) separately and together & observation during the interview - Methods of grounded theory (constant comparison) & narrative analysis	-Twenty community-dwelling elderly people with early stage dementia living in Flanders, Belgium <ul style="list-style-type: none"> 4 males, 16 females Age range of 69 to 91 years Types of dementia: AD (n=12), (sub) cortical atrophy (n=6), vascular dementia (n=1), mixed dementia (n=1) Living at home Relationship with family members: daughter(s) (n=10), spouse (n=5), son(n=2), daughters and sons (n=1), niece (n=1), not available (n=1)

Clare (2003) ⁴⁸	-To explore subjective experience of life and awareness of changes from the perspective of people with AD	-Phenomenology -Individual interviews of people with AD and their spouses -IPA	-Twelve community-dwelling people with early stage AD, England, UK <ul style="list-style-type: none"> • 9 males , 3 females • A mean age of 71 years (range 57-83) • White European origin • Living at home with his or her spouse • Varying levels of awareness, ranging from ‘very aware’ to ‘unaware’
Clare et al. (2008) ⁴⁹	-To explore the subjective experience of life with dementia in residential care from the perspective of people with dementia, and to understand the psychological impact of being in this situation	-Exploratory qualitative study -Unstructured conversations and field notes made by researchers and contextual information of residential homes - IPA	-Eighty individuals with dementia living in residential care homes, England and Wales, UK <ul style="list-style-type: none"> • 12 males , 69 females • A mean age of 83.4 years (range 59-96) • Middle to late stages of dementia • Living in 10 residential care homes; 3 care homes specializing in the care of people with dementia (n=45), 4 care homes for people with designated sections devoted to the care of people with dementia (n=21), and 3 homes catering to a mixed resident group (n=15)
Moyle et al. (2011b) ⁵⁰	-To understand the factors that influence quality of life for people living with dementia in long term care, including an understanding of how they perceived they were valued.	-Exploratory qualitative design -Semi-structured interviews -Concept-mapping	-Thirty-two people with dementia living in four care homes, New South Wales and Queensland, Australia <ul style="list-style-type: none"> • 10 males, 22 females • Age: 70-79 years (n=3), 80-89 years (n=25), >90 years (n=4) • Married (n=12), single/divorced (n=2), and widowed (n=18) • Length of stay (months): ≤6 (n=10), 7-12 (n=11), >12 (n=11)
Holthe et al. (2007) ⁵¹	-To gain knowledge of the occupational patterns of people with dementia in a care home and how the residents perceived the group activities in which they	-Ethnography -Interviews and participant observations of daily activities -Ethnographic methodology	-Eight people living in a residential care home, specially designed facility for persons with dementia, Norway <ul style="list-style-type: none"> • 1 male, 7 females • Age range of 82 to 92 years (the mean age of 86.7 years) • Middle stages of dementia • Mobility difficulties (n=4),

	participated		difficulties in expressing themselves verbally (n=5), complained about feeling tired (n=5)
Cedervall& Aberg (2010) ⁵²	-To improve the understanding of experiences of people with early stage AD and their significant others, regarding the afflicted persons' ability to be physically active, and to gain insight into their perception of the importance of physical activity in AD	-Qualitative case study design -Interviews and observations of daily activities -Thematic analysis	-Two community-dwelling married men with early stage AD, Sweden <ul style="list-style-type: none"> • Person 1: 74 years; he had been physically active before the onset of AD • Person 2: 63 years; he had not been physically active regularly but occasionally had exercised before the onset of AD (e.g., jogging, dancing, cycling)
Keller et al. (2010) ⁵³	- To examine the experience and meaning of food and mealtimes for persons with dementia and their primary care partners	-Grounded theory -Individual and dyad interviews -Constant comparative analysis derived from the grounded theory	-Twenty seven community-dwelling people living with dementia, Canada <ul style="list-style-type: none"> • People with dementia: 11 males, 16 females; age range of 56 to 88 years • Partners: 12 males, 16 females; age range of 30 to 88 years • Early to middle stages of dementia • Living together (n=24) • Spousal relationships (n=19), adult-child relationships (n=8) including three daughters, three sons, one niece, and one daughter in-law.
de Witt et al. (2009) ⁵⁴	-To understand the meaning and experience of living alone for people who were diagnosed with dementia	-Phenomenology -Interviews & observations during and after interviews -Thematic analysis	-Eight community-dwelling women with early to middle stages of dementia who lived alone in Ontario, Canada <ul style="list-style-type: none"> • A mean age of 78.1 years (range 58-87 years) • European descent (n=8) • Widowed (n=5), divorced (n=2), separated (n=1) • Level of education: elementary schooling (n=4), secondary schooling (n=3), an undergraduate degree (n=1) • Informal caregivers: adult child/children (n=7), sibling (n=1) • Proximity of family caregivers:

			<p>same neighborhood (n=2), town (n=3), province (n=3)</p> <ul style="list-style-type: none"> • Formal service use: (a) assistance with medications (n = 6), (b) adult day programs (n = 4), (c) bathing (n = 5), (d) transport (n = 4), (e) meal preparation (n = 4), (f) meal delivery (n = 3) and (g) grocery delivery (n = 1).
Molyneux et al. (2012) ⁵⁵	-To explore 1) what impact, if any, dementia have on a couple's relationship or a couple's relationship have on dementia and 2) how couples co-create their account of relationship in dementia	-Grounded theory -Interviews of couples -Constructivist grounded theory methodology	-Five cohabiting couples, where one partner from each couple had been diagnosed with AD and lived in North West England, UK <ul style="list-style-type: none"> • People with dementia: 3 males, 2 females; 72-83 years (mean age 76.8) • Cohabiting partners: 2 males, 3 females; 73-84 years (mean age 78) • The mean number of years married or living together: 45.2 years (range 11–55 years) • Varied cognitive ability and level of participation • Time diagnosed: range from 12 months to 4 years
Edvardsson et al. (2010) ⁵⁶	-To describe the content of person-centered care as described by people with dementia, family members and staff in residential aged care	-Exploratory qualitative design -Individual interviews & focus groups -Content analysis	-Eleven people with early onset dementia (<65 years at onset) who had experience of respite care, living in Victoria, Australia <ul style="list-style-type: none"> • No specific information on the participants' characteristics (e.g., age, gender, type/stage of dementia)
Gibson et al. (2007) ⁵⁷	-To determine if and how nature is important to people with dementia, both from their perspective and that of caregivers	-No mention about specific design -Semi-structured interviews, observations of daily activities, & focus groups -Thematic analysis	Twenty-six people living in England, UK (Age: 62-96 years) <ul style="list-style-type: none"> -People living at home (n=16) <ul style="list-style-type: none"> • 7 males, 9 females • Early to late stages • Living alone (n=4), living with an informal caregiver (e.g., spouse) (n=12) -People living in residential care homes (n=10) <ul style="list-style-type: none"> • 1 male, 9 females • Mild to severe stages

*AD: Alzheimer's disease, IPA: Interpretive phenomenological analysis

C. Themes, Subthemes, and Quotes

Themes	Subthemes	Examples of Quotes from Included Studies
Being connected to self	Engagement for continuity <i>'I keep doing what I used to do.'</i>	<p><i>'You gotta do something, especially if you've spent your whole life working with your hands, you couldn't just walk away and leave it.'</i> (p. 359, Phinney et al., 2013)</p> <p><i>'I always do the washing here, I always did this at home as well, I know how to do it.'</i> (p. 2494, van Zadelhoff et al., 2011)</p> <p><i>'We help around the church, anything they need. ... I keep doing and I don't want to stop.'</i> (p. 591, Beuscher & Grando, 2009)</p> <p><i>'I get bored here . . .they, they go to sleep, I feel like throwing something at them, because they, nobody talking or got nobody goes walking. . . . It's, you've gotta do something, haven't you, to help you go through, because it wasn't the things I've been used to. . . .They just sit here, it drives me mad.'</i> (p.717, Clare et al., 2008)</p> <p><i>'Although I am very forgetful now, I try to keep my usual routine, do exercise and read newspapers.'</i> (p. 596, Mok, et al., 2007)</p> <p><i>'Well I try to keep up a normal facade, like when I went to work, you know, I sort of more or less go through the same as I did then, as if I'm getting ready to go out, things like that pass the time.'</i> (p. 893, Smith et al., 2005)</p> <p><i>'I certainly would like to help people who can be helped and that's why I did most of my time as a teacher . . . and I saw that as a way, taking that those kinds of feelings and skills and trying to turn this thing, and I've been working on that 'what can I do?. . . '</i> (p.375, Menne et al., 2002)</p>
	Strategic participation in activities for one's own health benefits <i>'I deliberately engage in activities for myself.'</i>	<p><i>'I don't mind being alone, as I said I am never bored with my own company. I have so many memories to go back on that I can call them up and think of all the happy days I spent on the bowling green and the funny things that used to happen.'</i> (p. 1450, Moyle et al., 2011a)</p> <p><i>'I wouldn't say it was as good as home, like...er...you haven't got that same feeling or love or anything is... a ...at a place like this. You're just ... one of a number, group, who are pretty well in a similar position...but you do your best and. . . give as much help. I've been sorting books out all morning.'</i> (p. 716, Clare et al., 2008)</p> <p><i>'I spend most of my time reading the newspapers; knowing what the changes in Hong Kong are. Gradually, I will remember. For important news or information, I will try to remember it or even cut it out.'</i> (p. 596, Mok et al., 2007)</p> <p><i>'I like the [television] programmes where they ask questions and like that, to see if I can answer 'em . . . Quizzes and that, yes. I do like them</i></p>

		<p><i>'cause I can see if I can remember to answer them. I mean I miss a few of 'em, but I can, I remember quite a few of 'em.'</i> (p. 87, Van Dijkhuizen et al., 2006)</p> <p><i>'It's the only thing I've found, really, that, well, I'm sure there are other things, but it's supposed to restore your abilities. We do all these sorts of exercises that stretch various parts of the body . . . Yes, well, you know, it's something to do. Anyway, it's sort of given me the sense that I'm actually trying to fix it.'</i> (p. 121, Gilmour & Huntington, 2005)</p> <p><i>'I think it's good to do this [to bake], so I don't lose it.'</i> (p. 94, Öhman & Nygård, 2005).</p> <p><i>'Yes, that's why I keep on doing crosswords, because I want to keep it practiced.'</i> (p. 893, Smith et al., 2005)</p> <p><i>'I read a magazine and it [the worry] disappears.'</i> (p. 73, Nygård&Öhman, 2002)</p>
	<p>Engagement for personal time and rest</p> <p><i>'I sometimes want to be alone.'</i></p>	<p><i>'Not sleep, I don't need that – but rest! I can sense it quite clearly.... And I need to sit down or lie down to rest Of course – everything is getting worn out'</i> (p. 102, Holthe et al., 2007)</p> <p><i>'Every day I look forward to going for walks...I don't have to do anything. I just walk. I go places by myself and I can enjoy it without having to talk about it. So I just want to keep being able to walk, and do things, and uh, that's all, really.'</i> (p. 388, Phinney et al., 2007)</p>
Being connected to others	<p>Being with others not to be/feel alone</p> <p><i>'I don't want to be left alone.'</i></p>	<p><i>'I hate having nobody here . . . I'd like to know where they all are.'</i> (p.566, Cahill & Diaz-Ponce, 2011)</p> <p><i>'When you live alone you're not . . . corresponding with people . . . You're . . . not talking to them . . . It's a quiet life . . . I listen to the TV. Things like that. But it would be a pretty dead house if there wasn't a TV and something going on . . . it's music and talk you know. There's somebody here . . . The TV is a lot of company.'</i> (p. 278, De Witt et al., 2009)</p> <p><i>'I'm really frightened, you know . . . of being alone, I've no one here at all.'</i> (p. 716, Clare et al., 2008)</p>
	<p>Doing an activity with others</p> <p><i>'We do things together.'</i></p>	<p><i>' . . . usually there's the set-ups and the clean-ups, then there's the dishes, the whole thing . . . we had a large group in the kitchen doing dishes. And it was so... so much fun.'</i> (p.199, Kelelr et al., 2010)</p> <p><i>'I feel I can do what I want... I can lock my door and lie down, and nobody can ask me to get up and do something, unless I lie there for hours... Then they [staff] collect us [me]! I think it is boring too, to lie down, and then you lie there... it is much better to be with the others and doing something... Talking to each other, at least...'</i> (p. 101, Holthe et al., 2007)</p> <p><i>'I would like to talk to others, with someone who allows me to relax</i></p>

		<i>rather than giving me more pressure. I feel better after airing my feelings. I would like to share my difficulties with people who are calm, friendly, eager to help, who give me a sense of security.</i> (p. 596, Mok et al., 2007)
	Meaningful relationships <i>'I want to establish /maintain relationships.'</i>	<p><i>'We meet every Sunday morning at the coffee shop... Whoever is in town, or whoever wants it. We've been doing that for a couple years now. And the grandchildren come by and, you know, sit down and talk for, well, about an hour or so . . . I think we're quite close.'</i> (p. 360, Phinney et al, 2013)</p> <p><i>'I miss my family.'</i> (p. 566, Cahill & Diaz-Ponce, 2011)</p> <p><i>'My life is lonely...very lonely. My daughter doesn't come to see me; none of my children come to see me. Sometimes I would like to talk to one or other of them.'</i> (p. 1447, Moyle et al., 2011a)</p> <p><i>'But er...it's the people, you get to know them. I didn't at first. I'm not very good at, you know, getting to know people. I'd rather do without knowing them, you know, you know what I mean. But they have been friendly, it's been nice. And I think I've got in, at last. I hope I have, anyway.'</i> (p. 716, Clare et al., 2008)</p> <p><i>'I've got a pal; she helps me out.'</i> (p. 716, Clare et al., 2008)</p> <p><i>'The most important thing I like is for my family to support me, love me, and not force me to do things I do not want to do.'</i> (p. 595, Mok et al., 2007)</p> <p><i>'When my family member said, 'What is wrong, you cannot even do it, it is so simple'. I was extremely upset.'</i> (p. 595, Mok et al., 2007)</p> <p><i>'Friendship, real friendship or love is important.'</i> (p. 542, Dröes et al., 2006)</p> <p><i>'Well, from my perspective, I would want to be not just a number or a name on a piece of paper. I am a person. And, as such, you're dealing with me as a one-to-one person. I'd want to be dealt with by the health professionals that way.'</i> (p. 122, Gilmour & Huntington, 2005)</p>
Being connected to the environment	Being connected to one's own home and familiar environment <i>'I want to stay in my own home.'</i>	<p><i>'I don't want to do anything wrong . . . I don't want to make any big mistakes or anything . . . [friend's name] made mistakes and then they would put her in the old people's home.'</i> (p. 274, De Witt et al., 2009)</p> <p><i>'Our family, a lot of people say to us, 'Oh, what are you doing in this great big house?' I've probably said this to ou before, but we love this house, and we can cope with it, as long as [husband's name] can still mow the lawn.'</i> (p. 121, Gilmour & Huntington, 2005)</p>
	Being connected to	<i>'I've been involved in the church all my life. It's just a part of me.'</i> (p. 591, Beuscher & Grando, 2009)

	<p>community</p> <p><i>'I want to be involved or interested in what's happening in my community.'</i></p>	<p><i>'I love looking out, seeing everything. [Gesturing to her window] ... I ...watch the people... if I lived some place where I couldn't see all out through here I think that would bother me.'</i> (p. 278, De Witt et al., 2009)</p> <p><i>'Now tell me why I'd want to move out of a place like this, now it's quiet, you see all this scenery, you know everything that's going on, you see the kids playing all the time out there.'</i> (p. 278, De Witt et al., 2009)</p>
	<p>Being connected to natural environments</p> <p><i>'I enjoy being in the nature.'</i></p>	<p><i>'It must be hereditary in some way. It's sort of automatic. On a beautiful winter day you take the opportunity. You really want to get out in the open air. That is the motive... You can say that physical activity is a necessary ingredient in life.'</i> (p. 230, Cedervall& Aberg, 2010)</p> <p><i>'Being homely means being able to look out the window and liking what you're looking at ... Just normal things around you like a garden and animals, that's what I see as homely.'</i> (p. 2616, Edvardsson et al., 2010)</p>

Chapter 2: The Benefits of Individualized Leisure and Social Activity Interventions for People with Dementia: A Systematic Review

Abstract

This systematic review describes the benefits of individualized leisure and social activity interventions for people with dementia (aim 1), how these interventions were individually tailored (aim 2), and what recommendations or suggestions can be made for these interventions and further studies (aim 3). A total of 32 included studies were organized into four categories based on how the intervention was individually tailored. These categories include: 1) performance factors; 2) self-identity; 3) music preference; and 4) life experiences and past memories. The authors discuss benefits by synthesizing the finding of the included studies in each category and suggestions.

KEYWORDS: *Alzheimer's disease, dementia, individualized medicine, leisure activities, social participation*

Introduction

Person-centered care (PCC) is an individualized and holistic (biological-psychological-social-spiritual) approach to care addressing the whole person as one who has a unique history, interests, preferences, needs, strengths, and abilities (Brooker, 2007; Edvardsson, Fetherstonhaugh, & Nay, 2010; Institute of Medicine, 2001a; McCance, McCormack, & Dewing, 2011). PCC is regarded as the gold standard for healthcare by the Institute of Medicine while a traditional clinician-centered and disease-centered approach to the delivery of healthcare is criticized to be impersonal and fragmented (Institute of Medicine, 2001a). In PCC, the person's decision making about their own care, is facilitated by respecting the person's lived experience and offering choices in care (Mead & Bower, 2000). A partnership among the persons, practitioners, and their families (if appropriate), also, is emphasized to make sure whether care decisions reflect the person's wants, needs, and preferences and the person is supported for participation in making decisions of their own care (Institute of Medicine, 2001b).

Providing individually meaningful activities is an important element of person-centered care to maintain the self, fulfill psychological needs, and promote psychosocial well-being of people with dementia (Dementia Initiative, 2013; Edvardsson et al., 2010; Edvardsson, Varrailhon, & Edvardsson, 2014; Kelly, 2010). Individuals with dementia, just like everyone else and just as before they were diagnosed with dementia, do consider activities that give opportunities for enjoyment, positive social interaction, and self-determination to be meaningful and important in enhancing quality of life (Dröes et al., 2006; Phinney, Chaudhury, & O'connor, 2007; Smith et al., 2005). Leisure and social activities are more likely to provide these opportunities than other activities such as self-care activities, especially in later life (Kelly, 2010; Phinney & Moody, 2011).

Leisure can be defined as a nonobligatory, enjoyable activity that is driven by intrinsic motivation and freedom of choices and that people engage in during their free time (Mannell & Kleiber, 1997). Participation in leisure activities may help people with dementia maintain positive mood and reduce loneliness, and may give opportunities for enjoyment and self-expression of people with dementia (Dröes

et al., 2006; Moyle, Kellett, Ballantyne, & Gracia, 2011a; Phinney et al., 2007; Van Dijkhuizen, Clare, & Pearce, 2006). People with dementia may not be able to explore and participate in leisure activities without supports because of decreasing abilities in actively identifying their interests, required skills, and opportunities for leisure participation. In this case, understanding and knowing the person, thus, is needed to promote continuing engagement in their lifelong or enjoyable leisure activities.

Participation in social activities can involve direct or indirect social contacts, require active or passive roles, and take place at home or in the community. Social activities, for instance, can be being with people (requiring passive roles), doing an activity together (requiring active roles), and looking at the family photos or talking about family to feel connected to their families without direct social contacts with families (Cahill & Diaz-Ponce, 2011; Harmer & Orrell, 2008). People with dementia desire for maintenance of meaningful relationships (e.g., partner, children, grandchildren), and a loss of key relationships can be a source of loneliness (Cahill & Diaz-Ponce, 2011; Dröes et al., 2006; Moyle et al., 2011a). People with dementia can be socially isolated and feel lonely if they live in a task-oriented long-term care facility (Ward, Vass, Aggarwal, Garfield, & Cybyk, 2008). Residents with dementia, in addition, may lose opportunities for making social contacts if daytime activities provided by residential care facilities are not matched to their interests and abilities (van der Ploeg, Bax, Boorsma, Nijpels, & van Hout, 2013a).

Systematic reviews of non-pharmacological, psychosocial treatments in dementia often are conducted by focusing on what treatments are effective in reducing behavioral and psychological symptoms of dementia such as agitation, aggression, and depression (e.g., Kverno, Black, Nolan, & Rabins, 2009; O'Connor, Ames, Gardner, & King, 2009a ; 2009b; Seitz et al., 2012). These systematic reviews are helpful in determining effective treatments for managing symptoms that may affect quality of life of both people with dementia and caregivers. Systemic reviews of specific treatments, such as reminiscence therapy (Vasionytė & Madison, 2013) and music therapy (Blake, 2013), suggest how a specific type of intervention benefits broad areas of outcomes. None of the published systematic reviews

focused on benefits of individualized leisure and social activities to people with dementia or on ways of individually tailoring leisure and social activities to each person with dementia. Persons with dementia may not be able to engage in personally meaningful leisure and social activities without carefully considered, individually tailored strategies by health professionals.

The aim of the present study was to review the literature on benefits of individualized leisure and social activity interventions for people with dementia. This systematic review specifically addresses three questions: (1) what are the benefits of individualized leisure and social activity interventions to people with dementia?; (2) how are these interventions individually tailored based on what factors?; and (3) what recommendations or suggestions can be made for individually tailoring leisure and social activity interventions to benefit persons with dementia and for further studies?

Methods

The PRISMA Statement Explanation and Elaboration document (Liberati et al., 2009) was used as a general guide for conducting and reporting a quality systematic review.

Search Strategy

We systematically searched three electronic databases (PubMed, CINAHL, and PsycINFO) for peer-reviewed journal articles published in English until January, 2014. Search terms were entered by combining keywords related to individualized care, leisure, social participation, and dementia. Relevant search terms were entered to capture all relevant articles because authors might use different terms. For example, keywords for individualized care included ‘individualized’, ‘personalized’, ‘person-centered’, ‘patient-centered care’, ‘client-centered therapy’, ‘tailor*’, ‘choice*’, ‘preference*’, ‘value*’, ‘desire*’, ‘self-chosen’, and ‘self-decided.’ Keywords related to leisure activities (e.g., ‘leisure’, ‘recreation’, ‘recreational therapy’, ‘hobbies’, ‘arts therapy’, ‘music’, ‘exercise’) and social activities (e.g., ‘social participation’, ‘interpersonal interaction’, ‘social interaction’, ‘reminiscence’) were selected based on the literature of non-pharmacological interventions in aging and dementia journals for people with dementia. The search terms entered in electronic databases are described in Appendix 1. We also manually

searched articles through reference list checking (searching reference lists of identified articles and systematic reviews) and related-articles features in databases.

Inclusion Criteria

Studies were included if: (1) all participants were reported to have any types and stages of dementia; (2) the study used an experimental design (e.g., randomized controlled trials, repeated measures with randomized crossover), a quasi-experimental design (e.g., non-equivocal pretest-posttest control group design, one-group pretest-posttest design), or single-subject designs (e.g., A-B-A design); (3) the intervention was individually tailored for promoting leisure or social participation; and (4) the study included outcome measures for people with dementia. Outcomes were not restricted to a specific outcome (e.g., agitation) to identify a range of benefits. Studies were excluded if the intervention focused on self-care activities or involved a group of people with dementia, not a single person with dementia. Focus, thus, was on one-on-one social interaction involving a single person with dementia to guarantee the activity was truly individualized for the single person with dementia. Individualized interventions for broad areas of daily activities were included if activities involved leisure or social activities.

Data Synthesis

Quality of the included studies was estimated using the Effective Public Health Practice Project Quality Assessment Tool (EPHPP; Thomas, Ciliska, Dobbins, & Micucci, 2004), because the tool can be used for studies with a variety of study designs. EPHPP includes the following components: 1) selection bias; (2) study design; (3) confounders; (4) blinding; (5) data collection method; and (6) withdrawals/dropouts. Each component is rated as strong, moderate, or weak. The global rating is rated as strong if there is no weak rating in all components, moderate if there is one weak rating, or weak if there are two or more weak ratings. EPHPP is supported to have content and construct validity, excellent inter-rater reliability for the global rating, and fair inter-rater reliability for the individual component (Armijo-Olivo, Stiles, Hagen, Biondo, & Cummings, 2012; Thomas et al., 2004). Since EPHPP does not

evaluate study quality in terms of power, the ability to find a difference when a real difference exists, this component was added for assessing study quality.

Data were extracted to describe characteristics of the studies including design, sample size, descriptions of treatment and comparison groups, participant characteristics, outcomes, and results. Description of intervention included how the intervention was individualized in each included study. Meta-analysis, a statistical method to combine results of individual studies, was not conducted because the focus of the review is not on combining results statistically. We organized the included studies based on the aim 2 (how the intervention was tailored). Benefits (aim 1) were compared across the included studies depending on how the intervention was tailored (aim 2) to identify suggestions for individually tailoring leisure and social activity interventions to benefit persons with dementia (aim 3).

Results

Selection of Studies

Figure 1 describes study selection process. Of the 615 identified articles, there were 59 duplicates. A total of 479 articles were excluded based on title and abstract, and further 45 articles were excluded after reading full-text articles. Main reasons for exclusion included: the intervention did not involve individualized leisure or social activities; study design was not an experimental, a quasi-experimental, or a single-subject design study; intervention was a group therapy. For example, individualized exercise programs were only tailored to their abilities, and preferences or interests in exercise were not considered. These interventions, therefore, were excluded. A total of 32 studies met all the inclusion criteria. More detailed explanations of exclusion will be discussed in each part of results.

Characteristics and Quality of Included Studies

The detailed characteristics and quality rating of the included studies on individualized leisure and social activities for people with dementia are described in Table 1. Of the 32 included studies, 8 were rated as strong, 16 as moderate, and 8 as weak using EPHPP. One study (Janata, 2012) was rated as moderate according to EPHPP, but may be weak due to significant biases (e.g., contamination bias) that

are not considered in EPHPP. Component ratings in EPHPP are shown in Table 2. The sample size was justified by using a power analysis in only 9 studies. The included studies consist of 9 randomized controlled trials (RCTs), 12 repeated measures with randomized crossover (RMCs), 3 non-equivalent control group design (QNCs), 4 one-group pretest-posttest design (OPP), and 4 single subject designs (SSD). Twenty-two studies were conducted in USA, and participants of 21 studies were nursing home residents with dementia. Four studies involved community-dwelling older adults with dementia only. Participants in all of the included studies had moderate or severe stages of dementia except only one study (Chung, 2009) that was specifically designed for people with mild dementia.

The included studies were organized into separate categories based on how the intervention was individually tailored (aim 2). These categories include: 1) performance factors; 2) self-identity; 3) music preference; and 4) life experiences and past memories. Each category will be discussed in detail below.

Leisure and Social Activities Individualized Based on Performance Factors

This category included leisure and social activities individually tailored based on performance factors such as preference/interests in activities, cognitive or functional abilities, current needs, lifelong habits and roles, and health conditions. All of the included studies in this category were not specific in types of leisure and social activities, and types of activities varied among participants. Eleven studies of this category included 6 RCTs, 3 RMCs, 1 QNC, and 1 OPP (Table 1). Mean ages of participants with dementia ranged from 78.1 to 88.7 years, and percent of female ranged from 43.3 to 82.2 percent. All studies involved participants with moderate or severe stages of dementia and only one study (Mowrey, Parikh, Bharwani, & Bharwani, 2013) involved participants with mild dementia too. Of the 11 studies, two studies (Fitzsimmons & Buettner, 2002; Gitlin et al., 2008) involved older adults with dementia living in their own homes, and family caregivers in Gitlin et al. were trained to use and participate in the activities with relatives with dementia.

Preferences or interests in leisure and social activities and functional abilities were the most common factors considered in tailoring activities to each individual with dementia in all of the included

studies. Individually tailored activities based on leisure interests and functional abilities showed statistically significant effects in decreasing agitation, passivity, and other behavioral symptoms compared to usual care or attention control groups (Cohen-Mansfield, Parpura-Gill, & Golander, 2006; Cohen-Mansfield, Libin, & Marx, 2007; Cohen-Mansfield, Thein, Marx, Dakheel-Ali, & Freedman, 2012; Fitzsimmons & Buettner, 2002; Gitlin et al., 2008; Van Haitsma et al., 2013). Positive effects were also found in duration and levels of participation, attention, affect, and sleep (Cohen-Mansfield et al., 2006; 2007; 2012; Gitlin et al., 2008; Kolanowski, Litaker, & Buettner, 2005; Kolanowski, Litaker, Buettner, Moeller, & Costa, 2011; Richards, Beck, O'Sullivan, & Shue, 2005; Van Haitsma et al., 2013; van der Ploeg et al., 2013b).

Two studies compared activities matched to both interests and functional abilities with activities matched to either interests or to functional abilities alone (Kolanowski et al., 2005; 2011). Greater benefits were found when activities were matched to both interests and functional levels or to interests alone, with less benefit in activities matched to functional levels only. These greater benefits include more time on task, greater levels of participation and attention, more positive affect, and less passivity. One study (Van Haitsma et al., 2013) also compared individualized leisure and social activities matched to both interests and abilities with standardized one-on-one social activity involving conversation about a magazine. Negative outcomes were found in the standardized activity compared to individualized activities or even usual care. These negative outcomes include more anger, uncooperativeness, aggression, and negative verbal behaviors (swearing, screaming, and mocking) in the standardized leisure and social activity. These findings suggest that recreational activities should be at least matched to interests of each person with dementia.

Identification of preferences or interests in activities involved interviews with a family member of the person with dementia in all 11 studies. Differences, however, exist in studies depending on whether preferences or interests in activities were identified by interviewing: a family member of the person with dementia only (Gitlin et al., 2008; Kolanowski et al., 2005; 2011; Mowrey et al., 2013; van der Ploeg et

al., 2013b); both a family member and a formal caregiver, such as a nursing staff member (Cohen-Mansfield et al., 2007; 2012); the person with dementia and a family member (Fitzsimmons & Buettner, 2002; Richards et al., 2005); or the person with dementia, a family member, and a formal caregiver (Cohen-Mansfield et al., 2006; Van Haitsma et al., 2013). A family member of the person with dementia living in residential care homes may know past interests or preferences of the person with dementia better than the current interests or preferences in activities, and the direct care staff may better know the current ones (Van Haitsma et al., 2013). Excluding the person with dementia in identifying his or her interests and preferences in activities without making an attempt is not person-centered care that respects the person's perspective, and promotes participation and the remaining abilities. Van Histma et al. (2013) found that residents with moderate or severe stages of dementia were able to identify their past interests and preferences in activities. Specific assessment tools were used to identify past and/or current activity interests of the person with dementia, including the Pleasant Event Schedule (Gitlin et al., 2008), Farrington Leisure Assessment (Fitzsimmons & Buettner, 2002), and Preferences for Everyday Living Inventory-Nursing Home (PELI-NH; Van Haitsma et al., 2013).

Cognitive and functional status, as well as identification of activity interests or preferences, was assessed before prescribing individually tailored activities in all studies except van der Ploeg et al. (2013b). In van der Ploeg et al. (2013b), activity interests and health conditions that could hinder participation by chart reviews were used in prescribing activities, and an activity facilitator used Montessori principles during activities. Montessori principles include adjusting difficulty of tasks to individuals' ability by breaking tasks into smaller components, minimizing language demands, and providing external cues. Skill levels, thus, also was considered in delivering an individually tailored activity in van der Ploeg et al. (2013b). Examples of assessment tools used are: the Mini-Mental State Examination (MMSE) to assess cognitive functions (in Cohen-Mansfield et al., 2006; 2007; 2012; Kolanowski et al., 2005; 2011; Richards et al., 2005; Van Haitsma et al., 2013); the Global Deterioration Scale to assess global status, incorporating cognitive status, functional status, and behavioral symptoms

(in Fitzsimmons & Buettner, 2002); and the Minimum Data Set (MDS) to assess performance in activities of daily living (in Cohen-Mansfield et al., 2007; 2012; Van Hastima et al., 2013).

Additional considerations in individually tailoring activities, other than activity interests, cognition, and functional status, include: daily routines, dyadic communication between a family caregiver and the person with dementia, and home environments in Gitlin et al. (2008); social and occupational roles, physical evaluations (e.g., pain, vision) in Cohen-Mansfield et al. (2007; 2012); napping patterns in Richard et al. (2005); and leaning style and behavior profile in Mowrey et al. (2013).

Leisure and Social Activities Individualized Based on Self-identity

Self-identity can be achieved and maintained from occupational or social roles, personal attributes/traits/achievements, and lifelong leisure activities (Cohen-Mansfield et al., 2006). Six of the identified studies involved diverse types of leisure and social activities individually tailored based on self-identity of each of people with dementia, including 1 RCT (Politis et al., 2004) and 5 RMCs (Cohen-Mansfield et al., 2010a; Cohen-Mansfield, Marx, Thein, & Dakheel-Ali, 2010b; 2011; Cohen-Mansfield, Thein, Dakheel-Ali, & Marx, 2010c; Leone, Deudon, Piano, Robert, & Dechamps, 2012). Mean ages of participants with dementia ranged from 84 to 86 years, and percent of female ranged from 72.5 to 83.3 percent. Four studies (Cohen-Mansfield et al., 2010a; 2010b; 2010c; 2011) involved the same participants with dementia, and Cohen-Mansfield et al. (2010a) involved some of the participants who exhibited agitated behaviors.

All five RMC studies identified each participant's past and/or current interests in leisure, social, and work-related activities by interviewing the person with dementia and/or his or her family member on the Self-Identity Questionnaire (SIQ). Most salient self-identity, especially, was related to social activities involving a family member and leisure activities (Cohen-Mansfield et al., 2010c).

Participants with dementia showed greater levels of engagement, pleasure, and interest, and less agitation when provided with stimuli matched to the self-identity/interests than non-individualized stimuli, except live social stimuli (e.g., one-on-one social interaction with a research assistant, a real dog)

(Cohen-Mansfield et al., 2010a; 2010b; 2010c; 2011; Leone et al., 2012). One study (Cohen-Mansfield et al., 2010b) differentiated past and current preferences in music, arts, and pets, and assessed levels of engagement of the participant with dementia. Greater levels of engagement were found in leisure activities when matched to current preferences than past preferences. The findings of Cohen-Mansfield et al. (2010b) indicate the importance of identifying both past and current preferences in activities to provide nursing home residents with dementia with the most interesting and engaging activity in case preferences in activities may change.

Interests in leisure and social activities were identified in informal, relaxed, and unstructured ways in Politis et al. (2004). Each of people with moderate or severe stage of dementia was asked to talk about his or her past and interests and decide what activities she or he wanted to do together. The activity therapist introduced herself, asked if the person with dementia wanted to spend some time together, and explained the purpose of the visit before asking about past and interests of the person with dementia (Politis et al., 2004). Even this very simple one-on-one and person-centered approach supporting participation in individualized leisure and social activities showed benefits in reducing overall behavioral symptoms and apathy (loss of motivation and interest) and improving quality of life (Politis et al., 2004). All these findings suggest the importance of considering an individual's most salient self-identity to facilitate intrinsic motivation and participation and improve affect and agitated behaviors.

Music Listening Activities Individualized Based on Music Preference

This category included an individualized music listening activity in which the recorded music was selected based on music preference of each of people with dementia. Studies involving preferred music listening were excluded if the music listening activity was in a group format (e.g., Suzuki et al., 2004). One of the identified studies (Sakamoto, Ando, & Tsutou, 2013) involved listening to music related to an individual's special memories evoking pleasure. This study was excluded because the selected music related to positive memories may not be matched to music preference. Studies of individualized music listening during bathing (Clark, Lipe, & Bilbrey, 1998; Thomas, Heitman, &

Alexander, 1997) were excluded because activities should take place during their free time to be leisure activities, not during caregiving routines. These studies also did not identify whether participants enjoyed listening to preferred music during bathing, so preferred music listening during bathing of these studies could not be regarded as leisure activities. A study (Hicks-Moore & Robinson, 2008) was excluded because authors reported that the musical preferences of some residents with dementia were unknown, so the music list was selected by nursing staff. There was no description supporting how well nursing staff knew the music preferences of the resident with dementia.

Seven studies of this category included 2 RCTs (Guétin et al., 2009; Janata, 2012), 2 QNCs (Sung, Chang, & Abbey, 2006; Sung, Chang, & Lee, 2010), 1 RMC (Gerdner, 2000), and 2 SSD (Gerdner, 2005; Park & Pringle Specht, 2009). Gerdner (2005) used mixed methods design, but Gerdner (2005) met the inclusion criteria when considering quantitative part of Gerdner (2005) in this review paper. Mean ages of participants with dementia ranged from 80.1 to 86.1 years, and percent of female ranged from 44.2 to 100 percent. Participants with dementia in Guétin et al. (2009) had milder stages of dementia than participants in the other studies. Interventions of the included studies varied in duration, ranging from 20 to 30 minutes and once or twice a week, over a 2 to 16 weeks period. The exception (Janata, 2012) used the intervention lasting several hours per day 4 times a week for 12 weeks. Preferred music listening for 30 minutes was used in five studies (Gerdner, 2000; 2005; Park & Pringle Specht, 2009; Sung et al., 2006; 2010). All studies assessed effects of interventions on reducing behavioral or psychological symptoms, such as agitation, anxiety, and depression, in people with dementia living in long term care facilities except Park and Pringle Specht (2009) in which home-dwelling people with dementia participated in.

Two studies compared listening to individualized music based on music preference with listening to non-individualized music (Gerdner et al., 2000) or with reading and rest activity (Guétin et al., 2009). Statistically significant benefits in reducing agitation were found in individualized music listening compared to classical relaxation music listening during and following intervention (Gerdner et al., 2000).

These effects persisted for 30 minutes following intervention in preferred music listening only. Significantly lower anxiety and depression were found in preferred music listening compared to reading and rest activity during the intervention periods and even 8 weeks following the intervention (Guétin et al., 2009).

Three studies (Janata, 2012; Sung et al., 2006; 2010) compared individualized music activity to usual care. Listening to preferred music for 30 minutes per day twice a week was effective in reducing agitation (Sung et al., 2006) and anxiety (Sung et al., 2010) compared to usual care. Greater amount of music listening (several hours per day 4 times a week) was not different in reducing agitation, depression, and behavioral disturbances from usual care (Janata, 2012). In Janata (2012), however, participants were allowed to leave their rooms while the music was played due to the longer periods of exposure to music. These findings indicate that preferred music listening may benefit people with dementia only when music is played for a short duration (20 or 30 minutes) and thus they can concentrate on music within their limited attention span (Jennings & Vance, 2002). Music was played in the room of each resident with dementia (Gerdner, 2005; Guétin et al., 2009; Janata, 2012), and an area where the resident spent the majority of his/her time in residential care homes (Gerdner, 2000). The other studies did not mention the specific place where the preferred music listening activity was provided. Environmental factors, such as environmental distractions, may affect music listening activity of the person with dementia (Hall & Buckwalter, 1987).

Music preference of the person with dementia was identified by interviewing: a family member of the person with dementia only (Gerdner, 2000; 2005; Park & Pringle Specht, 2009); a person with dementia only (Guétin et al., 2009; Janata, 2012); or a person with dementia, his or her family members, and/or formal caregivers (Sung et al., 2010). Four studies used specific tools for identifying musical preference and the importance of music in life during the independent living of the person with dementia, including the Assessment of Personal Music Preference (APMP) in three studies (Gerdner, 2005; Park & Pringle Specht, 2009; Sung et al., 2010) and the Modified Hartsock Music Preference Questionnaire in

Gerdner (2000). Questions of these tools involve preferred kinds of genre, artists, music albums, specific song titles, and music activities as well as the importance of music in life. In Guétin et al. (2009) and Janata (2012), music preference and listening history/personal experience were assessed by interviewing a person with dementia and there were no descriptions on which specific questionnaires were used. No detailed descriptions of identifying music preference were provided in Sung et al. (2006).

Only three studies (Gerdner, 2005; Park & Pringle Specht, 2009; Sung et al., 2010) reported how important music was to the life of a person with dementia. Almost half of the participants with dementia rated music as slightly important in their life in Park and Pringle Specht (2009) and Sung et al. (2010). No comparison was made whether the importance of music in life would make difference in outcomes. Preferred music listening also was not compared to group music therapies involving more active and interactive participation by singing, clapping, and dancing together. No study identified whether benefits of individualized music listening based on music preference only would be different from benefits of individualized music listening based on the other personal and environmental factors as well as music preference.

Social Activities Individualized Based on Life Experiences and Past Memories

Individualized simulated presence therapy. Seven studies (Camberg et al., 1999; Cheston, Thorne, Whitby, & Peak, 2007; Cohen-Mansfield & Werner, 1997; Garland, Beer, Eppingstall, & O'Connor, 2007; Miller et al., 2001; Peak & Cheston, 2002; Woods & Ashley, 1995) of simulated presence therapy (SPT) were included as a specific type of therapy involving indirect, simulated social contact with a family member individually tailored based on an individual's own life experiences and past memories. SPT involves individualized interactive conversation audiotaped or videotaped from a family member of the person with dementia. SPT was developed to give comfort by replicating a caregiver's presence in the form of a telephone conversation and talking about pleasant past memories or shared life experiences from the past (Woods & Ashley, 1995). The recorded tape contains the family member's side of the conversation with pauses for the person with dementia to respond (Woods & Ashley). One

study (O'Connor, Smith, Nott, Lorang, & Mathews, 2011) using video-simulated presence therapy was excluded because the purpose of recording was for a family member to ask a person with dementia to comply with staff requests and participate in tasks while staff assists self-care tasks. SPT used in O'Connor et al. (2011) was not tailored based on life experiences and past memories of the person with dementia.

Seven included studies had varied study designs, including RMC (Camberg et al., 1999; Cohen-Mansfield & Werner, 1997; Garland et al., 2007), SSD (Cheston et al., 2007; Peak & Cheston, 2002), and OPP (Miller et al., 2001; Woods & Ashley, 1995). Mean ages of participants with dementia ranged from 74.3 to 86.8 years, and percent of female ranged from 63 to 85.7 percent. Participants of the included studies were residents with moderate or severe stages of dementia living in long term care facilities including nursing homes or hospitals. Participants with dementia of the included studies had varied types and prevalence of behavioral disturbances at baseline. For example, participants in Garland et al. (2007) displayed physically nonaggressive agitation (e.g., pacing, inappropriate disrobing) during 64.8% of the baseline observation, physically aggressive agitation (e.g., spitting, hitting) during 3.8%, and verbally aggressive (e.g., swearing, cursing) and nonaggressive agitation (e.g., repetitive questions, screaming) during 31.4%. Participants with verbal agitation only were included in Cohen-Mansfield & Werner (1997), and the most frequently observed specific types of verbal agitation were complaining (42.1%), shouting (35.4%), nonsense talk (32.1%), and repeating words (28.6%). In Camberg et al. (1999), agitation was not observed in almost 25% of the baseline observations, and the majority of observed physical and verbal agitation was fairly mild lasting only a few minutes. Participants had withdrawn behaviors, showing no interest in activities, people, or things during 47% of the direct observations, no pleasure during 75%, and no facial expressions during 82.5% (Camberg et al., 1999).

Two studies (Camberg et al., 1999; Garland et al., 2007) compared effects of SPT through an individualized interactive conversation audiotaped by family member to listening to neutral audiotapes (recordings of a person reading an emotionally neutral article or a book) and to usual care. SPT was more

effective in reducing overall agitation (Camberg et al.), physical agitation (Garland et al.), and withdrawn behaviors (Camberg et al.) compared to neutral audiotapes and usual care based on direct observation before, during, and after the intervention (Garland et al.) and daily observation logs documented by blinded staff (Camberg et al.). Effects of SPT in decreasing verbal agitation were not different from effects of neutral audiotapes, but different from effects of usual care (Garland et al.). Improvement in physical and verbal agitation during SPT and listening to neutral audiotapes maintained for 15 minutes after interventions (Garland et al.).

Two studies (Cohen-Mansfield & Werner, 1997; Garland et al., 2007) assessed effects of SPT compared to listening to preferred music and/or to one-to-one social interaction. Cohen-Mansfield and Werner (1997) found that all three interventions (videotaped SPT, preferred music listening, and one-to-one social interaction) were significantly better than usual care, by decreasing duration of verbal agitation 56% during one-to-one social interaction, 46% during SPT, 31% during preferred music listening, and 16% during usual care. In Garland et al. (2007), effects of SPT in decreasing counts of physical agitation were not different from effects of preferred music listening, and both were more effective than usual care by decreasing physical agitation 30% during SPT, and 25% during preferred music listening. Effects of preferred music listening in decreasing counts of verbal agitation, however, were not different from usual care, but effects of SPT significantly decreased verbal agitation compared to usual care (Garland et al.). Findings of these two studies may suggest that direct one-to-one social interaction work best in decreasing verbal agitation, and SPT can be used as an alternative to the one-to-one social interaction by decreasing verbal agitation more than preferred music listening.

The other four studies (Cheston et al., 2007; Miller et al., 2001; Peak & Cheston, 2002; Woods & Ashley, 1995) involved small number of participants with dementia (less than 10) and assessed changes in outcomes from pretest to posttest (Miller et al., 2001; Woods & Ashley, 1995) or across three conditions (two baseline conditions and SPT condition; Cheston et al., 2007; Peak & Cheston, 2002). Improvements were found in levels of disruptive behaviors (agitation, aggression, and wandering) and

social interaction when comparing pretest to posttest (Miller et al., 2001; Woods & Ashley, 1995). There was a significant improvement in levels of distressed behavior (especially for participants asking or seeking to go home) during SPT compared to two baseline conditions, but not in levels of positive social interaction (Cheston et al., 2007).

Six studies (Camberg et al., 1999; Cheston et al., 2007; Garland et al., 2007; Miller et al., 2001; Peak & Cheston, 2002; Woods & Ashley, 1995) used SPT through audio-taped conversations by family, and one study (Cohen-Mansfield & Werner, 1997) used SPT through video-taped conversations by family. None of the included studies directly assessed whether benefits of SPT would be different when provided with a recorded audiotape or videotape. Videotaped SPT, however, may work better for a person with hallucinations than audiotaped SPT. Videotaped SPT decreased hallucinations the most among verbally disruptive behaviors and more than one-to-one social interaction, listening to preferred music or neutral audiotapes, and usual care (Cohen-Mansfield & Werner). Miller et al. (2001) stated that residents with a history of hallucinations were withdrawn from the study because they became agitated with audiotaped SPT. Findings of these two studies (Cohen-Mansfield & Werner; Miller et al.) may suggest that having a history of or present hallucinations can be an important factor in implementing individualized SPT in the form of a videotape rather than an audiotape.

Relationships and shared memories with the person, who records a personalized tape for SPT, may affect effects of SPT. All of the included studies, except two studies (Cheston et al., 2007; Peak & Cheston, 2002) where the spouse of the person with dementia recorded an audiotape, did not mention exactly which family member recorded a tape. None of the included studies also did not address whether any efforts were made in identifying the family member who were most recognized by the person with dementia and who had positive and intimate relationships in the past. A family member of the person with dementia may serve as a primary family caregiver not because of their intimate relationships but because of living nearby. How much the relationship was intimate and close, and how much positive shared memories exist with the family member who recorded the tape may determine whether SPT would

result in improved behaviors, affect, and comfort. This information may in some parts help identifying why some participants with dementia became more agitated or declined SPT (Camberg et al., 1999; Garland et al., 2007; Woods & Ashley, 1995).

Individualized reminiscence therapy. Reminiscence therapy (RT) varies depending on functions and goals (e.g., intrapersonal vs. interpersonal, resolving conflicts in late life stage through reviewing one's life vs. talking about and sharing past memories and life experiences) (Subramaniam & Woods, 2012). Talking about or sharing past memories and life experiences is one way of interacting with others who are either directly involved in their life histories and past events or not. Some reminiscence programs, thus, can be included as a specific type of therapy promoting direct social interactions and individually tailored based on an individual's own life experiences and past memories.

Studies were included only if : 1) the reminiscence program involved one individual with dementia; 2) direct and active social interactions through sharing past experiences and memories were facilitated rather than focusing only on reviewing one's life or remembering past events for cognitive stimulation; 3) the program used an approach for individualizing reminiscence therapy to the individual with dementia. Main reasons for excluding studies involving reminiscence were that: 1) reminiscence was done in a group format (e.g., Serrani Azcurra, 2012); and 2) more focus was on evaluating one's own life histories, thus functioning in more intrapersonal level, (e.g., Haight, Gibson, & Michel, 2006).

Only one study (Chung, 2009) met the criteria. Two RCTs (Lai, Chi, & Kayser-Jones, 2004; Van Bogaert et al., 2013) involved individually tailored reminiscence programs but these programs had no description on whether the programs also had a focus on promoting social interaction with a facilitator through reminiscing activities. Chung (2009) clearly described that the program had a focus on promoting social interactions. Each of people with dementia and two youth volunteers reciprocally shared their life experiences, thus also promoting reciprocal relationship. Significant improvements in overall quality of life and depression were found compared to pre-test results. No significant improvement in cognition was found in Chung (2009) where participants had mild stages of Alzheimer's

disease (AD). This finding was consistent with the finding of Van Bogaert et al. (2013) in which effects of the reminiscence program on improving cognition did not remain when the data was analyzed with participants with mild stage AD only.

Discussion

This review support benefits of individualized leisure and social activities on people with dementia. Improvements in levels of engagement, agitation, withdrawn behaviors, and affect were found among the 32 included studies. Diverse or specific types of leisure and social activities were involved in each intervention study, and a single factor (music preference) or multiple performance factors (e.g., interests in activities, functional ability, lifelong roles) were considered for tailoring activities to each individual. Multiple performance factors were considered in tailoring diverse types of leisure and social activities to each individual, and a single factor for a specific type of activity or therapy (e.g., music listening activity). Benefits were found in leisure and social activities regardless of whether the activity was individualized based on a single factor or multiple factors.

The majority of the included studies involving activities individualized based on multiple performance factors considered a variety of factors, although interests and/or functional abilities predominated as factors. Findings of the included studies, however, suggest identifying interests or preferences in leisure and social activities as the most important factor for successfully tailoring an activity plan for each person. Recreational activities matched to interests or preferences in activities only showed greater benefits on levels of engagement and pleasure compared to activities matched to functional abilities only. There were similar benefits when compared to recreational activities matched to both functional abilities and interests (Kolanowski et al., 2005; 2011).

The included studies involving diverse types of leisure and social activities individualized based on multiple performance factors, or self-identity assessed not only behavioral symptoms (e.g., agitation) but also affect (interest, pleasure), mood, and participation in activities. Majority of the included studies of individualized music listening activities based on music preference and SPT only assessed behavioral

and psychological symptoms of the person with dementia. When considering the limited number of studies supporting a variety of outcomes beyond behavioral and psychological symptoms, a further study is needed to support that individualized music listening activities and SPT truly were leisure or social activities giving pleasure and meaningful social relationship, thus meeting their psychosocial needs and wants for occupation and belonging.

Some benefits may simply result from one-on-one social interaction during leisure activities matched to their interests. Negative effects (Van Hastima et al., 2013), however, were found in a non-individualized activity involving one-on-one social interaction without consideration of an interest of the person with dementia. One-on-one social interaction with a nursing assistant, by looking through a magazine and talking about it, resulted in more aggression, uncooperativeness, and negative behaviors in people with dementia (Van Hastima et al.). No negative effects were found due to individually tailored leisure and social activities.

Leisure and/or social activities involving simple, unstructured one-on-on social interaction, showed benefits on overall behaviors, affect, levels of engagement, and overall quality of life when the activity and interaction was individualized in a non-standardized way (Cohen-Mansfield et al., 2010a; 2011; Politis et al., 2004; van der ploeg et al., 2013b). Only one of the included studies (Politis et al., 2004) compared standardized, structured activities using activity kits allowing limited choices in activities to unstructured, individualized leisure and social activities and found no significant difference in outcome measures between two interventions. Unstructured social activities considering each individual's interests, however, showed significant improvement in more outcome measures (apathy, overall behavioral disturbance, and quality of life) compared to baseline, while standardized, structured activities allowing limited choice of activity resulted in improvements only in apathy. A further study is needed to identify if individualized activity programs result in different outcomes depending on whether the activity was structured or not.

Person-centered approach should be used to provide personalized leisure and social activities to each of people with dementia. Knowing and understanding an individual with dementia as a unique person with his or her life experience and history, interests or preferences in activities, strengths (remaining abilities) or past roles, should be preceded before providing activities to the person with dementia. To do this, collaboration with a person with dementia, family member, and/or primary formal caregiver (e.g., nursing staff) and giving a choice to the person with dementia among varied activity choices should be attempted rather than relying only on opinions of either formal or informal caregiver. Positive social environment also should be embedded during individualized leisure and/or social activities by promoting social identity (e.g., family-social or professional roles in Cohen-Mansfield et al., 2006), or involving direct or indirect positive social interactions (e.g., Chung, 2009; Garland et al., 2004; Politis et al., 2004).

Overall suggestions can be made based on the synthesized findings of the included studies. Further studies are needed to identify how individualized leisure and/or social activities based on person-centered approach benefit persons with earlier stages of dementia. Activities promoting reciprocal social relationships between a person with earlier stages of dementia and younger generation, may be one promising intervention that improves quality of life and psychosocial well-being (Chung, 2009). More studies translating research into practice should be conducted since only efficacy, not effectiveness, was tested in some studies and required staff training and cost to deliver the intervention in a real nursing home setting were not tested (e.g., Cohen-Mansfield et al., 2007; 2012).

Collaboration among interdisciplinary practitioners can be helpful in implementation of individualized leisure and social activities for persons with dementia since evidence supports individualized leisure and social activities based on multiple performance factors in varied outcomes beyond behavioral and psychological symptoms. Individually tailoring activities to both interests /preferences in activities and abilities or at least interests, particularly, is important to benefit people with dementia the most (e.g., Kolanowski et al., 2005; 2011). Identifying both past and current interests/

preference in activities, through involvement of a person with dementia, family member, and a primary formal caregiver in assessment, may be more helpful in identifying personally meaningful activities to the person with dementia (e.g., Cohen-Mansfield et al., 2010b; Van Hastima et al., 2013). When providing a specific individualized activity (e.g., preferred music listening, SPT), available and applicable in a nursing home, who would benefit from this activity should be considered by assessing how important and meaningful the specific activity and involved social relationship were/are to the person with dementia.

Limitations

The quality of the included studies varied. Sixteen studies of the 32 included studies were rated as moderate, and eight studies were rated as weak. Only 9 studies justified sample size by using a power analysis. Majority of the studies involved participants with moderate or severe stages of dementia and participant living in long-term care facilities. Benefits found from the majority of the included studies, therefore, may not generalize to community-dwelling older adults with earlier stages of dementia.

Limitations of the search should be noted because search was restricted to English-language publications through three electronic databases. There was a difficulty in determining whether the individualized reminiscence therapy could be regarded as an individualized social activity with a focus on promoting social interaction as well as on reminiscing itself. Most of the identified studies did not directly address social interaction through reminiscence as one of the focus of the intervention. Only one study, thus, was included because authors directly described it, but some studies might promote social interaction during reminiscing therapy. Benefits of individualized reminiscence therapy could be found better from qualitative studies where participants with dementia are likely to talk about benefits on social interaction during reminiscing therapy.

Conclusion

This systematic review found that individualized leisure and social activities can benefit people with dementia in a number of ways, in particular, by promoting engagement, improving affect, and reducing both agitation and withdrawn behaviors. The 32 studies included in this review documented

varied ways of individualizing leisure and social activities as means to benefit people with dementia. Majority of these activities were individually tailored to each person with dementia by focusing on the individual's preferences, interests, remaining abilities, memories, or personal history. All of the included studies but one study focused on people, living in a long term care facility and having with moderate or severe stages of dementia. This review found a gap in the literature about how people with earlier stages of dementia can be supported by providing individualized leisure and social activities in the community. Further study is needed to identify effective ways of promoting engagement through individualized leisure and social activities and thus mental health for people with dementia not only with later stages but also with earlier stages of dementia.

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Tables & Figures

Table 1. Summary of Included Studies on Individualized Leisure and Social Activities for People with Dementia

Authors	Design (N)	Treatment and comparison groups	Participants : mean age (years); female (%); severity of dementia; setting	Outcomes	Results	Quality /Power
Leisure and social activities individualized based on performance factors						
Cohen-Mansfield et al. (2007)	QNC (167)	- Treatment Routes for Exploring Agitation (TREA): Individualized activities matched to past role-identity, past and/or current preferences, and cognitive, mobility, sensory abilities with a systematic search of needs underlying agitated behaviors (n=89) -C: Staff education (n=78) -10 consecutive days during the 4 hours of greatest agitation	86; 80.2; moderate to severe; NHs, USA	Agitation (ABMI), affect (pleasure, interest, negative affect; LMBS)	-T > C: Reduced agitation**, increased pleasure*** and interest*** -T=C in negative affect	Moderate No
Cohen-Mansfield et al. (2012)	RCT (125)	-T: TREA (n=89) -C (n=36) -2 weeks	85.7; 74.4; moderate to severe; NHs, USA	Agitation (ABMI), affect (LMBS)	T > C : Reduced overall agitation***, physical nonaggressive***, and verbal agitation**, increased pleasure*** and interest*	Moderate No
Cohen-Mansfield et al. (2006)	RCT (93)	-Individualized activities based on a participant's most salient past and/or current role identity	87; 71; moderate to severe; senior day centers,	Affect (LMBS), involvement in activities	T > C : Increases in pleasure***, interest***, involvement in activities***, and	Moderate No

		among four domains (family-social role; professional role; leisure time and hobbies; and achievements and traits), cognitive, physical, and sensory abilities, and demographics (e.g., gender, educational level, primary language) (n=52); 5 days for 30 min a day -Usual care (n=41)	NHs, USA	(ABMI), well-being (MOSES), agitation (ABMI), self-identity awareness	self-identity awareness***, and declines in agitation*	
Gitlin et al. (2008)	RCT (60)	- Tailored activity program (TAP) matched to cognitive abilities, previous roles, habits and past/current interests (n=30) -C: Usual care (n=30) -8 sessions, 6 home visits (90 minutes per visit), and 2 (15 minute) telephone contacts over 4 months	79.4; 43.3; moderate; home, USA	Occurrence and number of behaviors, depressive symptoms (CSDD), activity engagement, overall quality of life (QoL-AD)	-T > C: Decreased frequency of behaviors** (Cohen's d = .72), greater activity engagement* (d = .61), greater pleasure in recreation* (d = .64), enhanced ability to keep busy* (d = .71), reduced agitation* (d = .75) and argumentation* (d = .77) at 4 months -T=C in depressed mood	Strong No
Fitzsimmons & Buettner (2002)	RMC (30)	-T: At-home individualized, therapeutic recreation therapy (e.g., art/craft therapy, therapeutic cooking, games, sports) tailored to current functioning level, past leisure interests, strengths, and current needs; 1 to 2 hours x 3 to 5 days per week x 2 weeks -C: Usual care	81.2; 65.5; moderate to severe; home, USA	Agitation (CMAI), passivity (PDS)	T > C: Decreased agitation* and passivity***	Moderate No
Kolano	RMC	-Ta: Individualized	82.3; 77;	Engagement	-More time on task:	Strong

wski et al. (2005)	(30)	recreational activities matched to functional levels only -Tb: Matched to interests/ preferences for leisure/social activities -Tc: Matched to both functional levels and interests -20 min. x 12 consecutive days per treatment x 3 treatments (total: 6 weeks)	moderate to severe; NHs, USA	nt (time on task, participation), affect (PGCARS), mood (DMPT), agitation (CMAI), passivity (PDS)	Tc > Ta**, Tb > Ta* -Greater participation: Tc > Ta***, Tc > Tb** -More positive affect: Tc > BL***, Tb > BL**, Tc > Ta* -Less negative affect: Ta, Tb, Tc > BL* -Less agitation: Ta, Tb, Tc > BL** -Less passivity: Tc > Ta*	Yes
Kolanowski et al. (2011)	RCT (128)	-Ta: Individualized recreational activities matched to functional levels (n=32) -Tb: Matched to interests (n=33) -Tc: Matched to both functional levels and interests (n=31) -AC: Unmatched to functional levels and interests (n=32) -20 min. x twice per day x 5 days each week x 3 weeks	-86; 76.6; moderate; NHs, USA	Engagement (time on task, participation), affect (PGCARS), mood (DMPT), agitation (CMAI), passivity (PDS)	- More pleasure in Tc > Ta, Tb, AC* -Greater engagement and more alertness and attention in Tb, Tc > Ta, AC - No group differences in agitation, passivity, anxiety, and self-reported mood	Strong Yes
Mowrey et al. (2013)	OPP (9)	- Behavior-based ergonomic therapy (BBET) program (individualized multimodal therapeutic activities with 24/7 availability via staff): Comforting (e.g., music, video, memory props) or stimulating activities (e.g., stage-specific games, puzzles) individualized based on interests,	88; 56; mild to severe; NH, USA	MDS behavior counts, MDS mood counts. falls, medication doses	65% reduction in MDS behavior counts*, 70% reduction in MDS mood counts, 53% reduction in the number of behavioral episodes, 33% reduction in falls, non-significant overall reductions in doses of antipsychotics and anxiolytics	Weak No

		personality, learning style, cognitive functions, and behavior profile -6 months				
Richards et al. (2005)	RCT (147)	-T: Individualized social activities based on interests (work and leisure history), cognition, functional status (mobility, hearing, vision, and fine motor skills), and napping patterns (n=71); 1 to 2 hours per day for 21 consecutive days -C: Usual care (n=68)	79; 48.2; moderate to severe; NHs, USA	Daytime minutes slept, nighttime variables (minutes to sleep onset, minutes slept, minutes awake, sleep efficiency), day/night sleep ratio (sleep/wake rhythm)	-T > C in daytime minutes slept**, nighttime minutes to sleep onset*, nighttime minutes awake*, day/night sleep ratio* -Participants with a sleep efficiency of less than 50% (n=50): T (n=20) > C (n=30) in daytime sleep**, day/night sleep ratio*, nighttime minutes to sleep onset*, nighttime minutes awake*	Moderate Yes
van der Ploeg et al. (2013b)	RMC (44)	-T: Individualized one-to-one activities based on former interests and hobbies, health conditions, and Montessori principles (adjusting difficulty of tasks to individuals' ability, minimizing language demands, providing external cues) -C: One-to-one social interaction (general conversation or conversation based on newspaper stories and pictures) (for 30 minutes twice per week for 4 weeks)	78.1; 68.2; moderate to severe; NHs, Australia	A single-targeted physically agitated behavior (e.g., pacing), affect (PGCARS), engagement (MPES)	-T > C in positive affect**, interested affect**, neutral affect***, constructive engagement***, negative engagement*** -T, C > BL in agitation***, positive affect**, interested affect***, neutral affect***, constructive engagement***, passive engagement***, negative engagement***	Strong Yes
Van Haitsma et al.	RCT (180)	-Ta: Individualized positive psychosocial	88.7; 82.2; moderate to severe;	Direct observations of	-Affect: Greater pleasure*** and alertness*** (Ta, Tb	Moderate Yes

(2013)		<p>intervention (IPPI) program matched to current leisure interests and abilities (n= 44)</p> <p>-Tb: Standardized one-on-on social interaction (conversation on a magazine they read through) (n= 43)</p> <p>-C: Usual care (n=93)</p> <p>-10 min, 3 days per week for 3 weeks</p>	NHs, USA	affect, nonverbal and verbal behaviors	<p>> C), more anger (Tb > Ta*, Tb > C**)</p> <p>-Nonverbal behaviors: Greater psychosocial task participation (Ta, Tb > C***), more general restlessness and eyes closed (C > Ta*, C > Tb**), more uncooperativeness (Tb > Ta*, Tb > C**), more aggression (Tb > C**), more positive touch behaviors (Ta, Tb > C***)</p> <p>-Verbal behaviors: more very negative verbal behaviors (Tb > Ta**, Tb > C***), more very positive verbal behaviors (Ta > Tb, C***), more positive verbal behaviors (Ta, Tb > C***, Tb > Ta**), more nonverbal responses (C > Ta, Tb***)</p>	
Leisure and social activities individualized based on self-identity						
Cohen-Mansfield et al. (2010a)	RMC (111)	<p>-Individualized activities matched to self-identity and other non-individualized activities, involving engagement through live social stimuli, simulated social stimuli, manipulative stimuli (e.g., squeeze ball, puzzle, building blocks), work/task-related, music, and reading materials; 3 weeks</p>	85.4; 80.2; severe; NHs, USA (participants with agitated behaviors among 193 participants)	Agitation (total, verbal, and physical agitation; ABMI)	<p>-Decreased overall agitation in all stimuli** except for manipulative stimuli, decreased physical agitation in all stimuli** than baseline</p> <p>-Significantly less agitation : live social stimuli > self-identity stimuli > manipulative, simulated stimuli</p>	Moderate No

		-BL: usual care				
Cohen-Mansfield et al. (2010b)	RMC (193)	-Individualized activities related to past/ present interests in art, music, babies, pets, reading, television, and office work -3 weeks (four stimuli per day)	86; 78; moderate to severe; NHs, USA	Engagement (duration, attention, attitude ; OME)	<p><i>Past preference for music</i></p> <p>-Music stimuli > non-music stimuli: duration***, attention***, and attitude***</p> <p>-Participants with past preference for music > those without past preference for music: duration*, attention*, and attitude* when presented with music stimuli</p> <p><i>Present preference for music</i></p> <p>-Music stimuli > non-music stimuli: duration*, attention***, and attitude***</p> <p>-Participants with present preference for music > those without present preference for music: duration***, attention***, and attitude** when presented with music stimuli</p> <p><i>Present preference for art</i></p> <p>-Coloring stimuli > non-coloring stimuli: duration***</p> <p>-Participants with present preference for art > those without present preference for art: duration***, attention*, and attitude** when presented with coloring stimuli</p>	Weak No

					<p><i>Past preference for pets</i></p> <ul style="list-style-type: none"> -Pet stimuli (a real dog) > non-pet stimuli: attention*, and attitude*** -Participants with past preference for pets > those without past preference for pets: duration* when presented with pet stimuli <p><i>Present preference for pets</i></p> <ul style="list-style-type: none"> -Pet stimuli > non-pet stimuli: attention** and attitude*** -Participants with present preference for pets > those without present preference for pets: attention* when presented with pet stimuli 	
Cohen-Mansfield et al. (2010c)	RMC (193)	- Individualized activities matched to self-identity and other non-individualized activities (e.g., engagement through work-related, gender-related, and comparison stimuli) -3 weeks	86; 78; moderate to severe; NHs, USA	Engagement (duration, attention, attitude ; OME)	Self-identity stimuli > non-individualized comparison stimuli in duration***, attention***, and attitude***	Weak No
Cohen-Mansfield et al. (2011)	RMC (193)	- Individualized activities matched to self-identity and other non-individualized activities (e.g., engagement through live social, simulated social, manipulative,	86; 78; moderate to severe; NHs, USA	Affect (pleasure, interest, negative affect; LMBS)	-Self-identity stimuli > non-individualized stimuli (except live social stimuli) in pleasure*** and interest*** -Non-individualized music stimuli > BL***, but lower	Moderate No

		work/task-related, music, and reading stimuli) -3 weeks			levels of pleasure and interest than other stimuli	
Leone et al. (2012)	RMC (40)	Engagement through objects (stimuli) tailored to interests in 4 categories of leisure, family, work-occupation and personal, and objects in "not interested" category, with and without guided interaction with a therapist; 15min per stimulus (n = 2) of each category (5×(15 min×2)) over 2 weeks	85.4; 72.5; mild to severe; NHs, France	Engagement (duration, attention, attitude ; OME)	-Significantly higher scores of duration, attention, and attitude in categories of interest compared to "non-interested" category - Guided > Non-guided: Duration of engagement in three categories of interest (leisure***, personal**, work**), but not in categories of family and "not-interested" -Guided > Non-guided in participants with apathy: Duration of engagement in categories of leisure* and personal*	Strong Yes
Politis et al. (2004)	RCT (36)	-Ta: Standardized, structured activity in which a participant chooses an activity among five types of activity in the kit (geography, fun foods, animals, vegetables, and musical instrument) for mental stimulation/ reminiscence (n=18); 30 min. x 3 times per week x 4 weeks -C: Unstructured, personalized leisure and social activities based on interests (n=18)	84; 83.3; moderate to severe; dementia-specific LTC, USA	Apathy (NPI), behavioral disturbance (NPI-total), quality of life (ADQRL), participation, cueing, and enjoyment in routine daily activities (CRAI)	-T = C -Ta > BL in total NPI* -C > BL in NPI-apathy**, total NPI*, ADQRL*	Moderate No
Music listening activities individualized based on music preference						

Gerdner (2000)	RMC (39)	-T: Listening to recorded individualized music tailored to music preference (30 min. x twice per week x 6 weeks) -C: Listening to classical relaxation music	82.6; 76.9; severe; LTC, USA	Agitation (modified CMAI)	-T > C: Reduction in agitation*** during (for 30 minutes) and following intervention (for 30 minutes) -T > BL*** during and following intervention - C > BL only during the final 10 minutes of classical music** and during the first 10 minutes after classical music*	Moderate No
Gerdner (2005)	Mixed methods/ SSD (8)	Listening to recorded individualized music tailored to music preference (30 min. x daily x 4 weeks prior to peak agitation time)	83.3; 100; moderate to severe; skilled care facility, USA	Agitation (modified CMAI, AVAS)	Significant reduction in agitation during the presentation of music*** compared to pre-intervention score, with an overall reduction in agitation on day shift during weeks 1-8*** and on evening shift during weeks 5-8*	Moderate No
Guétin et al. (2009)	RCT (30)	-T: Listening to recorded individualized music tailored to music preference (n=15) ; 20 minutes per week for 16 weeks -C: Reading and rest (n=15)	86.1; 73.4; mild to moderate AD; NH, France	Anxiety (HAS), depression (GDS)	-T > C: Reduction in anxiety at week 4**, 8***, 16***, 24***, in depression at week 4*, 8**, 16**, 24**	Strong Yes
Janata (2012)	RCT (38)	-T: Listening to recorded individualized music tailored to music preference, listening history, age, ADLs, where they grew up, and the time of day for appropriate tempo, instrumentation, and presence of vocals (n= 19); 4 times/	81.3; 65.8; severe; ALF, USA	Agitation (CMAI), depression (CSDD), behavioral disturbances (NPI)	-T = C -T, C > BL: Reduction in agitation***, depression***, and overall behavioral disturbances*** -	Moderate No

		several hours per day for 12 weeks -C: Usual care (n=19)				
Park & Pringle Specht (2009)	SSD (15)	T: Listening to individualized recorded music based on music preferences (30 min. x two times per week x 2 weeks prior to peak agitation time)	83.4; 73; severe; home, USA	Agitation (modified CMAI)	Significant reduction in agitation* during the intervention period compared to baseline and post-intervention periods	Moderate Yes
Sung et al. (2006)	QNC (57)	T: Listening to individualized recorded music based on music preferences (n=32); 30 min twice a week for 6 weeks C: Usual care (n=25)	No info about age, gender, and stages; LTC, Taiwan	Agitation (CMAI)	T>C* in overall agitation, T>C*** in physically non-aggressive behaviors	Weak No
Sung et al. (2010)	QNC (52)	T: Listening to individualized recorded music based on music preferences (n=29); 30 min in mid-afternoon twice a week for 6 weeks C: Usual care (n=23)	80.1; 44.2; moderate to severe; LTC, Taiwan	Anxiety (RAID)	T > C** at 6 week	Moderate Yes
Social activities individualized based on life experiences and past memories:						
(a) Individualized simulated presence therapy						
Camberg et al. (1999)	RMC (54)	-SPT audiotaped by family member (75%) or staff -Placebo audiotape: a recording of a person reading emotionally neutral articles from the newspaper (non-individualized, non-interactive) -Usual care -At least twice a day whenever the person exhibited an agitated or withdrawn behavior, each continued for 17	82.7; 77.2; severe; NHs, USA	-Daily staff observation log by blinded staff (agitation, withdrawal), and weekly staff survey (agitation using the CMAI, mood and interest using the	- Staff observation log: SPT > placebo, usual care in agitation*** and withdrawn behaviors*** -Staff survey: SPT > placebo**, usual care*** in interest (MOSES)	Strong No

		days over a 4-wk period and a 10-day washout period)		MOSES)		
Cheston et al. (2007)	SSD (6)	-SPT (B) audiotaped by spouse -Baseline conditions (no intervention/usual care): A1 (before intervention) and A2 (after the intervention) -21 periods of intervention and baseline conditions (No information on duration and content of the SPT)	83.3; 83.3; moderate to severe; NHs or hospital; England	Observation of distressed (e.g., asking or seeking to go home, hand-wringing) and pro-social (e.g., initiating positive interactions, talking calmly or happily) behaviors using the PRS	Significant reduction in distressed behaviors* during SPT(B) compared to A1 and A2	Weak No
Cohen-Mansfield & Werner (1997)	RMC (32)	- Ta: SPT videotaped by family member (87.5%) or surrogate person -Tb: Preferred music -Tc: One-to-on social interaction -C: Usual care (Each treatment: 30 min. for 2 weeks with a wash-out week)	86.8; 81.3; severe; NHs, Israel	Verbal agitation (tape recordings, standardized observations using the SBMI, and staff ratings using the CMAI)	Ta,Tb, Tc > C*** during intervention	Moderate No
Garland et al. (2007)	RMC (30)	- SPT audiotaped by family member -Preferred music -Placebo (neutral audiotape: a reading from a horticultural text) -Usual care (Each treatment : 15 min. once a day for three days over 3 weeks with a two-	79; 63; severe; NHs, Australia	Observation of target behaviors (verbal and physical agitation categorized using the CMAI)	-Physical agitation: SPT > placebo**, usual care**, music > usual care* during intervention; improvements during SPT, placebo, music maintained after 15 minutes - Verbal agitation : SPT, placebo >	Strong No

		day washout period)			usual care* during intervention; improvements during SPT and placebo maintained after 15 minutes	
Miller et al. (2001)	OPP (7)	-SPT audiotaped by family member when the resident displayed an agitated behavior (28 SPT sessions of 7 participants)	84; 85.7; moderate; LTC, USA	Observation of behaviors associated with agitation using 4 items of the HRS including language-conversation, social interaction, attention-awareness, and spatial orientation	Significant improvement* in two items of HRS (social interaction and attention awareness)	Weak No
Peak & Cheston (2002)	SSD (4)	-SPT (B) audiotaped by spouse -Baseline conditions (no intervention/ usual care): A1 (before intervention) and A2 (after the intervention) -No information on duration of SPT, 23 SPT sessions of 4 participants	74.3; 75; moderate to severe; hospital, UK	Observation of positive and negative behaviors using a modified PRS with 'anger' added	Significant reduction in distressed behaviors and increase in positive behaviors during SPT(B) compared to A1 and A2 in two participants having a secure attachment history	Weak No
Woods & Ashley (1995)	OPP (9)	-SPT audiotaped by established caregiver (twice a day in the scheduled time when behavior problems of each participant were anticipated) -A total of 425 episodes of target behaviors over the 2-month observation period	82; 77.8; moderate; NHs, USA	Observation of target behaviors categorized using the DBRS, including two rating scales, one for disruptive behaviors	Significant reduction*** in disruptive behaviors and social isolation	Moderate No

				(e.g., aggression, agitation, wandering), one for behaviors of affect (social isolation/withdrawal)		
Specific types of social activities individualized based on life experiences and past memories:						
(b) Individualized reminiscence therapy						
Chung (2009)	OPP (49)	Sharing positive and pleasurable life experiences from adolescence and adulthood with two to three youth volunteers and creating a personalized life story book (1.5 hours, weekly, 12 weeks)	79; 80; mild; day care centers, Hong Kong	Quality of life (QoL-AD), cognition (MMSE), depression (GDS)	Significant improvement in QoL-AD (mean change = - 1.91; 95% CI = -3.18, -0.64), GDS (mean change = 1.86; 95% CI = 0.92, 2.80)	Weak No

OPP: one-group pretest-posttest design, QNC: quasi-experimental/non-equivalent control group design, RCT: randomized controlled trial, RMC: repeated measures with randomized crossover, SSD: single subject design AD: Alzheimer’s disease, ALF: assisted living facility, BL: baseline, BPSD: behavioral and psychological symptoms related to dementia, LTC: long term care facilities, NHs: nursing homes

ABMI: Agitation Behavior Mapping Instrument, ADQRL: Alzheimer’s Disease Related Quality of Life scale, AVAS: Agitation Visual Analog Scale, CMAI: Cohen-Mansfield Agitation Inventory, CRAI: Copper Ridge Activities Index, CSDD: Cornell Scale for Depression in Dementia, DBRS: Disruptive Behaviour Rating Scale, DMPT: Dementia Mood Picture Test, GDS: Geriatric Depression Scale, HAS: Hamilton Anxiety Scale, HRS; Haycox Rating Scale, LMBS: Lawton’s Modified Behavior Stream, MDS: Minimum Data Set, MMSE: Mini- Mental State Examination, MOSES: Multi-dimensional Observation Scale for Elderly Subjects, MPES: Menorah Park Engagement Scale, NPI: Neuropsychiatric Inventory, OME: Observational Measurement of Engagement, PGCARS: Philadelphia Geriatric Center Affect Rating Scale, PDS: Passivity in Dementia Scale, PRS: Positive Response Schedule for Severe Dementia, QoL-AD: Quality of Life-Alzheimer’s Disease, RAID: Rating Anxiety in Dementia, SBMI: Screaming Behavioral Mapping Instrument, *p<0.05, **p<0.01, ***p<0.001, NS= not significant

Table 2. Quality Assessment of the Included Studies

Authors	Selection Bias	Study Design	Confounders	Blinding	Data Collection Methods	Withdrawals & Dropouts	Global Rating
Cohen-Mansfield et al. (2007)	W	S	S	M	S	S	M
Cohen-Mansfield et al. (2012)	W	S	S	M	S	S	M
Cohen-Mansfield et al. (2006)	W	S	S	M	S	S	M
Gitlin et al. (2008)	M	S	S	M	S	S	S
Fitzsimmons & Buettner (2002)	M	S	W	M	S	S	M
Kolanowski et al. (2005)	M	S	S	M	S	S	S
Kolanowski et al. (2011)	M	S	S	S	S	S	S
Mowrey et al. (2013)	W	M	W	M	W	M	W
Richards et al. (2005)	M	S	W	M	S	S	M
van der Ploeg et al. (2013b)	M	S	S	M	S	M	S
Van Haitsma et al. (2013)	W	S	S	M	S	S	M
Cohen-Mansfield et al. (2010a)	W	S	S	M	S	M	M
Cohen-Mansfield et al. (2010b)	W	S	W	M	S	M	W
Cohen-Mansfield et al. (2010c)	W	S	W	M	S	M	W
Cohen-Mansfield et al. (2011)	W	S	S	M	S	M	M
Leone et al. (2012)	M	S	S	M	S	S	S
Politis et al. (2004)	M	S	W	M	S	S	M
Gerdner (2000)	M	S	S	M	S	W	M

Gerdner (2005)	M	M	W	M	S	S	M
Guétin et al. (2009)	M	S	S	S	S	M	S
Janata (2012)	W	S	S	S	S	S	M
Park & Pringle Specht (2009)	M	M	W	M	S	S	M
Sung et al. (2006)	M	S	W	M	S	W	W
Sung et al. (2010)	M	S	S	W	S	S	M
Camberg et al. (1999)	M	S	S	M	S	S	S
Cheston et al. (2007)	M	M	W	M	S	W	W
Cohen-Mansfield & Werner (1997)	M	S	S	M	S	W	M
Garland et al. (2007)	M	S	S	M	S	S	S
Miller et al. (2001)	M	M	W	M	S	W	W
Peak & Cheston (2002)	M	M	W	M	S	W	W
Woods & Ashley (1995)	M	M	W	M	S	S	M
Chung (2009)	M	M	W	W	S	S	W

*M: moderate, S: strong, W: weak

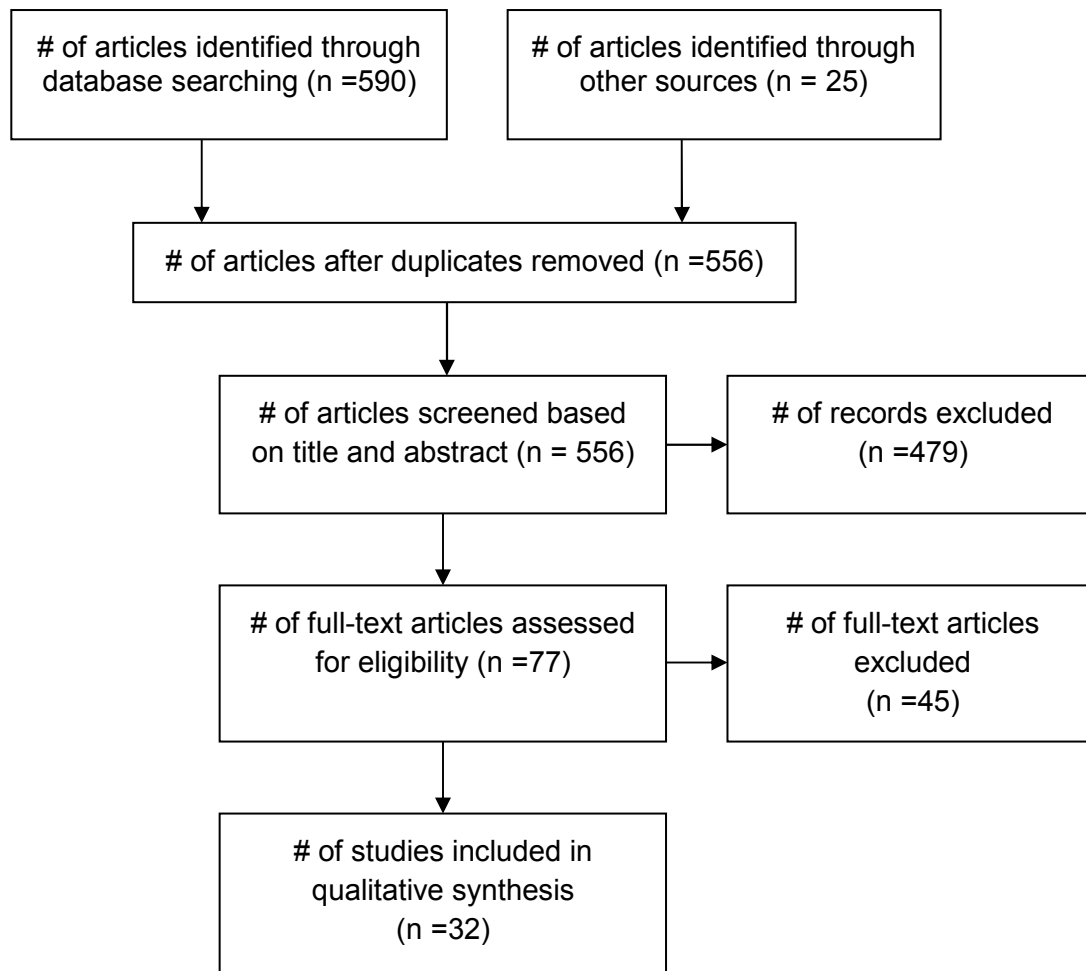


Figure 1. Flow of Studies through the Review Process. This figure illustrates the process in searching for and selecting studies based on the inclusion criteria.

Appendix: Search Terms Entered in Electronic Databases

Database	Search Terms
CINAHL	<p>TI ("dementia" OR "alzheimer's" OR "demented") AND ((MH "Individualized Medicine") OR (MM "Patient Centered Care") OR (MM "Self-Efficacy") OR (TI "person-cent*") OR (AB "person-cent*") OR (TI "patient-cent*") OR (AB "patient-cent*") OR (TI "client-cent*") OR (AB "client-cent*") OR (MM "Personal Values") OR (MM "Motivation") OR (TI "desire*") OR (AB "desire*") OR (TI "motivation*") OR (AB "motivation*") OR (TI "preference*") OR (AB "preference*") OR (TI "tailor*") OR (AB "tailor*") OR (TI "choice*") OR (AB "choice*") OR (TI "priorit*") OR (AB "priorit*") OR (TI "individualiz*") OR (TI "individualis*") OR (TI "self-chosen") OR (TI "self-decided") OR (TI "personaliz*") OR (TI "personalis*") OR (TI "empower*") OR (MH "Collaboration") OR (TI "collaborat*") OR (AB "individualiz*") OR (AB "individualis*") OR (AB "self-chosen") OR (AB "self-decided") OR (AB "personaliz*") OR (AB "personalis*") OR (AB "empower*") OR (AB "collaborat*")) AND ((MM "Interpersonal Relations") OR (MH "Friendship") OR (MH "Intergenerational Relations") OR (MM "Peer Group") OR (MH "Intimacy") OR (MH "Social Isolation+") OR (MM "Social Participation") OR (MH "Support, Psychosocial") OR (MH "Psychology, Social+") OR (MH "Social Environment") OR (MH "Social Networks") OR (MH "Socialization") OR (MH "Support Groups+") OR (MH "Leisure Activities+") OR (MH "Recreation+") OR (MM "Recreational Therapy") OR (MM "Art Therapy") OR (MM "Music") OR (MM "Music Therapy") OR (MM "Singing") OR (MM "Dancing") OR (MM "Dance Therapy") OR (MM "Handicrafts") OR (MH "Exercise+") OR (MH "Physical Fitness+") OR (MH "Sports+") OR (MH "Therapeutic Exercise+") OR (MH "Aerobic Exercises+") OR (MM "Group Exercise") OR (MM "Aquatic Exercises") OR (MM "Horticulture") OR (MM "Spirituality") OR (MM "Spiritual Care") OR (MH "Religion and Psychology+") OR (MH "Natural Environment+") OR (MH "Natural and Biologically Based Therapies+") OR (MH "Walking+") OR (MH "Storytelling+") OR (MH "Reading+") OR (MM "Reminiscence Therapy") OR (MM "Life History Review") OR (MM "Home Visits") OR (MM "Volunteer Workers") OR (MM "Volunteer Experiences") OR (TI "social activit*") OR (TI "leisure*") OR (TI "friend*") OR (TI "intergeneration*") OR (TI "social participation") OR (TI "social support*") OR (TI "recreation*") OR (TI "art") OR (TI "creativ*") OR (TI "music") OR (TI "danc*") OR (TI "craft*") OR (TI "garden*") OR (TI "exercise*") OR (TI "physical activit*") OR (TI "spiritual*") OR (TI "religio*") OR (TI "natur*") OR (TI "reminisce*") OR (TI "walk*") OR (TI "reading") OR (TI "volunteer*") OR (AB "social activit*") OR (AB "leisure*") OR (AB "friend*") OR (AB "intergeneration*") OR (AB "social participation") OR (AB "social support*") OR (AB "recreation*") OR (AB "art") OR (AB "creativ*") OR (AB "music") OR (AB "danc*") OR (AB "craft*") OR (AB "garden*") OR (AB "exercise*") OR (AB "physical activit*") OR (AB "spiritual*") OR (AB "religio*") OR (AB "natur*") OR (AB "reminisce*") OR (AB "walk*") OR (AB "reading") OR (AB "volunteer*") OR (TI "buddy*") OR (AB "buddy*") OR (TI "peer*") OR (AB "peer*") OR (TI "pair*") OR (AB "pair*") OR (MM "Pet Therapy")) NOT ((TI "caregiver*") OR (TI "carer*") OR (TI "caregiving*")))</p> <p>English Language; Peer Reviewed; Human; Publication Type: Journal Article; Age Groups: Aged: 65+ years</p>
PsycINFO	<p>TI ("dementia" OR "alzheimer's" OR "demented") AND ((MM "Individualism") OR (MM "Individual Psychology") OR (MM "Individual Differences") OR (MM "Individuality") OR (MM "Client Centered Therapy") OR (MM "Preferences") OR (MM "Empowerment") OR</p>

	<p>(MM "Self Efficacy") OR (MM "Collaboration") OR (MM "Desire") OR (MM "Values") OR (MM "Personal Values") OR (MM "Intrinsic Motivation") OR (MM "Psychological Needs") OR (TI "desire*") OR (AB "desire*") OR (TI "motivation*") OR (AB "motivation*") OR (TI "person-cent*") OR (AB "person-cent*") OR (TI "patient-cent*") OR (AB "patient-cent*") OR (TI "client-cent*") OR (AB "client-cent*") OR (TI "tailor*") OR (AB "tailor*") OR (TI "choice*") OR (AB "choice*") OR (TI "preference*") OR (AB "preference*") OR (TI "priorit*") OR (AB "priorit*") OR (TI "individualiz*") OR (TI "individualis*") OR (TI "self-chosen") OR (TI "self-decided") OR (TI "personaliz*") OR (TI "personalis*") OR (TI "empower*") OR (TI "collaborat*") OR (AB "individualiz*") OR (AB "individualis*") OR (AB "self-chosen") OR (AB "self-decided") OR (AB "personaliz*") OR (AB "personalis*") OR (AB "empower*") OR (AB "collaborat*")) AND ((MM "Interpersonal Interaction") OR (MM "Peer Relations") OR (MM "Interpersonal Relationships") OR (MM "Friendship") OR (MM "Intergenerational Relations") OR (MM "Social Groups") OR (MM "Social Networks") OR (MM "Peers") OR (MM "Peer Counseling") OR (DE "Peer Tutoring") OR (MM "Social Support") OR (MM "Social Interaction") OR (MM "Social Networks") OR (MM "Support Groups") OR (MM "Social Isolation") OR (MM "Online Social Networks") OR (MM "Socialization") OR (MM "Social Integration") OR (MM "Social Programs") OR (MM "Social Environments") OR (MM "Nature (Environment)") OR (MM "Leisure Time") OR (MM "Recreation") OR (MM "Recreation Therapy") OR (MM "Hobbies") OR (MM "Arts") OR (MM "Creative Arts Therapy") OR (MM "Painting (Art)") OR (MM "Art Therapy") OR (MM "Self Expression") OR (MM "Music") OR (MM "Music Therapy") OR (MM "Dance") OR (MM "Dance Therapy") OR (MM "Crafts") OR (MM "Exercise") OR (MM "Movement Therapy") OR (MM "Physical Activity") OR (MM "Horticulture Therapy") OR (MM "Spirituality") OR (MM "Nature (Environment)") OR (MM "Walking") OR (MM "Storytelling") OR (MM "Reading") OR (MM "Online Social Networks") OR (MM "Reminiscence") OR (MM "Life Review") OR (MM "Volunteers") OR (MM "Animal Assisted Therapy") OR (MM "Daily Activities") OR (TI "social activit*") OR (TI "leisure*") OR (TI "friend*") OR (TI "intergeneration*") OR (TI "social participation") OR (TI "social support*") OR (TI "recreation*") OR (TI "art") OR (TI "creativ*") OR (TI "music") OR (TI "danc*") OR (TI "craft*") OR (TI "garden*") OR (TI "exercise*") OR (TI "physical activit*") OR (TI "spiritual*") OR (TI "religio*") OR (TI "natur*") OR (TI "reminisce*") OR (TI "walk*") OR (TI "reading") OR (TI "volunteer*") OR (AB "social activit*") OR (AB "leisure*") OR (AB "friend*") OR (AB "intergeneration*") OR (AB "social participation") OR (AB "social support*") OR (AB "recreation*") OR (AB "art") OR (AB "creativ*") OR (AB "music") OR (AB "danc*") OR (AB "craft*") OR (AB "garden*") OR (AB "exercise*") OR (AB "physical activit*") OR (AB "spiritual*") OR (AB "religio*") OR (AB "natur*") OR (AB "reminisce*") OR (AB "walk*") OR (AB "reading") OR (AB "volunteer*") OR (TI "buddy") OR (AB "buddy") OR (TI "peer*") OR (AB "peer*") OR (TI "pair*") OR (AB "pair*")) NOT ((TI "caregiver*") OR (TI "carer*") OR (TI "caregiving*")))</p> <p>Publication Type: Peer Reviewed Journal; English; Age Groups: Aged (65 yrs & older); Population Group: Human; Document Type: Journal Article; Exclude Dissertations</p>
PubMed	<p>("Alzheimer Disease"[MeSH] OR "Dementia"[MeSH] OR dement*[Title] OR Alzheimer*[Title]) AND ("Patient-Centered Care"[MeSH] OR "Patient Participation"[MeSH] OR "Individuality"[MeSH] OR "Individualized Medicine"[MeSH] OR "Patient Preference"[MeSH] OR "Power (Psychology)"[MeSH] OR tailor*[Title/Abstract] OR choice*[Title/Abstract] OR priorit*[Title/Abstract] OR individualiz*[Title/Abstract] OR individualis*[Title/Abstract] OR self-chosen[Title/Abstract] OR self-decided[Title/Abstract] OR preference*[Title/Abstract] OR personaliz*[Title/Abstract] OR person-cent*[Title/Abstract] OR patient-</p>

cent*[Title/Abstract] OR client-cent*[Title/Abstract] OR empower*[Title/Abstract]) AND ("Interpersonal Relations"[MeSH] OR "Social Isolation"[MeSH] OR "Social Environment"[MeSH] OR "Social Participation"[MeSH] OR "Social Support"[MeSH] OR "Socialization"[MeSH Terms] OR "Loneliness"[MeSH Terms] OR "Friends"[MeSH Terms] OR "Self-Help Groups"[MeSH] OR "Leisure Activities"[MeSH] OR "Recreation Therapy"[MeSH] OR "Recreation"[MeSH] OR "Music"[MeSH] OR "Music Therapy"[MeSH] OR "Art Therapy"[MeSH] OR "Volunteers"[MeSH] OR "Peer Group"[MeSH] OR "Animal Assisted Therapy"[MeSH] OR friendship*[Title/Abstract] OR belonging*[Title/Abstract] OR connectedness[Title/Abstract] OR "social connection"[Title/Abstract] OR "social company"[Title/Abstract] OR companion*[Title/Abstract] OR "social participation"[Title/Abstract] OR "social engagement"[Title/Abstract] OR "social support*" [Title/Abstract] OR "social activities"[Title/Abstract] OR "social activity"[Title/Abstract] OR leisure[Title/Abstract] OR interest*[Title/Abstract] OR art[Title/Abstract] OR music*[Title/Abstract] OR creative*[Title/Abstract] OR hobb*[Title/Abstract] OR "Exercise"[MeSH] OR "Exercise Therapy"[MeSH] OR "Motor Activity"[MeSH] OR "Walking"[MeSH] OR exercise[Title/Abstract] OR physical activit*[Title/Abstract] OR walk*[Title/Abstract] OR "Nature"[MeSH] OR "Religion"[MeSH] OR "Spirituality"[MeSH] OR "Gardening"[MeSH] OR "Dancing"[MeSH] OR spiritual*[Title/Abstract] OR garden*[Title/Abstract] OR dancing[Title/Abstract] OR dance*[Title/Abstract] OR reminiscenc*[Title/Abstract] OR story-telling*[Title/Abstract] OR reading[Title/Abstract] OR buddy[Title/Abstract] OR peer*[Title/Abstract] OR pair*[Title/Abstract]) AND "humans"[MeSH Terms] AND English[lang] AND "aged"[MeSH Terms] AND Journal Article[ptyp] NOT (caregiver*[Title] OR carer*[Title] OR caregiving*[Title])

Chapter 3: The benefits of a person-centered social program for community-dwelling people with dementia: Interpretative phenomenological analysis

Abstract

This qualitative study aimed to explore the experience and impact of a person-centered social program for community-dwelling people in earlier stages of dementia. Semi-structured interviews with five people with dementia and their spouses were conducted 7-8 months after the program ended to assess persistence of the program's impact on people with dementia. An interview with each person with dementia went deeper and further, based on each person's salient experiences, having personally significant meaning and emotion. The present study used interpretative phenomenological analysis to support in-depth analysis of a small number of cases. Three main themes emerged for persons with dementia: theme 1) Participation in activities supporting self-identity; theme 2) The value of newly established intergenerational relationships; and theme 3) Empowerment (choice and control) and the student partner's attitude. These findings fill a gap in the literature, by demonstrating how a person-centered social program was experienced by and benefited community-dwelling people with dementia.

KEYWORDS: Alzheimer's disease; dementia; intergenerational relationship; personhood; qualitative research; social participation

Introduction

About 70% of an estimated 5 million older Americans with dementia live in the community, and the majority of them live with early to middle stages of dementia (Alzheimer's Association, 2014). People with dementia living at home tend to have higher quality of life, activities of daily living, and social connectedness compared to those living in institutional care, regardless of socio-demographic factors, cognitive severity, and depression (Nikmat, Hawthorne, & Al-Mashoor, 2013). Supporting community-dwelling people with dementia and their informal caregivers (such as family members) is important to help persons with dementia live well for as long as possible at home.

Dementia can affect identity, roles, routines, relationships, feelings, independence, and participation in meaningful activities (Bunn et al., 2012; Steeman, de Casterlé, Godderis, & Grypdonck, 2006). Studies suggest self-identity is not totally lost even in people with later stages of dementia, but aspects of self-identity may be compromised after onset of dementia (Caddell & Clare, 2010). Community-dwelling people with dementia experience threats to aspects of their self-identities by not being able to participate in activities with meaning for them, or to maintain meaningful roles and relationships due to the impact of dementia (Beard & Fox, 2008; Caddell & Clare, 2011; MacRae, 2011; Phinney, Dahlke, & Purves, 2013). Self-identity is a sense of self that is continually created, re-created, maintained, and expressed across the lifespan, through one's language use, participation in activities and roles, and relationships with others (Cohen-Mansfield, Golander, & Arnheim, 2000; Hewitt, 1991; Ray, 2000; Sabat & Harre, 1992). Self-identity also is a dynamic process that can be maintained, modified, or reshaped from ongoing interactions between the individual and social environment, as well as from participation in meaningful activities related to identity (Crichton & Koch, 2007). Living with dementia has been reported as a process of self-maintenance and self-adjustment in order to maintain continuity as the same person while, at the same time, incorporating a new self-identity as a person with dementia (Caddell & Clare, 2011; Van Dijkhuizen, Clare, & Pearce, 2006; Pearce, Clare, & Pistrang, 2002).

A growing literature has emphasized the importance of social interaction and relationships in maintaining self-identity of people with dementia (Genoe et al., 2010; MacRae, 2011; Smebye & Kirkevold, 2013). Symptoms of dementia and reactions to those symptoms, both by the person with dementia as well as others, may restrict and decrease opportunities for engagement in meaningful activities and relationships with others. Deliberate social withdrawal outside of the home may occur to avoid embarrassment or challenges to engaging in conversations, through worrying about reactions of others, and by feeling insecure about decreased cognition (Brataas, Bjugan, Wille, & Hellzen, 2010; Langdon, Eagle, & Warner, 2007; Vikström, Josephsson, Stigsdotter-Neely, & Nygård, 2008). A loss of meaningful relationships may also occur due to a lack of understanding of dementia or acceptance of symptoms by friends, thus leading to feelings of loneliness, depression, anxiety, and frustration on the part of the person with dementia (Logsdon, McCurry, & Teri, 2006; Moyle, Kellett, Ballantyne, & Gracia, 2011a; Vikström et al., 2008). Losing opportunities to engage in activities and relationships can threaten aspects of self-identity, even though people with dementia want to be socially connected and involved in community activities having meaning for them personally (Brataas et al., 2010; Dröes et al., 2006; Sørensen, Waldorff, & Waldemar, 2008). Providing opportunities for engagement in meaningful activities and relationships therefore is important for people with dementia, to maintain the continuity of preferred self-identity even as they experience losses and threats to some aspects of the self-identity.

Participating in intergenerational activity programs has been proposed as a way community-dwelling older adults with dementia can enrich their lives by having social relationships with younger persons and by fulfilling social roles (George, 2011). Positive benefits of intergenerational activity programs for community-dwelling people with dementia have been reported, including enjoyment, a sense of purpose and usefulness, improved quality of life, declines in stress levels and depression, and lessened feelings of social isolation (Chung, 2009; George, 2011; Harris & Caporella, 2014). However, these activities were chosen by researchers, with a focus on teaching roles to children (George, 2011), reminiscing activities with college students (Chung, 2009), or a specific leisure activity for a group of

people (an intergenerational choir; Harris & Caporella, 2014). The opportunity to choose the social activity featured in each of these programs was not given to each person with dementia, distancing the environment of these studies from being fundamentally person-centered.

Providing personally meaningful activities and positive social interactions is suggested as an important aspect of person-centered care aiming for maintaining self-identity, fulfilling psychosocial needs, and promoting psychosocial well-being of people with dementia (Dementia Initiative, 2013; Dröes et al., 2006; Edvardsson, Fetherstonhaugh, & Nay, 2010; Kelly, 2010). In person-centered care, the person is central by addressing the whole person as one who has a unique history, interests, preferences, needs, strengths, and abilities (Brooker & Woolley, 2007; McCance, McCormack, & Dewing, 2011). The person-centered approach to dementia care involves: a) valuing people with dementia; b) treating them as individuals; c) understanding the world from the perspective of the person with dementia; and d) providing a positive social environment where the person's psychosocial needs for occupation, identity, inclusion, attachment, comfort, and agency can be met (Brooker, 2004; Kaufmann & Engel, 2014; Kitwood, 1997). The importance of relationships with others in person-centered care is emphasized, through which the intrinsic value of individuals as unique human beings can be nurtured (Kitwood, 1997). People with dementia also may act as their own agents, maintaining self-identity through active engagement in activities, communication, and social interaction (Crichton & Koch, 2007; Davies, 2011; Smebye & Kirkevold, 2013).

Employing a person-centered approach in long term care settings and for people in later stages of dementia is good practice, with studies often having a focus on observing behaviors and task performance (Cohen-Mansfield, Libin, & Marx, 2007; van der Ploeg et al., 2013). By contrast, there is a lack of evidence on the impact of a person-centered social program for community-dwelling people with earlier stages of dementia, particularly through respecting individual preferences, supporting personal choice in activities, and providing positive social environments. A few qualitative studies report benefits of leisure and social activity programs for community-dwelling people with dementia, but the activities were in

group and chosen either completely or partially by researchers and/or therapists (Brataas et al., 2010; George, 2011; Phinney & Moody, 2011). Therefore, it is hard to know whether the provided activity itself was meaningful to each person with dementia. Moreover, any sustained benefits of such programs have not been explored, although conducting interviews several months after program implementation can be a feasible way to gain such insight (Brataas et al., 2010).

The University of Kansas Medical Center (KUMC) launched the KUMC PAIRS program in 2013, modeled after Boston University's *Partnering in Alzheimer's Instruction Research Study* (PAIRS; Jefferson, Cantwell, Byerly, & Morhardt, 2012). Both of these PAIRS programs grew out of the established *Buddy Program*TM at Northwestern University which was developed based on the theoretical concepts of person-centered care (Morhardt, 2006). The KUMC PAIRS program is organized as a service learning program, pairing community-dwelling people in the early to middle stages of dementia to first-year medical students. The KUMC PAIRS experience was intended to encourage medical students to improve attitudes, knowledge, and skills regarding the care of people with dementia. The KUMC PAIRS program promotes engagement of students and people with dementia in mutually chosen, one-on-one activities, and encourages flexibility in customizing individual's preferences and interests beyond existing social contacts and limited settings such as support group.

To date, the original Buddy Program and each of the similar replications have focused on student outcomes (Jefferson et al., 2012; Morhardt, 2006). The purpose of this study was to explore the experience and the impact of a person-centered, social program on community-dwelling people with dementia. I anticipated findings of the present study would help understand how such programs like the KUMC PAIRS program are experienced and whether benefits of the program persisted after the program ended, in the daily lives of people with dementia. New findings may accrue because the KUMC PAIRS program is distinct from the more typical group-based social programs with little flexibility for customizing group activities to accommodate individual preferences and interests.

Methods

This qualitative study used interpretative phenomenological analysis (IPA; Smith, Flowers, & Larkin, 2009) to focus on what the paired partner experience meant for each person with dementia taking part in the KUMC PAIRS program. The IPA method is suited to study of a very small sample (often three to six people for case comparisons) to emphasize in-depth analysis of single cases in their unique contexts, followed by a thorough search for patterns across cases. This method allowed researchers to identify themes shared among individuals while preserving the uniqueness of each individual's experience as it contributes to that shared theme. The intent was to explore the lived experience of individuals, and to achieve full understanding of an individual's perspective and experience through a dual interpretation process, in which a researcher made sense of individual's meaning making process. Semi-structured interviews were conducted 7-8 months after the KUMC PAIRS program ended and documented persistent elements of the PAIRS experience based on each person's salient experiences, having personally significant meaning and emotion.

Participants

People with dementia in the KUMC PAIRS program originally were recruited from the Alzheimer's Association-Heart of America Chapter, which serves 66 counties in Kansas and Missouri. Eligibility criteria for participation in the KUMC PAIRS program included: 1) having been diagnosed with dementia; 2) self-recognition of memory loss and some degree of recognition the loss may stem from dementia, as evidenced by a direct statement by the individual; 3) a willingness to interact with a first-year medical student as a dyad pair; 4) commitment to meeting with the same student for a minimum of 4 hours per month for 8 months; 5) ability to demonstrate an adequate ability to converse verbally; 6) no functional impairments requiring assistance or supervision by the student (i.e., assistance with toileting); 7) no psychiatric disabilities that may negatively affect an ability to engage in a meaningful relationship with the student ; and 8) a willingness to complete evaluation questionnaires. These eligibility criteria were confirmed by a social worker of the Alzheimer's Association-Heart of America Chapter, who was

well-acquainted with each individual with dementia. A total of 13 participants with dementia meeting these criteria were paired with 13 medical students, based on a compatibility of interests and demographic preferences. The directors of the KUMC PAIRS program met with each student individually to facilitate the best match possible.

All 13 people with dementia who participated in the KUMC PAIRS program from September 2013 to April 2014 and their primary informal caregivers (e.g., family members) were invited to participate in the present study. An affiliate of the Alzheimer's Association and the KUMC PAIRS program introduced this research opportunity to potential participants as the program concluded in late April, 2014. I then met with interested participants having dementia and with their caregivers, to provide detailed information about the study. At that time, seven participant-caregiver dyads consented to take part when the study commenced in December, 2014. Of the 7 dyads that consented, we excluded one man (and his caregiver) who exhibited symptoms consistent with more advanced stages of dementia. The remaining six dyads were contacted again in December, 2014 to confirm they remained interested in study participation. Two of these dyads declined to participate (one due to a death). One additional participant-caregiver dyad from the original 13 KUMC PAIRS participants consented to take part in the study in December, 2014.

Five people with dementia (3 men and 2 women) participated in the present study (Table 1). All participants were self-described as being non-Hispanic White, aged between 64 and 89. The number of years since diagnosis varied for these participants with dementia, ranging from one to six years. Participants with dementia all were retired, attending a daytime activity group twice a week (from 9 a.m. to 3 p.m.), and a monthly support group with their caregiver spouse (twice a month in the evening) at the Alzheimer's Association during the KUMC PAIRS program period.

Procedures

IRB approval for the study was obtained (HSC #00000561). Participants were recruited in December, 2014, and informed consent was obtained from each person with dementia and from the

caregiver. Face-to-face interviews were conducted in the homes of participants seven to eight months after the KUMC PAIRS program ended. All participants were asked to complete demographic information forms before the interview started.

Interviews

All the interviews took place between mid-December, 2014 and mid-January, 2015. A semi-structured format was used for interviews as this is the optimal method to collect data for analysis when using IPA (Smith et al., 2009). A flexible interview process (see Appendix 7) was prepared as a general guide, based on recommendations made by Smith et al. (2009). Each interview began with a general question asking about the experience of participating in the KUMC PAIRS program and included open-ended questions with general, non-directive remarks used to encourage further explanation or elaboration on the initial statements about the experience. Minimal open-ended probes were used such as “Can you tell me more about that?”, “What do you mean by that?” and “How did you feel about that?” Further open-ended questions were used to seek information about the perceived impact of the KUMC PAIRS program on the persons with dementia themselves. Interviews with people with dementia were intended to explore each person’s salient experiences with personal meaning and emotion even 7-8 months after the program ended. All interviews were audio-recorded with consent of participants.

The first phase of an interview began by speaking just with the person with dementia, without allowing the caregiver to speak during this initial phase. Each caregiver was free to leave or stay during this phase (two caregivers remained present; the other three left the room). The second phase of the interview involved conversing with both the person with dementia and the caregiver together. This strategy was adopted to allow collection of insights from the person with dementia without influence by the caregiver, while also allowing a later opportunity for the caregiver to provide supplementary insight and commentary. Interviews lasted between 55 and 82 minutes, with a mean of 70 minutes.

Data Analysis

Audio recordings of interviews were transcribed verbatim and analyzed according to IPA methods, following the series of steps described by Smith et al. (2009). Each interview transcript was read closely and multiple times to become familiar with the content. Notes about key points were recorded in one margin while reading each transcript, focusing on content, language use, context, observations made during the interview, and initial interpretations. These notes were transformed into emergent themes and recorded in the opposite margin. Emergent themes were examined for connections. As the clustering of themes emerged, the transcript text was re-checked to certify the abstracted connections remained valid when the actual words of the participant were considered. This iterative process involved a close interaction between researcher and text, with constant checking of interpretation and meaning against what the participant actually said. This process strengthened analytical rigor by verifying themes reflected actual data. A list of themes for the interview transcript of each participant was compiled with all relevant extracts. Repeating patterns were sought and new emerging issues were identified across participants, to illustrate shared themes (similarities) and differences within these shared themes.

Specific strategies were used to increase trustworthiness of this data analysis. Member checking was used actively during interviews by a process of reflecting and probing. Member checking at the end of the interview was done again, to verify a correct understanding of what the participant had said and meant. Including caregivers in the second phase of the interview allowed for data triangulation as well as for understanding the caregiver's perspective. One of two research assistants checked the accuracy of transcripts before data analysis began. The IPA process requires researchers to document decision points, to track how a participant's accounts transformed to the themes. Weekly meetings among investigators took place during data extraction and analysis to ensure emerging themes were well-grounded and represented in the transcripts.

Results

Three main themes emerged for persons with dementia, including: 1) Participation in activities supporting self-identity; 2) The value of newly established intergenerational relationships; and 3) Empowerment (choice and control) and the student partner's attitude (Figure 1). The participant quotes reproduced here have been modified to improve readability, by adjusting grammar and eliminating pauses and filler words (e.g., umm, "you know") while being careful to avoid altering the participant's inherent meaning.

Theme 1. Participation in Activities Supporting Self-identity

The KUMC PAIRS program promoted engagement in activities supporting self-identity of each person with dementia. Participants with dementia reported they found enjoyment in PAIRS activities, and they also found PAIRS activities were easy to do when these activities aligned with their self-identity. Descriptions of self-identity tended to emerge naturally and without prompting as the participants with dementia spoke during the interview about experience of the KUMC PAIRS program and about their daily lives.

Subtheme 1a. I enjoyed PAIRS because of the continuity of my self-identity. Participants with dementia appeared to enjoy the KUMC PAIRS program because it promoted participation in activities having personal meaning for these people. This supported the continuity of the self-identity of each person with dementia. The self-identity of two female participants related to their personality traits exemplifies this continuity: the continuity of self-identity as a family-oriented person (Julie), and the continuity of self-identity as an active and social person (Chloe). Three male participants' self-identities also were supported. These included self-identity related to leisure activities (Paul and Albert) and self-identity related to a past profession (Victor).

Julie enjoyed having family-oriented time with her student partner. She regards herself as a "very family-oriented" person. She particularly enjoyed hearing about her student partner's family and meeting each others' family for dinner. Julie believes being family-oriented means "doing family things" and

“being connected to others like a family.” Julie reported she has nurtured this trait for her entire life feeling others as a part of her family such as her neighbors, her high school friends, and her helpers. Having family-oriented time with her student partner aligned the activity with this important aspect of Julie’s self-identity. Julie reported the presence of her family circle and feelings of being supported by those people have helped overcome her fears and frustration arising from current and possible future impact of dementia. Engaging in family-oriented activities, such as those with her student partner, provide Julie with enjoyment, satisfaction, and feelings of being supported.

Julie: I enjoyed hearing about her [Julie’s student partner] family and her little boy and her husband. I’m very family-oriented and it is so matched for me. This was always pleasant. I enjoyed having her meet some of my family because they were such a nice couple and a cute little boy. ...

Being active and social is a large aspect of Chloe’s self-identity. Participation in the KUMC PAIRS program was an opportunity for Chloe to feel more active and socially engaged by doing different, personally meaningful activities with a new person outside of her immediate family and outside of her group at the Alzheimer’s Association. Chloe reported she and her husband were not that active in finding something else to do and they were bored by doing the same things. Participation in the KUMC PAIRS program served as an outlet for Chloe, whose expression of self- identity through activities had become limited. Chloe reported this was because she experienced uncomfortable feelings and a fear of being identified as an individual with dementia outside of these restricted settings. Chloe reported, however, she felt comfortable when meeting with medical students at the orientation of the KUMC PAIRS program, because she was with “her friends” at the Alzheimer’s Association, so she was not the only person singled out as having dementia. She also reported the KUMC PAIRS program was a setting where she felt a sense of belonging, and said she enjoyed talking about the KUMC PAIRS program with her group at the Alzheimer’s Association. Socializing with a new person through the KUMC PAIRS program may serve as a good medium to link people like Chloe to the larger community. The KUMC

PAIRS setting gave Chloe opportunities to do different, meaningful activities in the community and to feel more active and more social while also feeling both included and comfortable.

Chloe: I think it [participation in the KUMC PAIRS program] gives us an outlet to be just not in my home and just not in our place [group at the Alzheimer's Association]. There's an opportunity to get out and be in the community.

The self-identity of both Julie and Chloe was related to existing personality traits that were supported through participation in the KUMC PAIRS program. By contrast, participation in the KUMC PAIRS program provided Victor with what he described as an “enjoyable” opportunity to maintain continuity of his self-identity related to his past profession. Victor had earned a PhD in microbiology and had attained the rank of professor in a medical school. He reported enjoying sharing past work experience with his student partner, and learning about changes in his profession. Posing a question and discussing the answer with his student partner were familiar activities for Victor, in his prior role as a scientist who worked with students and collaborated with colleagues. Having these exchanges with his student partner supported Victor's self-identity by promoting a connection to his past profession. The PAIRS program also provided an opportunity for Victor to assume a mentoring role with medical students, similar to his past role as a professor in a medical school. Victor expressed his desire to help medical students, saying “it was nice to know them [medical students of the KUMC PAIRS program] and try to help them if they had a question” (Victor). Victor's wife said he had been very involved with students during his career, and that his participation in the KUMC PAIRS program gave him a chance to resume that role and to become “Dr. Victor” once again. Having opportunities to meet medical students and help them learn clearly was a new and rewarding opportunity for Victor, supporting his self-esteem and the continuation of a pre-existing self-identity.

Victor: What did I enjoy? There were things that I had worked for about 15 years ago, so there were a lot of changes for me. I learned a lot about what was going on, so, it was

good for me to get to be with it. We asked questions or say “Oh, I wonder how they did that.” If neither one of us knew, we got together and found out what was happening.

The self-identity of two participants, Paul and Albert, related to leisure activities that were supported through the KUMC PAIRS program. Paul said he enjoyed all the activities he did with his student partner because going to art galleries, plays, and the symphony had been Paul’s valued leisure activities throughout his adult life. Early in the KUMC PAIRS program, Paul proactively suggested activities they did based on his leisure interests: “What we did was mostly my suggestion. We did things that I enjoyed” (Paul). Paul described himself as an outgoing person who enjoys socializing with people by sharing his interest in the arts. Engagement in his leisure activities with a new person through the KUMC PAIRS program was an enjoyable opportunity for Paul to feel the continuity of his self-identity as an outgoing person who enjoys sharing his leisure interests. Paul’s wife spoke about the pleasure that Paul derived in introducing his student partner to aspects of the city as they pursued these activities, since Paul’s student partner was not familiar with the city: “Paul took pleasure in it. He felt he was giving a service to upcoming doctors, and understanding something about his environment because Paul’s student partner didn’t grow up in it” (Paul’s wife).

Albert had required his wife’s involvement in choosing activities for the KUMC PAIRS program due to more progression in dementia, and she did so based on the couple’s long-standing shared interests in music and the arts as leisure activities. Although Albert was unable to recall anything related to the KUMC PAIRS program that ended 7 months earlier, he enthusiastically expressed his self-identity related to music and the arts with joy and excitement. Albert spoke frequently, and often for extended periods without pause, on these topics during the first phase of his interview, making statements such as “Music has been part of our lives since I was born.” and “We’ve been very active in supporting the arts and music.” A review of Albert’s transcript documents how strongly he perceives his self-identity to be related to these activities, his enjoyment being engaging in these activities, and in happily recalling memories related to the couple’s experiences with music and the arts. His wife spoke about the couple’s

difficulty in continuing their participation in these activities because of his frustration at not being able to drive by himself. The KUMC PAIRS program was an opportunity for Albert to engage in leisure activities he had valued, along with a new younger person. Albert's wife described this emotional support: "With his student partner was like being on a date. I mean it really perked him up and that lifted his spirits."

Subtheme 1b. It was easy to participate in PAIRS. Paul and Julie were two participants with dementia who each stated explicitly that participation in the PAIRS program was easy. This may have been because the activities also were aligned with aspects of the self-identity held by these participants. Paul said he found participation easy because he found "pure joy" when engaging in the familiar activities he had enjoyed, such as going to an art gallery or a play rehearsal, and talking about the arts generally: "I enjoyed the program. It was easy to participate because of the pure joy of certain things. I didn't find it uncomfortable and it wasn't even challenging" (Paul). Julie felt it was easy to talk to her student partner when having family-oriented time, a situation aligned with her self-identity: "We had no problems in talking. I mean our conversations were not strained. They were very easy. I liked to hear about her son" (Julie). Although the ease of participation in the KUMC PAIRS activities was not mentioned by other people with dementia explicitly, they did not express finding it difficult to participate. For these people, the ease of participation in their different activities may have been an unremarkable aspect of doing pleasurable activities aligned with their own self-identity, interests, and values.

Theme 2. The Value of Newly Established Intergenerational Relationships

Four of the five participants reported the KUMC PAIRS program promoted new, satisfying relationships with the student partners, by establishing a friendship based on sharing of life interests, by feeling as if the student partner was a proxy daughter, or by assuming a maternal role with the student partner. These newly established relationships persisted over the 7-8 months after the KUMC PAIRS program came to an end, with participants with dementia reporting continuing feelings of emotional closeness and affection, despite no further contact with the student partners except Paul.

Subtheme 2a. Friendship by sharing life interests. Two male participants (Paul and Victor) regarded each of their student partners as a good friend and referred to their student partners as “my friend” several times during the interview. The other male participant (Albert) with more progressed dementia also may have felt friendship with his student partner based on statements made by his wife.

The friendship between Paul and his student partner developed through sharing leisure activities as Paul guided his student partner to leisure sites in the community: “I selected the art gallery and we went to a theater that I am familiar with. We went to a play rehearsal which I enjoy” (Paul). Visiting an art gallery, attending live theater and symphony concerts, and discussing arts and movies were Paul’s most valued leisure activities. This relationship did not, however, develop necessarily because the student partner had the same leisure interests as Paul; rather it was because Paul felt his student partner was very compatible despite their difference in age and life experience. Paul and his wife both suggested this compatibility may have arisen because they shared outgoing personality and the student partner seemed to enjoy Paul’s leisure activities. Enjoyment and the satisfying aspect of the relationship appears to have developed through interacting with a compatible partner, who enjoyed the time the pair spent together through sharing Paul’s leisure interests.

Victor reported developing an enjoyable, new friendship with his student partner based upon sharing their mutual interests in medicine. Victor’s wife stated that, as a professor in a medical school, Victor developed actual friendships with his students in addition to professor-student relationships. Both Victor and his wife reported having a new friend through the KUMC PAIRS program was particularly meaningful to Victor, because this couple was new to Kansas City and had a few acquaintance and friends when the KUMC PAIRS program began. Going out with the student partner and spending time together became personally meaningful to Victor: “[The best part was] being with him [his student partner]. Talking with him about various things that were going on and what he was doing” (Victor). Victor’s wife stated her husband’s participation in the KUMC PAIRS program enriched his life and elevated his spirits.

Because Albert was unable to recall taking part in the KUMC PAIRS program, directly determining if he felt friendship with his student partner is not possible. Instead, his wife reported his elevated spirits when Albert was with his student partner and they engaged in those activities chosen based on his leisure interests. Albert's wife also said visiting community sites related to his leisure interests in music and the arts "gave him something to talk about with his student partner." This may be interpreted as supporting the possibility Albert enjoyed having a new friendship with his student partner by sharing his leisure interests.

Subtheme 2b. A proxy daughter and maternal roles. Julie regarded her student partner as another daughter, while the other female participant, Chloe, assumed a maternal role with her student partner according to Chloe's husband.

Julie reported that living far away from her own daughters had been hard because she was very family-oriented and she felt emotionally close to her daughters. Julie emphasized physical distance in relationship with her family several times during her interview, when she was speaking about her daughters who live far away and about a sister who lives very close. Julie described herself as a "touchy-feely person" who "likes to get hugs." Julie said she felt as if her student partner was like another daughter. With her student partner, Julie could experience physical and emotional closeness similar to when her own daughters lived nearby. Inviting the student partner's family to Julie's family dinner was one instance she mentioned specifically and several times during her interview, and event that took place because Julie felt her student partner was a part of Julie's family. Enjoying time spent with the student partner, who Julie regarded as another daughter, might help Julie maintain her valued mother-daughter relationship by being physically and emotionally close.

Julie: I have two daughters I adore who are living in California and Ohio. So, she [the student partner] was my other... ha ha... little one. I am very close to my daughters and I miss them so much, so having her [the student partner] come was really an added bonus for me. ... That's just what I nurture. I mean that's what I want because I am close to my

family, and I was close to my children. It's been a very hard thing for me that neither of my daughters lives close.

Unlike Julie, Chloe did not directly state if she felt her student partner like another daughter. Chloe did describe the relationship with her student partner as being an enjoyable, good relationship. Chloe's husband, however, spoke about Chloe assuming a very maternal role during the KUMC PAIRS program period: "There was some mother-daughter relationship. My wife was very maternal toward the student" (Chloe's husband). Chloe was unable to recall details of the activities she and her student partner did together, and this may underlie difference in this couple's descriptions on this aspect of the relationship. Chloe did remember going to a Pumpkin Patch in the fall with the student partner and the student's young children. Chloe described that she had "a lot of fun" because playing with young children at the Pumpkin Patch was something she enjoyed doing with her own children when they were younger. Chloe met her student partner four times fewer than Julie due to scheduling conflicts, and this may have been a factor influencing the strength of her relationship with the student partner.

Subtheme 2c. Sustained emotional closeness. Three of the five participants with dementia (Paul, Julie, and Victor) strongly expressed the continued emotional closeness with their student partners although only Paul reported continued contact with his student partner once the program ended. His outgoing personality, active engagement, and positive attitude in the relationship may be factors supporting the continued contact. Paul's student partner also made him feel comfortable about seeking further contacts: "He [Paul's student partner] had made it clear that Paul can call him [the student partner] any time" (Paul's wife).

Julie and Victor, on the other hand, did not seek further contact with their respective student partners. These two participants reported they still felt very close to their student partners at the time of the interviews and they expressed a strong desire to meet again with the student partners. Examples of such statements include: "She [her student partner] and her whole family were just sweet. That's how I feel about. They are in my heart. I couldn't be any closer. They are just important to me." (Julie); and

“I’d like to much see him [his student partner] and find out what he has been doing” (Victor). Not seeking further contact might be due to Victor’s more passive attitude in the relationship by waiting his student contact: “If my boy [his student partner] would call me back, I would go immediately” (Victor). Knowing the student partners are busy with medical school may possibly cause Julie and Victor to wait for the students to initiate contact rather than contacting the students themselves: “I really haven’t kept in touch with her [the student partner] because I knew she is a student with a little one.” (Julie); and “He [the student partner] was very busy. Medical students are really busy, and he was trying to be the top of the students” (Victor). Retained emotional closeness with the student partners, despite having limited contact or no contact at all for over half a year, attests to a persistent positive effect of the KUMC PAIRS experience for these participants with dementia.

Theme 3. Empowerment (Choice and Control) and the Student Partner’s Attitude

The KUMC PAIRS program provided community-dwelling people in earlier stages of dementia with degree of empowerment, by maximizing their personal choice and control over the PAIRS activities. In practice, participants reported experiencing varying levels of choice and control depending upon the student partner’s attitude and approach. The juxtaposition of two participant’s descriptions of their PAIRS experience illustrates the most (Paul) and the least (Victor) empowering experiences emerging from the present study.

Paul’s experience demonstrates a positive example applying a person-centered approach effectively, with a direct outcome of empowering this participant despite his diagnosis. Paul’s student partner ceded all control and choice in deciding activities to Paul, freeing Paul to choose activities based solely on his own interests. Paul stated he initially faced a degree of challenge in planning activities by himself for activities the pair could do together. Paul reported he easily overcome this challenge because his student partner was accommodating, with the student partner agreeing to all the activities Paul proposed: “My pair was so easily adaptable to anything I wanted to do. I think I even thought of going to a baseball game at one point and he [the student partner] would be agreeable to do that” (Paul). Paul also

felt that his student partner seemed to enjoy the activities Paul chose as well as the time they spent together. His student partner's supportive attitude served to increase Paul's confidence and motivation for planning activities. Maximizing Paul's freedom to choose activities and supporting both his control in the relationship and his participation in activities may have further contributed to Paul's enjoyment of the KUMC PAIRS experience and to his satisfaction with the program in general. Paul also described the relationship with his student partner as being a "two-way partnership" and as a "very pleasant relationship", suggesting Paul's perspective included having an equal, satisfying relationship with his student partner.

By contrast, Victor's experience illustrates the consequences when the person-centered approach is lacking. Victor experienced much less choice or control in deciding activities and in the relationship with his student partner generally. Victor's student partner decided upon the activities they did together: "I didn't let him [hi student partner] choose activities. He wanted to do. Ha Ha. I didn't ask him to do it" (Victor). With one exception (an art gallery visit), this pair established a routine of watching a movie at a movie theater and then going out to a restaurant, doing this activity 7 times in 8 months. Because Victor was very new to the city, he said that he wanted to go to different, interesting places in the city rather than repeatedly going to the movie theater during the interview. Based on statements by both Victor and his wife, his student partner was very busy, both as a first year medical student and by being involved in another research project. This couple, especially Victor, stated several times with emphasis that his student partner was very busy: "He [Victor's student partner] wanted to see the movies. He is really busy [emphasizing]" (Victor). Despite his desire to explore new settings, Victor exhibited a passive attitude and did not insist upon altering his student partner's plans. Victor also was diagnosed with dementia 6 years previously, the longest of any participant in this study, and routinely experienced the memory lapses and diminished cognitive functions associated with dementia. It seems possible Victor's more passive attitude, his difficulty in coming up with names of places, and his unfamiliarity with living in a new city might have been contributing factors for why his student partner assumed control when deciding the

PAIRS activities. As their meetings continued, the meetings assumed a routine structure of going to a movie and then eating at a restaurant afterward. Although Victor regarded his student partner as a friend and spoke of enjoyed time with the student partner because of a shared interest in the medical profession, Victor's current interests and his preference for going to new, different, interesting places as a new comer to the city were not recognized and valued by his student partner. During his interview 7 months after the KUMC PAIRS program ended, Victor expressed his feelings of being disempowered and helpless in the relationship with his student partner when his student had much control in deciding activities and in the relationship generally. Victor talked about the unequal relationship with his student partner: "He [the student partner] was the boss and I was just an old man standing" (Victor). Victor was the only participant who expressed a desire for all PAIRS groups to gather together in order to discuss the activities of each PAIRS group, and what assistance each group needed. Victor's experience illustrates the important need for including training on person-centered approach to the paired students to make the ideal program structured to be person-centered.

Discussion

The findings of this study demonstrate a person-centered, social activity program, like the KUMC PAIRS program, can support the continuity of self-identity, help establish a new, satisfying relationship with a younger person, and provide opportunities to be empowered by maximizing personal freedom to choose activities. No previous studies of group-based activity programs have explored whether these activity programs could support the self-identity of each person with dementia (e.g., Phinney & Moody, 2011). Participants with dementia also found enjoyment and participation in the KUMC PAIRS program to be easily accomplished, through engaging in personally meaningful activities they themselves had selected to align with their self-identities and interests. This was a direct outcome emerging from how the KUMC PAIRS program was implemented, with each person with dementia encouraged to choose activities in which to participate with a younger person over an extended period of time in the community. A factor determining the degree of success for this arrangement was having the student partner recognize

and respect preferences and interests of a person with dementia. The statements of several participants documented how the student partner's attitude influenced the level of empowerment in people with dementia, through prohibiting or providing them with the freedom to choose activities and the autonomy to control participation in those activities and the PAIRS partnership. The findings also suggest a social activity program can produce sustained feelings of closeness with a younger person, even over a half year after the program ends. No prior study has explored whether intergenerational social activity programs provide sustained social benefits for people with dementia (e.g., George, 2011). The sustained emotional closeness of people with dementia for their student partners might have occurred because the people with dementia developed emotional ties to the younger partners over the 8-month long program, through repeatedly sharing leisure interests or sharing life experiences having personally significant meaning.

The KUMC PAIRS program allowed people with dementia to be empowered by having freedom to choose activities, and control over participation in those activities. Empowerment is defined as a process in which a person actively engages in decision-making and control over one's life (Linhorst, Hamilton, Young, & Eckert, 2002). Notably, as in the cases of Paul and Victor, the perceived degree of benefit related to the level of choice and control, and depended on the attitude and approach of individual student partners. Facilitating participation in decision making and meaningful activities by respecting the perspective of people with dementia is a means to maintain self-identity and promote personhood (Smebye & Kirkevold, 2013). People with dementia may not be given the opportunity for decision-making and personal choice by others who assume an inability of people with dementia in self-determination although the majority of people with dementia may have retained ability (Sabat, 2005). Previous studies report community-dwelling people with dementia do consider activities particularly meaningful and important in enhancing their quality of life when opportunities for enjoyment, positive social interaction, and self-determination are present (Dröes et al., 2006; Phinney et al., 2007; Smith et al., 2005). Self-determination facilitates intrinsic motivation, and well-being and intrinsic motivation may be enhanced by promoting self-determination, relatedness, and competence (Ryan & Deci, 2000). How

much the student partner respected the values and interests of each person with dementia may have influenced how much that person felt empowered and competent in the relationship by supporting feelings of connection and comfort (Mok, Lai, Wong, & Wan, 2007).

The present study supports the concept that participation in activities extending beyond existing social contact with immediate family and through support groups can benefit people with dementia as they experience changing roles or relationships, as access to friends changes, or as the individual experiences more limited social engagement with their community (Davies, 2011). Although new friendships and companionships may occur by participating in support groups or a community-based social recreation programs designed for people with dementia (Phinney & Moody, 2011), such opportunities may not meet an individual's psychosocial needs fully. This may be because such support groups often limit participation to people with dementia rather than a wider range of people and abilities, and because the focus, activities, and interactions of the group may not be aligned with the self-identity of the person with dementia. Participants with dementia and their caregivers in the present study spoke about the value of being in the larger community while participating in personally meaningful activities and developing a new social relationship with a younger person. This suggests a need for more social programs that engage people with dementia more actively in their community, beyond a diagnosis-specific support group. Community-dwelling people with dementia appreciated activities related to places where they had visited in the past, to their own life histories, and to regional history when they have lived their lives in that same area (Brataas et al., 2010). Target locations for activities and the activities themselves should therefore be different depending on each person's interests and life experiences. In addition, three participants with dementia or their spouses of the five couples reported most of their social contacts were older adults and they were not able to visit their children and grandchildren as often as they wanted. Socialization with younger people provide people with dementia opportunities for developing an enjoyable relationship with younger persons, and to assume roles like friends, parents, or grandparents (Chung, 2009; George, 2011; Harris & Caporella, 2014; van der Ploeg et

al., 2013). Talking about and sharing past memories and life experiences also support people with dementia in expressing, maintaining, and recovering a sense of identity, offset their current difficult situations, normalize difficulties, and make them not feel alone (Keller et al., 2010; Molyneaux, Butchard, Simpson, & Murray, 2012; Moyle et al., 2011b).

The participants with dementia reported they experienced threats to some aspects of self-identity. All participants expressed or demonstrated frustration due to the negative impact of dementia in their daily lives. For example, not being able to remember names of friends was frustrating and irritating to Julie who enjoys socializing with people. Chloe also expressed embarrassment and frustration when she was identified in a public setting as a person with dementia because of memory lapses. Not remembering names of people and having memory loss revealed in public also has been reported by others as contributing to making people with dementia feel embarrassed, lonely, and disconnected from others (Moyle et al., 2011a). Not being able to drive was a threat to Albert's self-identity, as he had been the primary driver for the couple. His frustration with not being able to drive led to disagreements and prevented Albert and his wife from participating in community activities in music and the arts. Both of Albert's and Victor's wives also reported their husbands' experienced weakened social ties with friends and encountered being "invisible" in interactions among groups. Similar threats to self-identity of people with dementia have been reported (Beard & Fox, 2008; Caddell & Clare, 2011). Providing opportunities for participation in activities that support self-identity help people with dementia to maintain a sense of continuity while experiencing such threats to identity (Genoe et al., 2010; Steeman, Tournoy, Grypdonck, Godderis, & De Casterlé, 2013). The present findings support the concept that self-identity of people with dementia may be maintained and promoted through participation in personally meaningful activities, and this contributes to a positive influence on mood and quality of life of people with dementia (Caddell & Clare, 2012).

The present study has several particular strengths. This study explored perspectives of both people with dementia and their spouses, by first interviewing the person with dementia alone, and later

interviewing the couple together. A growing literature demonstrates value in jointly interviewing couples (Davies, 2011; Molyneaux et al., 2012; Robinson, Clare, & Evans, 2005). Co-constructed experiences and consensus may better be revealed when more than one person collaborate to filling gaps in each other's stories and recollections (Davies, 2011; Molyneaux et al., 2012). Joint interviewing also encourages the person with dementia to feel comfortable in expressing him or herself by providing an atmosphere of equality and support (Davies, 2011). Interviewing the person with dementia without contributions or direction from the spouse provides an opportunity for the person with dementia to express opinions and perspectives that differ from those of the spouse (Harmer & Orrell, 2008). The present study also interviewed participants more than half a year after the KUMC PAIRS program ended, permitting an exploration of the sustaining impact of the KUMC PAIRS program on participations months after the program ended. By interviewing participants 7-8 months later, particularly in this study population, a more clear understanding of which aspects of the PAIRS program were most salient and persisted for an extended period without being reinforced by regular contact with the PAIRS partner.

The present study also must be considered in relation to potential limitations. The study employed a cross-sectional qualitative design in which participants were interviewed only one time, over half a year after the KUMC PAIRS program ended. This is useful from the perspective of assessing those aspects of the 8-month long program that persisted for the next half year, although interviewing participants with dementia more than once may better capture changing perspectives or perceptions about benefits of the program. This may be particularly useful given the nature of cognitive and memory impairments that characterize dementia. Including spouses in the second phase of the interview in this study, however, complemented the initial interview. This aspect of the study's design provided an important means to supplement information and capture elements otherwise having potential to be missed, and to enhance or clarify details of the initial narrative. Interviewing soon after program participation ends and at least once again after a span of time offers the potential to better capture changes in feelings and shifting perspectives about program participation.

Conclusions and Implications

The way people with dementia participated in activities and socialized with the student partner through the KUMC PAIRS program generally aligned with a person-centered approach, although individual differences in the quality and extent of person-centeredness were documented. The KUMC PAIRS program was structured to be person-centered, recognizing each person with dementia to be a unique individual with experiences, preferences, interests, history, and abilities. Also, the KUMC PAIRS program was structured to provide opportunities to engage in activities in the community with a younger person and in a personally meaningful way. As illustrated by the present study's findings, and Victor's experience in particular, person-centered aspects of the KUMC PAIRS program were effective, although not all student partners implemented a person-centered approach to the same degree. This illustrates how the KUMC PAIRS and similar social partner programs may be improved, through more thorough training of the student partners in strategies for applying a person-centered approach effectively, and by seeking participant feedback during the program rather than only after the program ends.

Participants with dementia reported they participated in activities aligned with their individual self-identity by having the freedom to choose activities with personal relevance and autonomy in their participation in community-based activities. A person-centered social activity program, like the KUMC PAIRS program, may provide better options for meeting an individual's psychosocial needs, by supporting that person to engage in activities having personal meaning, contributing to an added benefit of supporting the continuity in self-identity for these people with dementia. Further studies of person-centered social activity programs for community-dwelling people with dementia are needed to confirm how successfully such programs address each individual's unmet psychosocial needs, and to identify additional elements that may be required to achieve this critical outcome. Further attention in research and development of social programs should be directed toward exploring this approach with this population because people in the early stages of dementia risk becoming socially isolated, disempowered,

and stigmatized despite continuing to live in their community (Brataas et al., 2010; Burgener & Berger, 2008; Burgener, Buckwalter, Perkhounkova, & Liu, 2013; Sørensen et al., 2008).

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Table 1
Descriptions of Participants

Participant	Age	Gender	Ethnicity	Marital Status	Education	Previous Job	Years since Diagnosis
Paul	89	M	W	Married	BA	Executive in the film and TV profession	1
Albert	81	M	W	Married	MD	Pediatrician	4.5
Julie	76	F	W	Married	College	Administrative assistant	2
Victor	83	M	W	Married	PhD	Medical school professor	6
Chloe	61	F	W	Married	BA	Business owner	3.75

*F= Female; M= Male; W= Non-Hispanic White

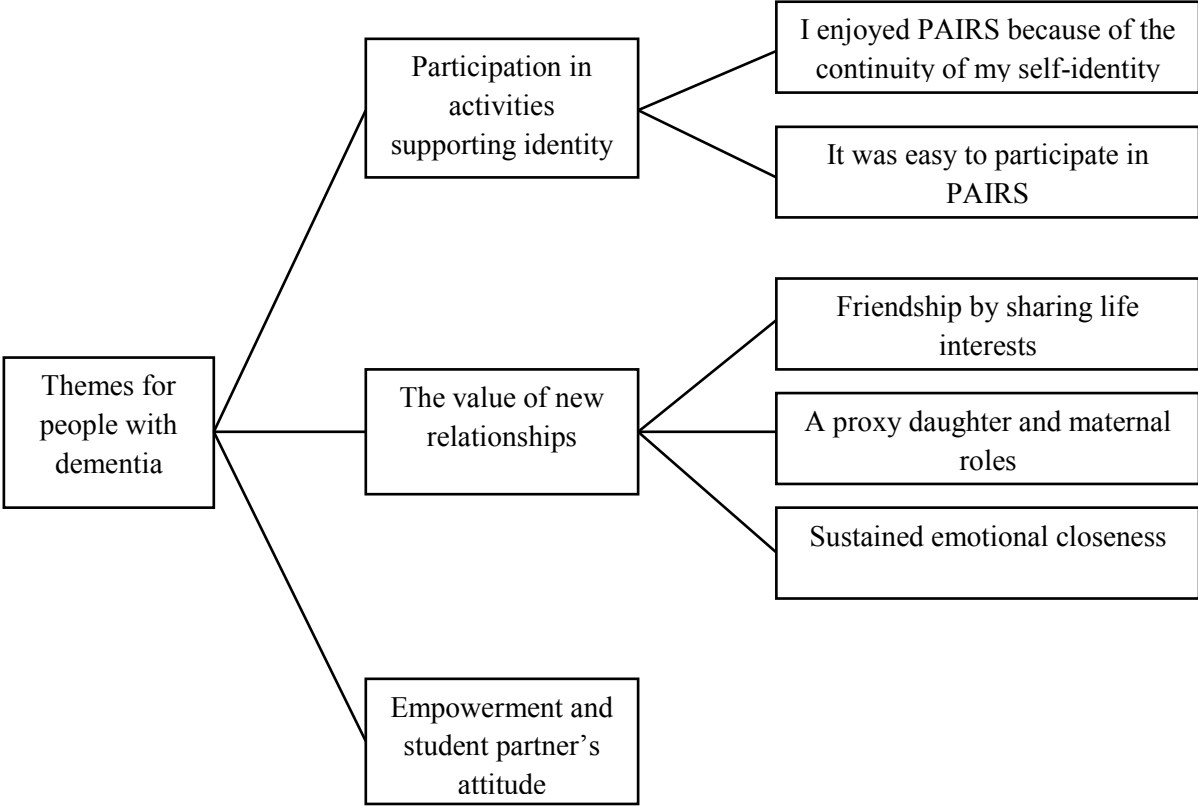


Figure 1. Themes for People with Dementia. This figure illustrates three themes with subthemes that emerged from the perspective of people with dementia.

Chapter 4: Perspectives of caregivers on the participation of their spouses with dementia in a person-centered social program: Interpretative phenomenological analysis

Abstract

This qualitative study explored the experience and impact of a person-centered social activity program on the caregivers whose spouses with dementia participated in the program. Interviews with five family caregivers and the spouses with dementia were conducted 7-8 months after the program ended to explore the sustained impact of the program. Interpretative phenomenological analysis was used to support in-depth exploration of the caregiver interviews. Three main themes emerged including: theme 1) benefits of the program for caregivers; theme 2) initial expectations and the later perspectives of caregivers about the program; and theme 3) conflicting values and perspectives between caregivers and the spouses. These findings suggest participation in a person-centered social program by people with dementia does provide benefit to their caregivers, by meeting the caregivers' desire for their spouses with dementia to increase both social participation and engagement in personally meaningful activities. Conflicting perspectives held by these caregivers and their spouses indicate the needs and desires of both caregivers and community-dwelling people with dementia need to be heard and considered when structuring social activities.

KEYWORDS: Caregivers, dementia, personhood, qualitative research, social participation

Introduction

Family members often are the primary caregivers for community-dwelling people with dementia, providing emotional and practical support for participation in meaningful daily activities and accessing healthcare and support services (Alzheimer's Association, 2014; Phinney, Dahlke, & Purves, 2013). The values, beliefs, and coping strategies of caregivers can influence the number and quality of opportunities available to their relatives with dementia for engagement in meaningful activities. For example, some family caregivers value activities they believe will help maintain the current functional abilities of their relatives (Harmer & Orrell, 2008). These caregivers may, however, simply increase opportunities for social contact or involvement in activities without considering the relative's preference for specific types of social contacts and activities (Dröes et al., 2006; Harmer & Orrell, 2008; Moyle, Kellett, Ballantyne, & Gracia, 2011; Smith et al., 2005). In addition, family caregivers, especially spouses acting as primary caregivers, may increasingly de-emphasize these values and preferences in deference to accomplishing daily activities and meeting increased care needs of the family member with dementia. They also risk under-estimating the negative effect on the person with dementia with progressive restriction in self-determination or decision making related to planning of daily activities (Reamy, Kim, Zarit, & Whitlatch, 2011; 2013).

Finding meaningful and positive activities for family members with dementia can be challenging for caregivers, despite an acknowledgment of the importance for engagement in meaningful activities (Cedervall & Aberg, 2010). Seeking additional supports by using community-based support services is an option available to family caregivers to resolve such challenges (Stirling, Dwan, & McKenzie, 2014; Zwaanswijk, Peeters, van Beek, Meerveld, & Francke, 2013). Family members of people with dementia, especially when spouses live together, may not seek support services because they believe that caregiving is their role and responsibility, and that a relative with dementia will be resistant to the service (Robinson, Buckwalter, & Reed, 2013). Family members of people with dementia may feel guilty for considering use of a non-family service, believing that the service will result in negative outcomes for their relatives

with dementia, that use of such services represents role failure, or that such services simply exist to provide respite to the caregiver (Phillipson, Magee, & Jones, 2013; Robinson et al., 2013). A more positive attitude toward support service use and increased problem-solving or more effective coping by caregivers, on the other hand, may promote using diverse services to meet the increasingly complex and varied needs of the person with dementia and the rest of the family (Roelands, Van Oost, & Depoorter, 2008). Family caregivers' attitudes and beliefs toward using a support service can be influential in deciding to adopt that strategy, although a number of other factors also may influence the decision (Phillipson, Magee, & Jones, 2013; Roelands et al., 2008; Scalmana et al., 2013).

Available services for activities and social company may, however, not match the interests and preferences of people with dementia, limiting their engagement in meaningful activities or quality of interactions. Limited daytime activities, restricted companionship, and psychological distress are the most common unmet needs reported by community-dwelling people with dementia and by their family caregivers, even through the majority of professional supports these people received were for daytime activities and company (Miranda-Castillo, Woods, & Orrell, 2013; van der Roest et al., 2009). Family caregivers of people with dementia stated the most important quality requirements for activity and social programs include the content and suitability of activities, their relation to preferences and abilities of the person with dementia, and a well-trained staff having an affectionate manner (Donath, Winkler, Graessel, & Luttenberger, 2011). A few qualitative studies report benefits of community-based activity programs for people with dementia, but the activities were provided in a group format and chosen entirely by researchers and/or therapists (Brataas, Bjugan, Wille, & Hellzen, 2010; George, 2011; Phinney & Moody, 2011). It therefore is hard to know whether the activities provided had meaning for each person with dementia in that group. Moreover, the sustained benefits of such programs have not been explored from the perspective of people with dementia and their primary informal caregivers (e.g., family members), although interviews several months after the program implementation have been suggested as a feasible way to explore this aspect (Brataas et al., 2010).

Providing personally meaningful activities and positive social interactions is emphasized in person-centered care for the purpose of maintaining personhood, fulfilling psychosocial needs, and promoting psychosocial well-being of people with dementia (Dementia Initiative, 2013; Dröes et al., 2006; Edvardsson, Fetherstonhaugh, & Nay, 2010; Edvardsson, Varrailhon, & Edvardsson, 2014; Kelly, 2010). The person is held central in person-centered care, by recognizing the whole person as having a unique history, interests, preferences, needs, strengths, and abilities (Brooker & Woolley, 2007; Edvardsson et al., 2010; McCance, McCormack, & Dewing, 2011). Much attention has been directed toward adopting a person-centered approach in long term care settings or for people with later stages of dementia (Cohen-Mansfield, Libin, & Marx, 2007; van der Ploeg et al., 2013), with less emphasis in using this approach with community-dwelling people experiencing earlier stages of dementia even though these individuals often remain quite capable of self-determination and decision making.

In accord with person-centered care, relationship-centered care is recognized as a more inclusive way to provide dementia care and conduct research, through understanding the person with dementia in the context of important relationships (Nolan, Ryan, Enderby, & Reid, 2002; O'Connor et al., 2007). Recognizing subjective experiences and perspectives of a person with dementia and of those in close relationships (e.g., families) is needed to fully understand the experience as it is shaped by interdependence and reciprocities in relationships, and to promote quality of lives (MacDonald, 2002; McCormack, 2003; Nolan, Davies, Brown, Keady, & Nolan, 2004).

In September 2013, the University of Kansas Medical Center launched the KUMC PAIRS program. The KUMC PAIRS program is modeled after Boston University's *Partnering in Alzheimer's Instruction Research Study* (PAIRS; Jefferson, Cantwell, Byerly, & Morhardt, 2012). Both of these PAIRS programs were replicated from the established *Buddy Program*TM at Northwestern University (Morhardt, 2006). The KUMC PAIRS program was designed as a service learning program in which first year medical students were paired to community-dwelling people with dementia based on shared interests and demographic preferences. To date, the original program and replicated programs have focused on

student outcomes only (Jefferson et al., 2012; Morhardt, 2006). These programs also promote engagement of people with dementia in personally meaningful leisure and social activities beyond their existing social contacts and limited settings such as support group. Such engagement additionally may have positive benefit for family caregivers of people with dementia. This study explored the experience and the impact of a person-centered, social activity program on community-dwelling people with dementia and their family caregivers. This report focuses on the experience of the caregivers, extending an understanding of how programs like the KUMC PAIRS program are viewed and experienced by family caregivers of people with dementia. New insight regarding sustained benefits of the program also were sought by conducting interviews more than half a year after the program ended, in the daily lives of both people with dementia and their family caregivers.

Methods

This was a qualitative study in which interviews with family caregivers and their relatives with dementia were conducted 7-8 months after the end of the KUMC PAIRS program. These interview data were analyzed using interpretative phenomenological analysis (IPA; Smith, Flowers, & Larkin, 2009). In IPA, the lived experience of individuals is explored, with a focus on what an experience means for an individual in the unique contexts, and researchers make sense of each individual's meaning making. This methodology recommends a very small sample size (three to six people for case comparisons) for an in-depth analysis of single cases, followed by the search for patterns across cases. In IPA, shared themes among cases are identified, and the uniqueness of an individual's experience within that shared theme is preserved.

Participants

All thirteen family caregivers, whose relatives with dementia participated in the KUMC PAIRS program for 8 months (from September, 2013 to April, 2014), were invited to participate in the present study. These couples originally were recruited from the Heart of America Chapter of the Alzheimer's Association, which serves 66 counties in Kansas and Missouri. Five family caregivers (all spouses; 3

women and 2 men; Table 1) and their spouses with dementia then agreed to participate in the present study once the KUMC PAIRS program ended. All family caregivers were self-described as being non-Hispanic White. Three caregivers were retired, and two caregivers were employed. Three caregivers reported averaging more than 40 caregiving hours per week, another as between 21-39 hours, and the final caregiver reporting 9-20 hours. All the family caregivers were attending monthly support groups (two evenings a month) at the Alzheimer's Association, and all the spouses with dementia attended a daytime activity group (twice a week, from 9 a.m. to 3 p.m.) at the Alzheimer's Association during the KUMC PAIRS program period.

Procedures

The study was conducted with IRB approval from the host institution (HSC #00000561). Each caregiver and the spouses with dementia gave informed consent, including consent for audio-recording of interviews. Face-to-face interviews took place in the homes of participants, 7 to 8 months after the KUMC PAIRS program ended. All caregivers and their spouses with dementia completed demographic information forms prior to beginning the interview. All interviews were conducted between mid-December, 2014 and mid-January, 2015.

Interviews

Interviews with each couple had two phases. The first phase involved the person with dementia only, and the second phase involved the caregiver and the person with dementia together. A semi-structured interview guide (based on Smith et al., 2009; see Appendix 7) was used as a flexible general guide during the interview. The second phase of an interview involved general, open questions asking about the caregiver's perspective of the KUMC PAIRS experience of the spouse with dementia and of the program's perceived impact on the spouse with dementia and on the caregiver. The interview probed deeply, by encouraging the caregiver's further explanation or elaboration on the initial statements about the experience and perspective. Minimal open-ended probes were used such as "Can you tell me more

about that?”, “What do you mean by that?” and “How did you feel about that?” The interviews lasted from 55 to 82 minutes (mean: 70 minutes).

Data Analysis

Audio recordings of interviews were transcribed verbatim and analyzed according to Smith et al. (2009). These steps included: reading each interview transcript closely and multiple times; making notes for key points, focusing on content, language use, context, observations during interviews, and initial interpretations; transformed notes into emerging themes while; examining emergent themes to search for connections; creating a list of themes for each interview transcript with all relevant quotes; and searching for repeating patterns and newly emerging issues across participants to identify shared themes (similarities) and individual differences within the shared themes.

Several additional strategies ensured trustworthiness of the data analysis. These strategies included: using member checking during interviews through the process of reflecting and probing; having the accuracy of transcripts checked by one of two research assistants before data analysis began; documenting the process showing how a participant’s accounts transformed to the themes; and having weekly meeting among researchers to ensure emerging themes were well-grounded and represented in the transcripts. The interpretation and derived meaning constantly were checked against the transcript text to strengthen analytical rigor, by verifying the emerging themes remained reflective of the actual data.

Results

Three main themes emerged for family caregivers, including theme 1) benefits of the program on caregivers, theme 2) initial expectations and later perspectives about the program held by the caregivers, and theme 3) conflicting values and perspectives between family caregivers and the spouses (Figure 1).

Theme 1. Benefits of the Program on Caregivers

Caregivers of people with dementia stated they believed they also derived benefit from their spouse’s participation in the KUMC PAIRS program. The nature of that benefit varied depending on the caregivers’ level of involvement in the program. All five caregivers reported one shared benefit

(subtheme 1a). Two of five caregivers participated in activities and reported further benefits (subtheme 1b, 1c, and 1d).

Subtheme 1a. Knowing my spouse enjoyed the program was important to me. All five caregivers reported enjoyment and satisfaction by noticing their spouses' enjoyment when participating in the program, regardless of the caregiver's own level of involvement in the program. Three caregivers (Maria, John, and Judy) did not engage in any of the activities pursued by their spouses with dementia and the student partners. These caregivers recognized their spouses' enjoyment and elevated spirits when the spouse returned and shared stories about the activities done with the student partner. Expressions by these caregivers include: "I enjoyed knowing that he [Maria's husband] was in it because he was always enthusiastic about it and told me about things they did. In general, it was a pleasant experience for him" (Maria); "I felt she [John's wife] was enjoying her experience. It was nice to see the support situation" (John); and "He [Judy's husband] was happier. ... I could enjoy the benefits he got from it" (Judy). The other two caregivers (Laura and Fred), who were more involved in the program, also expressed their enjoyment and satisfaction by noticing their spouses' enjoyment while their spouses were with the student partners: "It gave him [Laura's husband] some happy times. That was important to me" (Laura); and "There were obvious satisfaction and joy during the meeting" (Fred).

Subtheme 1b. It was a nice, fun opportunity to do something with my friend or by myself. Laura reported one benefit of the program was that it allowed her the freedom to participate in fun activities with a friend or alone while her spouse was occupied with the PAIRS activity: "It was nice for me to do fun things with my friend. I even had fun going around by myself" (Laura). Laura reported being very aware of the program's requirement for one-on-one activity between the person with dementia and the student partner. Laura went to the location of the PAIRS activity together with her husband, but Laura chose to engage in the activity with a friend or by herself, separate from her husband and student partner. For example, Laura invited a friend to a symphony concert and had lunch with her friend, and they sat separately from Laura's husband and his student partner at the symphony concert and at the

restaurant: “My husband and his student partner sat separately from my friend and me. We also went out to lunch before then. We sat at a separate table. It encouraged me to do things with my friend, which was nice” (Laura). Laura also reported that she enjoyed the freedom of going to interesting places by herself. Visiting places of interest to her allowed Laura time to think about something other than her usual concerns. Laura reported that having personal time to enjoy activities related to her interest in arts and music was particularly good for her, since she had primary responsibility for all daily activities because her husband was not independent.

Laura: The good thing was going to some places interesting. You don’t just sit and talk. Go some place and they give you something to talk about and think about, like the Nelson Gallery and Zoo. Take you out of your petty concerns. ... It gave us something to think about other than our usual concerns.

Subtheme 1c. I am trying to be more active in arranging fun activities for us. Although the KUMC PAIRS program ended 7-8 months earlier, Laura reported the program had encouraged her to resume arranging activities the couple had once enjoyed but now had more difficulty in pursuing. This behavior change may have arisen because she perceived benefits for her spouse (e.g., elevated spirits) and herself (e.g., not thinking about usual concerns) during their participation in the KUMC PAIRS program. Laura and her husband had experienced difficulty in maintaining shared leisure activities because of her husband’s frustration with being unable to drive a car safely. Arguments arose related to driving, which removed Laura’s desire to pursue any activities requiring transportation with her husband: “The fighting about the driving really took away my desire to go around places” (Laura). The commitment to be in the KUMC PAIRS program along with her spouse’s elevated spirits encouraged Laura to make the effort to arrange and participate in activities as a couple. Laura reported she also was glad to have the commitment and the pressure to do the PAIRS activities because she had experienced depression at that time: “... and also I suffer from depression and I don’t feel like arranging activities much. It’s hard to force myself to arrange things. I was glad to have the pressure to do it because they were very beneficial

for both of us (Laura).” Laura reports her husband remains frustrated and upset when she drives and he does not, but she has become more active in arranging activities and more motivated to find new transportation strategies. Laura and her husband now use the local Jewish Family Service for transportation, allowing them to continue going to art and music events and supporting this couple’s shared leisure activities such as attending symphony concerts and art galleries: “I am trying to be more active about engaging in fun things like going to the Nelson [Nelson-Atkins Art Gallery]. We [she and her husband] went to the Nelson Gallery just recently. We already have season tickets for several events like the [Kansas City] Symphony” (Laura).

Subtheme 1d. I enjoyed meeting a new, younger person and we had a good time together.

Fred reported he derived benefit from the KUMC PAIRS program by participating in all the activities together with his wife and her student partner. He reported he enjoyed meeting a new, younger person who was very different from the couple’s normal everyday social contacts. Fred stated most of the couple’s new and current contacts were older adults, who he and his wife had met through their support group meetings at the Alzheimer’s Association. He also reported that socializing with the student partner and the student’s young children was fun, because some activities were those the couple used to do with their own children and grandchildren, and these activities reminded him of his own happy memories. The KUMC PAIRS program provided this couple with additional roles, including feeling like parents to and friends with the student partner. The multiple aspects to this relationship were both positive and natural for Fred, with Fred explaining the student partner was about the age of their oldest daughter and that he enjoyed interacting with younger people: “It was a good opportunity to meet someone very different than our normal everyday activities. It gave us, once again, to establish these multiple relationships or multiple level relationships. Having an exposure to younger people is still a good thing” (Fred).

Theme 2. Initial Expectations and Later Perspectives about the PAIRS Program held by Caregivers

The caregivers of people with dementia reported varied expectations and perspectives on the KUMC PAIRS program that may have depended upon the current social participation of their spouses with dementia and the caregivers' past life experiences.

Subtheme 2a. Contributing to research and medical students' learning. Two caregivers (Maria and Fred) decided to participate in the KUMC PAIRS program because they wanted to contribute to research and to the education of medical students. Maria had several family members with dementia in addition to her husband, and stated her experiences with family members having dementia contributed to her desire to contribute to dementia research; "...So, I have some acquaintance with dementia. People with cancer know that there is a lot of research going on and maybe they can escape the ravages of the disease. Alzheimer's patients don't have that" (Maria). Similarly, Fred stated he wanted to help research and teaching of medical students who then may be able to treat people with dementia better having benefited from the KUMC PAIRS program experience: "If we help the students understand Alzheimer's better, so they can treat people better. That's a good thing. This was much about helping the Alzheimer's research" (Fred). Both of these caregivers found satisfaction in taking part in the KUMC PAIRS program and felt they were being helpful by contributing to the future of health care. "I think that's beneficial. I found satisfaction and enjoyment by being able to participate in somehow hopefully help future Alzheimer's patients. That was good" (Fred).

Both Maria and Fred did not expect direct benefit to themselves from having their spouses participate in the PAIRS program: "This was much about helping the Alzheimer's research, more so than something that will be a direct benefit to us" (Fred). This may be because both of their spouses with dementia enjoyed an active lifestyle and engaged actively in social participation. Maria reported her husband was independent in daily activities and had many acquaintances with whom to socialize. Although Fred's wife was not independent in all daily activities, he and his wife engaged in their shared leisure and social activities when he was not working. Both Maria's husband and Fred's wife also had assumed leadership roles in their daytime activity groups at the Alzheimer's Association, by actively

helping their peers who also had dementia. These two caregivers (Maria and Fred) did not feel a specific need of social participation for their spouses with dementia through the KUMC PAIRS program, but found emotional satisfaction by witnessing the satisfaction and enjoyment their spouses derived from new opportunities for social participation with student partners in the KUMC PAIRS program (subtheme 1a).

Subtheme 2b. An outlet for my spouse to socialize with somebody other than family. Three caregivers (Laura, Judy, and John) stated they expected the KUMC PAIRS program would provide their spouses with dementia a chance to establish a new enjoyable relationship with someone other than family members. For example, Laura expected her husband would be able to socialize with a person other than herself, and she stated this expectation was met by the KUMC PAIRS program. Laura believed that providing her husband with an opportunity to spend time with a new friend was good because social contact with previous friends had diminished since her husband's dementia diagnosis: "I think the best part was a long conversation with someone other than me. I mean we are together most of the time and our social life isn't so great. When you have Alzheimer's, your friends can lift away" (Laura). This couple had to do things together because Laura's spouse was not independent in most daily activities. While Laura was an active participant in her own leisure and social activities (e.g., playing in a band, attending a book club and bridge group, volunteering in a mathematics club), her husband was not able to participate socially without Laura's involvement or help. The opportunity for her husband to interact with another, new person through the KUMC PAIRS program made Laura feel good and she reported this opportunity "took a load off her mind." Similarly, Judy wanted her husband to socialize with another person having a mutual interest because the couple had recently moved to the city and her husband did not have friends living nearby. Judy reported her expectation was met because participation in the program enriched the life of her husband by establishing a satisfying new friendship: "I think it enriched his life considerably by having the opportunity to go out with somebody who isn't a family member [emphasizing]. And he considers his pair as a friend. That way enriched his life" (Judy). John also regarded the KUMC PAIRS program as another very supportive social outlet, in addition to support of

their family and the support group meetings at the Alzheimer's Association: "Very supportive. It was a more social outlet in a sense that shows supporting her, so that was good" (John).

Subtheme 2c. A specialized social program providing intellectual stimulus. Judy expected the KUMC PAIRS program to give Victor, her husband, greater intellectual stimulation. She regarded the KUMC PAIRS program as a specialized social program that would provide intellectual challenges through working with a medical student who "was picked over and very bright." Her experience in teaching medical students in a laboratory and Victor's past profession as a professor at a medical school might have influenced her belief that medical students would provide more intellectual stimulus than would age-peers having dementia. Victor's perspective was, however, different from Judy's, with Victor regarding the KUMC PAIRS program as the same type of support available from other meetings at the Alzheimer's Association.

Judy: It wasn't just any social group. It was a specialized friend [emphasizing]. ... And so, that kind of stimulus that you get from a really bright person as opposed to just a friend you are chatting with in the same boat. You are making a frowny face. [Looking at her husband] You don't agree with that?

Theme 3. Conflicting Values and Perspectives between Family Caregivers and Spouses

Conflicting values and perspectives regarding meaningful activities between caregivers and their spouses with dementia were noted during interviews. Such conflicting values and perspectives will be described with relevance to perspectives on the KUMC PAIRS program because this can help better understand the importance of considering the potential for different perspectives of caregivers and their spouses with dementia, to provide insight for healthcare professionals and to acknowledge the impact of these differences on families in similar situations.

Subtheme 3a. His cognitive engagement vs. my personal time. One couple brought up an issue during the interview, arising due to conflicting values. Maria's husband with dementia (Paul) had been going to daytime activity group meetings at the Alzheimer's Association, and Maria reported that he was

thinking about dropping out. Maria stated she regarded the daytime activity group as the most useful group in which her husband takes part because that group does things that are stimulating and which keep his mind busy. While Maria values keeping her husband's mind busy, Paul stated his personal values included more of a focus on enjoying the rest of his life. Paul proposed to do this by spending more time on what he considered to be fun activities until his dementia progressed further. This situation illustrates the complexity of balancing the needs and desires of people having conflicting values, and represents both a challenge for the healthcare professional and an opportunity to provide insightful support.

Participation in the KUMC PAIRS program matched the most important value expressed by Paul (enjoying himself), who found "participation easy" (not challenging physically or mentally) and saying he found "pure joy" because he and the student partner did activities together that had been his lifelong leisure pursuits. Paul said he thought going to the daytime group meetings took up too much of his time, and he did not want to spend the rest of his life becoming depressed by only interacting with people debilitated by advancing dementia. Paul also expressed awareness of his own mortality, stating that he did not think he would live much longer considering he was 89 years old. Paul stated he was using the wife's value on keeping his mind busy as an excuse for going to art galleries, a favorite activity, by telling his wife going to art galleries would keep his mind busy. Paul also stated that he sometimes pretended to be busy.

Although Maria thought that participation in the KUMC PAIRS program was a rewarding opportunity for her husband to be helpful for the future and to improve his self-esteem, she believed that he would get more from his daytime activity group. Maria stated she believed her husband was wrong in not devoting his time to doing productive activities, and that he only wanted to enjoy himself. Maria's experience of having several other family members with dementia may have supported seeking a means to provide intellectual stimulation for Paul, thinking this would slow progression of his cognitive symptoms. The progression of symptoms may represent a greater fear or concern for Maria because she

has experienced dementia with other family members, including her mother, stepfather, brother, and uncle, and because she is witnessing similar changes emerge in her husband.

Subtheme 3b. KUMC PAIRS program vs. other supports. John is a caregiver who said he viewed the KUMC PAIRS program as providing similar support as did group activity meetings at the Alzheimer's Association. On the other hand, his wife reported she felt the KUMC PAIRS program was quite different from those group activity meetings because her activities with the student partner closely aligned with her self-identity. Perspectives of another couple (Judy and her husband) reported an opposite perspective from that of John and his wife. In this case, Judy (caregiver) viewed the KUMC PAIRS program as different from other group meetings for people with dementia. Judy stated she regarded the KUMC PAIRS program as providing a social bond based on her husband's past profession in medicine while she believed the activity group providing social bonds based on having a diagnosis of dementia. She thought her husband was unique in the KUMC PAIRS program because he had something in common with the medical student in terms of professional focus. Judy's view, however, conflicted with the view of her husband, Victor. He reported thinking there was no difference between the KUMC PAIRS group and his daytime activity group for people with dementia because he believed all his social partners were interested in dementia.

This set of conflicting views may be explained by Judy's preference to recognize and support the identity of her husband as a professor in a medical school, speaking frequently about this aspect of his identity and his leisure and social activities before his diagnosis with dementia. By contrast, her husband expressed his self-identity as a person with dementia during the interview more often than his self-identity as a professor. Judy's husband also frequently spoke about his daily life and activities of his group at the Alzheimer's Association, dwelling on these topics often than focusing on his past activities or his lifestyle before diagnosis. These conflicting perspectives also may explain why this couple had different views on activities during the KUMC PAIRS program period. Judy reported that having a two-hour movie and then two hours of conversation was a better format for her husband's social exposure than going to

different places like other KUMC PAIRS participants. Judy said she based this upon an interest about medicine he shared with the student partner. Victor, however, said he would have preferred to go to different places in the city rather than going to the movie theater all the time, stating he was new to the city and was interested in exploring the city's activities and offerings. Judy also expressed satisfaction related to Victor doing activities similar to those he used to do in the past (i.e., discussions, mentoring) in the format of a one-on-one interaction with a medical student. She appeared to want to keep the continuity of her husband's identity intact as it related to his past profession, and to protect Victor's self-esteem through engagement in activities supporting her perception of his identity. She expressed a particular need to do so by describing experiences where her husband was ignored or not respected by others (e.g., at a doctor's visit).

Discussion

Participation of spouses with dementia in the KUMC PAIRS program also provided benefit to family caregivers. Caregivers enjoyed knowing their spouses with dementia had satisfying experiences with the student partners. This positive outcome met the caregivers' need and desire for supporting social participation and engagement in meaningful activities for their spouses, and supports similar outcomes reported by others (Miranda-Castillo et al., 2013; Phinney & Moody, 2011; Stirling et al., 2014). Caregivers who engaged in activities, either separately from or together with the spouse and the student partner, reported they enjoyed opportunities to engage in activities aligned with the couple's shared interests and family history, with several participants saying these experiences reminded the couples of happy memories. Reminiscing about the shared life history and engaging in shared activities may promote a shared sense of identity as a couple, and offset current concerns or difficult situations (Molyneaux, Butchard, Simpson, & Murray, 2012). Participation in the KUMC PAIRS program by the spouse also represented a positive social opportunity for caregivers, who otherwise may have few social interactions with a younger person, or whose own social life may be affected negatively by the spouse's diagnosis with dementia. Providing caregivers with more frequent and positive social interactions may

decrease caregiver burden while increasing the subjective well-being of caregivers (Han et al., 2014; Kaufman, Kosberg, Leeper, & Tang, 2010).

Participation in the KUMC PAIRS program provided substantial benefit for one couple in particular (Laura: the caregiver, and Albert: her husband with dementia), by having a sustained impact on this couple's daily activities 7-8 months after the program ended. Laura perceived benefits during the KUMC PAIRS experience for both her husband and herself. This encouraged her to continue pursuing the leisure activities this couple once enjoyed in the community prior to her husband receiving a diagnosis of dementia. Laura said that both she and her husband had experienced depression and their social life was limited and not ideal. This outcome aligns with the suggestion that participation in leisure-based social activities increases motivation for social activities in the community, while decreasing depression and perceived stress of people with dementia (Brataas et al., 2010; Buettner & Fitzsimmons, 2012). Engaging in leisure activities provides the person with dementia with opportunities for enjoyment, self-expression, satisfaction, and distraction from thinking about dementia and other worries, help maintain positive mood, and reduce loneliness (Gilmour & Huntington, 2005; Moyle et al., 2011; Phinney, Chaudhury, & O'Connor, 2007; Sixsmith & Gibson, 2007; Van Dijkhuizen, Clare, & Pearce, 2006).

The present study found family caregivers have a strong desire and need for supporting their relatives with dementia to have enjoyable social opportunities with other members of the community, supporting reports by others (Miranda-Castillo et al., 2013). Some caregivers of people with dementia anticipated the KUMC PAIRS program would provide their spouses with dementia with new and positive social interactions with people other than immediate family. This expectation emerges from a loss of meaningful relationships and interactions with others in the community, due for example to fear, social discomfort, or a lack of understanding or acceptance of dementia by friends (Logsdon, McCurry, & Teri, 2006; Moyle et al., 2011; Vikström, Josephsson, Stigsdotter-Neely, & Nygård, 2008). The present study supports the value of providing people with dementia with opportunities to establish new, positive social interactions, and demonstrates family caregivers derive enjoyment and satisfaction thorough observing

the positive effect of the KUMC PAIRS program on their relatives with dementia (Phinney & Moody, 2011; Stirling et al., 2014). Family caregivers' subjective burden has been reported to be an independent predictor of nursing home admission of people with dementia (Rozzini et al., 2006; Yaffe et al., 2002). Improved quality of life and enhanced mood of people with dementia may lead to decreased subjective burden of family caregivers (Holst & Edberg, 2011; Mohamed, Rosenheck, Lyketsos, & Schneider, 2010). Community-based services providing people with dementia opportunities for social interaction also may reduce caregiver's subjective burden better than in-home services that often focus only on physical needs (Sussman & Regehr, 2009).

Conflicting values and perspectives between some caregivers and their spouses with dementia were found. One caregiver valued activities that focused on cognitive stimulation, while her husband preferred pursuing leisure and social activities he enjoyed. Caregivers may pay more attention to the negative impact of dementia on engagement in daily activities, try to increase participation to maintain functional abilities of their relatives with dementia, and focus less on the perceived value of engagement in activities (Harmer & Orrell, 2008; Smith et al., 2005). Some caregivers and their spouses expressed differing views on the value of specific types of social contacts and activities. Having family-oriented time was the most valued social activity for one woman with dementia, but her husband did not identify this as being her preference. Instead, he described the different types of social support his wife received (e.g., KUMC PAIRS vs. support group) as being equivalent. The most desired social relationship expressed by another participant with dementia was friendship based on experiencing new and interesting places, but his caregiver expected he would value a friendship based on a shared professional interest and conversation taking place in a routine setting. These findings illustrate that preference and value for specific types of social contacts and activities must be sought and considered from the perspective of both the person with dementia and the caregiver, rather than from the perspective of a caregiver alone.

The present study has several strengths and limitations. A joint interviewing of each spouse caregiver and the person with dementia was employed, providing a deeper understanding of the co-

constructed experiences in addition to understanding possible conflicting perspectives of the couple (Davies, 2011; Harmer & Orrell, 2008; Moleneaux et al., 2012). Interviewing caregivers and the spouses with dementia over half a year after the program ended allowed exploration of sustained benefits of the program. However, interviewing only once several months after the program ended might allow participants to forget some parts of the experience and the program's immediate benefits. Interviewing twice, near the end of the program and several months after the program ended, may better capture both immediate and sustained benefits of the program's participation on family caregivers and people with dementia.

Conclusions and Implications

Providing meaningful activities and positive social interaction to people with dementia through activity programs can benefit family caregivers as well as their relatives with dementia. A person-centered social activity program like the one-on-one partnership of the KUMC PAIRS program can be a viable way to maximize enjoyment and satisfaction of people with dementia and of their family caregivers. Such program may fulfill caregivers' psychosocial needs for support and engagement in meaningful activities and relationship for their relatives with dementia. Further studies of person-centered social activity programs for community-dwelling people with dementia are needed to identify if such programs can meet psychosocial needs of people with dementia and their family caregivers and what the critical elements of these programs are required to promote the quality of lives.

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Table 1
Descriptions of Caregivers

Caregiver (Spouse)	Age	Gender	Ethnicity	Marital Status	Education	Current Employment	Caregiving hours per week
Maria	89	F	W	Married	College	Not employed	40+
Laura	77	F	W	Married	PhD	Employed part time	21-39
John	79	M	W	Married	BA	Not employed	40+
Judy	80	F	W	Married	BA	Not employed	9-20
Fred	64	M	W	Married	MS	Employed full time	40+

*F= Female; M= Male; W= Non-Hispanic White

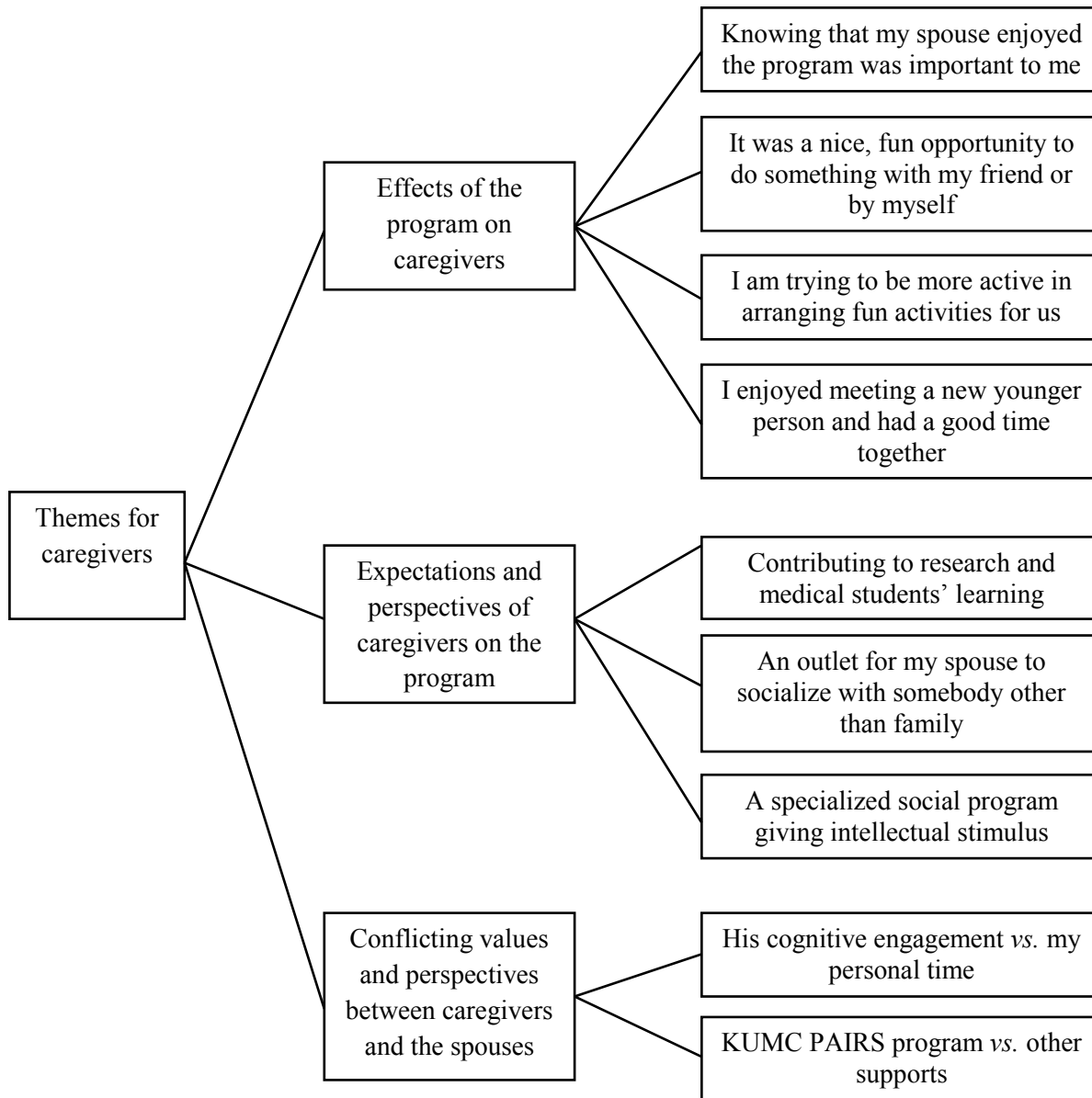


Figure 1. Themes for Caregivers. This figure illustrates three themes and nine subthemes that emerged from the perspective of family caregivers of people with dementia.

Overall Conclusions and Implications

Although scholars have emphasized the importance of a person-centered approach to dementia care, few intervention studies have been conducted to identify how a person-centered approach to leisure and social activity programs may benefit people in the earlier stages of dementia, such as those who still live in the community (Brataas, Bjugan, Wille, & Hellzen, 2010). There is a lack of understanding about how person-centered care can be implemented for community-dwelling people with dementia, who may lack opportunities for meaningful leisure and social activities due to reduced social contacts, diminished motivation, and embarrassment or insecurity about decreased cognitive abilities (Langdon, Eagle, & Warner, 2007; Moyle, Kellett, Ballantyne, & Gracia, 2011). Findings of this dissertation research fill an important gap in the literature by exploring the personal experiences and benefits derived from such programs by community-dwelling people with dementia and their family caregivers.

Positive social environments and relationships are the key to promoting participation in meaningful leisure pursuits and social activities in the community, improving psychological well-being and quality of life, and reducing excess disability of persons with dementia that occur because of the social consequences since dementia diagnosis (Teitelman, Raber, & Watts, 2010). The KUMC PAIRS program provided a positive social environment for the participant with dementia by recognizing each person as an active collaborator and partner of the program, rather than a passive recipient of services. Participation in the KUMC PAIRS program allowed people with dementia not only to enjoy themselves but also to become active, helpful members of the community. This KUMC PAIRS community reached beyond an established community of support groups at the Alzheimer's Association to include personally meaningful places where these people with dementia once had done a variety of leisure and social activities. These people with dementia engaged in meaningful activities, roles, and relationships through the KUMC PAIRS program, an environment that respected each individual's preferences and choice in activities, and recognized people with dementia as collaborators in the program. These findings provide

evidence of the benefit for programs to help people with dementia be connected and feel included in the larger community, while being empowered themselves.

Current community-based leisure and social activity programs for community-dwelling people with dementia typically are organized as a group format and offer little flexibility to customize participation according to individual preferences and choice, often due to limited human resources. Providing one-on-one social interaction with younger people through a service-learning program can be one way for community-dwelling people with dementia to engage in personally meaningful activities beyond progressively more restricted social contacts and settings, to be more engaged, and to continue to feel included in their community. There is a lack of evidence on how intergenerational service learning student programs may influence community-dwelling people with dementia because such studies have focused on student outcomes (Lokon, Kinney, & Kunkel, 2012). The present studies were needed to document the lived experiences of people with dementia and their caregivers in an intergenerational service learning program, and the benefit derived from such a program even after the program was ended.

The KUMC PAIRS and related social partner programs have paired students with older partners. Older volunteers also may be valuable partners for people with dementia who desire to participate in community-based leisure and social activity programs. Programs providing companionship and emotion-focused relationships through one-on-one visits from volunteers (termed “befriending programs) exist for older adults with diverse health conditions, but no empirical studies assessing benefits of these programs for people with dementia have been described. A meta-analysis found a modest effect on depressive symptoms and emotional distress across varied populations, although the findings described are inconsistent and depend on population characteristics and befriending interventions (Lester, Mead, Graham, Gask, & Reilly, 2012; Mead, Lester, Chew-Graham, Gask, & Bower, 2010). New insight may accrue when an approach similar to that used by the KUMC PAIRS program is applied to age-peer groups, where older adults with dementia are paired to older adults without dementia based on specific, shared leisure interests. The experiences and benefits of such age-peer groups may be different from

those of an intergenerational service learning program, however. Nevertheless, people with dementia may feel enjoyment and experience the continuity of self-identity by engaging in one-on-one activities with peers based on shared leisure interests rather than peer groups organized around having a dementia diagnosis. Findings and insights from such research will further develop social programs that provide increased benefit to community-dwelling people with dementia and more options based on personal, individual preferences for socialization and participation for people with dementia, offered through partnerships with universities and community centers.

Findings emerging from this study support core beliefs of occupational therapy, including the view that occupations (meaningful daily activities) are unique to each person, and key factors essential for maintaining self-identity of persons with dementia within the contexts of relationships (Christiansen, 1999; Law, Polatajko, Baptiste, & Townsend, 1997). The profession's core beliefs lie in the positive relationship between well-being, occupation, and a view of people as occupational beings (American Occupational Therapy Association, 2008, p. 625). These core beliefs are not, however, applied consistently to research or practice for community-dwelling people with earlier stages of dementia or their informal caregivers. A few scholars with backgrounds in social work or nursing have conducted relevant research emphasizing the importance of participation in meaningful activities for people with dementia (Phinney, Chaudhury, O'Connor, 2007). More interdisciplinary care and perspectives may be gained from involvement of occupational therapy practitioners for practice in community-based settings for people with dementia and scholars with insights from core beliefs of occupational therapy. Such interdisciplinary team perspectives may contribute to enhancing current practice and research for quality care for community-dwelling people with dementia and their caregivers.

Engagement in meaningful activities and positive social interactions are important determinants for successful aging and maintaining a high quality of life in older adults (Alma, Van der Mei, Groothoff, & Suurmeijer, 2012; Bowling, 2007; Depp & Jeste, 2006). Social isolation and loneliness have negative associations with health and well-being, while the benefits of social participation also have been

described in the aging literature (Cherry et al., 2013; Ichida et al., 2013). Community-dwelling older adults with dementia and their caregivers should be supported to achieve full participation in personally meaningful activities and positive social relationships with others. This will encourage well-being and a higher quality of life for both people with dementia and for their caregivers. Social activity programs based on a person-centered approach can serve as a basis for supporting full participation in meaningful activities and relationships for community-dwelling people with dementia.

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Appendices

- Appendix 1.** Social Participation for Successful Aging of Older Adults: A review
(1st comprehensive review of the literature)
- Appendix 2.** **Perspectives of people with dementia about meaningful activities: A synthesis**
(2nd comprehensive review of the literature)
- Appendix 3.** **Benefits of Individualized Leisure and Social Activity Interventions
for People with Dementia: A Systematic Review**
(3rd comprehensive review of the literature)
- Appendix 4.** Raw data/Coded Data
- Appendix 5.** Data Collection Forms
- Appendix 6.** Human Subjects Consent Forms
- Appendix 7.** Semi-structured Interview Guide

Appendix 1: Social Participation for Successful Aging of Older Adults: A review

(1st comprehensive review of the literature)

Abstract

Engagement in social activities and social relationships are important determinants of successful aging, identified both subjectively and objectively. An older adult's health conditions, functions, or disability status may influence the opportunities and the types and varieties of social participation options available to that individual. This review article describes key concepts in the medical, psychological, and social science literature related to social participation as a factor in promoting successful aging of older adults. Key concepts emerging from this review include [a] social participation of older adults through social activities and social support, such as informal social activities, volunteering, peer-led activities, inter-generational programs, and interactions using technology; [b] strategies for promoting social participation and balanced social relations of older adults; and [c] environmental factors that contribute to social participation and positive social relations in older adults. Health care professionals should recognize the benefits of social participation on quality of life and health. Biopsychosocial factors, environmental features, and evidence-based approaches should be incorporated into care plans to promote social participation and thereby enhance quality of life of in older adults irrespective of their health status.

Keywords: interpersonal relations, quality of life, self-efficacy, social environment, volunteer workers

Recognizing a demographic shift toward an increase in the aging population, scholars and the general public have become interested in promoting successful aging (U.S. Census Bureau, 2011). There is little consensus of what successful aging means however, or how to measure this process. Scholars often define successful aging differently, focus upon their own discipline's theories and conceptual frameworks, and often include different criteria or domains of measures. Scholars in the biomedical field approached the topic of successful aging by emphasizing the number of diagnosed chronic conditions, level of disability, and physical functioning (Depp & Jeste, 2006). Rowe and Kahn's (1997) model of successful aging, a well-known model in biomedical research, includes three components: (1) avoidance of diseases and disability, (2) maintenance of high cognitive and physical functioning, and (3) active engagement with life. This expanded model is more comprehensive than their original one-factor model (the absence of disease), including not only health conditions and functioning, but also engagement with life. A greater emphasis is placed on the disease-related disability and impairments by using dichotomous objective measures in this model, with little emphasis on psychosocial or contextual factors even though these factors affect health behaviors, engagement in various activities, quality of life, and psychological well-being in older adults. Rowe & Kahn's model's focus on disease-related disability and impairments does not recognize the heterogeneity of the aging process among older adults; the majority of older adults will acquire additional health conditions and will experience decreasing functioning as they age (Weir, Meisner, & Baker, 2010). Objective criteria of health conditions and functioning do not explain the entire experience of aging successfully (Pruchno, Wilson-Genderson, Rose, & Cartwright, 2010). Some older adults actively engage and are satisfied with life despite disability or chronic illness, by using compensatory psychological resources, engaging in social activities, or having social interactions and support (Bowling & Iliffe, 2006). By contrast with a disability-focused perspective, psychosocial models emphasize psychological and social well-being by focusing on developing a sense of control over life, practicing effective coping strategies, and encouraging adaptation as change occurs. This approach also

encourages older adults to engage in social activities, despite accumulating health conditions and decreased functioning (Baltes & Baltes, 1990; Bowling, 2007).

There is little agreement on how to measure successful aging. Objective measures help identifying an older adult's status in health, function, and social connectedness compared to their peer. For example, physical function can be measured by assessing grip strength and cognitive function can be measured by using a cognitive screening test (e.g., Mini-Mental State Examination). These objective measures, however, often lack the older adult's own perspective on successful aging (Ferri, James, & Pruchno, 2009). Many older adults report believing they are aging successfully, although some have chronic illness or disability and therefore do not meet the objective criteria (Montross et al., 2006; Strawbridge & Wallhagen, 2003; Strawbridge, Wallhagen, & Cohen, 2002). Some older adults without a chronic illness also rate themselves as not aging successfully. These discrepant results may be due to older adults' different perspectives on what constitutes either normal aging or successful aging. Some older adults may have a biased perspective on normal aging, and they rate themselves as aging successfully, not considering actual performance or function (Weir et al., 2010). Combining both objective and subjective measures, therefore, may help measuring successful aging more accurately and comprehensively than using only objective or subjective measures (Bowling, 2007; Pruchno et al., 2010; Weir et al., 2010). Pruchno et al. (2010) suggested a multidimensional model of successful aging incorporating both objective and subjective measures. The authors emphasized the importance of having both objective and subjective measures of successful aging to capture different trajectories of successful aging among older adults, including those identified as successfully aging from both objective and subjective measures, subjective only, objective only, and neither. The objective criteria included the number of chronic illness, functional abilities, and pain, and the subjective measures included the older adult's own perspective on the aging processes. Pruchno et al. found that the older adults, identified as successfully aging by the subjective measures only, tend to be older and female and to have higher BMI scores and better social support networks, and to be more religious than the older adults, identified as

successfully aging by the objective criteria only. The older adults, identified as successfully aging by both objective and subjective measures, also had higher levels of education, lower BMI scores, higher engagement in physical exercises, and better social support than the older adults, identified as successfully aging by subjective only, objective only, and neither. Further study is needed, but the study's findings show how differently the older adults can be identified as aging successfully depending on whether researchers use subjective, objective, or both measures.

Older adults often define successful aging from multidimensional perspectives, rather than the more uni-dimensional perspectives favored by scholars. Hung, Kempen, and de Vries (2010), for example, conducted a literature review of published studies until 2008 to compare the perspectives of scholars and lay older people. Of 34 included studies, 11 studies that described older adults' views included a greater number and varieties of domains in defining successful aging than the studies that described scholars' views. Some domains, such as adaptation, spirituality, and living with/close to family were identified as key components of successful aging in the studies that indicated older people's views, but were not in the studies that indicated scholars' views. Older adults tend to consider biopsychosocial and environmental factors as being important for successful aging, and place a greater emphasis on psychosocial factors (Phelan, Anderson, LaCroix, & Larson, 2004; Reichstadt, Depp, Palinkas, Folsom, & Jeste, 2007; Reichstadt, Sengupta, Depp, Palinkas, & Jeste, 2010). According to a recent systematic review of qualitative studies that examined lay perspectives of successful aging by Cosco, Prina, Perales, Stephan, and Brayne (2013), for instance, varied psychosocial components were identified by older people in all the included studies, followed by biomedical components (76% in the included studies) and environmental components (58% in the included studies). These psychosocial factors include engagement, self-awareness, adjustment, spirituality, autonomy, and personal outlook and attitude. Among all the identified components of successful aging by older people, engagement (e.g., social involvement) and personal resources (e.g., attitude) were mentioned most frequently by older people, suggesting them as most significant factors for successful aging. Identifying older adults' views on

successful aging helps scholars develop a better model of successful aging that reflects what older adults truly believe in aging successfully and that go beyond the biased, favored perspectives from scholars' own disciplines. Factors found to be important for successful aging from older adults help health care providers' understanding and guide care approaches to older adults by considering these factors as important areas throughout the entire care process.

Acknowledging individually different processes of aging and compensation mechanisms adjusting to age-related changes, Young, Frick, and Phelan (2009) defined successful aging as a state where an individual's ability to use compensatory psychological and social mechanisms against disease and disability contributes to a good quality of life and a sense of fulfillment in a personally satisfying way. Young et al. (2009)'s conceptual model of successful aging incorporates three dimensions of health, including physiological (diseases and functional impairments), psychological (emotional vitality), and social (engaging with life and spirituality). Young et al. (2009)'s multidimensional model is more comprehensive and consistent with older adults' perspectives, has both objective criteria and subjective measures, and allows continuity in measuring by having graded scoring, compared to Rowe and Kahn's model (1997). Young's model also allows different trajectories in reaching successful aging among older adults by having compensatory mechanisms even in the existence of decreasing health conditions. Further research, however, is needed to support validation generalizable to broader population besides community dwelling older women (Young, Fan, Parrish, & Frick, 2009).

Engagement in social activities and maintenance of meaningful social relations are important determinants of successful aging, identified both subjectively and objectively (Bowling, 2007; Bowling & Dieppe, 2005; Depp & Jeste, 2006; Reichstadt et al., 2010). Parslow, Lewis, and Nay (2011) developed structural equation model of factors contributing to successful aging and they found that social contact and support (frequency of contact with friends and families, extent can rely on or confide in friends, families, or partners) contributed significantly to successful aging, measured by self-assessed physical and mental health, life satisfaction, and cognition (MMSE scores). Social participation and positive social

interactions also contribute to quality of life in older adults with and without disability, along with biopsychosocial and environmental factors (Alma, Van der Mei, Groothoff, & Suurmeijer, 2012; Blazer, 2008; Netuveli & Blane, 2008). When considering social interaction's effects on older adults' quality of life and well-being, and its role as a critical determinant of successful aging, better understanding of social participation among older adults is needed in the context of varied biopsychosocial and environmental factors. Identifying various ways of social participation will help varied older individuals engage in social activities, matched with their interests, values, abilities, and opportunities in the community. Approaches are needed to facilitate an older adult's motivation for engaging in and maintaining social activities and to enhance satisfaction of the older adult from positive social relationships and supports.

Purpose and Methods

This review article describes key concepts reported in the literature related to social participation for successful aging of older adults. I searched medical, psychological, and social science literature published in English before June 2013 using PubMed, CINAHL, PsycInfo, and Google Scholar. Keyword searching and subject searching were used to find the current best evidence, based on the scientific levels of evidence and publication date. An example of keywords used for the literature search include [(Elderly OR Aging OR Older OR Seniors) AND (Social engagement OR Social participation OR Social involvement)]. I also used more specific search terms to specify the various types of social participation, such as [(Voluntary workers) AND (Older OR Seniors OR Aging OR Elderly)]. I searched for relevant articles in all levels of evidence (from levels I to VII; Polit & Beck, 2012) with greater emphasis on the higher levels of evidence, and on more recently published research when available.

Results

One hundred and twenty-eight articles were included in this review: 12 Level I articles, 23 Level II articles, 12 Level III article, 43 Level IV articles, 2 Level V article, 31 Level VI articles, and 5 Level VII articles. The key concepts identified were [a] social participation through social activities and social

support, such as informal social activities, volunteering, peer-led activities, intergenerational programs, and interaction using technology; [b] approaches for promoting social participation and balanced social relations of older adults; and [c] environmental factors contributing to social participation and positive social relations. I defined some of these key concepts *a priori* and some concepts emerged from the literature during the literature review process. Approaches and clinical implications are described below in each section for various means of social participation.

Social Participation and Psychological Factors for Successful Aging

The concept of social participation found in the aging literature refers to a person's involvement in social activities and interactions with others in society or the community (Levasseur, Richard, Gauvin, & Raymond, 2010). Levasseur et al. (2010) identified social participation depending on the goal of the social activities and level of involvement: (1) simply socializing with others without doing any activity; (2) doing an activity with others; (3) helping others; and (4) engaging in social organizations. The authors distinguished social participation from social engagement (e.g., social activities for others), although some researchers use these terms interchangeably. This distinction can be helpful to understand various ways of involvement and goals of social activities among older adults. These factors may vary according to an older adult's needs, interests, values, and abilities. Older adults with or without impairment or chronic diseases thus may choose to participate in varied social activities that are matched with their abilities, values, and interests. Some leisure and productive activities can be social activities, although leisure activities mostly are done solely for enjoyment.

According to a review article by Adams (2011), older adults showed greater well-being and life satisfaction, and reduced levels of depression over time with participation in social activities among various activities. Older adults with dementia not only have a reduced sense of loneliness and isolation but also have an enhanced sense of self-worth by increasing meaningful social interaction with others (Ruthirakuhan et al., 2012). A review article by Ruthirakuhan et al. (2012) found positive effects of physical, intellectual, or social activities on cognition and well-being of older adults with dementia, but

there is much less evidence on the benefits of each activity on various measures of cognition and well-being. In other words, some physical activities without any social interaction may not enhance psychological well-being or may reduce motivation for continuing exercise and other healthy behaviors, although there is greater evidence on the benefits of physical activity on cognition than the benefits of socialization on cognition. This indicates an importance of incorporating social aspects into physical exercise, such as group exercises, to compensate for the missing benefit of physical activity or socialization itself on older adults' cognition and well-being. Some social activities involve physical activity and cognitively stimulating environments, and doing these types of social activities may slow progressive cognitive decline, enhance psychological well-being and life satisfaction, and provide older adults with meaningful social interactions.

Social interactions often involve emotional benefits. Older adults tend to focus on emotional satisfaction in their social interactions and relationships and minimize adverse emotional relationships (Peningroth & Scott, 2012), supported by the socioemotional selectivity theory (Carstensen, Isaacowitz, & Charles, 1999). The quality of social relationships, measured by an older individual's satisfaction with contacts with children, friends, and neighbors and subjective, self-reported loneliness, is more associated with older adults' well-being than quantity of social contacts, such as frequencies of contact with families, friends, and neighbors and frequencies of engagement in informal and formal social activities (Litwin & Shiovitz-Ezra, 2006). In other words, maintaining or establishing satisfying social interactions may contribute to older adults' well-being more than simply participating in social activities without meaningful relations. The association between social engagement and life satisfaction may vary according to an older adult's disease, disability status, or perceived values. Older adults with both disease and disability may value social engagement more than those with disease only, showing stronger association with life satisfaction in those with both disease and disability (Jang, Mortimer, Haley, & Borenstein Graves, 2004). This may indicate that older adults with both disease and disability use compensation by revising their values to place more emphasis on social engagement (Jang et al.). For

example, the personal value of the older people with visual impairments was the most important determinant of social participation among a variety of biopsychosocial factors (Alma et al., 2012). This supports the concept that an older adult's personal values must be considered in rehabilitation goal-setting to maximize motivation, enhance social participation, and to support well-being.

Some older adults can become socially isolated due to a lack of social participation, or they can feel lonely due to a lack of satisfying social relationships or connections. Both social isolation and loneliness can lead to a reduced quality of life of older adults (Jakobsson & Hallberg, 2005), and they have negative correlations with physical and mental health of older adults (Masi, Chen, Hawkey, & Cacioppo, 2011; Nicholson, 2012). Feelings of loneliness, or the perceived degree of social isolation, may not be related to the number of social contacts, however. Constraints in the quality of or satisfaction with relationships may be more strongly associated with loneliness (Routasalo, Savikko, Tilvis, Strandberg, & Pitkala, 2006). This means that simply increasing opportunities for social interaction may not alleviate the subjective experience of loneliness for the older adults who have limited satisfaction with their existing social network.

Social isolation and loneliness among older adults are regarded as important issues but there is limited evidence on the effectiveness of interventions. Dickens, Richards, Greaves, and Campbell (2011) conducted a systematic review to identify the effectiveness of interventions for reducing social isolation and loneliness in older adults. The authors found that group-based interventions having a theoretical basis and allowing older adults' active participation were more beneficial to social, mental, and physical health of older adults. There was, however, variability of effectiveness among studies and only 58 % of interventions that specifically targeted socially isolated or lonely older adults produced positive outcomes. For example, Routasalo, Tilvis, Kautiainen, & Pitkala (2009) reported on a goal-oriented, group-based intervention, aimed to empower older adults and promote social interaction that did enhance psychological well-being of lonely older adults. The authors suggested this probably was due to enhanced feelings of mastery and self-esteem, and the acquisition of meaningful, active roles in a group.

There were, however, no differences in loneliness or social networks between groups in this study. Masi, Chen, Hawkley, and Cacioppo (2011) conducted a meta-analysis of studies published from 1970 to 2009 that were targeted to reduce loneliness. Masi et al. (2011) found that interventions addressing maladaptive perceptions in interactions or affect had a larger effect size than interventions targeting to improving social skills, enhancing social support, or increasing opportunities for social interaction. These findings indicate that more effective interventions may be those that are matched with the older adult's needs, by distinguishing social isolation and loneliness, and considering related psychosocial and environmental factors. In order to develop suitably targeted health promotion activities, health professionals should identify an older adult's patterns of engagement in social activities, the quality of relations (positive and negative), social network size, perceived social support, and demographic characteristics. Knowing the older adult's current activity patterns, interests, and resources can be critical for identifying those at risk for social isolation, and to better tailor the program to an individual's needs and interests.

Older adults can have a good quality of life by selecting activities or goals matched with their abilities (selection), finding alternative ways to perform activities or to achieve goals (compensation), or by maximizing reserves (optimization) (Baltes & Baltes, 1990; Freund & Baltes, 1998; Jopp, & Smith, 2006). An older adult's effective use of these strategies helps them to maintain a realistic sense of self by maintaining meaningful social activities and allowing that person's flexibility in adjusting personal goals. This leads to greater subjective perception of well-being and more positive emotions (Brandstadter & Greve, 1994). In addition, other psychological resources for successful aging can include a greater sense of control over life (self-efficacy), effective coping strategies, and creativity (Bowling & Dieppe, 2005). For example, when an older adult experiences negative life events (such as health or interpersonal impediments), adopting effective coping strategies may lead to better event outcomes, physical and mental health, life satisfaction, and greater social involvement (Moos, Brennan, Schutte, & Moos, 2006; Windsor, 2009). Such coping strategies may include problem-solving or positive reappraisal of

alternative approaches to the problem. Helping older adults identify positive aspects of a situation and be more assertive are thus effective ways to address proactively these unavoidable life events experienced by older adults. An approach labeled creative engagement can also promote older adults' sense of control and meaningful social engagement by encouraging self-expression and social connections (McFadden & Basting, 2010). Facilitating the use of these strategies among older adults is important in developing and administering rehabilitation and health promotion programs.

Informal social activities. Older adults often choose to engage formal social activities, such as volunteering in support of an organization, and more informal social activities, such as eating at a restaurant with family, having conversations on the telephone with friends or playing cards with neighbors. Informal social activities may occur more frequently, and form social routines or preferences that can originate in childhood or early adulthood and are maintained through later years. Such informal social activities may have greater influence on an older adult's well-being and risk of depression over time than more formal social, leisure, or religious activities (Hong, Hasche, & Bowland, 2009). This may be due to the higher intimacy and frequency of engagement in informal social activities, or to the personal value, meaning, and satisfaction assigned to these activities and relations. Some older adults may come to rely on only a few informal social activities because of limitations in social network size, reduced social opportunities, and health conditions that pose barriers to social activities. Reduced socialization may occur despite the desire of the individual to engage in more or varied social activities (Gilmour, 2012). Health professionals can identify the older adults' interests and desires for engaging in various social activities and relations, provide opportunities in the individual's chosen meaningful activities, find ways to overcoming barriers and facilitating participation. Some older adults may lose their long-standing informal social activities and social routines because of the death of spouse or close friends, or moving to a new location or home setting. Health professionals can help the older adults establish new meaningful relations by providing opportunities for meeting new people, maintaining their previous social activities, or establishing new social routines after change-causing life events occur.

Volunteering and reciprocity of social exchange. Defining meaningful social interactions depends on the individual. Older adults, however, tend to find helping or supporting others to be meaningful (Hendricks, & Cutler, 2004). An increasing number of older adults engage in volunteer activities as a way of meaningful, social engagement after retirement (U.S. Bureau of Labor Statistics, 2013). Twenty-four percent of older adults living in the United States engaged in volunteer activities during the period from September 2011 to September 2012. They spent a median of 90 hours on volunteer activities during the period, which is highest among all age groups. Older adults are more likely to volunteer for religious or social and community services, with a strong motivation for helping others and being active in the community (Okun & Schultz, 2003; U.S. Bureau of Labor Statistics, 2013; Witucki Brown et al., 2011). In contrast, younger and middle aged older adult volunteers are more motivated by skill development and advancement of careers. Volunteering in later life allows older adults to identify their productive roles and enhance their self-esteem, sense of meaning in life, and social connection in the community, leading to positive well-being (Hinterlong, Morrow-Howell, & Rozario, 2007; Warburton & Stirling, 2007; Witucki Brown et al., 2011).

Volunteering is often regarded as a unidirectional help from a healthier or wealthier individual to others less fortunate, but there often is a mutual benefit. Literature supported the benefits of continued engagement in volunteering of older adults (von Bonsdorff & Rantanen, 2011), including reduced depressive symptoms (Li & Ferraro, 2005), increased physical function (Lum, 2005), physical activity (Tan et al., 2009), cognitive function (Fried et al., 2004), and positive affect (Pilkington, Windsor, & Crisp, 2012). Exercise gives similar benefits, but engagement in volunteering activities may be more sustainable than engagement in exercising programs (Tan, Xue, Li, Carlson, & Fried, 2006). This may be because volunteering gives greater value and motivation as a productive member of the society and feeling socially connected in the community. This indicates that volunteering can be a way of being physically, socially, or mentally active and of having greater life satisfaction, self-worth, purpose in life, and meaningful social interactions among older adults.

An older adult's functional health conditions can be a barrier to formal volunteering work. Older adults, however, can participate in volunteering or giving help or support to others if matched with their personal abilities, needs, and motivation. For instance, an older adult with reduced physical function can be a conversational partner for a non-English speaking student who is learning English, and the older participants showed a significantly enhanced life satisfaction (Yuen, 2002). Older adults living in long-term care facilities may have a lack of opportunity in engaging altruistic activities even though some are willing to do (Cipriani, Faig, Ayres, Brown, & Johnson, 2006). Older residents may maintain self-identity and self-esteem and enjoy the opportunity for social engagement with the recipient, other residents, or staff. An older adult's interests, needs, and values for participating in these activities should be considered to help the older adult engage in these valued activities.

Older people who engage in socially productive activities, such as volunteering, caring for another person, and other forms of informal help do not always have positive psychological well-being. According to the equity theory, balanced support exchange affects well-being positively, and imbalanced relationships in terms of support exchange (receiving either more or fewer support than giving) lead to negative well-being (Adams, 1965). Although there are mixed results whether giving support is better for the well-being of older people or if receiving support is better, unbalanced relationships elicit more mental distress in older adult volunteers and caregivers than balanced relationships (Fyrand, 2010). The association between psychological well-being and socially productive activities depends on whether an older adult who provides help received reciprocal social exchange such as appreciation and satisfaction from activities (Wahrendorf, von dem Knesebeck, & Siegrist, 2006). Older adults may have positive well-being given greater reciprocal social exchange (McMunn, Wahrendorf, Nazroo, Breeze, & Zaninotto, 2009), high autonomy, and perceived control (Wahrendorf, Ribet, Zins, & Siegrist, 2008). This reciprocal social exchange motivates an older adult to continue participation in these socially productive activities and improve quality of life (Siegrist & Wahrendorf, 2009). Lower quality of life and higher risk of depression of caregivers may be due to non-reciprocity in caring (McMunn et al., 2009;

Wahrendorf et al., 2006). An older caregiver caring for a spouse with Alzheimer's disease may have a lack of reciprocity in the relationships thus feeling burdened, but the caregiver can compensate for the lack of reciprocity and have indirect reciprocity by attending to nonverbal behaviors. Finding ways of facilitating balanced social relationship, therefore, is needed for older volunteers and informal caregivers to engage in these socially productive activities with positive psychological well-being and motivation. One way is to enhance emotional support from families, other volunteers, and care-receivers on engaging in socially productive activities. This may maintain or enhance satisfaction and self-worth. Reciprocity in dyadic relationships is also important to the recipient of help (McPherson, Wilson, Chyurlia, & Leclerc, 2010). An older adult who is in a dependent position may become more dependent and feel powerless, leading to the reduced self-esteem and self-efficacy. Health care professionals, therefore, should suggest ways of establishing and keeping reciprocal balanced relationships between caregivers or friends providing support and older adults who receive support (del-Pino-Casado, Frias-Osuna, & Palomino-Moral, 2011). One way is to help older adults, who receive care, maintain their independence as much as possible in a safe, supportive environment, matched with their abilities. Another strategy is to help older people who receive care understand acceptance of care can be a gift to the caregiver. The enhanced independence and more balanced social relationships may enhance the psychological well-being of both caregivers and recipients of help, sustain their relationships, and reduce the caregiver's burden (del-Pino-Casado et al. 2011).

Peer-led activities. An older individual can be an active provider of delivering health promotion activities to other older adults. Older people, who participated in a 14-week exercise program led by trained peer mentors or trained college students showed equivalent improvements in fitness measures (Dorgo, King, & Brickey, 2009). Additionally, only peer-mentored older adults, among older adults either peer-mentored or student-mentored, showed significant enhancements in perceived physical, mental, and social functioning (Dorgo, Robinson, & Bader, 2009). A randomized controlled trial compared self-determined physical activity, objectively measured physical activity by accelerometer, and

cardiorespiratory fitness in older adults who received peer-led advice and support with the same measures in older adults who received a standard community-based intervention (Buman et al., 2011). Both groups showed significant enhancement in physical activity behavior and in cardiorespiratory fitness at 16 weeks, but the peer-mentored group better maintained their physical activity behaviors at the study's 18-month follow-up. These results suggest peer mentors may provide older adults with a more supportive social environment in which individuals intrinsically are motivated to be physically active through meaningful, satisfying relationships, support, and role modeling (Buman et al.).

To examine the relative effectiveness of the delivery agent (volunteer peer mentors vs. professional staff) and the program itself, a 12-month RCT was conducted, where older adults received telephone-based physical activity advice from either trained peer mentors or trained professional staff members (Castro, Pruitt, Buman, & King, 2011). Older adults in both groups showed significant improvements in self-reported moderate or greater intensity leisure-time physical activity. In addition to the positive results in the physical activity of older adults, researchers found that volunteering peer mentors could not only learn and deliver evidence-based physical activity programs to older adults but did so even more successfully than professional staff (Buman et al., 2011; Castro et al., 2011). More research is needed to support objective health benefits of peer-led physical activity programs for older adults. These positive results of the previous studies, however, suggest that older peer mentors contribute to enhancing physical activity levels and providing supportive social environments to older adults with sedentary lifestyle or low physical activity level. Similar peer-mentored programs have been applied to other types of programs for older adults, such as a strength training program (Layne et al., 2008), a falls prevention program (Waters, Hale, Robertson, Hale, & Herbison, 2011), and a diabetes self-management program (Lorig, Ritter, Villa, & Armas, 2009). Older adults with physical disability can provide physical activity promotion programs to older adults with physical disability if peer-mentors receive training (Robinson-Whelen et al., 2006). A secondary benefit of the engagement in these volunteered programs

may also enhance peer mentors' emotional well-being and overall health by socializing with more people and having meaningful relationships with that larger group of people.

In addition to social interaction and support from peer mentors, older adults may enhance their self-efficacy beliefs by interacting with a peer mentor who is similar in age, life experience, or health conditions to them. Self-efficacy may mediate the positive effects of intervention on health and health behaviors because self-efficacy plays an important role in health behavior, health behavior change, and improvements of physical and psychological health (Robinson-Whelen et al., 2006). Self-efficacy enhancing skills, such as individualized goal-setting, problem solving skills, and reinforcement, should be included as parts of the programs, and peer mentors should receive training on facilitating and using these skills (Buman et al., 2011; Castro et al., 2011). A strengths-based approach, focusing on individual's abilities and resources, can be incorporated into goal-setting and finding strategies to facilitate their strengths in peer-led activities (Chapin et al., 2013). This approach may help enhancing self-efficacy and subjective quality of life of older adults and eliciting more collaborative relationships between care providers and receivers.

Intergenerational programs. Older adults can have mutual learning and support with younger generations through various intergenerational programs. Intergenerational programs involve different forms, types, and settings of activities. Older adults can help learning of children and youth as academic mentors in schools (e.g., Experience Corps in Glass et al., 2004). Younger people can also help older adults improve or acquire computer skills (e.g., Sanders, O'Sullivan, DeBurra, & Fedner, 2013), or older and younger people can work together for the same goal (e.g., recycling in D'Abundo, Fugate-Whitlock, & Fiala, 2011). These intergenerational programs benefit older people, younger people, and the community.

A good example showing the mutual benefits of intergenerational programs is Experience Corps program in Baltimore, a well-designed intergenerational program to benefit both older adults and children in public schools (Glass et al., 2004). Trained older adult volunteers played multiple roles, such as

tutoring children for literacy and supporting other older volunteers as a team, in school for at least 15 hours a week over the full school year. These multiple roles and training in various skills to play roles were intended to promote physical, social, and cognitive activities of the older adults, leading to the improvement of health. The majority of the older volunteers were African American women with low income and education. Researchers conducted a pilot RCT and found short-term benefits for the older adults, children, and schools. Older adults in the intervention group increased physical, cognitive, and social activity levels as compared to those in the control group (Fried et al., 2004). Children in the intervention schools significantly performed better on a standardized reading test and decreased classroom misbehaviors more than those in the control schools (Rebok et al., 2004). These benefits were only measured after a short-term period, so the long-term benefits are unknown. The program, however, is valuable in that only 2.3 % of the Experience Corps participants dropped out during the first school year, and 82% reported their willingness to participate in the program 2 or more years (Fried et al. 2004).

The older people's high motivation is an important factor to maintain health promotion activities. Their high motivation could be explained by older adults' desire for generativity, caring for and giving back to younger generations defined by Erikson (Erikson, 1997), and by meaningful roles and relations embedded in social environments across ages. Diverse older adults as well as African American women can benefit from engaging in this highly attracting intergenerational program to meet their developmental needs and to promote health by being physically, cognitively, and socially active.

A few other studies used a RCT design to identify the effects of intergenerational volunteering programs on older adults. Older adults who shared their memories with adolescents at school for 4 months showed significantly enhanced perceptions of neighbors' helpfulness and trust and of family relationships compared to the older adults in the control group (de Souza & Grundy, 2007). Another RCT study by George (2011) used mixed methods to evaluate the effects of the intergenerational volunteering program on the quality of life and health outcomes of the older adults with mild to moderate dementia. The older adults in the intervention group interacted with children by engaging in various

school activities and by sharing their life experiences. The intervention group showed significantly decreased stress and reported enhanced quality of life by positively affecting perceived health status, sense of purpose and of usefulness, and relationships. Sharing life stories with younger generations is one effective way to have meaningful relations between older adults and younger generations. This approach does not require older adults to exert high physical or cognitive abilities, and older individuals have gained their own life stories regardless of socioeconomic status. Their life stories and experiences are thus older adults' strengths that they can share their wisdom and values with younger generations. Health professionals can apply this easy but effective approach into various health promotion programs to facilitate intergenerational interaction, health, and quality of life of older adults.

An intergenerational service learning program is another way of linking older adults to college students. These service learning programs are designed to facilitate students' learning although programs may benefit older adults too. There is evidence to support the benefits of intergenerational service learning programs on college students' academic learning and attitude changes. Studies showed the students' improvement of positive attitudes toward older adults and aging through either a face-to-face interaction (Gonzales, Morrow-Howell, & Gilbert, 2010; Leung et al., 2012; Yamashita, Kinney, & Lokon, 2013; Zuccherro, 2011) or a virtual interaction (Butler & Baghi, 2008; Chase, 2007). The positive attitudes of these students and their better understanding of older people may influence their career plans by increasing willingness and interests in working with older adults and reducing stereotypes toward older adults (Bates, Cohan, Bragg, & Bedinghaus, 2006; Kalisch, Coughlin, Ballard, & Lamson, 2013; Vandsberger & Wakefield, 2005). Most of these studies measured the benefits of college students and a few studies assessed the benefits of older adults. For example, older adults expressed the benefits of meaningful relationship and increased understanding to younger generation after engaging in the service learning program (Underwood & Dorfman, 2006; Zuccherro, 2010). There is a lack of evidence on how service learning programs influence older adults' quality of life, well-being, and loneliness, and more studies are needed.

Not only developmental theories support the importance of intergenerational interactions, but also older adults themselves enjoy having meaningful relations with younger generations. For example, 45 % of older adults aged 50 to 70 years who were working in retirement said they were interested in working with youth (Metlife Foundation & civic Ventures, 2005). Older adults with dementia also expressed more positive affect during intergenerational activities than they did during non-intergenerational activities (Jarrott & Bruno, 2003). For example, an older individual, who is living in an assisted living facility, may live far away from her or his grandchildren and miss relationships with them. In this case, engaging in an intergenerational program is an alternative way for the older adult to establish and maintain meaningful relations with younger generations. Older adults' interest and value in interacting with younger generations should thus be facilitated by various activities and interaction.

Computer and Internet use for promoting social participation and psychosocial well-being.

Using computers and the Internet as a communication tool \ help older adults increase communication with family and friends, develop new friendships, and enhance social support and interaction with families, friends, and professionals (Marziali & Donahue, 2006; Russell, Campbell, & Hughes, 2008; Xie, 2007). For example, older adults used the Internet to communicate with friends and relatives, who did or did not live in their local areas, access a community website, participate in online groups, and find and meet new people for social interaction (Sum, Mathews, & Hughes, 2009). Increasing numbers of older adults use computers and the Internet although the percent of these older adults is less than the percent of all other age groups (U.S.Census Bureau, 2013). According to a recent survey of the Pew Internet and American Life Project in 2012, 53 % of older adults (aged 65 and older) living in the United States used the Internet (Zickuhr & Madden, 2012). Among the older computer and Internet users, 86 % used e-mail, and 34 % used social networking sites (e.g., Facebook) in 2012, showing tremendous increase compared to 13% in 2009. These results indicate that increasing numbers of older adults use computers and the Internet for maintaining social interaction. Some studies found that older computer and Internet users are more likely to engage in community organizations and activities than nonusers (Cresci, Yarandi, &

Morrell, 2010; Werner, Carlson, Jordan-Marsh, & Clark, 2011), and to have a friend or a grown child who uses a computer and give informal help (Russell et al., 2008). This suggests that older computer and Internet users may have a larger social network and receive more social support on-line and off-line. Some older adults may not use computers and the Internet because they cannot afford the cost of computers and internet access, they have a lack of motivation and usefulness in learning how to use computers and the Internet, or they have nobody who can teach computer and internet skills (Choi & Dinitto, 2013). Identifying individualized barriers and perceived benefits of using computers and the Internet as a communication tool will help health professionals select appropriate computer and internet programs for facilitating social interaction and support of older people.

Online communication may benefit older adults' psychosocial well-being, especially who have low levels of social interaction and support. Homebound older adults may increase their social participation and thus avoid feelings of isolation through the online community (Bradley & Poppen, 2003). Older nursing home residents showed significantly lower levels of loneliness and depression, and enhanced emotional social support over a year after having 3-month videoconference interaction with their family members (Tsai & Tsai, 2011). According to a recent meta-analysis by Choi, Kong, and Jung (2012), computer and internet programs benefit older adults who live alone at home and live in rural areas or nursing homes by significantly reducing their loneliness, negative feelings coming from unsatisfying social interaction. This result is also supported by cross sectional studies showing the association between a greater use of the Internet for communication and a lower level of loneliness (Cotton, Anderson, & McCullough, 2013; Sum, Mathews, Hughes, & Campbell, 2008). More study is needed to identify what types of intervention benefit what types of older adults because of the small number of studies and their mixed findings (Blaschke, Freddolino, & Mullen, 2009).

Environmental Factors for Promoting Social Participation

The World Health Organization (WHO) proposed that “an age-friendly city promotes active aging by optimizing health, participation, and security in order to enhance quality of life as people age”

(WHO, 2007, p. 1). This definition views active aging as a life-long process, determined by combined effects of personal, social, economic, and environmental factors. The eight features of age-friendly cities include three aspects of physical environment (outdoor spaces and buildings; transportation; and housing), three aspects of social environment or culture (social participation; respect and social inclusion; and civic participation and employment), and two features involving both social environments and health and social service determinants (communication and information; and community support and health services). An older adult's participation in social activities will be facilitated in the age-friendly city, with more accessible physical environment, available social activities near neighborhood, and diverse social activities matched with an individual's interests.

While the WHO's model of Global Age-Friendly Cities (2007) relies on the involvement of policy-makers to assess the community against established criteria, some approaches focus on older adults' active participation in enhancing their neighborhoods (Lui, Everingham, Warburton, Cuthill, & Bartlett, 2009). For example, the CALL-ME project is based on the participatory, collaborative participation among older people and local stakeholders in four disadvantaged urban communities in Manchester, UK, to promote social interaction and active community involvement by designing, planning, and implementing community initiatives (Murray & Crummett, 2010). Empowering older adults to use available resources and capacities even in disadvantaged neighborhoods and to take control over their environments are key strategies with giving opportunities for social interaction. One of the initiatives is a garden project in which groups of older residents developed community gardens near a busy crossroad. The older residents showed increased socialization, enjoyment of gardening, sense of achievement and belonging, physical and mental health, and control (Middling, Bailey, Maslin-Prothero, & Scharf, 2011). This project indicates that older residents in disadvantaged urban communities can benefit from actively participating in community engagement, and they can provide benefit to other residents and the community at the same time. Middling et al. (2011) did not mention whether an older resident had a choice on types of gardens (e.g., a vegetable garden, a flower garden). This matters if older

people participate in and enjoy gardening for different reasons and have personal interests in specific types of gardens (e.g., having a good memory in gardening a tomato garden with parents when the person was young). Giving a choice of or matching an older adult to types of gardening should be considered when developing a gardening project.

A neighborhood's physical and social environments are important for promoting older adults' social participation. Neighborhood characteristics promoting social participation include greater perceived accessibility to neighborhood resources (Richard, Gauvin, Gosselin, & Laforest, 2009), greater perceived safety of neighborhood (King, 2008), greater availability of social and community resources, and greater perceived neighborliness and trust (Bowling & Stafford, 2007). Older people may be more emotionally attached to their neighborhoods than younger people because of the time they lived in the neighborhood. An older adult, who knows neighbors well and has trustful relationships with them, establishes a stable social network in the neighborhood. The enhanced sense of belonging to the neighborhood and trust in neighbors has a positive impact upon physical and mental health (Norstrand, Glicksman, Lubben, & Kleban, 2012) and reduces psychological distress of older adults, due to the enhanced feelings of security, self-esteem, and confidence (Phongsavan, Chey, Bauman, Brooks, & Silove, 2006). Physical spaces within the neighborhood, such as parks, cafes, and walkable streets, may facilitate social relationships of older people in the neighborhood by providing pleasant places to socialize and increasing frequency of interactions (Litman, 2012).

Some environmental factors may affect older adults' social participation differently depending on the disability status related to the degree of person-environment fit (Levasseur et al., 2011). For example, limited accessibility to existing community centers can limit mobility-impaired older adults from engaging in social activities due to the features of building, such as steps, long-walking distance, and no parking place for the person with disability. Negative attitudes of staff regarding disabled older adults can also interfere with motivation and self-esteem of individuals with disability, also leading to reduced

social participation. Eliminating environmental barriers at the interpersonal level and the community level is important for promoting social participation of older people, regardless of disability status.

Many older adults are faced with moving from a home in the community to an assisted living facility or nursing home. These older adults must then establish new social relationships with other residents and staff in a new living environment where different rules and routines exist. The quality of these social ties is important for adjusting to the new environment and for maintaining (or enhancing) quality of life (Street, Burge, Quadagno, & Barrett, 2007). Environmental characteristics of the assisted living facility can influence establishing meaningful social relationships with other residents and staff. Home-like surroundings may help older adults form friendships with other residents and staff in a pleasant place, with the resident feeling comfortable and at ease. Home-like environments include both physical and social aspects of the environment, including design of the facility similar to a typical home, respect of privacy, and choice of participation in daily life activities such as meal preparation (Verbeek, Zwakhalen, van Rossum, Kempen, & Hamers, 2012). These facilities allow residents' own furniture and familiar decoration, and residents can maintain their lifestyles by having choices of meals, personal care, sleep, and activities (Verbeek, van Rossum, Zwakhalen, Kempen, & Hamers, 2009). Being in a personalized environment and providing meaningful activities can promote a continuation of self and facilitate meaningful relationships with other residents and staff (Edvardsson, Fetherstonhaugh, & Nay, 2010). Better work environment can also influence job satisfaction of staff and resident satisfaction (Sikorska-Simmons, 2006) and reduce turnover rates of staff (Chou & Robert, 2008). The enhanced job satisfaction and establishing valued interpersonal relations over time may promote higher quality interactions of staff and residents, and may promote an enhanced quality of life and satisfaction for both groups in people.

Conclusion

Older adults may choose to participate in various social activities and to receive or provide social support to other older adults, to younger people, and to the community. An older adult's health, disability

status, and their ability or desire to function, may influence their opportunities, types, and varieties of social participation options. Despite potential limitations, older adults often are willing to participate in different social activities, and establish or maintain meaningful social interactions with others, when these options are matched appropriately with the older adult's abilities, values, and interests. This review paper explores a variety of forms of social participation and alternate approaches that may play important roles in facilitating meaningful social interactions, enhancing subjective quality of life, and promoting health of older adults. Older adults with and without disability regard social participation and meaningful social interactions as important determinants of successful aging, but health care professionals tend to focus on biomedical factors and attend less to the importance of psychosocial factors. Social participation facilitates older adults' subjective quality of life and health, and enhances self-efficacy and social connection. Health care professionals therefore should recognize the benefits of social participation, and incorporate both evidence-based psychosocial approaches into their client's care plans. In addition, professionals should encourage and provide older adults and their families, friends, and caregivers with ways of participating in various social activities, having balanced, meaningful social relations, and creating supportive environments for social participation of older adults.

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Appendix 2: Perspectives of people with dementia about meaningful activities: A synthesis

(2nd comprehensive review of the literature)

Abstract

Thirty-four qualitative studies were synthesized to describe perspectives of people with dementia regarding meaningful activities and meaning of engagement in activities. Three themes of connectedness pertaining to self, others, and the environment were identified using a meta-ethnography approach. The theme of being connected with oneself encompasses engagement for continuity, for health promotion, and for personal time and rest. The theme of being connected with others includes being with others not to be/feel alone, doing an activity with others, and meaningful relationships. The theme of being connected with environment encompasses being connected to one's familiar environment, to community, and to nature. This synthesis suggests that connectedness is an important motivation for engagement in daily activities. Findings indicate that identifying the underlying motivation for an individual with dementia to engage in different activities is important for matching a person with activities that will be satisfying. This review may inform the development of interventions for engaging older adults with dementia in meaningful, daily activities and creating connectedness to self, others and the environment.

Keywords: connectedness, dementia, engagement, meaningful activities, qualitative, synthesis

Introduction

This research paper aims to synthesize published qualitative studies reporting perspectives of people with dementia about meaningful activities. Individuals' motivation and meanings in engagement for activities could be different. To understand not only what types of activities are meaningful but also why people with dementia want to engage in these activities will facilitate the development of a better intervention matched with their wants and needs for daily activities. This paper, therefore, focuses on identifying and synthesizing meanings and motivations for engagement in daily activities reported by people with dementia.

Engagement in personally valued, meaningful activities is an important determinant of successful or active aging and quality of life in older adults (Bowling, 2008; Stenner, McFarquhar, & Bowling, 2011; Wilhelmson, Andersson, Waern, & Allebeck, 2005). Older adults with dementia, however, may no longer participate in their valued activities because they lose abilities to initiate and participate in the activities as the way they used to in the past (Cook, Fay, & Rockwood, 2008). Support is needed for people with dementia to participate in their meaningful activities and thus meet human needs and wants for engagement with life.

Unmet needs exist for people with dementia living in the community and residential care homes. People with dementia report not participating in daytime activities and having social company to the extent they need, and having psychological distress such as depression and anxiety (Hancock, Woods, Challis, & Orrell, 2006; Meaney, Croke, & Kirby, 2005; Miranda-Castillo, Woods, & Orrell, 2010; Miranda-Castillo, Woods, & Orrell, 2013; Orrell, Hancock, Liyanage, Woods, Challis, & Hoe, 2008; van der Roest et al., 2009). Family caregivers and health professionals indicate similar unmet needs for persons with dementia in these three areas (Miranda-Castillo et al., 2013; van der Roest et al., 2009). Higher unmet needs were not associated with severity of dementia, but associated with higher depressive symptoms and anxiety that may result in poor quality of life (Hancock et al., 2006; Hoe, Hancock,

Livingston, & Orrell, 2006). These results suggest that meeting needs for daytime activities and social company may reduce psychological distress and improve quality of life.

It is important to identify why people with dementia have higher unmet needs for daytime activities and social company. Residents with dementia in care homes had statistically significant higher unmet needs in daytime activities and social contact than residents without dementia (van der Ploeg, Bax, Boorsma, Nijpels, & van Hout, 2013). For example, the daytime activities provided by care homes may not interest residents with dementia because the activities are not carefully developed considering values, psychosocial needs, interests, and abilities of residents with dementia. In this case, residents with dementia lose motivation for engaging in daytime activities and opportunities for making social contacts. Community-dwelling people with dementia and their informal caregivers also stated that available community services were not what they wished and preferred for daytime activities (van der Roest et al., 2009). All these findings suggest a critical need for identifying which daytime activities would be meaningful to people with dementia and how to meet their needs for daytime activities and social contact.

Activity programs are available for people with dementia to provide daytime activities and social company. Engagement in activities has been used as a means for improving quality of life and reducing behavioral and psychological symptoms in people with dementia. The effectiveness of varied activity programs were supported in systematic review articles (Guzman-Garcia, Hughes, James, & Rochester, 2012; Letts et al., 2011; O'Connor, Ames, Gardner, & King, 2009a; O'Connor, Ames, Gardner, & King, 2009b; Olazaran et al., 2010; Perkins, Bartlett, Travers, & Rand, 2008; van Mierlo, van der Roest, Meiland, & Droes, 2010; Wall & Duffy, 2010). These activity programs include reminiscence therapy, recreational activities, dancing, dog-assisted therapy, and music therapy as an isolated intervention, or an activity program is included as a part of multicomponent interventions. Some activity programs were individually tailored to match preserved abilities, previous roles, habits, and interests of individuals with dementia to the activity level and found benefits on behavioral symptoms and increased engagement and pleasure during sessions (Gitlin et al., 2008; Gitlin et al., 2009; Kolanoswki, Litaker, & Buettner, 2005).

The interests and roles of participants with dementia, however, were only collected by caregivers' reports. Activities were then selected by therapists based on their own perspectives on meaningful activities considering caregivers' reports, results of cognitive and functional assessment, and observation of home environment. Although behaviors are viewed as an expression of unmet needs according to the need-driven dementia-compromised behavior theory (Algase et al., 1996), it is hard to know whether these activities were truly meaningful to the persons with dementia by meeting their psychosocial needs.

While researchers above identified the effectiveness of activity programs in some outcome measures, several questions remain unknown. It is hard to understand why some activity programs worked better and whether the activity itself as a whole is effective or involved approaches in the activity mattered. It is also unknown whether provided activities were truly meaningful to persons with dementia. These remaining questions can be answered by synthesizing findings of qualitative studies reporting perspectives of people with dementia on meaningful activities.

Methods

Search Strategy

I defined meaningful activities as self-chosen activities derived from an individual's interests, preferences, values, motivations, pleasure, or sense of the importance of participating in certain activities (Trombly, 1995). I then searched the relevant literature comprehensively by using different approaches, such as keyword searching, citation searching, using related-articles features, and hand-searching in electronic databases, specific journal websites (e.g., *Dementia*, *Qualitative Health Research*) and Google Scholar. The SPIDER (Sample, Phenomenon of Interest, Design, Evaluation, and Research type) search strategy, instead of PICO (Population/Problem, Intervention, Comparison, and Outcomes), was used because this strategy is more suitable for searching qualitative studies (Cooke, Smith, & Booth, 2012). The search terms (Table 1) were combined and entered in electronic databases, including PubMed, CINAHL, and PsychINFO. Peer-reviewed journal articles, published in English between 1990 and 2013, were searched, and 796 articles were initially identified by using these search terms.

Inclusion Criteria

Of the 796 articles initially identified by the search terms, findings of qualitative studies and mixed method studies had to include views of people with dementia, living in community or residential care homes, on meaningful activities to be included in the synthesis. Studies had to use qualitative methods in collecting and analyzing data, and use qualitative interviews as the main method for data collection. I attempted to identify all relevant qualitative journal articles, and I did not restrict to specific types of qualitative study, types of dementia, and age of persons with dementia.

I read titles and abstracts of the identified articles and determined their eligibility for inclusion. Studies were excluded if all participants were not people with dementia and if studies did not have findings regarding how people with dementia consider daily activities to be meaningful to them and why they want to engage in these activities.

Quality Appraisal

The Critical Appraisal Skills Programme (CASP), developed for appraising quality of a qualitative study (Milton Keynes Primary Care Trust, 2002), was used for quality appraisal of included studies. This checklist includes 10 questions assessing its rigor, credibility, and relevance. Studies were not excluded based on the study quality because there are no criteria of excluding studies based on quality and we may miss valuable findings (Sandelowski & Barroso, 2006). I found no study with fewer than 7 points out of the 10 points possible on the CASP checklist.

Analysis

I chose Noblit and Hare's (1988) meta-ethnographic approach as the synthesis method. Meta-ethnography is a widely used method for synthesizing multiple qualitative studies with diverse study designs (Britten et al., 2002; Cook et al., 2012). Meta-ethnography uses the authors' interpretations and explanations of original qualitative studies as the raw data for the synthesis in addition to the reported quotations of participants. In other words, the revealed themes, perspectives, or concepts from each qualitative study are selected as data for synthesis (Campbell et al., 2011). This prevents

misinterpretation of data from its' original collector and preserves the meaning of the text (Weed, 2005). Meta-ethnography is interpretative rather than aggregative, that creates new interpretations, concepts, or themes, and that helps in achieving better understanding beyond individual studies (Malpass et al., 2009).

I followed steps recommended in Noblit and Hare (1988)'s meta-ethnographic approach. I carefully read the included studies multiple times, and identified and listed relevant key metaphors (concepts, themes, perspectives, and phrases) included in the findings of each study. I then compared metaphors of an individual study into one another (called 'reciprocal translations') and created working themes that emerged from the key metaphors. I reviewed the emerged themes to create new overarching themes that meaningfully integrate and interpret related concepts as a whole.

Results

Description of Studies

A total of 34 studies were included, and Table 2 describes characteristics of these studies. Main reasons for excluding the other studies are: participants included older adults without dementia (e.g., Murphy, Shea, & Cooney, 2007); qualitative data didn't have perspectives about meaningful activities (e.g., Beard, Fetterman, Wu, & Bryant, 2009); the paper is a review paper (e.g., de Boer et al., 2007); and data was not collected by interviews (e.g., Palo-Bengtsson, Winblad, & Ekman, 1998).

Description of Themes

I found that being connected is an important motivation for people with dementia to engage in activities. A person with dementia was connected or wanted to be connected to oneself (theme 1), others (theme 2), and environment (theme 3) through engagement in the individual's meaningful activities. The central themes, subthemes, and examples of quotes from original studies in each subtheme are described in Table 3. The nine subthemes will be discussed in detail below.

Theme 1: Being connected to oneself

Subtheme 1a: Engagement for continuity. This subtheme involves engagement in long-held habits, routines, local traditions, and leisure or work-related activities to maintain previous life-style, long-held beliefs, faiths, values, interests, identity, and culture.

Community-dwelling people with early and middle stages of dementia had a significant desire for continuing engagement in typical everyday activities that they had done before the dementia to maintain some level of continuity with their previous lifestyle, long-held beliefs, and values (Menne, Kinney, & Morhardt, 2002; Mok, Lai, Wong, & Wan, 2007; Öhman & Nygård, 2005; Phinney, Chaudhury, & O'connor, 2007; Phinney, Dahlke, & Purves, 2013; Preston, Marshall, & Bucks, 2007; Smith et al., 2005; Van Dijkhuizen, Clare, & Pearce, 2006). For example, engaging in household chores was very meaningful to some people with dementia although they had to engage in these activities differently from how they had done previously (Phinney et al., 2007). Staying interesting was a value for one woman with dementia who kept watching television programs of interest to her, reading books, and meeting friends to maintain her value of being an interesting person (Phinney, 1998). Two of the male subjects had past lifestyles of hard work and valued achievement through hard work (Phinney et al., 2013). Having no activity requiring work hard to achieve a goal caused these men to feel empty and uncomfortable. They therefore tried to continue engaging in daily activities, including work-related activities, to maintain their identities.

Activities supporting each individual's habits, routines, and roles were meaningful because people with dementia could engage in daily activities as much as possible, feel a sense of normality, and maintain their preferred lifestyle (Nygård & Öhman, 2002; Öhman & Nygård, 2005, Phinney, 1998; Phinney et al., 2007; Preston et al., 2007; Van Dijkhuizen et al., 2006). Remaining involved in work-related activities and household chores helped some people with dementia maintain a sense of identity; one as a previous choral conductor, another as a helpful husband for his wife with disability, and a third as a good father for his children (Phinney et al., 2007). Helping others was another important way of maintaining continuity of lifestyle to a person with dementia related to his previous occupational role as a

teacher (Menne et al., 2002). One person with dementia who attended a support group maintained his long-held belief about the importance of a sense of humor for life, and helped members of his support group laugh and see humor (Menne et al.).

Continuing engagement in cultural and spiritual activities helped people with dementia maintain their culture and long-held faiths. Community-dwelling older adults with mild dementia valued cultural activities related to traditions, local history, folk music, and their own life histories (Brataas, Bjugaz, Wille, & Hellzen, 2010). Some people with dementia continued participating in spiritual activities by engaging in personal practices at home (e.g., prayer, reading the Bible), attending church, playing roles and helping others in church, and by being informed of events within the wider spiritual communities (Beuscher & Grando, 2009; Dalby, Sperlinger, & Boddington, 2012; Dröes et al., 2006; Lawrence et al., 2011). They were strongly motivated to engage in these spiritual activities because of their sense of identity and continuity in faith, and the fellowship with and support from other members in the spiritual community. Praying to God, praying for others, and having conversations with supportive people who have the same spiritual values provided people with opportunities to express their feelings and spirituality in a peaceful, warm social environment.

Activities giving certain levels of stimulation and contact with others were meaningful to people with dementia living in residential care settings (Aggarwal et al., 2003). Little human contact and activity, and limited level of stimulation in care homes were supported by observational data. This new daily life with little human contact and activity at residential homes was not matched with the life they used to have at home.

Individual differences in preferences for activities exist among residents with dementia. Some residents with dementia liked participating in home-like activities (e.g., setting the table, folding linen) that gave them a sense of continuity (van Zadelhoff, Verbeek, Widdershoven, van Rossum, & Abma, 2011). On the other hand, some older residents with dementia in care homes liked having little

responsibility for household chores and meal preparation and more time for leisure and social activities (Moyle et al., 2011b; van Zadelhoff et al., 2011).

Although individual differences exist, culture and ethnicity to some extent contribute to determining valued activities, roles, and relationships that are integral to culturally determined identity of people with dementia (Lawrence et al., 2011). Black Caribbean and White British older adults with dementia living in the United Kingdom valued being independent of others. Continuing engagement in practical activities (e.g., cooking, shopping) needed for independent living promoted their sense of psychological and emotional well-being. The White British participants, especially, wished to contribute equally to their relationships, roles, activities by assisting their partner, and thus not to be a burden to families. South Asian and Chinese people, on the other hand, valued family and support from families, and being part of a family by interacting with and getting support from family was important to them (Lawrence et al., 2011; Mok et al., 2007). The importance of being autonomous not to be a burden to family was more emphasized in younger individuals with dementia than older people (Steeman, Godderis, Grypdonck, De Bal, & Dierckx de Casterlé, 2007).

Subtheme 1b: Strategic participation in activities for one's own health benefits. The second subtheme addresses engagement in activities to have enjoyment, satisfaction, and distractions from worries, improve and maintain health and well-being, feel useful and autonomous, and recover a sense of identity.

Community-dwelling people with dementia found enjoyment, satisfaction, and distraction from other worries by engaging in leisure activities, such as gardening, going for walks, music activities, communal activities (Gilmour & Huntington, 2005; Nygård & Åhman, 2002; Phinney et al., 2007). Listening to music and singing were identified as common past and current leisure activities, and these activities were not too demanding to do, so people with dementia could actively engage in these activities with pleasure and without thinking about dementia (Cahill & Diaz-Ponce, 2011; Cohen-Mansfield, Golander, & Arnheim, 2000; Dröes et al., 2006; Smith et al., 2005). Music-related activities were also

enjoyed by people with dementia because of positive benefits in their spirits and concentration by soothing and uplifting their feelings and expressing themselves non-verbally (Harmer & Orrell, 2008; Sixsmith & Gibson, 2007). Music, in addition, promoted participation in routine activities by being accompanied as background sound that made activities more enjoyable (Sixsmith & Gibson, 2007).

Engaging in intellectual, physical, and leisure activities (e.g., reading, doing crossword puzzles, and going out for daily walks) was meaningful to community-dwelling people with dementia because they believed that these activities would improve memory and restore their abilities (Gilmour & Huntington, 2005; Nygård & Öhman, 2002; Phinney, 1998; Smith et al., 2005). Some women with dementia, for example, watched television believing this would help maintain active mind (Van Dijkhuizen et al., 2006). Intellectual activities, however, were avoided or abandoned if the people with dementia regarded that activity as too demanding (Nygård & Öhman, 2002; Öhman & Nygård, 2005). Keeping an active mind, being physically active, and maintaining health and well-being were of great value to people with dementia, who strategically participated in such activities to produce a sense of improved well-being (Gilmour & Huntington, 2005; Mok et al., 2007; Öhman & Nygård, 2005; Phinney, 1998). Older people with early stage dementia engaged in leisure activities and service-run activities to keep busy and occupied and thus to reduce loneliness and get some distractions from social isolation (Moyle, Kellett, Ballantyne, & Gracia, 2011a; Van Dijkhuizen, Clare, & Pearce, 2006).

Being or feeling useful provides older adults with dementia with feeling valuable to others and self-worth (Smith et al., 2005; Steeman et al., 2007). Some people with dementia maintained feeling valued and a sense of purpose by doing household chores for their busy children (Steeman et al., 2007; Van Dijkhuizen et al., 2006). Finding new ways of feeling useful was meaningful to people with early stage dementia and one way of these was participating in Alzheimer's research (Clare, 2003; Preston et al., 2007). Volunteering for Alzheimer's research provided them with an opportunity to reflect on their experiences and feel useful through the interview process (Preston et al., 2007). Residents in care homes also expressed frustration and a need for feeling useful (Clare et al., 2008; Moyle et al., 2011b). The

search by residents for active engagement in helping activities was useful in helping them feel more satisfied with living in care homes (Clare et al., 2008).

Some people with dementia appreciated activities supporting their feelings of autonomy in order to maintain self-esteem as they become increasingly dependent on others (Öhman & Nygård, 2005). Continuing engagement in everyday activities could help a person with dementia feel that she is still an independent and valuable person despite dementia (Phinney et al., 2007). Doing things together with family members prevented women with early stage AD from feelings of being a burden (Van Dijkhuizen et al., 2006). Doing things together, thus, allowed them to feel autonomous while accepting some help.

Reviewing past experiences and one's life was pleasurable to residents with dementia living in care homes because engaging in this activity recovered their sense of identity by compensating their current losses (Clare et al., 2008). Talking about past activities, experiences, and interests associated with one's social and occupational roles were enjoyed and meaningful to people with dementia as an expression of their identity (Harmer & Orrell, 2008; Öhman & Nygård, 2005). Looking back over pleasurable memories was a way for an individual with early stage dementia to enjoy being alone and not to feel lonely (Moyle et al., 2011a).

Subtheme 1c: Engagement for personal time and rest. This subtheme describes engagement in activities by oneself to relax with freedom and peace, and without interruptions from others. People with dementia considered having time alone (Harmer & Orrell, 2008) and rest (Holthe, Thorsen, & Josephsson, 2007) meaningful to themselves. Outdoor walking alone was the activity that provided relaxation and a low level of social stress (Cedervall & Aberg, 2010; Phinney et al., 2007). Having quiet meals alone was a way of connecting with self by allowing time for being with one's own thoughts (Keller et al., 2010). Being in a private space alone and engaging in activities in the private space provided people with dementia with feelings of freedom, peace, and enjoyment (Öhman & Nygård, 2005; van Zadelhoff et al., 2011).

Theme 2: Being connected to others

Subtheme 2a: Being with others not to be/feel alone. Having company was meaningful to people with dementia to avoid being or feeling alone. Attending day care centers with highly satisfying levels of human contact was enjoyable to community-dwelling people with dementia because of being around with people (Aggarwal et al., 2003). Having social contact was also significantly important to residents with dementia living in nursing homes and care homes regardless of their stages of dementia (Cahill & Diaz-Ponce, 2011; Harmer & Orrell, 2008). Residents with moderate and severe dementia in care homes expressed fear of being alone and loneliness coming from a socially isolated life at care homes (Clare et al., 2008). Those living alone listened to the radio and watched television in order not to feel alone with some background noise from them and to feel a sense of connection to others by having virtual company (de Witt, Ploeg, & Black, 2009).

Subtheme 2b: Doing an activity with others. People with dementia participated in social activities to have social interactions and enjoyment coming from interactions, maintain shared identity and quality of life, promote relationships, and cope with difficulties.

Some community-dwelling people with dementia regarded ‘doing things together with my partner’ as an activity that positively affect their quality of life (p. 542, Dröes et al., 2006). ‘Sitting at the table together’ and ‘going out together’ were mentioned by nursing home residents (p. 542, Dröes et al., 2006). Doing things together with others in a day care center promoted a sense of belonging and motivation for engagement in activities (Phinney et al., 2007). Working together in the garden was a meaningful activity to a man with dementia and his family because of a sense of shared identity as the family who worked hard together with partnership to overcome any challenge (Phinney et al., 2013). Residents with dementia in care homes were motivated to participate in group activities (e.g., newspaper-reading, gymnastics) offered in care homes because of a sense of belonging by doing things with others together (Holthe et al., 2007). Being invited to group activities and thus having feelings of being included and chances for socialization were meaningful to the residents because most of them lacked motivation

for initiating activities by themselves. The residents found more enjoyment in some group activities matched with their abilities and interests so that they could participate equally with the others.

Having meals together with family and friends was regarded as a way of being connected to others physically, psychologically, and emotionally (Keller et al., 2010). Both community-dwelling people with dementia and their partners believed that eating together promoted their relationships and strengthened bonds by providing time to be face to face, by talking about the day and sharing past events in a relaxed way, and by getting and giving support among them. Togetherness at meals may not always strengthen connection among families however, particularly if other family members are not similarly motivated (Mok et al., 2007).

Talking to or sharing with others was a meaningful activity for people with dementia, and personality and attitude of the person they talk to did matter whether they would feel at ease and connected to others (Mok et al., 2007). Talking and sharing with similar people, in terms of dementia or unrelated to dementia (e.g., attending a women's group), helped people with early stage dementia normalize difficulties, learn different ways of coping from others, and not to feel alone (Preston et al., 2007). Talking to and about family gave residents feelings of being connected to their families by reminding residents with dementia of past memories and proving their existence outside of care homes (Harmer & Orrell, 2008; Moyle et al., 2011b). Couples reminisced together focusing on their shared history, especially positive memories, to maintain their shared sense of identity and couplehood and to offset their current difficult situations (Molyneaux, Butchard, Simpson, & Murray, 2012). Looking at personally significant items (e.g., family photographs, cushions made by a family member) and talking about related stories helped people with dementia maintain feelings of connection with family as well as connection with themselves (Öhman & Nygård, 2005). Listening to music also helped people with dementia recall past memories and thus encouraged meaningful conversations with others by talking about their past experiences (Sixsmith & Gibson, 2007).

Activities involving music, such as singing together and dancing, involved and encouraged social interaction by being physically and emotionally close with others (Sixsmith & Gibson, 2007).

Engagement in cultural activities with others who could share local life experiences facilitated their feelings of belonging by culture not by dementia itself (Brataas et al., 2010).

Subtheme 2c: Meaningful relationships. This subtheme is related to establishing and maintaining meaningful relations with others to overcome loneliness, and feel a sense of acceptance and companionship.

Older people with dementia who lived in community and long term care desired for maintenance of meaningful relationships (e.g., partner, children, grandchildren), and a loss of key relationships was a source of loneliness (Cahill & Diaz-Ponce, 2011; Dröes et al., 2006; Moyle et al., 2011a). The death of a spouse, living distance from family or friends, comorbid frailty, and dementia symptoms were barriers of maintaining relationships, and thus giving feelings of loneliness (Moyle et al., 2011a). Telephone use was important for the women living alone to maintain relationships with family (Van Dijkhuizen et al., 2006). Participating in weekly get-togethers at a local café was a meaningful family ritual to a man with dementia and his family (Phinney et al., 2013). He did not actively engage in conversations, but he valued maintaining relationships among families and felt a sense of belonging. Some couples maintained their relationships and couplehood by trying to be active and sociable together, for instance, going out for Sunday lunch and doing crosswords together (Molyneaux et al., 2012).

Some older residents with dementia felt hurt and sad when their family did not visit the homes and care them as much as they expected and they did for them in early years (Moyle et al., 2011b). Understanding and accepting that family members could not visit the home too often helped residents with dementia maintain positive relationships with family members and a sense of acceptance by family even if the real family visits were fewer than their wished visits (Clare et al., 2008). Some people with dementia worried about being a burden to their family. These people desired to maintain positive

relationships by receiving support and love from their family, and by being respected for their remaining abilities, their autonomy, and their continued usefulness (Mok et al., 2007).

Maintaining relationships with friends and neighbors were also valued for a sense of affiliation. Friends and neighbors, in addition, provided practical support to the women whose family caregiver lived far (Van Dijkhuizen et al., 2006). Family caregivers and people with early stage dementia recognized that friends' lack of understanding and accepting dementia contributed to the loss of relationships to some degree (Moyle et al., 2011a). Not remembering names of people and being discovered of their memory loss in public also made people with early stage dementia feel embarrassed, lonely, and disconnected to others (Moyle et al., 2011a).

Establishing meaningful relationships or having friends was valued by both community-dwelling and nursing home residents with dementia (Cedervall & Aberg, 2010; Dröes et al., 2006). Some people established positive social relations with others in homes or day centers and felt a sense of acceptance by others (Clare et al., 2008; Smith et al., 2005). Some were not satisfied with their newly established relationships with others in long term care as much as with long-held relationships with family (Moyle et al., 2011a). Establishing meaningful relationships with other residents and staff and thus having companionship with others in care homes were considered hard because of little chance for conversations with them (Moyle et al., 2011b). Residents with dementia recognized that staff members were too busy in doing their jobs and other residents were placed in bed in the early evening. Establishing and maintaining positive relationship with health professionals by being treated with respect was also valued to some community-dwelling people with dementia (Gilmour & Huntington, 2005).

Theme 3: Being connected to environment

Subtheme 3a: Being connected to one's own home and familiar environment. This subtheme is associated with being connected to one's own home and personal items that give feelings of peace and comfort, help coping and maintaining identity, and facilitate participation in activities. People with and without dementia want to stay in one's own home with a strong sense of connectedness to their homes

because of feelings of peace and comfort at home where their life histories and memories are embedded in (de Witt et al., 2009; Gilmour & Huntington, 2005). Moving to a nursing home can be a big threat to people who have a strong tie to home and value of independent living at home, and those living alone might not avoid this situation. Engagement in safety maintenance activities by using checking strategy, giving attention, and avoiding any activity that beyond their current abilities were important for people with dementia living alone to stay at home and not to move to a nursing home (de Witt et al., 2009).

Being in familiar environments promoted a sense of coherence of people with dementia and these feelings supported participation in activities, including talking walks, shopping, and using public transportation in the familiar environment where they had grown up (Öhman & Nygård, 2005). Being in the familiar environment with personal things like photographs, furniture, plants, decorations and other memorabilia, support their identity continuation of self and provide the person with dementia with feelings of being at home (Edvardsson, Fetherstonhaugh, & Nay, 2010).

Subtheme 3b: Being connected to community. This subtheme addresses being connected to community that helps overcome loneliness, gives a sense of belonging, and promotes quality of life. Some older people living alone may feel confined at home as they lose the ability to drive and do not have close social connections they can frequently socialize with (de Witt et al., 2009). Looking out through a window at home was the way they could feel connected to their communities. A woman with dementia living alone found enjoyment in being out in the community when she went out for the groceries by seeing other people and feeling good in the air. Another woman, however, felt disconnected from her neighborhood and did not like going shopping which she used to enjoy (p. 281, de Witt, 2009). This shows how the engagement in the same activity could bring different feelings and meanings even between the two women both living alone. Being involved in the things around oneself and being interested in what is happening in the world were important for quality of life in both community-dwelling older people and nursing home residents with dementia (p. 541, Dröes et al., 2006). Participating in activities

that give an atmosphere of community (e.g., parties, barbecues and celebrations of national events) was valued (Edvardsson et al., 2010).

Subtheme 3c: Being connected to natural environments. This subtheme describes being connected to the nature that gives enjoyment, pleasure, and stimulation and promotes participation in activities. Being in the nature and enjoyment and positive feelings derived from it were strong motivations for daily walks in community-dwelling men with mild AD (Cedervall & Aberg, 2010). Pleasure coming from being connected to nature strengthened their value of staying physically active by making a routine of daily walks. The men and their wives used adaptation strategies for the men to continue engaging in outdoor walks themselves in order to compensate for their reduced ability due to AD and to feel secure while walking. For example, a man slowed down his pace when he lost energy. The other men contacted his wife by cell phone several times while walking and this helped the couple feel secure. Being outdoors and garden was important to residents with moderate dementia because of stimulation and pleasure the nature provides (p. 567, Cahill & Diaz-Ponce, 2011). Outside activities such as walking were not allowed in care homes because of safety issues, and residents with dementia expressed how much they enjoyed participating in these activities in the past (Moyle et al., 2011b).

People with dementia living at home and in residential care homes participated in and enjoyed nature-related activities that provided them with interaction and connection with nature (Gibson, Chalfont, Clarke, Torrington, & Sixsmith, 2007). These activities included indoor activities (e.g., looking out of the window, having a view out of window, observing nature, flowers, trees, birds, seeing and feeling weather, sunshine, or a breeze, enjoying plants and animals, and reminiscing about gardening, walks, or driving through the countryside), going outdoors near the home (e.g., gardening, looking at or sitting in the garden or sunshine, walking the dog), going somewhere (going for walks, day trips, local place of interest or farm), and reminiscing activities (gardening, potting plants or weeding, going to the countryside) (p. 63, Gibson et al., 2007). Participants identified varied factors enabling and challenging participation in these activities, including retaining their own interests and desires for nature-related

activities, being in good physical health/mobile, assistance and support from caregivers, access to nature, and accepting participation at a certain level by caregivers (p. 64-66). These results indicate that people with dementia could participate in and enjoy different forms of activities to be connected to nature depending on their own interests or preferences, abilities, support of formal or informal caregivers, and access to nature. An individual's want and interest for connection to nature, therefore, should be listened and discovered by carefully identifying any factor that may obscure the person's want or reduce motivation and interest. Looking out the windows and views from windows or interior gardens were important to people with dementia because of not only feelings of being connected to nature but also feeling at home (p. 2615, Edvardsson et al., 2010).

Theme Interactions

Figure 1 describes interactions among some subthemes. I found that engagement for continuity facilitated maintaining meaningful relationships and being connected to community. Families or friends helped people with dementia continue engaging in activities matched with lifestyles, life-long held beliefs, values, and interests. For example, a wife left a note with instructions and schedules for her husband with dementia every morning to help him plan his day, engage in work-related activities, go out in a town for errands, and go to church with his son (Phinney et al., 2007). These supports from his wife promoted not only continuing engagement but also a sense of connection to his wife and the community. Going to church also facilitated a sense of belonging to the spiritual community and meaningful relationships from church members as well as maintenance of spiritual identity and faiths (Dalby et al., 2012). Engagement for continuity was strengthened while doing an activity with others, being connected to familiar environments, and being connected to natural environments. Working together in the garden allowed a man with dementia and his family to maintain a sense of shared identity (Phinney et al., 2013), and reminiscing shared histories together promoted maintenance of their shared sense of identity and couplehood (Molyneaux et al., 2012). Being in the familiar environments supported continuing engagement in daily activities and identity continuation of self (Edvardsson et al., 2010; Öhman &

Nygård, 2005). Enjoyment coming from being in the nature facilitated continuing engagement of staying physically active by making a routine of daily walks (Cedervall & Aberg, 2010).

Discussion

This synthesis is the first to integrate findings of qualitative studies on meaningful activities from perspectives of people with dementia. A synthesis focused on how people live with early stage dementia and deal with loss from pre-diagnostic to post-diagnostic phases (Steeman, de Casterlé, Godderis, & Grypdonck, 2006). Another synthesis provided more general aspects of living with dementia (de Boer et al., 2007). This synthesis is different from two previous ones since the focus is on what activities are meaningful and why people with dementia want to engage in these activities rather than addressing losses, feelings, and coping strategies people experience or use.

I found that being connected is a strong motivation for engaging in activities and engagement in meaningful activities also helps the person with dementia to be connected. The findings support that being connected in personally meaningful ways promote their sense of belonging, physical, mental, and emotional health, self and family identity, independence, interdependence, and life satisfaction of people with dementia. Individual differences in ways of being connected depended on values, beliefs, interests, culture, living environment, and previous lifestyles and roles. The common meaning and motivation for engagement, however, was to be connected to oneself, others, and environment. These findings indicate the importance of identifying the individual's meaning in engagement by showing that individuals engage in the same activity with different meanings or engage in different activities for the same meaning. Watching TV, for example, was meaningful to maintain the value of being an interesting person (Phinney, 1998), maintain active mind (Van Dijkhuizen et al., 2006), or not to feel alone (de Witt, Ploeg, & Black, 2009). The identified themes and subthemes suggest how people with dementia are connected or want to be connected through engagement in personally meaningful activities.

Although the aim of this synthesis was not on perspectives of caregivers, some of the included studies documented differing views on meaningful activities, between caregivers and persons with

dementia. Being useful and maintaining religious faith, reported by people with dementia as being important for their quality of life, were not mentioned by professional caregivers (Dröes et al., 2006). Family caregivers and staff valued social activities organized by care homes more than contact with family, and activities that help maintaining motor and functional abilities (Harmer & Orrell, 2008). Family caregivers also had little awareness of values of reminiscence activity and music activity that were important to their relatives with dementia (Harmer & Orrell, 2008) and reported the difficulty of finding meaningful activities for their loved ones (Cedervall & Aberg, 2010). Caregivers seem to pay more attention to negative impacts of dementia on engagement in daily activities and lack understanding the meanings of engagement in activities (Harmer & Orrell, 2008; Smith et al., 2005). These findings underscore the importance of identifying the nature and scope of meaningful activities from the perspective of people with dementia when providing patient-centered care.

Identifying why the person with dementia wants to engage in the particular activity is important for caregivers and health professionals to support engagement of the individual with dementia. As dementia progresses, a person with dementia may not be able to engage in his or her valued, meaningful activity even by using compensation strategies or adaptive tools or equipment. In the case that the same activity is not possible or safe to do, similar or alternative activity could be sought by health professionals or caregivers and used to help the person with dementia engage in without understanding why the particular activity was important to the person with dementia to help. The alternative activity sought may be matched in the type of activity but may not be matched with the value or need imbedded in the previous activity. A man with dementia, for instance, liked cycling because of being connected to nature. After moving to a long term care setting, staff identify he liked cycling and interpret that he enjoy physical activity. The staff facilitates him to ride the indoor bicycle without knowing why he liked cycling. In this case, he may enjoy being in the garden more than riding the indoor bicycle.

Health professionals and caregivers, thus, should understand the underlying meaning of engagement in the activity and help the person with dementia express and engage in activities matched

with their psychosocial needs as dementia progresses. An awareness of connectedness as an important motivation for engagement and of different ways of being connected will facilitate development of better intervention and care for people with dementia. Further studies are needed to identify if interventions tailored to meet an individual's need for being connected to self, others, and environment affect psychosocial well-being and quality of life of people with dementia.

Our findings can be applied to other people with dementia because findings are derived from 34 studies involving participants with varied characteristics. Participants of the included studies, living in community (25) or residential care homes (13), had varied stages and types of dementia and marriage/living status. Most of the included studies used separate individual interviews of people with dementia, but some studies also used dyadic interviews involving a person with dementia and a family member that may better capture shared experience of the family. The included studies were done in UK (13), Canada (4), USA (3), Australia (3), Sweden (3), Norway (2), Netherlands (2), New Zealand (1), Belgium (1), Israel (1), and Hong Kong (1). Some studies involved people with different ethnicity such as Jewish, Black, South Asian, British Asian. The themes and subthemes developed based on 34 studies' findings may capture common but broad perspectives of people with dementia on meaningful activities.

Register and Herman (2006) proposed a middle-range theory, suggesting that 6 interrelated processes of being connected (metaphysically connected, spiritually connected, biologically connected, connected to others, environmentally connected, and connected to society) lead to quality of life for the elderly (p. 344). In a later qualitative study of community-dwelling older adults, Register and Scharer (2010) found four processes involved with being connected in older adults, including (a) having something to do, (b) having relationships, (c) having a stake in the future, and (d) having a sense of continuity (p. 471). Although these studies did not involve older adults with dementia, these findings support our findings that being connected to oneself, others, and environments are an important mechanism for engagement in their personally meaningful activities.

Conclusion

The aim of the synthesis was to identify meanings of engagement in daily activities based on perspectives of people with dementia in qualitative studies. A person with dementia engaged or wanted to engage in personally meaningful activities to be connected with oneself, others, and environment. The synthesis supports the premise that being connected is an important motivation for engagement in daily activities, and suggests the importance of identifying this underlying motivation for an individual being engaging in different activities and differing ways used by people to achieve being connected.

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Table 1. The Search Terms Used in Databases

SPIDER Tool	Search Terms
S (Sample)	dement* OR Alzheimer*
P of I (Phenomenon of Interest)	‘meaningful activit*’ OR ‘daytime activit*’ OR ‘daily activit*’ OR engagement OR occupation* OR ‘quality of life’ OR activit* OR meaning* OR valu*
D (Design)	interview* OR ‘focus group*’ OR survey* OR questionnaire* OR ‘case stud*’
E (Evaluation)	view* OR experienc* OR opinion* OR perspective* OR belie* OR feel*
R (Research type)	qualitative OR ‘mixed method*’ OR ethnograph* OR phenomenology OR ‘grounded theor*’

Table 2. Characteristics of Included Studies

Authors	Aims / Questions	Design/ sampling / data collection method/analysis approach	Characteristics of the participants
Phinney et al. (2013)	-To explore how men and their families experience changing patterns of everyday activity in the initial months after a diagnosis of dementia	-Phenomenology -Purposive sampling (two cases from a broader study) - Individual, dyadic, and group interviews (with three daughters) & participant observations of engagement in routine activities over a 3- to 4-month period -Interpretive phenomenological analysis *A follow up interview with the 80 year old couple 1 year later	-Two men with early stage AD and members of their families (n=7), Canada <ul style="list-style-type: none"> • 80 year old male with AD and his wife; 74 year old male with AD, his common-law partner, and three daughters • Both men were diagnosed with AD within the previous 6 months • Lived with their spouses • Enjoyed close relationships with their adult children who lived nearby
Dalby et al. (2012)	-To build an understanding of how people's experience of spirituality, religion, or faith is influenced by dementia, and to understand how the spiritual aspects of their lives affect the experience of dementia	-Phenomenology -Purposive sampling -Semi-structured interviews -Interpretive Phenomenological Analysis	-Six people with mild to moderate dementia living in England, UK <ul style="list-style-type: none"> • 5 females, 1 male • Age range: 70-74 years (n=2), 75-79 years (n=3), 90-94 years (n=1) • Ethnicity: White British (n=5), British Asian/Indian (n=1) • Alzheimer's disease (n=3), vascular dementia or a mixed diagnosis (n=3) • Main spiritual/religious belief: Christianity (n=4), belief systems linked to eastern philosophies (n=2): follows teachings of an Indian Guru; spiritual (esoteric) healing • Living alone at home (n=3), living with a husband at home (n=1), living semi-independently in warden-assisted accommodation (n=1), living in a care home

			<p>because of physical needs (n=1)</p> <ul style="list-style-type: none"> • Professional backgrounds (n=6) • Length of time since diagnosis ranged from 3 months to 2 years
Molyneaux et al. (2012)	<p>-To explore 1) what impact, if any, dementia have on a couple's relationship or a couple's relationship have on dementia and 2) how couples co-create their account of relationship in dementia</p>	<p>-Grounded theory -Convenience sampling -Interviews of couples (together) -Constructivist grounded theory methodology</p>	<p>-Five cohabiting couples, where one partner from each couple had been diagnosed with AD and lived in North West England, UK</p> <ul style="list-style-type: none"> • People with dementia: 3 males, 2 females; 72-83 years (mean age 76.8) • Cohabiting partners: 2 males, 3 females; 73-84 years (mean age 78) • The mean number of years married or living together: 45.2 years (range 11–55 years) • Varied cognitive ability and level of participation • Time diagnosed: range from 12 months to 4 years
Cahill & Diaz-Ponce (2011)	<p>-To elicit people's own subjective views and individual accounts about their quality of life in general and in relation to their lives in nursing homes. -Interview questions included asking about their daily lives in long-term care, what was important to them now, sources of happiness and sadness, privacy, homeliness, activities, interactions with fellow residents and staff, what</p>	<p>-A descriptive/exploratory qualitative design -Purposive sampling -Semi-structured interviews -Thematic analysis</p>	<p>-Sixty-one people with dementia living in three nursing homes, Dublin, Ireland, UK</p> <ul style="list-style-type: none"> • 13 males , 48 females • A mean age of 85.3 years (range 62-100) • Mild dementia (n=13), moderate (n=20), severe (n=28) • Married (n=6), single(n=16), separated (n=2), and widowed (n=37)

	residents favored most about living in long-term care and what they liked least.		
Lawrence et al. (2011)	-To examine attitudes, experiences, and beliefs of people with dementia within the 3 largest ethnic groups in the United Kingdom	-Grounded theory -Purposive sampling - Individual interviews -Constant comparative analysis derived from the grounded theory	-Thirty community-dwelling people with dementia living in London, UK - <i>Black Caribbean (n=11)</i> <ul style="list-style-type: none"> • 3 males and 8 females • Place of birth: Jamaica (n=10), Trinidad (n=1) • Age range of 67-87 years (mean=76 years) • Mild dementia (n=6), moderate (n=3), severe (n=2) • Single (n=1), married (n=3), divorced (n=2), widowed (n=5) • Living alone (n=4), with spouse (n=1), with family (n=4), in sheltered accommodation (n=2) - <i>South Asian (n=9)</i> <ul style="list-style-type: none"> • 5 males and 4 females • Place of birth: India (n=8), Kenya (n=1) • Age range of 65-87 years (mean=77 years) • Mild dementia (n=4), moderate (n=2), severe (n=3) • Married (n=7), widowed (n=2) • Living with spouse (n=4), with family (n=4), in sheltered accommodation (n=1) - <i>White British (n=10)</i> <ul style="list-style-type: none"> • 5 males and 5 females • Place of birth: England (n=10) • Age range of 72-96 years (mean=82 years) • Mild dementia (n=3), moderate (n=4), severe (n=3) • Married (n=7), widowed (n=3)

			<ul style="list-style-type: none"> • Living alone (n=1), with spouse (n=7), with family (n=1), in sheltered accommodation (n=1)
Moyle et al. (2011a)	<p>-To explore and describe loneliness from the perspective of people with early-stage dementia and their family caregivers</p> <p>-Interview questions included ‘Who are the people that are most important to you?’, ‘What needs do these people fulfill in your life?’, ‘What effect has your memory loss had on your relationships with other people?’, ‘What do you do to overcome the feelings of loneliness?’, ‘How do such feelings affect your life?’</p>	<p>- A descriptive/exploratory qualitative design</p> <p>-Purposive sampling</p> <p>-Semi-structured Interviews</p> <p>-Thematic analysis</p>	<p>-Seventy people with early-stage dementia living in community or long term care, South East Queensland, Australia</p> <ul style="list-style-type: none"> • Age range of 66 to 97 years • Female (n=70.2%) • Living in community (n=10), LTC (n=60)
Moyle et al. (2011b)	<p>-To understand the factors that influence quality of life for people living with dementia in long term care, including an understanding of how they perceived they were valued.</p> <p>-Interview questions included ‘What things are you able to do that make your life good?’, ‘What factors do make your life</p>	<p>- An exploratory qualitative design</p> <p>-Convenience sampling</p> <p>-Semi-structured interviews</p> <p>-Concept-mapping</p>	<p>-Thirty-two people with dementia living in four care homes, New South Wales and Queensland, Australia</p> <ul style="list-style-type: none"> • 10 males, 22 females • Age: 70-79 years (n=3), 80-89 years (n=25), >90 years (n=4) • Married (n=12), single/divorced (n=2), and widowed (n=18) • Length of stay (months): ≤6 (n=10), 7-12 (n=11), >12 (n=11)

	<p>meaningful?', 'What factors do influence the way you feel valued in the care home?', 'What do you contribute/like to contribute?', 'What does quality of life mean to you?', 'What factors allow you to have a good quality of life?'</p>		
<p>van Zadelhoff et al. (2011)</p>	<p>-To investigate experiences of residents, their family caregivers and nursing staff in group living homes for people with dementia and their perception of the care process -The interviews started with an open question: "how is living in group living?" Topics included experiences related to daily life and activities, well-being of residents, possibility to continue family habits and rituals, contacts and communication between residents, and staff-family-resident interactions.</p>	<p>-Naturalistic design -Purposive sampling -Semi-structured Interviews and observations during daily life, care and activities in both homes over a period of 6 months -An inductive analysis</p>	<p>-Five residents with dementia of two group living units, in an urban area in the southern Netherlands</p> <ul style="list-style-type: none"> • Age range of 68 to 93 years • Moderate to severe dementia (MMSE scores ranged from 0 to 14, with a mean of 10) • Each unit has a living room with an open kitchen, and a large wooden table is situated in the kitchen, which serves as the central part of the house. Residents are able to bring their own furniture and all spaces were decorated to create a homelike feeling. Eight residents have a private bedroom with their own furniture, 12 share a bedroom with someone else. Each home housed 10 residents with dementia (nine women and one man per unit).
<p>Brataas et al. (2010)</p>	<p>- To explore whether and how person-centered and collaborative client day care programs gave</p>	<p>-A narrative qualitative design -Purposive sampling -Narrative interviews -A narrative content analysis</p>	<p>-Nine community-dwelling Norwegian people who participated in person-centered and collaborative day care program activities, once a week for seven weeks, Central Norway</p>

	<p>meaning to the everyday lives of persons with mild dementia</p> <p>-Interview questions included meaning of events and of experiences of the day care, experiences of social interaction and collaboration, and if and how the day programs had any significance for everyday life</p>		<ul style="list-style-type: none"> • 2 males , 7 females • A mean age of 82 years (range 77-88) • Mild dementia • No mention about specific types of dementia but exclusion of frontal lobe dementia
Cedervall & Aberg (2010)	<p>-To improve the understanding of experiences of people with mild AD and their significant others, regarding the afflicted persons' ability to be physically active, and to gain insight into their perception of the importance of physical activity in AD</p> <p>-Questions dealt with how the subjects felt AD had influenced the ability to be physically active and their thoughts about the importance of physical activity</p>	<p>-A qualitative case study design</p> <p>-Purposive sampling</p> <p>-Interviews and observations of daily activities</p> <p>-Thematic analysis</p>	<p>-Two community-dwelling married men with mild AD, Sweden</p> <ul style="list-style-type: none"> • Person 1: 74 years; he had been physically active before the onset of AD (eg., playing tennis, skiing, taking regular walks in the countryside during leisure time); he walked on his own to and from the day care center (about 2 kilometers in each direction) and took regular walks with his wife after the onset of AD • Person 2: 63 years; he had not been physically active regularly but occasionally had exercised before the onset of AD (e.g., jogging, dancing, cycling); he took daily walks with the family dog and went shopping locally on his bicycle and drove his car when necessary to do errands after the onset of AD
Edvardsson et al. (2010)	<p>-To describe the content of person-centered care as described by people with dementia, family members and staff in residential aged</p>	<p>- An exploratory qualitative design</p> <p>-Convenience sampling</p> <p>-Individual interviews & focus groups</p> <p>-Content analysis</p>	<p>-Eleven people with early onset dementia (<65 years at onset) who had experience of respite care, living in Victoria, Australia</p> <ul style="list-style-type: none"> • No specific information on the participants' characteristics (e.g., age, gender, type/stage of

	care		dementia)
Keller et al. (2010)	<p>- To examine the experience and meaning of food and mealtimes for persons with dementia and their primary care partners</p> <p>-To investigate how experiences and meanings of food and mealtimes impact the care partner/care recipient relationship and family unit in the dementia context</p>	<p>-Grounded theory</p> <p>-Selective and theoretical sampling</p> <p>-Individual and dyad interviews</p> <p>-Constant comparative analysis derived from the grounded theory</p>	<p>-Twenty seven community-dwelling people living with dementia, Canada</p> <ul style="list-style-type: none"> • People with dementia: 11 males, 16 females; age range of 56 to 88 years • Partners: 12 males, 16 females; age range of 30 to 88 years • Early to middle stages of dementia • Living together (n=24) • Spousal relationships (n=19), adult-child relationships (n=8) including three daughters, three sons, one niece, and one daughter in-law.
Beuscher & Grando (2009)	<p>-To explore how people with early-stage AD use their spirituality to cope with their disease, what spiritual practices support this process, and how AD has affected their spirituality or spiritual practices</p>	<p>-Ethnography</p> <p>-Purposive sampling</p> <p>-Semi-structured Interviews, observations of home environments, observations during interviews</p> <p>-Content analysis & Constant comparison</p>	<p>-Fifteen community-dwelling people with early stage AD, Arkansas, USA</p> <ul style="list-style-type: none"> • 7 males , 8 females • A mean age of 78.67 years (range 67-91) • Caucasian (n=9), Black (n=6) • Living alone (n=5), living with spouse (n=8), living with adult children (n=2) • Christian religious affiliation (n=15)
de Witt et al. (2009)	<p>-To understand the meaning and experience of living alone for people who were diagnosed with dementia</p> <p>-Interview questions included (a) what it was like to live alone with memory loss, (b) continuing to live alone (c) safety when living alone with memory loss, (d) what it was like</p>	<p>-Phenomenology</p> <p>-Purposive sampling</p> <p>-Interviews & observations during and after interviews</p> <p>-Thematic analysis</p> <p>* interviewed twice at intervals averaging 8 to 10 weeks (n=6)</p>	<p>-Eight community-dwelling women with mild to moderate dementia who lived alone in Ontario, Canada</p> <ul style="list-style-type: none"> • A mean age of 78.1 years (range 58-87 years) • European descent (n=8) • Widowed (n=5), divorced (n=2), separated (n=1) • Level of education: elementary schooling (n=4), secondary schooling (n=3), an undergraduate degree (n=1) • Type of housing: house (n=5), apartment (n=3) • Informal caregivers: adult child/children (n=7), sibling

	to need help and to ask for help and (e) the future.		<p>(n=1)</p> <ul style="list-style-type: none"> • Proximity of family caregivers: same neighborhood (n=2), town (n=3), province (n=3) • Formal service use: (a) assistance with medications (n = 6), (b) adult day programs (n = 4), (c) bathing (n = 5), (d) transport (n = 4), (e) meal preparation (n = 4), (f) meal delivery (n = 3) and (g) grocery delivery (n = 1).
Clare et al. (2008)	-To explore the subjective experience of life with dementia in residential care from the perspective of people with dementia, and to understand the psychological impact of being in this situation	-An exploratory qualitative study -Convenience sampling -Unstructured conversations and field notes made by researchers and contextual information of residential homes - Interpretative phenomenological analysis	-Eighty individuals with dementia living in residential care homes, England and Wales, UK <ul style="list-style-type: none"> • 12 males , 69 females • A mean age of 83.4 years (range 59-96) • Moderate to severe dementia • Living in 10 residential care homes; 3 care homes specializing in the care of people with dementia (n=45), 4 care homes for people with designated sections devoted to the care of people with dementia (n=21), and 3 homes catering to a mixed resident group (n=15)
Harmer & Orrell (2008)	-To explore the concept of meaningful activity for people with dementia living in care homes, from the perspectives of staff, family caregivers and residents themselves. - Interview questions included 'could you tell us a bit about what sort of things you do here that you	-No mention about specific design -Purposive sampling -Focus groups -Thematic content analysis	-Seventeen people with dementia living in care homes, London, UK <ul style="list-style-type: none"> • 5 males, 12 females • A mean age of 85.6 years (range 72-99 years) • Mild to severe dementia • Married (n=3), single(n=4), widowed (n=10) • White British (n=14), Irish (n=2), black Caribbean (n=1)

	<p>particularly enjoy/are important to you/make your day worthwhile/look forward to?’ and ‘what sort of things would you like to do but do not get the chance?’</p>		
Gibson et al. (2007)	<p>-To determine if and how nature is important to people with dementia, both from their perspective and that of caregivers -Interview questions included asking about activities in which people with dementia participated and enjoyed, either currently or in the past; difficulties participating in such activities; the meaning that an individual may derive from participation.</p>	<p>-No mention about specific design -Purposive sampling -Semi-structured interviews, observations of daily activities, & focus groups -Thematic analysis</p>	<p>Twenty-six people living in England, UK (Age: 62-96 years) -People living at home (n=16) <ul style="list-style-type: none"> • 7 males, 9 females • Mild to severe stages • Living alone (n=4), living with an informal caregiver (e.g., spouse) (n=12) -People living in residential care homes (n=10) <ul style="list-style-type: none"> • 1 male, 9 females • Mild to severe stages </p>
Holthe et al. (2007)	<p>-To gain knowledge of the occupational patterns of people with dementia in a care home and how the residents perceived the group activities in which they participated</p>	<p>-Ethnography -Convenience sampling -Interviews and participant observations of daily activities -An ethnographic methodology</p>	<p>-Eight people living in a residential care home, specially designed facility for persons with dementia, Norway <ul style="list-style-type: none"> • 1 male, 7 females • Age range of 82 to 92 years (the mean age of 86.7 years) • Moderate stages of dementia • Mobility difficulties (n=4), difficulties in expressing themselves verbally (n=5), complained about feeling tired (n=5) • Neither type of dementia nor MMSE scores were collected, because the study concentrated on residents’ </p>

			<p>everyday occupations, rather than investigating individual characteristics</p> <p>*Two residents were unable to participate in an interview due to impaired hearing and difficulties in expressing themselves</p>
Mok et al. (2007)	<p>-To describe the lived experiences of Chinese people with early-stage dementia and their ways of coping with the illness</p> <p>- Interview questions included ‘Can you tell me your experience with early-stage dementia?’, ‘What does early-stage dementia mean to you?’ or ‘What is your world like after having the illness?’</p>	<p>-Phenomenology</p> <p>-Convenience sampling</p> <p>-Interviews & observations during the interview</p> <p>- Phenomenological data analysis</p> <p>*cross-sectional</p>	<p>-Fifteen community-dwelling Chinese people with early stage dementia living in Hong Kong</p> <ul style="list-style-type: none"> • 4 males, 11 females • Age range of 56 to 80 years: 56-59 years (n=2), 60-69 years (n=4), 70-79 years (n=4), 80 years (n=5) • Living at home with family members (n=15) • Married(n=6), widowed (n=8), and divorced (n=1) • Previous occupations: housewife (n=9), engineer (n=1), taxi driver (n=1), driver instructor (n=1), teacher (n=1), bank administrator (n=1), primary school principal (n=1) • Relationship with caregiver: daughter (n=9), daughter & daughter-in-law (n=1), daughter-in-law (n=1), son (n=1), husband (n=1), wife (n=1), sister (n=1) • No major psychiatric illnesses
Phinney et al. (2007)	<p>-To explore how people with mild to moderate dementia perceive and understand meaningful activity in the context of their everyday lives</p> <p>-Interview questions included what it was like to live with this disease and how they experienced its impact on their</p>	<p>-Naturalistic design</p> <p>-Purposive sampling</p> <p>-In-depth conversational interviews & participant observations of daily activities</p> <p>- Interpretive Phenomenological Analysis</p> <p>* Repeated interviews and observations conducted over several months with each participant (over a period</p>	<p>-Eight community-dwelling people living at home with at least one family member, Vancouver, Canada</p> <ul style="list-style-type: none"> • 4 males, 4 females • Age range of 64 to 88 years • Mild to moderate stages of AD • European descent and born in the United States • Retired • No obvious physical disabilities

	<p>everyday activities</p> <p>-Specific questions were ‘What types of activities are important to you?’, and ‘What does involvement in these types of activities mean to you?’</p>	<p>of two to six months.)</p>	
<p>Preston et al. (2007)</p>	<p>-To develop a comprehensive understanding of the range of coping methods and strategies used by people with mild dementia</p> <p>-Interview questions included ‘Has there been anything difficult that you have had to manage/deal with/cope with?’, ‘What separates a good day from a bad day?’, ‘So how do you think you coped with this?’, ‘What helped you to manage this?’/‘How did you react?’</p>	<p>-Phenomenology</p> <p>-Purposive sampling</p> <p>-Semi-structured Interviews & observations during the interview</p> <p>-Interpretative phenomenological analysis</p>	<p>- Twelve community-dwelling people with early stage dementia, UK</p> <ul style="list-style-type: none"> • 7 males, 5 females • A mean age of 71.1 years (range : 58 to 81 years) • White ethnic origin (11 British, 1 European had lived in England for 20 years) • Alzheimer’s disease (n=9), vascular dementia (n=3) • Living at home with their spouse (n=9) or alone (n=2), and living in supported accommodation (n=1)
<p>Sixsmith & Gibson (2007)</p>	<p>-To explore: (a) the meaning and importance of music in everyday life; (b) the benefits derived from participation in music-related activities; (c) and the problems of engaging with music</p> <p>-Interview questions included:</p>	<p>-No mention about specific design</p> <p>-Purposive sampling</p> <p>-In-depth interviews & observations during the interview</p> <p>-No mention about specific data analysis method</p>	<p>-Twenty-six people living in England, UK</p> <ul style="list-style-type: none"> • 8 males, 18 females • Age range of 62 to 96 years • Mild to severe stages • Any type of dementia included • Living at home (n=18) and living in residential care (n=8) • Three regions of England (Merseyside =8, Northamptonshire= 8, South

	the everyday and enjoyable activities that people took part in; the reasons why they enjoyed or did not enjoy activities ; the factors enabling and constraining the activities; the impact of these activities on the everyday life and wellbeing of the person		Yorkshire= 10)
Steeman et al. (2007)	-To explore what it means for elderly people to live with early-stage dementia	-An exploratory qualitative study -Purposive sampling -Interviews with the person with dementia and family member(s) separately and together & observation during the interview - methods of grounded theory (constant comparison) & narrative analysis *interview each person 3 to 4 times over 1.5 years	-Twenty community-dwelling elderly people with mild dementia living in Flanders, Belgium <ul style="list-style-type: none"> • 4 males, 16 females • Age range of 69 to 91 years • Types of dementia: AD (n=12), (sub) cortical atrophy (n=6), vascular dementia (n=1), mixed dementia (n=1) • Living at home • Dutch speaking • Relationship with family members: daughter(s) (n=10), spouse (n=5), son(n=2), daughters and sons (n=1), niece (n=1), not available (n=1) • No severe aphasia • No severe psychiatric problems
Dröes et al. (2006)	-To explore what people with dementia, living in the community and in nursing homes, and their caregivers consider important for the quality of life in dementia -Interview questions included	- Convenience sampling -Interviews, focus groups, literature study -Constant comparison derived from the grounded theory	-A total of 106 community-dwelling people with dementia, the Netherlands <ul style="list-style-type: none"> • Mostly in the age range between 70 and 80 • Mild to moderately severe dementia • Recruited from 10 meeting centers in the Netherlands -A total of 37 nursing home residents with dementia, the Netherlands

	asking about which aspects of daily life have an influence on quality of life; what makes them feel happy; what bothers or upsets them.		<ul style="list-style-type: none"> • 11 males, 26 females • Age range of 69-98 years • Mild to moderately severe dementia • Recruited from four wards in three nursing homes in Netherlands
Van Dijkhuizen et al. (2006)	-To capture a subjective account of women's experiences of early-stage Alzheimer's disease and how the subjects managed memory difficulties	-Phenomenology -Purposive sampling -Semi-structured Interviews -Interpretative phenomenological analysis *Caregiver interviews with husbands (n=2), male partner (n=1), daughters (n=5), and granddaughter (n=1)	-Nine community-dwelling women with early-stage AD, London and Essex, UK <ul style="list-style-type: none"> • Age range of 70 to 86 years (a mean of 77.89 years) • MMSE scores ranged from 20 to 29 (a mean of 23.11) • White (n=9) • Born in UK (n=7), Ireland (n=1), Southern Europe (n=1) • Widowed (n=6): living alone (n=2), living with daughters (n=2), living with her granddaughter (n=1), living with her son (n=1); living with husband (n=2); unmarried and living with her male partner (n=1)
Gilmour & Huntington (2005)	-To explore explicitly the everyday experience of people with dementia	-No mention about specific design -Purposive sampling -Semi-structured interviews -Thematic analysis	-Nine community-dwelling people with dementia, New Zealand <ul style="list-style-type: none"> • 5 males, 4 females • Age range of 56 to 79 years • Alzheimer's disease, multi-infarct or frontal lobe dementia • The time from diagnosis ranged from 1 to 8 years • Living with partners (n=8), living alone (n=1) • No mention about stages of dementia • All used Alzheimer's Society services
Öhman & Nygård (2005)	-To uncover and describe the meanings and motives for engagement in self-chosen daily life	-An exploratory qualitative study -Purposive sampling -Interviews & observations of daily activities and during the	-Six community-dwelling people living at home, Sweden <ul style="list-style-type: none"> • 3 males, 3 females • Age range of 65 to 80 years • Mild to moderate stages of AD

	<p>activities among community-dwelling elderly individuals with Alzheimer's disease</p> <p>-Interview questions focused on the participants' descriptions of their daily activities, their habits and routines, their motives for engagement, and the significance their meaningful activities held to them.</p>	<p>interviews</p> <p>-Qualitative comparative and interpretative methods</p>	<ul style="list-style-type: none"> • Married (n=3), widowed (n=2), and divorced (n=1)
Smith et al. (2005)	<p>- To develop a conceptual framework of health-related quality of life in dementia from the perspective of people with dementia and their caregivers and to examine differences in the reports of the health-related quality of life</p> <p>-Interview guiding questions and prompts were developed to encourage participants to talk in personal terms about health-related quality of life and to elicit their feelings about aspects of five domains (involvement in activities, autonomy and</p>	<p>-No mention about specific design</p> <p>-Purposive sampling</p> <p>-Individual interviews</p> <p>-Content analysis</p>	<p>- Nineteen people with dementia from local secondary care services in London, UK</p> <ul style="list-style-type: none"> • 4 males, 15 females • Age range of 69 to 85 years • Stages of dementia: mild or mild/moderate (n=8), moderate (n=7), moderate/severe or severe (n=4) • Living at home (n=18) • Having a main family carer (n=16): spouse (n=14), other close relatives (n=2)

	choice, social and family relationships, health and well-being, and life satisfaction), including the extent to which they considered these domains to be important		
Aggarwal et al. (2003)	-To explore how people with dementia and their relatives experience dementia and to examine how they perceive and receive care provision, by directly eliciting their views, experiences, feelings and needs	-No mention about specific design -Random sampling -Semi-structured interviews and observations of daily activities -No mention about specific data analysis approach	- Twenty-seven people with dementia from residential (n=17) and day care settings (n=10), London, UK <ul style="list-style-type: none"> • Jewish origin • Various stages of dementia
Clare (2003)	-To explore subjective experience of life and awareness of changes from the perspective of people with AD	-Phenomenology -Purposive sampling -In-depth individual interviews of people with AD and their spouses -Interpretative phenomenological analysis	-Twelve community-dwelling people with early stage AD, England, UK <ul style="list-style-type: none"> • 9 males , 3 females • A mean age of 71 years (range 57-83) • White European origin • Living at home with his or her spouse Varying levels of awareness, ranging from 'very aware' to 'unaware'
Menne et al. (2002)	-To explore the experience of dementia from the perspective of the person with early stages of dementia -Interview questions included 'On a daily basis, what are your major concerns?', 'What are your fears associated with the disease and what has	-No mention about specific design -Convenience sampling -Individual interviews -Constant comparative analysis	-Six community-dwelling people with early stage dementia who attended an early stage dementia support group, Illinois, USA <ul style="list-style-type: none"> • 3 males, 3 females • A mean age of 72 years (range: 57-88 years) • Caucasian (n=5) and African American (n=1) • Alzheimer's disease (n=4), mild cognitive impairment without dementia (n=1), frontotemporal dementia (n=1),

	helped you to lessen these fears?', 'Has the disease limited you in anyway and what has helped you to lessen the limitations?', 'How have the effects of the disease changed your relationship with your primary caregiver and other family members?'		<ul style="list-style-type: none"> • Mild dementia (n=4), moderate dementia (n=1), mild cognitive impairment without dementia (n=1) • Married (n=5), Widowed (n=1)
Nygård & Åhman (2002)	-To uncover and describe how people with dementia respond to and manage difficulties and change they experience in everyday activities.	-Phenomenology -Purposive sampling -Interviews & observations of daily activities -A phenomenological approach	-Seven people with mild dementia living in their own homes, Stockholm, Sweden <ul style="list-style-type: none"> • 4 males, 3 females • A mean age of 71 years (range: 62 to 78 years) • Alzheimer's disease (n=7) • Married (n=4), divorced (n=1), and widowed (n=2)
Cohen-Mansfield et al. (2000)	-To explore past roles, the degree to which those roles are maintained in the present, and strategies for bolstering the sense of self-identity from the perspectives of residents with dementia, family members, and nursing staff members -Interview questions included asking about which activities he or she liked, and what they wanted to do and were not able to in nursing homes.	-No mention about specific design -Purposive sampling -Structured interviews -No mention about specific data analysis approach	-Thirty-eight residents of two nursing homes in Israel <ul style="list-style-type: none"> • 9 males, 29 females • A mean age of 79.4 years (range 56-89 years) • Type of Dementia: AD (48%), vascular dementia (17%), dementia with Parkinson's (7%), unknown (10%), other (17%) • Mild to severe dementia (a mean score of MMSE: 8.7; range: 0-22) • Place of birth: Eastern Europe (64%), Central/Western Europe (4%), Israel (7%), Asia/Africa (7%) • Widowed (71%), married (21%), divorced (8%)
Phinney (1998)	-To understand the experience of	-A qualitative descriptive study	-Five community-dwelling people, San Francisco, CA, USA

	<p>living with dementia from the perspective of people who have a diagnosis of Alzheimer's disease</p> <p>-Interview questions included: the regular routines of their day-to-day lives (those things they particularly enjoyed and those they disliked); what stood out for them when living with AD, what changes they noticed and what the changes meant to them; what they had done and experienced in previous years</p>	<p>-Convenience sampling</p> <p>-Semi-structured Interviews of people with dementia and three spouses & observations of daily activities</p> <p>-Thematic analysis</p> <p>*repeated interviews and spouse interviews (2 or 3 times)</p>	<ul style="list-style-type: none"> • 1 male, 4 females • Age range of 75 to 89 years • Mild to moderate stages of AD • Living in their own homes (n=4) & living in a seniors' residence (n=1) • Being in good physical health
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Table 3. Themes, Subthemes, and Quotes

Themes	Subthemes	Examples of Quotes from Included Studies
Being connected to oneself	Engagement for continuity <i>'I keep doing what I used to do.'</i>	<p><i>'You gotta do something, especially if you've spent your whole life working with your hands, you couldn't just walk away and leave it.'</i> (p. 359, Phinney et al., 2013)</p> <p><i>'I always do the washing here, I always did this at home as well, I know how to do it.'</i> (p. 2494, van Zadelhoff et al., 2011)</p> <p><i>'We help around the church, anything they need. ... I keep doing and I don't want to stop.'</i> (p. 591, Beuscher & Grando, 2009)</p> <p><i>'I get bored here . . .they, they go to sleep, I feel like throwing something at them, because they, nobody talking or got nobody goes walking. . . . It's, you've gotta do something, haven't you, to help you go through, because it wasn't the things I've been used to. . . .They just sit here, it drives me mad.'</i> (p.717, Clare et al., 2008)</p> <p><i>'Although I am very forgetful now, I try to keep my usual routine, do exercise and read newspapers.'</i> (p. 596, Mok, et al., 2007)</p> <p><i>'Well I try to keep up a normal facade, like when I went to work, you know, I sort of more or less go through the same as I did then, as if I'm getting ready to go out, things like that pass the time.'</i> (p. 893, Smith et al., 2005)</p> <p><i>'I certainly would like to help people who can be helped and that's why I did most of my time as a teacher . . . and I saw that as a way, taking that those kinds of feelings and skills and trying to turn this thing, and I've been working on that 'what can I do? . . .'</i> (p.375, Menne et al., 2002)</p>
	Strategic participation in activities for one's own health benefits <i>'I deliberately engage in activities for myself.'</i>	<p><i>'I don't mind being alone, as I said I am never bored with my own company. I have so many memories to go back on that I can call them up and think of all the happy days I spent on the bowling green and the funny things that used to happen.'</i> (p. 1450, Moyle et al., 2011a)</p> <p><i>'I wouldn't say it was as good as home, like...er...you haven't got that same feeling or love or anything is... a ...at a place like this. You're just ... one of a number, group, who are pretty well in a similar position...but you do your best and. . . give as much help. I've been sorting books out all morning.'</i> (p. 716, Clare et al., 2008)</p> <p><i>'I spend most of my time reading the newspapers; knowing what the changes in Hong Kong are. Gradually, I will remember. For important news or information, I will try to remember it or even cut it out.'</i> (p. 596, Mok et al., 2007)</p> <p><i>'I like the [television] programmes where they ask questions and like that, to see if I can answer 'em . . . Quizzes and that, yes. I do like</i></p>

		<p><i>them 'cause I can see if I can remember to answer them. I mean I miss a few of 'em, but I can, I remember quite a few of 'em.'</i> (p. 87, Van Dijkhuizen et al., 2006)</p> <p><i>'It's the only thing I've found, really, that, well, I'm sure there are other things, but it's supposed to restore your abilities. We do all these sorts of exercises that stretch various parts of the body . . . Yes, well, you know, it's something to do. Anyway, it's sort of given me the sense that I'm actually trying to fix it.'</i> (p. 121, Gilmour & Huntington, 2005)</p> <p><i>'I think it's good to do this [to bake], so I don't lose it.'</i> (p. 94, Öhman & Nygård, 2005)</p> <p><i>'Yes, that's why I keep on doing crosswords, because I want to keep it practiced.'</i> (p. 893, Smith et al., 2005)</p> <p><i>'I read a magazine and it [the worry] disappears.'</i> (p. 73, NygÅrð & Åhman, 2002)</p>
	<p>Engagement for personal time and rest</p> <p><i>'I sometimes want to be alone.'</i></p>	<p><i>'Not sleep, I don't need that – but rest! I can sense it quite clearly.... And I need to sit down or lie down to rest Of course – everything is getting worn out'</i> (p. 102, Holthe et al., 2007)</p> <p><i>'Every day I look forward to going for walks...I don't have to do anything. I just walk. I go places by myself and I can enjoy it without having to talk about it. So I just want to keep being able to walk, and do things, and uh, that's all, really.'</i> (p. 388, Phinney et al., 2007)</p>
Being connected to others	<p>Being with others not to be/feel alone</p> <p><i>'I don't want to be left alone.'</i></p>	<p><i>'I hate having nobody here . . . I'd like to know where they all are.'</i> (p.566, Cahill & Diaz-Ponce, 2011)</p> <p><i>'When you live alone you're not . . . corresponding with people . . . You're . . . not talking to them . . . It's a quiet life . . . I listen to the TV. Things like that. But it would be a pretty dead house if there wasn't a TV and something going on . . . it's music and talk you know. There's somebody here . . . The TV is a lot of company.'</i> (p. 278, de Witt et al., 2009)</p> <p><i>'I'm really frightened, you know . . . of being alone, I've no one here at all.'</i> (p. 716, Clare et al., 2008)</p>
	<p>Doing an activity with others</p> <p><i>'We do things together.'</i></p>	<p><i>' . . . usually there's the set-ups and the clean-ups, then there's the dishes, the whole thing . . . we had a large group in the kitchen doing dishes. And it was so... so much fun.'</i> (p.199, Kelelr et al., 2010)</p> <p><i>'I feel I can do what I want... I can lock my door and lie down, and nobody can ask me to get up and do something, unless I lie there for hours... Then they [staff] collect us [me]! I think it is boring too, to lie down, and then you lie there... it is much better to be with the</i></p>

		<p><i>others and doing something... Talking to each other, at least... ’ (p. 101, Holthe et al., 2007)</i></p> <p><i>’I would like to talk to others, with someone who allows me to relax rather than giving me more pressure. I feel better after airing my feelings. I would like to share my difficulties with people who are calm, friendly, eager to help, who give me a sense of security.’ (p. 596, Mok et al., 2007)</i></p>
	<p>Meaningful relationships</p> <p><i>’I want to establish /maintain relationships.’</i></p>	<p><i>’We meet every Sunday morning at the coffee shop... Whoever is in town, or whoever wants it. We’ve been doing that for a couple years now. And the grandchildren come by and, you know, sit down and talk for, well, about an hour or so . . . I think we’re quite close.’ (p. 360, Phinney et al, 2013)</i></p> <p><i>’I miss my family.’ (p. 566, Cahill & Diaz-Ponce, 2011)</i></p> <p><i>’My life is lonely...very lonely. My daughter doesn’t come to see me; none of my children come to see me. Sometimes I would like to talk to one or other of them.’ (p. 1447, Moyle et al., 2011a)</i></p> <p><i>’But er...it’s the people, you get to know them. I didn’t at first. I’m not very good at, you know, getting to know people. I’d rather do without knowing them, you know, you know what I mean. But they have been friendly, it’s been nice. And I think I’ve got in, at last. I hope I have, anyway.’ (p. 716, Clare et al., 2008)</i></p> <p><i>’I’ve got a pal; she helps me out.’ (p. 716, Clare et al., 2008)</i></p> <p><i>’The most important thing I like is for my family to support me, love me, and not force me to do things I do not want to do.’ (p. 595, Mok et al., 2007)</i></p> <p><i>’When my family member said, ’What is wrong, you cannot even do it, it is so simple’. I was extremely upset.’ (p. 595, Mok et al., 2007)</i></p> <p><i>’Friendship, real friendship or love is important.’ (p. 542, Dröes et al., 2006)</i></p> <p><i>’Well, from my perspective, I would want to be not just a number or a name on a piece of paper. I am a person. And, as such, you’re dealing with me as a one-to-one person. I’d want to be dealt with by the health professionals that way.’ (p. 122, Gilmour & Huntington, 2005)</i></p>
Being connected to the environment	Being connected to one’s own home and familiar	<p><i>’I don’t want to do anything wrong . . . I don’t want to make any big mistakes or anything . . . [friend’s name] made mistakes and then they would put her in the old people’s home.’ (p. 274, de Witt et al., 2009)</i></p>

	<p>environment <i>'I want to stay in my own home.'</i></p>	<p><i>'Our family, a lot of people say to us, 'Oh, what are you doing in this great big house?' I've probably said this to ou before, but we love this house, and we can cope with it, as long as [husband's name] can still mow the lawn.'</i> (p. 121, Gilmour & Huntington, 2005)</p>
	<p>Being connected to community <i>'I want to be involved or interested in what's happening in my community.'</i></p>	<p><i>'I've been involved in the church all my life. It's just a part of me.'</i> (p. 591, Beuscher & Grando, 2009)</p> <p><i>'I love looking out, seeing everything. [Gesturing to her window] ... I ... watch the people... if I lived some place where I couldn't see all out through here I think that would bother me.'</i> (p. 278, de Witt et al., 2009)</p> <p><i>'Now tell me why I'd want to move out of a place like this, now it's quiet, you see all this scenery, you know everything that's going on, you see the kids playing all the time out there.'</i> (p. 278, de Witt et al., 2009)</p>
	<p>Being connected to natural environments <i>'I enjoy being in the nature.'</i></p>	<p><i>'It must be hereditary in some way. It's sort of automatic. On a beautiful winter day you take the opportunity. You really want to get out in the open air. That is the motive... You can say that physical activity is a necessary ingredient in life.'</i> (p. 230, Cedervall & Aberg, 2010)</p> <p><i>'Being homely means being able to look out the window and liking what you're looking at ... Just normal things around you like a garden and animals, that's what I see as homely.'</i> (p. 2616, Edvardsson et al., 2010)</p>

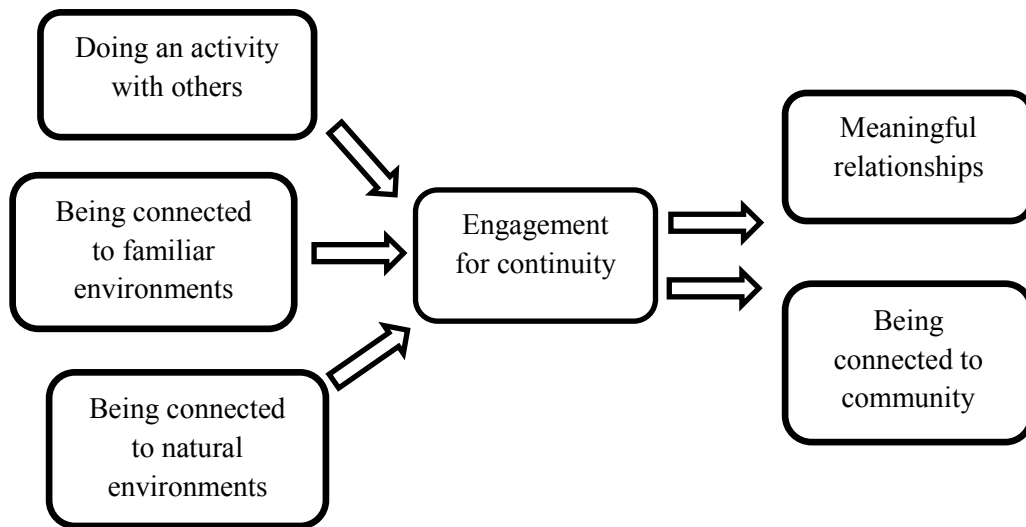


Figure 1. Theme Interactions. This figure illustrates interactions among themes.

Appendix 3: Benefits of Individualized Leisure and Social Activity Interventions for People with Dementia: A Systematic Review

(3rd comprehensive review of the literature)

Introduction

This review will discuss benefits of the individualized leisure and social activity interventions to persons with dementia by systematically searching literature and organizing studies based on how these interventions were individually tailored. A person with dementia may not be able to explore and participate in personally meaningful leisure and social activities without supports due to decreasing abilities in actively identifying their interests, required skills, and opportunities for participation in meaningful activities. Knowledge of how to best individualize leisure and social activities to a person with dementia, thus, is needed to support and promote continuing engagement in lifelong or enjoyable meaningful activities of the person with dementia. Before discussing these findings, I will address person-centered care as a theoretical and conceptual model supporting individualized activities.

Theoretical and Conceptual Background

Person-Centered Care

Person-centered care (PCC) is an individualized and holistic (biological-psychological-social-spiritual) approach to care addressing the whole person as one who has a unique history, interests, preferences, needs, strengths, and abilities (Brooker, 2007; Edvardsson, Fetherstonhaugh, & Nay, 2010; Institute of Medicine, 2001a; McCance, McCormack, & Dewing, 2011). PCC is regarded as the gold standard for healthcare by the Institute of Medicine while a traditional clinician-centered and disease-centered approach to the delivery of healthcare is criticized to be impersonal and fragmented (IOM, 2001a). The Patient Protection and Affordable Care Act of 2010 (ACA) encourages using person-centered approach in the delivery of health care, long-term services, and services funded by the Centers for Medicare and Medicaid Services (Kietzman, 2012). The concept of PCC developed from the humanistic psychologist Carl Rogers who described people as unique and multidimensional beings with

their own life experiences and feelings and the ability to direct their own care (Rogers, 1961; 1980). In PCC, the person's decision making about their own care, thus, is facilitated by respecting the person's lived experience and offering choices in care (Mead & Bower, 2000). A partnership among the persons, practitioners, and their families (if appropriate), also, is emphasized to make sure whether care decisions reflect the person's wants, needs, and preferences and the person is supported for participation in making decisions of their own care (IOM, 2001b).

Although PCC is based on similar underlying concepts above, varied concepts, models, and frameworks of PCC exist depending on health professions (e.g., medicine, nursing, gerontology, rehabilitation) and health care settings (e.g., hospitals, nursing homes) (Morgan, & Yoder, 2012). A study (Leplege et al., 2007), for example, conducted a concept analysis of PCC in rehabilitation and identified four dimensions of PCC. These dimensions of PCC are that: a) PCC should adopt an individualized and holistic approach; b) interventions should address the person's difficulties in everyday life; c) the person is an expert about their own situation and participation and empowerment should be emphasized in the rehabilitation process; and d) persons should be treated with respect and dignity, regardless of their impairment or disability (p. 1556-1558, Leplege et al., 2007). A framework for Person-centered nursing (McCormack & McCance, 2006) consists of four main elements: a) prerequisites of the nurse (e.g., being professionally competent, having interpersonal skills); b) care environment (e.g., effective staff relationships, supportive organizational systems); c) care process (e.g., working with the person's beliefs and values, quality of the relationship between the person and the nurse); and d) person-centered outcomes (e.g., satisfaction with care, feeling of well-being) (p. 475-477). Another example is a person-centered model of care for older people in acute care developed to apply complex co morbidities and care needs of older adults to care in a person-centered manner (Peek, Higgins, Milson-Hawke, McMillan, & Harper, 2007). These are a few examples of proposed concepts, models, and frameworks of PCC.

Person-Centered Dementia Care

Person-centered dementia care was proposed by Tom Kitwood who first applied Rogers' person-centered approach to dementia care against the biomedical and behavioral approach for people with diminished cognitive ability (Kitwood, 1988). In the biomedical paradigm, dementia is conceptualized regarding neurodegenerative pathology, loss, and decline (Kitwood, & Bredin, 1992). According to Kitwood (1997), PCC aims to maintain or support personhood, defined as "a standing or status that is bestowed on one human being, by others, in the context of relationship and social being, implying recognition, respect, and trust (p. 8)." Kitwood (1997), thus, emphasized not only respect of the person's life history, remaining abilities, and choices, regardless of the person's ability level, but also the importance of positive social relationships in person-centered dementia care. He suggested that depersonalization can result from a dialectical process between neurological impairment and negative social environment (e.g., where the person is objectified or stigmatized), leading to psychological damage to the person with dementia (Kitwood, 1997). Kitwood (1997) argued that positive interaction, on the other hand, could meet the person's psycho-social needs for love, occupation, identity, inclusion, attachment, and comfort.

Brooker (2004) further developed Kitwood's philosophy of PCC by creating the VIPS practice model with four major elements of PCC in the context of dementia care. These four elements include: a) valuing people with dementia and those who care for them (V); b) taking an individualized approach by recognizing the individual as a unique person (I); c) understanding the world from the perspective of the person with dementia (P); d) providing a positive social environment that supports psychological needs (S) (p. 216, Brooker, 2004).

The Dementia Initiative's person-centered dementia care framework was developed to make a single, multidimensional conceptual framework for person-centered dementia care (Dementia Initiative, 2013). The framework consists of four parts: a) core values and philosophy; b) structural elements; c) operational practices; and d) individualized practices (p. 13). Core values and philosophy, the foundation for the framework, involve: a) knowing the individual as a unique person with his or her own meaning of

life, personality, personal history, interests, preferences, and needs; b) focusing on the strengths of the person with dementia rather than on diminished or lost abilities; and c) entering the world of the person with dementia from their perspective (p. 18). The structural elements, the frame for the framework, include: a) relationships and community (belonging); b) governance; c) leadership; d) care partners or workforce; e) services; f) meaningful life and engagement; g) environment; and h) accountability.

Operational practices make each structural element functional. Individualized practices are the individual ways of honoring the person's interests, preferences, and needs to support the well-being of the person with dementia.

Engagement in Meaningful Activities by People with Dementia

Maintaining and supporting the self is recognized as the core element of PCC and one way of maintaining the self, fulfilling psychological needs, and promoting psychosocial well-being is through providing individually meaningful activities (Dementia Initiative, 2013; Edvardsson et al., 2010; Edvardsson, Varrailhon, & Edvardsson, 2014; Kelly, 2010; Zingmark, Sandman, & Norberg, 2002). In other words, supporting engagement in individually meaningful activities helps an older adult with or without dementia maintain his or her unique preferences, sense of self, identity, and values and thus promotes psychosocial well-being and quality of life (Cooney, Murphy, & O'Shea, 2009; Dröes et al., 2006). Engaging in personally meaningful activities also is what persons with dementia use as a coping strategy for living well with dementia, by having feelings of enjoyment, belonging, and personal identity (Beard, Knauss, & Moyer, 2009; Phinney, Chaudhury, & O'connor, 2007).

Engagement in Leisure and Social Activities by People with Dementia

Individuals with dementia, just like everyone else and just as before they were diagnosed with dementia, do consider activities that give opportunities for enjoyment, positive social interaction, and self-determination to be meaningful and important in enhancing quality of life (Dröes et al., 2006; Phinney et al., 2007; Smith et al., 2005). Leisure and social activities are more likely to provide these opportunities than other activities such as self-care activities, especially in later life (Kelly, 2010; Phinney & Moody,

2011). Leisure and social activities are often self-chosen and fun, and many leisure activities involve social contact (Phinney, 2006). Older adults, thus, can be more motivated to participate in leisure and social activities than other activities (Murphy, Shea, & Cooney, 2007).

Leisure can be defined as a nonobligatory, enjoyable activity that is driven by intrinsic motivation and freedom of choices and that people engage in during their free time (Mannell & Kleiber, 1997). People with later stages of dementia may not be able to explore and participate in leisure activities without supports due to decreasing abilities in actively identifying their interests, required skills, and opportunities for leisure participation. In this case, understanding and knowing the person, thus, is needed to promote continuing engagement in their lifelong or enjoyable leisure activities. People with earlier stages of dementia who are able to verbally express individual preferences in activities report not participating in daytime activities or not having social interactions to the extent they desire (Miranda-Castillo, Woods, & Orrell, 2013; van der Roest et al., 2009). Community-dwelling people with earlier stages of dementia and their informal caregivers stated that available community services were not what they wished and preferred for daytime activities including leisure activities (van der Roest et al., 2009). People with earlier stages of dementia may have a lack of opportunities in participating in leisure activities in the community due to a lack of understanding and accepting dementia by friends who used to participate in leisure activities together (Moyle, Kellett, Ballantyne, & Gracia, 2011a). Change in cognition (e.g., decreased initiation of activities, memory) itself may affect participation in leisure activities of the person with earlier stages of dementia, so the person needs to alter leisure or ask for assistance from families or health professionals to participate in leisure activities (Cook, Fay, & Rockwood, 2008; Genoe & Dupuis, 2014; Phinney, 2006). Supports, therefore, may be needed to promote continued engagement in leisure activities regardless of stages of dementia.

Participation in social activities can involve direct or indirect social contacts, require active or passive roles, and take place at home or in the community. Social activities, for instance, can be being around with people (requiring passive roles), doing an activity together (requiring active roles), and

looking at the family photos or talking about family to feel connected to their families without direct social contacts with families (Cahill & Diaz-Ponce, 2011; Harmer & Orrell, 2008). Older people with dementia who lived in the community or long term care facilities desired for maintenance of meaningful relationships (e.g., partner, children, grandchildren), and a loss of key relationships was a source of loneliness (Cahill & Diaz-Ponce, 2011; Dröes et al., 2006; Moyle et al., 2011a). People with dementia can be socially isolated and feel lonely if they live in a task-oriented long-term care facility (Ward, Vass, Aggarwal, Garfield, & Cybyk, 2008). Establishing meaningful relationships with other residents and staff and having companionship with others in residential care facilities were considered hard because of little chance for conversations with them (Moyle et al., 2011b). Residents with dementia recognized that staff members were too busy in doing their jobs and other residents were placed in bed in the early evening. Residents with dementia, in addition, may lose opportunities for making social contacts if daytime activities provided by residential care facilities are not matched to their interests and abilities (van der Ploeg, Bax, Boorsma, Nijpels, & van Hout, 2013a). The death of a spouse, living distance from family or friends, co morbid frailty, and dementia symptoms were barriers of maintaining relationships, and thus giving feelings of loneliness (Moyle et al., 2011a).

Qualitative studies support benefits of participation in personally meaningful leisure and social activities from perspectives of people with dementia. Community-dwelling people with dementia found enjoyment, satisfaction, and distraction from other worries by engaging in leisure activities, such as gardening, going for walks, and music activities (Gilmour & Huntington, 2005; Nygård & Åhman, 2002; Phinney et al., 2007). Listening to music and singing were identified as common past and current leisure activities, and these activities were not too demanding to do, so people with dementia could actively engage in these activities with pleasure and without thinking about dementia (Cahill & Diaz-Ponce, 2011; Cohen-Mansfield, Golander, & Arnheim, 2000; Dröes et al., 2006; Smith et al., 2005). Music-related activities also were enjoyed by people with dementia because of positive benefits in their spirits and concentration by soothing and uplifting their feelings and expressing themselves non-verbally

(Harmer & Orrell, 2008; Sixsmith & Gibson, 2007). Reviewing past experiences and one's life was pleasurable to residents with dementia living in care homes because engaging in this activity recovered their sense of identity by compensating their current losses (Clare, Rowlands, Bruce, Surr, & Downs, 2008). Talking about past activities, experiences, and interests associated with one's social and occupational roles were enjoyed and meaningful to people with dementia as an expression of their identity (Harmer & Orrell, 2008; Öhman & Nygård, 2005).

People with dementia self-reported benefits of participation in social activities, including a sense of belonging, companionship, enjoyment, shared identity, promoted meaningful relationships, and improved quality of life (Clare et al., 2008; Dröes et al., 2006; Holthe, Thorsen, & Josephsson, 2007; Keller et al., 2010; Molyneaux, Butchard, Simpson, & Murray, 2012; Phinney, Dahlke, & Purves, 2013; Smith et al., 2005). For example, a man with dementia and his family reported that working together in the garden promoted a sense of shared identity as the family who worked hard together with partnership to overcome any challenge (Phinney et al., 2013). Talking and sharing with similar people, in terms of dementia or unrelated to dementia (e.g., attending a women's group), helped people with early stage dementia normalize difficulties, learn different ways of coping from others, and not to feel alone (Preston, Marshall, & Bucks, 2007). Talking to and about family gave residents feelings of being connected to their families by reminding residents with dementia of past memories and proving their existence outside of residential care facilities (Harmer & Orrell, 2008; Moyle et al., 2011b). Listening to music also helped people with dementia recall past memories and thus encouraged meaningful conversations with others by talking about their past experiences (Sixsmith & Gibson, 2007).

Findings of the qualitative studies mentioned above demonstrate what perceived benefits were to people with dementia, how people with dementia could engage in leisure and social activities despite dementia from the available resources and assistance in supportive environment, or by using their coping strategies and remaining abilities. Persons with dementia may not be able to engage in personally meaningful leisure and social activities without carefully considered, individually tailored strategies by

health professionals. A resident with dementia living in nursing home, for example, may not be able to verbally express what activities he or she enjoy, value, and want to do, and may not participate in activity programs delivered by the nursing home because these are not matched to interests of the resident with dementia. The resident with dementia, in this case, may feel bored, lonely, socially isolated if the staff does not know his or her unique history, preferences, interests, and needs.

Systematic reviews of non-pharmacological, psychosocial treatments in dementia often are conducted by focusing on what treatments are effective in reducing behavioral and psychological symptoms of dementia such as agitation, aggression, and depression (Kverno, Black, Nolan, & Rabins, 2009; O'Connor, Ames, Gardner, & King, 2009a; O'Connor et al., 2009b; Seitz et al., 2012). These systematic reviews are helpful in determining effective treatments for managing symptoms that may affect quality of life of both people with dementia and caregivers. Specific treatments, such as reminiscence therapy (Vasionytè & Madison, 2013) and music therapy (Blake, 2013), also target identification of benefits accruing to people with dementia. These systematic reviews, therefore, suggest how a specific type of intervention benefits broad areas of outcomes. None of the published systematic reviews focused on benefits of individualized leisure and social activities to people with dementia or on ways of individually tailoring leisure and social activities to each person with dementia.

Aims

The objective of this systematic review was to identify and summarize benefits of individualized leisure and social activity interventions to people with dementia. This systematic review specifically addresses three questions: (1) what are the benefits of individualized leisure and social activity interventions to people with dementia?; (2) how are these interventions individually tailored based on what factors?; and (3) what recommendations or suggestions can be made in individually tailoring leisure and social activity interventions to benefit persons with dementia?

Methods

I used the PRISMA Statement Explanation and Elaboration document (Liberati et al., 2009) as a guide for conducting and reporting quality of a systematic review.

Search Strategy

I systematically searched three electronic databases (PubMed, CINAHL, and PsycINFO) for peer-reviewed journal articles published in English until January, 2014. Search terms were entered by combining keywords related to individualized care, leisure, social participation, and dementia. I entered relevant search terms to capture all relevant articles because authors may use different terms. For example, keywords for individualized care included ‘individualized’, ‘personalized’, ‘person-centered’, ‘patient-centered care’, ‘client-centered therapy’, ‘tailor*’, ‘choice*’, ‘preference*’, ‘value*’, ‘desire*’, ‘self-chosen’, and ‘self-decided.’ Keywords related to leisure activities (e.g., ‘leisure’, ‘recreation’, ‘recreational therapy’, ‘hobbies’, ‘arts therapy’, ‘music’, ‘exercise’) and social activities (e.g., ‘social participation’, ‘interpersonal interaction’, ‘social interaction’, ‘reminiscence’) were selected based on literature of non-pharmacological interventions in aging and dementia journals for people with dementia. The search terms entered in electronic databases are described in Table 1. I also manually searched articles through reference list checking (searching reference lists of identified articles and systematic reviews) and related-articles features in databases.

Inclusion Criteria

Studies were included if: (1) all participants were reported to have any types and stages of dementia; (2) the study used an experimental design (e.g., randomized controlled trials, repeated measures with randomized crossover), a quasi-experimental design (e.g., non-equivocal pretest-posttest control group design, one-group pretest-posttest design), or single-subject designs (e.g., A-B-A design); (3) the intervention was individually tailored for promoting leisure or social participation; and (4) the study included outcome measures for people with dementia. Outcomes were not restricted to a specific outcome (e.g., agitation) to identify a range of benefits. Studies were excluded if the intervention focused on self-care activities or involved a group of people with dementia, not a single person with dementia.

Focus, thus, was on one-on-one social interaction involving a single person with dementia to guarantee the activity was truly individualized for the single person with dementia. Individualized interventions for broad areas of daily activities were included if activities involved leisure or social activities.

Data Synthesis

Quality of the included studies was estimated using the Effective Public Health Practice Project Quality Assessment Tool (EPHPP; Thomas, Ciliska, Dobbins, & Micucci, 2004), because the tool can be used for studies with a variety of study designs. EPHPP includes the following components: 1) selection bias; (2) study design; (3) confounders; (4) blinding; (5) data collection method; and (6) withdrawals/dropouts. Each component is rated as strong, moderate, or weak. The global rating is rated as strong if there is no weak rating in all components, moderate if there is one weak rating, or weak if there are two or more weak ratings. EPHPP is supported to have content and construct validity, excellent inter-rater reliability for the global rating, and fair inter-rater reliability for the individual component (Armijo-Olivo, Stiles, Hagen, Biondo, & Cummings, 2012; Thomas et al., 2004). Since EPHPP does not evaluate study quality in terms of power, the ability to find a difference when a real difference exists, this component was added for assessing study quality.

Data were extracted to describe characteristics of the studies including design, sample size, descriptions of treatment and comparison groups, participant characteristics, outcomes, and results. Description of intervention included how the intervention was individualized in each included study. Meta-analysis, a statistical method to combine results of individual studies, was not conducted because the focus of the review is not on combining results statistically. I organized the included studies based on the aim 2 (how the intervention was tailored), and benefits (aim 1) were compared across the included studies depending on how the intervention was tailored (aim 2) to identify suggestions in individually tailoring leisure and social activity interventions to benefit persons with dementia (aim 3).

Results

Selection of Studies

Figure 1 describes study selection process. Of the 615 identified articles, there were 59 duplicates. A total of 479 articles were excluded based on title and abstract, and further 45 articles were excluded after reading full-text articles. Main reasons for exclusion included: the intervention did not involve individualized leisure or social activities; study design was not an experimental, a quasi-experimental, or a single-subject design study; intervention was a group therapy. For example, individualized exercise programs were only tailored to their abilities, and preferences or interests in exercise were not considered. These interventions, therefore, were excluded. A total of 32 studies met all the inclusion criteria. More detailed explanations of exclusion will be discussed in results.

Characteristics and Quality of Included Studies

The detailed characteristics and quality rating of the included studies on individualized leisure and social activities for people with dementia are described in Table 2. Of the 32 included studies, 8 were rated as strong, 16 as moderate, and 8 as weak using EPHPP. One study (Janata, 2012) was rated as moderate according to EPHPP, but may be weak due to significant biases (e.g., contamination bias) that are not considered in EPHPP. Component ratings in EPHPP are shown in Table 3. The sample size was justified by using a power analysis in only 9 studies. The included studies consist of 9 randomized controlled trials (RCTs), 12 repeated measures with randomized crossover (RMCs), 3 non-equivalent control group design (QNCs), 4 one-group pretest-posttest design (OPP), and 4 single subject designs (SSD). Twenty-two studies were conducted in USA, and participants of 21 studies were nursing home residents with dementia. Four studies involved community-dwelling older adults with dementia only. Participants in the majority of the included studies had moderate or severe stages of dementia; only one study (Chung, 2009) was specifically designed for people with mild dementia.

The included studies were organized into separate categories based on how the intervention was individually tailored (aim 2). These categories include: 1) performance factors; 2) self-identity; 3) music preference; and 4) life experiences and past memories. Each category will be discussed in detail below.

Leisure and Social Activities Individualized Based on Performance Factors

This category included leisure and social activities individually tailored based on performance factors such as preference/interests in activities, cognitive or functional abilities, current needs, lifelong habits and roles, and health conditions. All of the included studies in this category were not specific in types of leisure and social activities, and types of activities varied among participants. Eleven studies of this category included 6 RCTs, 3 RMCs, 1 QNC, and 1 OPP (Table 2). Mean ages of participants with dementia ranged from 78.1 to 88.7 years, and percent of female ranged from 43.3 to 82.2 percent. Eight studies involved participants with moderate or severe stages of dementia. Of the 11 studies, two studies (Fitzsimmons & Buettner, 2002; Gitlin et al., 2008) involved older adults with dementia living in their own homes, and family caregivers in Gitlin et al. were trained to use and participate in the activities with relatives with dementia.

Preferences or interests in leisure and social activities and functional abilities were the most common factors considered in tailoring activities to each individual with dementia in all of the included studies. Individually tailored activities based on leisure interests and functional abilities showed statistically significant effects in decreasing agitation, passivity, and other behavioral symptoms compared to usual care or attention control groups (Cohen-Mansfield, Parpura-Gill, & Golander, 2006; Cohen-Mansfield, Libin, & Marx, 2007; Cohen-Mansfield, Thein, Marx, Dakheel-Ali, & Freedman, 2012; Fitzsimmons & Buettner, 2002; Gitlin et al., 2008; Van Haitsma et al., 2013). Positive effects were also found in duration and levels of participation, attention, affect, and sleep (Cohen-Mansfield et al., 2006; 2007; 2012; Gitlin et al., 2008; Kolanowski, Litaker, & Buettner, 2005; Kolanowski, Litaker, Buettner, Moeller, & Costa, 2011; Richards, Beck, O'Sullivan, & Shue, 2005; Van Haitsma et al., 2013; van der Ploeg et al., 2013b).

Two studies compared activities matched to both interests and functional abilities with activities matched to either interests or to functional abilities alone (Kolanowski et al., 2005; 2011). Greater benefits were found when activities were matched to both interests and functional levels or to interests alone, with less benefit in activities matched to functional levels only. These greater benefits include

more time on task, greater levels of participation and attention, more positive affect, and less passivity. One study (Van Haitsma et al., 2013) also compared individualized leisure and social activities matched to both interests and abilities with standardized one-on-one social activity involving conversation about a magazine. Negative outcomes were found in the standardized activity compared to individualized activities or even usual care. These negative outcomes include more anger, more uncooperativeness, more aggression, and more negative verbal behaviors (swearing, screaming, and mocking) in the standardized leisure and social activity. These findings suggest that recreational activities should be at least matched to interests of each person with dementia.

Identification of preferences or interests in activities involved interviews with a family member of the person with dementia in all 11 studies. Differences, however, exist in studies depending on whether preferences or interests in activities were identified by interviewing a family member of the person with dementia only (Gitlin et al., 2008; Kolanowski et al., 2005; 2011; Mowrey, Parikh, Bharwani, & Bharwani, 2013; van der Ploeg et al., 2013b), both a family member and a formal caregiver, such as a nursing staff member (Cohen-Mansfield et al., 2007; 2012), the person with dementia and a family member (Fitzsimmons & Buettner, 2002; Richards et al., 2005), or the person with dementia, a family member, and a formal caregiver (Cohen-Mansfield et al., 2006; Van Haitsma et al., 2013). A family member of the person with dementia living in residential care homes may know past interests or preferences of the person with dementia better than the current interests or preferences in activities, and the direct care staff may better know the current ones (Van Haitsma et al., 2013). Excluding the person with dementia in identifying his or her interests and preferences in activities without making an attempt is not person-centered care that respects the person's perspective, and promotes participation and the remaining abilities. Van Histma et al. (2013) found that residents with moderate or severe stages of dementia were able to identify their past interests and preferences in activities. Specific assessment tools were used to identify past and/or current activity interests of the person with dementia, including the Pleasant Event Schedule (Gitlin et al., 2008), Farrington Leisure Assessment (Fitzsimmons & Buettner,

2002), and Preferences for Everyday Living Inventory-Nursing Home (PELI-NH; Van Haitsma et al., 2013).

Cognitive and functional status, as well as identification of activity interests or preferences, was assessed before prescribing individually tailored activities in all studies except van der Ploeg et al. (2013b). In van der Ploeg et al. (2013b), activity interests and health conditions that could hinder participation by chart reviews were used in prescribing activities, and an activity facilitator used Montessori principles during activities. Montessori principles used include adjusting difficulty of tasks to individuals' ability by breaking tasks into smaller components, minimizing language demands, and providing external cues. Skill levels, thus, also was considered in delivering an individually tailored activity in van der Ploeg et al. (2013b). Examples of assessment tools used are: the Mini-Mental State Examination (MMSE) to assess cognitive functions (in Cohen-Mansfield et al., 2006; 2007; 2012; Kolanowski et al., 2005; 2011; Richards et al., 2005; Van Haitsma et al., 2013); the Global Deterioration Scale to assess global status, incorporating cognitive status, functional status, and behavioral symptoms (in Fitzsimmons & Buettner, 2002); and the Minimum Data Set (MDS) to assess performance in activities of daily living (in Cohen-Mansfield et al., 2007; 2012; Van Haitsma et al., 2013).

Additional considerations in individually tailoring activities, other than activity interests, cognition, and functional status, include: daily routines, dyadic communication between a family caregiver and the person with dementia, and home environments (in Gitlin et al., 2008); social and occupational roles, physical evaluations (e.g., pain, vision) (in Cohen-Mansfield et al., 2007; 2012); napping patterns (in Richard et al., 2005); and leaning style and behavior profile (in Mowrey et al., 2013).

Leisure and Social Activities Individualized Based on Self-identity

Self-identity can be achieved and maintained from occupational or social roles, personal attributes/traits/achievements, and leisure time activities /hobbies important and enjoyed during one's lifetime (Cohen-Mansfield et al., 2006). Six of the identified studies involved diverse types of leisure and social activities individually tailored based on self-identity of the person with dementia, including 1 RCT

(Politis et al., 2004) and 5 RMCs (Cohen-Mansfield et al., 2010a; Cohen-Mansfield, Marx, Thein, & Dakheel-Ali, 2010b; 2011; Cohen-Mansfield, Thein, Dakheel-Ali, & Marx, 2010c; Leone, Deudon, Piano, Robert, & Dechamps, 2012). Mean ages of participants with dementia ranged from 84 to 86 years, and percent of female ranged from 72.5 to 83.3 percent. Four studies (Cohen-Mansfield et al., 2010a; 2010b; 2010c; 2011) involved the same participants with dementia, and Cohen-Mansfield et al. (2010a) involved some of the participants who exhibited agitated behaviors.

All five RMC studies identified each participant's past and/or current interests in leisure, social, and work-related activities by interviewing the person with dementia and/or his or her family member on the Self-Identity Questionnaire (SIQ). Most salient self-identity, especially, was related to social activities involving a family member and leisure activities (Cohen-Mansfield et al., 2010c).

Participants with dementia showed greater levels of engagement, pleasure, and interest, and less agitation when provided with stimuli matched to their self-identity/interests than non-individualized stimuli, except live social stimuli (e.g., one-on-one social interaction with a research assistant, a real dog) (Cohen-Mansfield et al., 2010a; 2010b; 2010c; 2011; Leone et al., 2012). One study (Cohen-Mansfield et al., 2010b) differentiated past and current preferences in music, arts, and pets, and assessed levels of engagement of the participant with dementia. Greater levels of engagement were found in leisure activities when matched to current preferences than past preferences. The findings of Cohen-Mansfield et al. (2010b) indicate the importance of identifying both past and current preferences in activities to provide nursing home residents with dementia with the most interesting and engaging activity in case preferences in activities may change.

Interests in leisure and social activities were identified in informal, relaxed, and unstructured ways in Politis et al. (2004). A participant with moderate or severe stage of dementia was asked to talk about his or her past and interests and decide what activities she or he wanted to do together. The activity therapist introduced herself, asked if the person with dementia wanted to spend some time together, and explained the purpose of the visit before asking about past and interests of the person with dementia

(Politis et al., 2004). Even this very simple one-on-one and person-centered approach supporting participation in individualized leisure and social activities showed benefits in reducing overall behavioral symptoms and apathy (loss of motivation and interest) and improving quality of life (Politis et al., 2004). All these findings suggest the importance of considering an individual's most salient self-identity to facilitate intrinsic motivation and participation and improve affect and agitated behaviors.

Music Listening Activities Individualized Based on Music Preference

This category included an individualized music listening activity in which the recorded music was selected based on music preference of a person with dementia. Studies involving preferred music listening were excluded because the music listening activity was in a group format (e.g., Suzuki et al., 2004). One of the identified studies (Sakamoto, Ando, & Tsutou, 2013) involved listening to music related to an individual's special memories evoking pleasure. This study was excluded because the selected music related to positive memories may not be matched to music preference. Studies of individualized music listening during bathing (Clark, Lipe, & Bilbrey, 1998; Thomas, Heitman, & Alexander, 1997) were excluded because activities should take place during their free time to be leisure activities, not during caregiving routines. These studies also did not identify whether participants enjoyed listening to preferred music during bathing, so preferred music listening during bathing of these studies could not be regarded as leisure activities. A study (Hicks-Moore & Robinson, 2008) was excluded because authors reported that the musical preferences of some residents with dementia were unknown, so the music list was selected by nursing staff. There was no description supporting how well nursing staff knew the music preferences of the resident with dementia.

Seven studies of this category included 2 RCTs (Guétin et al., 2009; Janata, 2012), 2 QNCs (Sung, Chang, & Abbey, 2006; Sung, Chang, & Lee, 2010), 1 RMC (Gerdner, 2000), and 2 SSD (Gerdner, 2005; Park & Pringle Specht, 2009). Gerdner (2005) used mixed methods design, but Gerdner (2005) met the inclusion criteria when considering quantitative part of Gerdner (2005) in this review paper. Mean ages of participants with dementia ranged from 80.1 to 86.1 years, and percent of female

ranged from 44.2 to 100 percent. Participants with dementia in Guétin et al. (2009) had milder stages of dementia than participants in the other studies. Interventions of the included studies varied in duration, ranging from 20 to 30 minutes and once or twice a week, over a 2 to 16 weeks period. The exception (Janata, 2012) used the intervention lasting several hours per day 4 times a week for 12 weeks. Preferred music listening for 30 minutes was used in five studies (Gerdner, 2000; 2005; Park & Pringle Specht, 2009; Sung et al., 2006; 2010). All studies assessed effects of interventions on reducing behavioral or psychological symptoms, such as agitation, anxiety, and depression, in people with dementia living in long term care facilities except Park and Pringle Specht (2009) in which home-dwelling people with dementia participated in.

Two studies compared listening to individualized music based on music preference with listening to non-individualized music (Gerdner et al., 2000) or with reading and rest activity (Guétin et al., 2009). Statistically significant benefits in reducing agitation were found in individualized music listening compared to classical relaxation music listening during and following intervention (Gerdner et al., 2000). These effects persisted for 30 minutes following intervention only in preferred music listening. Significantly lower anxiety and depression were found in preferred music listening compared to reading and rest activity during the intervention periods and even 8 weeks following the intervention (Guétin et al., 2009).

Three studies (Janata, 2012; Sung et al., 2006; 2010) compared individualized music activity to usual care. Listening to preferred music for 30 minutes per day twice a week was effective in reducing agitation (Sung et al., 2006) and anxiety (Sung et al., 2010) compared to usual care. Greater amount of music listening (several hours per day 4 times a week) was not different in reducing agitation, depression, and behavioral disturbances from usual care (Janata, 2012). In Janata (2012), however, participants were allowed to leave their rooms while the music was played due to the longer periods of exposure to music. These findings indicate that preferred music listening may benefit people with dementia only when music is played for a short duration (20 or 30 minutes) and thus they can concentrate on music within their

limited attention span (Jennings & Vance, 2002). Music was played in the room of the resident with dementia (Gerdner, 2005; Guétin et al., 2009; Janata et al., 2012), and an area where the resident spent the majority of his/her time in residential care homes (Gerdner, 2000). The other studies did not mention the specific place where the preferred music listening activity was provided. Environmental factors, such as environmental distractions, may affect music listening activity of the person with dementia (Hall & Buckwalter, 1987).

Music preference of the person with dementia was identified by interviewing a family member of the person with dementia only (Gerdner, 2000; 2005; Park & Pringle Specht, 2009), a person with dementia only (Guétin et al., 2009; Janata et al., 2012), or a person with dementia, his or her family members, and/or formal caregivers (Sung et al., 2010). Four studies used specific tools for identifying musical preference and the importance of music in life during the independent living of the person with dementia, including the Assessment of Personal Music Preference (APMP) in three studies (Gerdner, 2005; Park & Pringle Specht, 2009; Sung et al., 2010) and the Modified Hartsock Music Preference Questionnaire in Gerdner (2000). Questions of these tools involve preferred kinds of genre, artists, music albums, specific song titles, and music activities as well as the importance of music in life. In Guétin et al. (2009) and Janata et al. (2012), music preference and listening history/personal experience were assessed by interviewing a person with dementia and there were no descriptions on which specific questionnaires were used. No detailed descriptions of identifying music preference were provided in Sung et al. (2006).

Only three studies (Gerdner, 2005; Park & Pringle Specht, 2009; Sung et al., 2010) reported how important music was to the life of a person with dementia. Almost half of the participants with dementia rated music as slightly important in their life in Park and Pringle Specht (2009) and Sung et al. (2010). No comparison was made whether the importance of music in life would make difference in outcomes.

None of the included studies involved more active participation such as playing musical instruments or dancing while listening to preferred music. Preferred music listening was not compared to

group music therapies involving more active and interactive participation by singing, clapping, and dancing together. No study identified whether benefits of individualized music listening based on music preference only would be different from benefits of individualized music listening based on the other personal and environmental factors as well as music preference.

Social Activities Individualized Based on Life Experiences and Past Memories

Individualized Simulated Presence Therapy

Seven studies (Camberg et al., 1999; Cheston, Thorne, Whitby, & Peak, 2007; Cohen-Mansfield, & Werner, 1997; Garland, Beer, Eppingstall, & O'Connor, 2007; Miller et al., 2001; Peak & Cheston, 2002; Woods & Ashley, 1995) of simulated presence therapy (SPT) were included as a specific type of therapy involving indirect, simulated social contact with a family member individually tailored based on an individual's own life experiences and past memories. SPT involves individualized interactive conversation audiotaped or videotaped from a family member of the person with dementia. SPT was developed to give comfort by replicating a caregiver's presence in the form of a telephone conversation and talking about pleasant past memories or shared life experiences from the past (Woods & Ashley, 1995). The recorded tape contains the family member's side of the conversation with pauses for the person with dementia to respond (Woods & Ashley). One study (O'Connor, Smith, Nott, Lorang, & Mathews, 2011) using video-simulated presence therapy was excluded because the purpose of recording was for a family member to ask a person with dementia to comply with staff requests and participate in tasks while staff assists self-care tasks. SPT used in O'Connor et al. (2011), thus, was not tailored based on life experiences and past memories of the person with dementia.

Seven included studies had varied study designs, including RMC (Camberg et al., 1999; Cohen-Mansfield & Werner, 1997; Garland, Beer, Eppingstall, & O'Connor, 2007), SSD (Cheston et al., 2007; Peak & Cheston, 2002), and OPP (Miller et al., 2001; Woods & Ashley, 1995). Mean ages of participants with dementia ranged from 74.3 to 86.8 years, and percent of female ranged from 63 to 85.7 percent. Participants of the included studies were residents with moderate or severe stages of dementia living in

long term care facilities including nursing homes or hospitals. Participants with dementia of the included studies had varied types and prevalence of behavioral disturbances at baseline. For example, participants in Garland et al. (2007) displayed physically nonaggressive agitation (e.g., pacing, inappropriate disrobing) during 64.8% of the baseline observation, physically aggressive agitation (e.g., spitting, hitting) during 3.8%, and verbally aggressive (e.g., swearing, cursing) and nonaggressive agitation (e.g., repetitive questions, screaming) during 31.4%. Participants with verbal agitation only were included in Cohen-Mansfield & Werner (1997), and the most frequently observed specific types of verbal agitation were complaining (42.1%), shouting (35.4%), nonsense talk (32.1%), and repeating words (28.6%). In Camberg et al. (1999), agitation was not observed in almost 25% of the baseline observations, and the majority of observed physical and verbal agitation was fairly mild lasting only a few minutes. Participants had withdrawn behaviors, showing no interest in activities, people, or things during 47% of the direct observations, no pleasure during 75%, and no facial expressions during 82.5% (Camberg et al., 1999).

Two studies (Camberg et al., 1999; Garland et al., 2007) compared effects of SPT through an individualized interactive conversation audiotaped by family member to listening to neutral audiotapes (recordings of a person reading an emotionally neutral article or a book) and to usual care. SPT was more effective in reducing overall agitation (Camberg et al.), physical agitation (Garland et al.), and withdrawn behaviors (Camberg et al.) compared to neutral audiotapes and usual care based on direct observation before, during, and after the intervention (Garland et al.) and daily observation logs documented by blinded staff (Camberg et al.). Effects of SPT in decreasing verbal agitation were not different from effects of neutral audiotapes, but different from effects of usual care (Garland et al.). Improvement in physical and verbal agitation during SPT and listening to neutral audiotapes maintained for 15 minutes after interventions (Garland et al.).

Two studies (Cohen-Mansfield & Werner, 1997; Garland et al., 2007) assessed effects of SPT compared to listening to preferred music and/or to one-to-one social interaction. Cohen-Mansfield and

Werner (1997) found that all three interventions (videotaped SPT, preferred music listening, and one-on-one social interaction) were significantly better than usual care, by decreasing duration of verbal agitation 56% during one-to-one social interaction, 46% during SPT, 31% during preferred music listening, and 16% during usual care. In Garland et al. (2007), effects of SPT in decreasing counts of physical agitation were not different from effects of preferred music listening, and both were more effective than usual care by decreasing physical agitation 30% during SPT, and 25% during preferred music listening. Effects of preferred music listening in decreasing counts of verbal agitation, however, were not different from usual care, but effects of SPT significantly decreased verbal agitation compared to usual care (Garland et al.). Findings of these two studies may suggest that direct one-to-one social interaction work best in decreasing verbal agitation, and SPT can be used as an alternative to the one-to-one social interaction by decreasing verbal agitation more than preferred music listening.

The other four studies (Cheston et al., 2007; Miller et al., 2001; Peak & Cheston, 2002; Woods & Ashley, 1995) involved small number of participants with dementia (less than 10) and assessed changes in outcomes from pretest to posttest (Miller et al., 2001; Woods & Ashley, 1995) or across three conditions (two baseline conditions and SPT condition; Cheston et al., 2007; Peak & Cheston, 2002). Improvements were found in levels of disruptive behaviors (agitation, aggression, and wandering) and social interaction when comparing pretest to posttest (Miller et al., 2001; Woods & Ashley, 1995). There was a significant improvement in levels of distressed behavior (especially for participants asking or seeking to go home) during SPT compared to two baseline conditions, but not in levels of positive social interaction (Cheston et al., 2007). In Peak and Cheston (2002), two of the four participants, who had a secure attachment style, showed improvements in levels of distressed behaviors and positive social interaction during SPT compared to two baseline conditions. The participant having an avoidant attachment style in Cheston et al. (2007), however, responded to SPT like the other five participants having a secure attachment style.

Six studies (Camberg et al., 1999; Cheston et al., 2007; Garland et al., 2007; Miller et al., 2001; Peak & Cheston, 2002; Woods & Ashley, 1995) used SPT through audio-taped conversations by family, and one study (Cohen-Mansfield & Werner, 1997) used SPT through video-taped conversations by family. None of the included studies directly assessed whether benefits of SPT would be different when provided with a recorded audiotape or videotape. Videotaped SPT, however, may work better for a person with hallucinations than audiotaped SPT. Videotaped SPT decreased hallucinations most among verbally disruptive behaviors and more than one-to-one social interaction, listening to preferred music or neutral audiotapes, and usual care (Cohen-Mansfield & Werner). Miller et al. (2001) stated that residents with a history of hallucinations were withdrawn from the study because they became agitated with audiotaped SPT. Findings of these two studies (Cohen-Mansfield & Werner; Miller et al.) may suggest that having a history of or present hallucinations can be an important factor in implementing individualized SPT in the form of a videotape rather than an audiotape.

Relationships and shared memories with the person, who records a personalized tape for SPT, may affect effects of SPT. All of the included studies, except two studies (Cheston et al., 2007; Peak & Cheston, 2002) where the spouse of the person with dementia recorded an audiotape, did not mention exactly which family member recorded a tape. None of the included studies also did not address whether any efforts were made in identifying the family member who were most recognized by the person with dementia and who had positive and intimate relationships in the past. A family member of the person with dementia may serve as a primary family caregiver not because of their intimate relationships but because of living nearby. How much the relationship was intimate and close, and how much positive shared memories exist with the family member who recorded the tape may determine whether SPT would result in improved behaviors, affect, and comfort. This information may in some parts help identifying why some participants with dementia became more agitated or declined SPT (Camberg et al., 1999; Garland et al., 2007; Woods & Ashley, 1995).

Individualized Reminiscence Therapy

Reminiscence therapy (RT) varies depending on functions and goals (e.g., intrapersonal vs. interpersonal, resolving conflicts in late life stage through reviewing one's life vs. talking about and sharing past memories and life experiences) (Subramaniam & Woods, 2012). Talking about or sharing past memories and life experiences is one way of interacting with others who are either directly involved in their life histories and past events or not. Some reminiscence programs, thus, can be included as a specific type of therapy promoting direct social interactions and individually tailored based on an individual's own life experiences and past memories.

Studies were included only if : 1) the reminiscence program involved one individual with dementia; 2) direct and active social interactions through sharing past experiences and memories were facilitated rather than focusing only on reviewing one's life or remembering past events for cognitive stimulation; 3) the program used an approach for individualizing reminiscence therapy to the individual with dementia. Main reasons for excluding studies involving reminiscence were that: 1) reminiscence was done in a group format (e.g., Serrani Azcurra, 2012); and 2) more focus was on evaluating one's own life histories, thus functioning in more intrapersonal level, (e.g., Haight, Gibson, & Michel, 2006).

Only one study (Chung, 2009) met the criteria. Two RCTs (Lai, Chi, & Kayser-Jones, 2004; Van Bogaert et al., 2013) involved individually tailored reminiscence programs but these programs had no description on whether the programs also had a focus on promoting social interaction with a facilitator through reminiscing activities. Chung (2009) clearly described that the program had a focus on promoting social interactions. Both a participant with dementia and two youth volunteers reciprocally shared their life experiences, thus also promoting reciprocal relationship. Significant improvements in overall quality of life and depression were found compared to pre-test results. No significant improvement in cognition was found in Chung (2009) where participants had mild stages of Alzheimer's disease (AD). This finding was consistent with the finding of Van Bogaert et al. (2013) in which effects of the reminiscence program on improving cognition did not remain when the data was analyzed with participants with mild stage AD only.

Discussion

This review support benefits of individualized leisure and social activities on people with dementia. Improvements in levels of engagement, agitation, withdrawn behaviors, and affect were found among the 32 included studies. Diverse or specific types of leisure and social activities were involved in each intervention study, and a single factor (music preference) or multiple performance factors (e.g., interests in activities, functional ability, lifelong roles) were considered for tailoring activities to each individual. Multiple performance factors were considered in tailoring diverse types of leisure and social activities to each individual, and a single factor for a specific type of activity or therapy (e.g., music listening activity). Benefits were found in leisure and social activities regardless of whether the activity was individualized based on a single factor or multiple factors.

The majority of the included studies involving activities individualized based on multiple performance factors considered a variety of factors, although interests and/or functional abilities predominated as factors. Some studies, however, suggest identifying interests or preferences in leisure and social activities as the most important factor for successfully tailoring an activity plan for each person. Recreational activities matched to interests or preferences in activities only showed greater benefits on levels of engagement and pleasure compared to activities matched to functional abilities only. There were similar benefits when compared to recreational activities matched to both functional abilities and interests (Kolanowski et al., 2005; 2011).

Among four categories of the included studies, included studies involving diverse types of leisure and social activities individualized based on multiple performance factors, or self-identity assessed not only behavioral symptoms (e.g., agitation) but also affect (interest, pleasure), mood, and participation in activities. Majority of the included studies of individualized music listening activities based on music preference and SPT only assessed behavioral and psychological symptoms of the person with dementia. When considering the limited number of studies supporting a variety of outcomes beyond behavioral and psychological symptoms, a further study is needed to support that individualized music listening activities

and SPT truly were leisure or social activities giving pleasure and meaningful social relationship, thus meeting their psychosocial needs and wants for occupation and belonging.

Some benefits may simply result from one-on-one social interaction during leisure activities matched to their interests. Negative effects (Van Hastima et al., 2013), however, were found in a non-individualized activity involving one-on-one social interaction without consideration of an interest of the person with dementia. One-on-one social interaction with a nursing assistant, by looking through a magazine and talking about it, resulted in more aggression, uncooperativeness, and negative behaviors in people with dementia (Van Hastima et al.). No negative effects were found due to individually tailored leisure and social activities.

Leisure and/or social activities involving simple, unstructured one-on-on social interaction, showed benefits on overall behaviors, affect, levels of engagement, and overall quality of life when the activity and interaction was individualized in a non-standardized way (Cohen-Mansfield et al., 2010a; 2011; Politis et al., 2004; van der ploeg et al., 2013b). Only one of the included studies (Politis et al., 2004) compared standardized, structured activities using activity kits allowing limited choices in activities to unstructured, individualized leisure and social activities and found no significant difference in outcome measures between two interventions. Unstructured social activities considering each individual's interests, however, showed significant improvement in more outcome measures (apathy, overall behavioral disturbance, and quality of life) compared to baseline, while standardized, structured activities allowing limited choice of activity resulted in improvements only in apathy. A further study is needed to identify if individualized activity programs result in different outcomes depending on whether the activity was structured or not.

Person-centered approach should be used to provide individualized leisure and social activities to the person with dementia. Knowing and understanding an individual with dementia as a unique person with his or her life experience and history, interests or preferences in activities, strengths (remaining abilities) or past roles, should be preceded before providing activities to the person with dementia. To do

this, collaboration with a person with dementia, family member, and/or primary formal caregiver (e.g., nursing staff) and giving a choice to the person with dementia among varied activity choices should be attempted rather than relying only on opinions of either formal or informal caregiver. Positive social environment also should be embedded during individualized leisure and/or social activities by promoting social identity (e.g., family-social or professional roles in Cohen-Mansfield et al., 2006), or involving direct or indirect positive social interactions (e.g., Chung, 2009; Garland et al., 2004; Politis et al., 2004).

Overall suggestions can be made based on the synthesized findings of the included studies. Further studies are needed to identify how individualized leisure and/or social activities based on person-centered approach benefit persons with earlier stages of dementia. Activities promoting reciprocal social relationships between a person with earlier stages of dementia and younger generation, may be one promising intervention that improves quality of life and psychosocial well-being (Chung, 2009). More studies translating research into practice should be conducted since only efficacy, not effectiveness, was tested in some studies and required staff training and cost to deliver the intervention in a real nursing home setting were not tested (e.g., Cohen-Mansfield et al., 2007; 2012).

Collaboration among interdisciplinary practitioners can be helpful in implementation of individualized leisure and social activities for persons with dementia since evidence supports individualized leisure and social activities based on multiple performance factors in varied outcomes beyond behavioral and psychological symptoms. Individually tailoring activities to both interests /preferences in activities and abilities or at least interests, particularly, is important to benefit the person with dementia most (e.g., Kolanowski et al., 2005; 2011). Identifying both past and current interests/ preference in activities, through involvement of a person with dementia, family member, and a primary formal caregiver in assessment, may be more helpful in identifying personally meaningful activities to the person with dementia (e.g., Cohen-Mansfield et al., 2010b; Van Hastima et al., 2013). When providing a specific individualized activity (e.g., preferred music listening, SPT), available and applicable in a nursing

home, who would benefit from this activity should be considered by assessing how important and meaningful the specific activity and involved social relationship were/are to the person with dementia.

Limitations

The quality of the included studies varied. Sixteen studies of the 32 included studies were rated as moderate, and eight studies were rated as weak. Only 9 studies justified sample size by using a power analysis. Majority of the studies involved participants with moderate or severe stages of dementia and participant living in long-term care facilities. Benefits found from the majority of the included studies, therefore, may not generalize to community-dwelling older adults with earlier stages of dementia.

Limitations of the search should be noted because search was restricted to English-language publications through three electronic databases. There was a difficulty in determining whether the individualized reminiscence therapy could be regarded as an individualized social activity with a focus on promoting social interaction as well as on reminiscing itself. Most of the identified studies did not directly address social interaction through reminiscence as one of the focus of the intervention. Only one study, thus, was included since authors directly described it, but some studies might promote social interaction during reminiscing therapy. Benefits of individualized reminiscence therapy could be found better from qualitative studies where participants with dementia are likely to talk about benefits on social interaction during reminiscing therapy.

Conclusion

This systematic review found that individualized leisure and social activities can benefit people with dementia in a number of ways, in particular, by promoting engagement, by improving affect, and by reducing both agitation and withdrawn behaviors. The 32 studies included in this review documented varied ways of individualizing leisure and social activities as means to benefit people with dementia. Majority of these activities were individually tailored to each person with dementia by focusing on the individual's preferences, interests, remaining abilities, memories, or personal history. All of the included studies but one study focused on people, living in a long term care facility and having with moderate or

severe stages of dementia. This review found a gap in the literature about how people with earlier stages of dementia can be supported by providing individualized leisure and social activities in the community. Further study is needed to identify effective ways of promoting engagement in individualized leisure and social activities and thus mental health for people with dementia not only with later stages but also with earlier stages of dementia.

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Table 1. Search Terms Entered in Electronic Databases

Database	Search Terms
CINAHL	<p>TI ("dementia" OR "alzheimer's" OR "demented") AND ((MH "Individualized Medicine") OR (MM "Patient Centered Care") OR (MM "Self-Efficacy") OR (TI "person-cent*") OR (AB "person-cent*") OR (TI "patient-cent*") OR (AB "patient-cent*") OR (TI "client-cent*") OR (AB "client-cent*") OR (MM "Personal Values") OR (MM "Motivation") OR (TI "desire*") OR (AB "desire*") OR (TI "motivation*") OR (AB "motivation*") OR (TI "preference*") OR (AB "preference*") OR (TI "tailor*") OR (AB "tailor*") OR (TI "choice*") OR (AB "choice*") OR (TI "priorit*") OR (AB "priorit*") OR (TI "individualiz*") OR (TI "individualis*") OR (TI "self-chosen") OR (TI "self-decided") OR (TI "personaliz*") OR (TI "personalis*") OR (TI "empower*") OR (MH "Collaboration") OR (TI "collaborat*") OR (AB "individualiz*") OR (AB "individualis*") OR (AB "self-chosen") OR (AB "self-decided") OR (AB "personaliz*") OR (AB "personalis*") OR (AB "empower*") OR (AB "collaborat*")) AND ((MM "Interpersonal Relations") OR (MH "Friendship") OR (MH "Intergenerational Relations") OR (MM "Peer Group") OR (MH "Intimacy") OR (MH "Social Isolation+") OR (MM "Social Participation") OR (MH "Support, Psychosocial") OR (MH "Psychology, Social+") OR (MH "Social Environment") OR (MH "Social Networks") OR (MH "Socialization") OR (MH "Support Groups+") OR (MH "Leisure Activities+") OR (MH "Recreation+") OR (MM "Recreational Therapy") OR (MM "Art Therapy") OR (MM "Music") OR (MM "Music Therapy") OR (MM "Singing") OR (MM "Dancing") OR (MM "Dance Therapy") OR (MM "Handicrafts") OR (MH "Exercise+") OR (MH "Physical Fitness+") OR (MH "Sports+") OR (MH "Therapeutic Exercise+") OR (MH "Aerobic Exercises+") OR (MM "Group Exercise") OR (MM "Aquatic Exercises") OR (MM "Horticulture") OR (MM "Spirituality") OR (MM "Spiritual Care") OR (MH "Religion and Psychology+") OR (MH "Natural Environment+") OR (MH "Natural and Biologically Based Therapies+") OR (MH "Walking+") OR (MH "Storytelling+") OR (MH "Reading+") OR (MM "Reminiscence Therapy") OR (MM "Life History Review") OR (MM "Home Visits") OR (MM "Volunteer Workers") OR (MM "Volunteer Experiences") OR (TI "social activit*") OR (TI "leisure*") OR (TI "friend*") OR (TI "intergeneration*") OR (TI "social participation") OR (TI "social support*") OR (TI "recreation*") OR (TI "art") OR (TI "creativ*") OR (TI "music") OR (TI "danc*") OR (TI "craft*") OR (TI "garden*") OR (TI "exercise*") OR (TI "physical activit*") OR (TI "spiritual*") OR (TI "religio*") OR (TI "natur*") OR (TI "reminisce*") OR (TI "walk*") OR (TI "reading") OR (TI "volunteer*") OR (AB "social activit*") OR (AB "leisure*") OR (AB "friend*") OR (AB "intergeneration*") OR (AB "social participation") OR (AB "social support*") OR (AB "recreation*") OR (AB "art") OR (AB "creativ*") OR (AB "music") OR (AB "danc*") OR (AB "craft*") OR (AB "garden*") OR (AB "exercise*") OR (AB "physical activit*") OR (AB "spiritual*") OR (AB "religio*") OR (AB "natur*") OR (AB "reminisce*") OR (AB "walk*") OR (AB "reading") OR (AB "volunteer*") OR (TI "buddy") OR (AB "buddy") OR (TI "peer*") OR (AB "peer*") OR (TI "pair*") OR (AB "pair*") OR (MM "Pet Therapy")) NOT ((TI "caregiver*") OR (TI "carer*") OR (TI "caregiving*"))</p> <p>English Language; Peer Reviewed; Human; Publication Type: Journal Article; Age Groups: Aged: 65+ years</p>
PsycINFO	<p>TI ("dementia" OR "alzheimer's" OR "demented") AND ((MM "Individualism") OR (MM "Individual Psychology") OR (MM "Individual Differences") OR (MM "Individuality") OR (MM "Client Centered Therapy") OR (MM "Preferences") OR (MM "Empowerment") OR (MM "Self Efficacy") OR (MM "Collaboration") OR (MM "Desire") OR (MM "Values") OR (MM "Personal Values") OR (MM "Intrinsic Motivation") OR (MM "Psychological</p>

	<p>Needs") OR (TI "desire*") OR (AB "desire*") OR (TI "motivation*") OR (AB "motivation*") OR (TI "person-cent*") OR (AB "person-cent*") OR (TI "patient-cent*") OR (AB "patient-cent*") OR (TI "client-cent*") OR (AB "client-cent*") OR (TI "tailor*") OR (AB "tailor*") OR (TI "choice*") OR (AB "choice*") OR (TI "preference*") OR (AB "preference*") OR (TI "priorit*") OR (AB "priorit*") OR (TI "individualiz*") OR (TI "individualis*") OR (TI "self-chosen") OR (TI "self-decided") OR (TI "personaliz*") OR (TI "personalis*") OR (TI "empower*") OR (TI "collaborat*") OR (AB "individualiz*") OR (AB "individualis*") OR (AB "self-chosen") OR (AB "self-decided") OR (AB "personaliz*") OR (AB "personalis*") OR (AB "empower*") OR (AB "collaborat*")) AND ((MM "Interpersonal Interaction") OR (MM "Peer Relations") OR (MM "Interpersonal Relationships") OR (MM "Friendship") OR (MM "Intergenerational Relations") OR (MM "Social Groups") OR (MM "Social Networks") OR (MM "Peers") OR (MM "Peer Counseling") OR (DE "Peer Tutoring") OR (MM "Social Support") OR (MM "Social Interaction") OR (MM "Social Networks") OR (MM "Support Groups") OR (MM "Social Isolation") OR (MM "Online Social Networks") OR (MM "Socialization") OR (MM "Social Integration") OR (MM "Social Programs") OR (MM "Social Environments") OR (MM "Nature (Environment)") OR (MM "Leisure Time") OR (MM "Recreation") OR (MM "Recreation Therapy") OR (MM "Hobbies") OR (MM "Arts") OR (MM "Creative Arts Therapy") OR (MM "Painting (Art)") OR (MM "Art Therapy") OR (MM "Self Expression") OR (MM "Music") OR (MM "Music Therapy") OR (MM "Dance") OR (MM "Dance Therapy") OR (MM "Crafts") OR (MM "Exercise") OR (MM "Movement Therapy") OR (MM "Physical Activity") OR (MM "Horticulture Therapy") OR (MM "Spirituality") OR (MM "Nature (Environment)") OR (MM "Walking") OR (MM "Storytelling") OR (MM "Reading") OR (MM "Online Social Networks") OR (MM "Reminiscence") OR (MM "Life Review") OR (MM "Volunteers") OR (MM "Animal Assisted Therapy") OR (MM "Daily Activities") OR (TI "social activit*") OR (TI "leisure*") OR (TI "friend*") OR (TI "intergeneration*") OR (TI "social participation") OR (TI "social support*") OR (TI "recreation*") OR (TI "art") OR (TI "creativ*") OR (TI "music") OR (TI "danc*") OR (TI "craft*") OR (TI "garden*") OR (TI "exercise*") OR (TI "physical activit*") OR (TI "spiritual*") OR (TI "religio*") OR (TI "natur*") OR (TI "reminisce*") OR (TI "walk*") OR (TI "reading") OR (TI "volunteer*") OR (AB "social activit*") OR (AB "leisure*") OR (AB "friend*") OR (AB "intergeneration*") OR (AB "social participation") OR (AB "social support*") OR (AB "recreation*") OR (AB "art") OR (AB "creativ*") OR (AB "music") OR (AB "danc*") OR (AB "craft*") OR (AB "garden*") OR (AB "exercise*") OR (AB "physical activit*") OR (AB "spiritual*") OR (AB "religio*") OR (AB "natur*") OR (AB "reminisce*") OR (AB "walk*") OR (AB "reading") OR (AB "volunteer*") OR (TI "buddy") OR (AB "buddy") OR (TI "peer*") OR (AB "peer*") OR (TI "pair*") OR (AB "pair*")) NOT ((TI "caregiver*") OR (TI "carer*") OR (TI "caregiving*")))</p> <p>Publication Type: Peer Reviewed Journal; English; Age Groups: Aged (65 yrs & older); Population Group: Human; Document Type: Journal Article; Exclude Dissertations</p>
PubMed	<p>("Alzheimer Disease"[MeSH] OR "Dementia"[MeSH] OR dement*[Title] OR Alzheimer*[Title]) AND ("Patient-Centered Care"[MeSH] OR "Patient Participation"[MeSH] OR "Individuality"[MeSH] OR "Individualized Medicine"[MeSH] OR "Patient Preference"[MeSH] OR "Power (Psychology)"[MeSH] OR tailor*[Title/Abstract] OR choice*[Title/Abstract] OR priorit*[Title/Abstract] OR individualiz*[Title/Abstract] OR individualis*[Title/Abstract] OR self-chosen[Title/Abstract] OR self-decided[Title/Abstract] OR preference*[Title/Abstract] OR personaliz*[Title/Abstract] OR person-cent*[Title/Abstract] OR patient-cent*[Title/Abstract] OR client-cent*[Title/Abstract] OR empower*[Title/Abstract]) AND ("Interpersonal Relations"[MeSH] OR "Social Isolation"[MeSH] OR "Social</p>

Environment"[MeSH] OR "Social Participation"[MeSH] OR "Social Support"[MeSH] OR "Socialization"[MeSH Terms] OR "Loneliness"[MeSH Terms] OR "Friends"[MeSH Terms] OR "Self-Help Groups"[MeSH] OR "Leisure Activities"[MeSH] OR "Recreation Therapy"[MeSH] OR "Recreation"[MeSH] OR "Music"[MeSH] OR "Music Therapy"[MeSH] OR "Art Therapy"[MeSH] OR "Volunteers"[MeSH] OR "Peer Group"[MeSH] OR "Animal Assisted Therapy"[MeSH] OR friendship*[Title/Abstract] OR belonging*[Title/Abstract] OR connectedness[Title/Abstract] OR "social connection"[Title/Abstract] OR "social company"[Title/Abstract] OR companion*[Title/Abstract] OR "social participation"[Title/Abstract] OR "social engagement"[Title/Abstract] OR "social support"*[Title/Abstract] OR "social activities"[Title/Abstract] OR "social activity"[Title/Abstract] OR leisure[Title/Abstract] OR interest*[Title/Abstract] OR art[Title/Abstract] OR music*[Title/Abstract] OR creative*[Title/Abstract] OR hobb*[Title/Abstract] OR "Exercise"[MeSH] OR "Exercise Therapy"[MeSH] OR "Motor Activity"[MeSH] OR "Walking"[MeSH] OR exercise[Title/Abstract] OR physical activit*[Title/Abstract] OR walk*[Title/Abstract] OR "Nature"[MeSH] OR "Religion"[MeSH] OR "Spirituality"[MeSH] OR "Gardening"[MeSH] OR "Dancing"[MeSH] OR spiritual*[Title/Abstract] OR garden*[Title/Abstract] OR dancing[Title/Abstract] OR dance*[Title/Abstract] OR reminiscenc*[Title/Abstract] OR story-telling*[Title/Abstract] OR reading[Title/Abstract] OR buddy[Title/Abstract] OR peer*[Title/Abstract] OR pair*[Title/Abstract]) AND "humans"[MeSH Terms] AND English[lang] AND "aged"[MeSH Terms] AND Journal Article[ptyp] NOT (caregiver*[Title] OR carer*[Title] OR caregiving*[Title])

Table 2. Summary of Included Studies on Individualized Leisure and Social Activities for People with Dementia

Authors	Design (N)	Treatment and comparison groups	Participants : mean age (years); female (%); severity of dementia; setting	Outcomes	Results	Quality /Power
Leisure and social activities individualized based on performance factors						
Cohen-Mansfield et al. (2007)	QNC (167)	- Treatment Routes for Exploring Agitation (TREA): Individualized activities matched to past role-identity, past and/or current preferences, and cognitive, mobility, sensory abilities with a systematic search of needs underlying agitated behaviors (n=89) -C: Staff education (n=78) -10 consecutive days during the 4 hours of greatest agitation	86; 80.2; moderate to severe; NHs, USA	Agitation (ABMI), affect (pleasure, interest, negative affect; LMBS)	-T > C: Reduced agitation**, increased pleasure*** and interest*** -T=C in negative affect	Moderate No
Cohen-Mansfield et al. (2012)	RCT (125)	-T: TREA (n=89) -C (n=36) -2 weeks	85.7; 74.4; moderate to severe; NHs, USA	Agitation (ABMI), affect (LMBS)	T > C : Reduced overall agitation***, physical nonaggressive***, and verbal agitation**, increased pleasure*** and interest*	Moderate No
Cohen-Mansfield et al. (2006)	RCT (93)	-Individualized activities based on a participant's most salient past and/or current role identity among four domains (family-	87; 71; moderate to severe; senior day centers, NHs, USA	Affect (LMBS), involvement in activities (ABMI), well-being (MOSES),	T > C : Increases in pleasure***, interest***, involvement in activities***, and self-identity awareness***, and	Moderate No

		social role; professional role; leisure time and hobbies; and achievements and traits), cognitive, physical, and sensory abilities, and demographics (e.g., gender, educational level, primary language) (n=52); 5 days for 30 min a day -Usual care (n=41)		agitation (ABMI), self-identity awareness	declines in agitation*	
Gitlin et al. (2008)	RCT (60)	- Tailored activity program (TAP) matched to cognitive and functional abilities, previous roles, habits and past/current interests (n=30) -C: Usual care (n=30) -8 sessions, 6 home visits (90 minutes per visit) , and 2 (15 minute) telephone contacts over 4 months	79.4; 43.3; moderate; home, USA	Occurrence and number of behaviors, depressive symptoms (CSDD), activity engagement, overall quality of life (QoL-AD)	-T > C: Decreased frequency of behaviors** (Cohen's d = .72), greater activity engagement* (d=.61), greater pleasure in recreation* (d=.64), enhanced ability to keep busy* (d = .71), reduced agitation* (d = .75) and argumentation* (d = .77) at 4 months -T=C in depressed mood	Strong No
Fitzsimmons & Buettner (2002)	RMC (30)	-T: At-home individualized, therapeutic recreation therapy (e.g., art/craft therapy, therapeutic cooking, games, sports) tailored to current functioning level, past leisure interests, strengths, and current needs; 1 to 2 hours x 3 to 5 days per week x 2 weeks -C: Usual care	81.2; 65.5; moderate to severe; home, USA	Agitation (CMAI), passivity (PDS)	T > C: Decreased agitation* and passivity***	Moderate No
Kolanow	RMC	-Ta: Individualized	82.3; 77;	Engagement	-More time on task:	Strong

ski et al. (2005)	(30)	recreational activities matched to functional levels only -Tb: Matched to interests/ preferences for leisure/social activities -Tc: Matched to both functional levels and interests -20 min. x 12 consecutive days per treatment x 3 treatments (total: 6 weeks)	moderate to severe; NHs, USA	(time on task, participation), affect (PGCARS), mood (DMPT), agitation (CMAI), passivity (PDS)	Tc > Ta**, Tb > Ta* -Greater participation: Tc > Ta***, Tc > Tb** -More positive affect: Tc > BL***, Tb > BL**, Tc > Ta* -Less negative affect: Ta, Tb, Tc > BL* -Less agitation: Ta, Tb, Tc > BL** -Less passivity: Tc > Ta*	Yes
Kolanowski et al. (2011)	RCT (128)	-Ta: Individualized recreational activities matched to functional levels (n=32) -Tb: Matched to interests (n=33) -Tc: Matched to both functional levels and interests (n=31) -AC: Unmatched to functional levels and interests (n=32) -20 min. x twice per day x 5 days each week x 3 weeks	-86; 76.6; moderate; NHs, USA	Engagement (time on task, participation), affect (PGCARS), mood (DMPT), agitation (CMAI), passivity (PDS)	- More pleasure in Tc > Ta, Tb, AC* -Greater engagement and more alertness and attention in Tb, Tc > Ta, AC - No group differences in agitation, passivity, anxiety, and self-reported mood	Strong Yes
Mowrey et al. (2013)	OPP (9)	- Behavior-based ergonomic therapy (BBET) program (individualized multimodal therapeutic activities with 24/7 availability via staff): Comforting (e.g., music, video, memory props) or stimulating activities (e.g., stage-specific	88; 56; mild to severe; NH, USA	MDS behavior counts, MDS mood counts. falls, medication doses	65% reduction in MDS behavior counts*, 70% reduction in MDS mood counts, 53% reduction in the number of behavioral episodes, 33% reduction in falls, non-significant overall reductions in doses of antipsychotics and	Weak No

		games, puzzles) individualized based on interests, personality, learning style, cognitive functions, and behavior profile -6 months			anxiolytics	
Richards et al. (2005)	RCT (147)	-T: Individualized social activities based on interests (work and leisure history), cognition, functional status (mobility, hearing, vision, and fine motor skills), and napping patterns (n=71); 1 to 2 hours per day for 21 consecutive days -C: Usual care (n=68)	79; 48.2; moderate to severe; NHs, USA	Daytime minutes slept, nighttime variables (minutes to sleep onset, minutes slept, minutes awake, sleep efficiency), day/night sleep ratio (sleep/wake rhythm)	-T > C in daytime minutes slept**, nighttime minutes to sleep onset*, nighttime minutes awake*, day/night sleep ratio* -Participants with a sleep efficiency of less than 50% (n=50): T (n=20) > C (n=30) in daytime sleep**, day/night sleep ratio*, nighttime minutes to sleep onset*, nighttime minutes awake*	Moderate Yes
van der Ploeg et al. (2013b)	RMC (44)	-T: Individualized one- to- one activities based on former interests and hobbies, health conditions, and Montessori principles (adjusting difficulty of tasks to individuals' ability, minimizing language demands, providing external cues) -C: One-to-one social interaction (general conversation or conversation based on newspaper stories and pictures)	78.1; 68.2; moderate to severe; NHs, Australia	A single- targeted physically agitated behavior (e.g., pacing), affect (PGCARS), engagement (MPES)	-T > C in positive affect**, interested affect**, neutral affect***, constructive engagement***, negative engagement*** -T, C > BL in agitation***, positive affect**, interested affect***, neutral affect***, constructive engagement***, passive engagement***, negative engagement***	Strong Yes

		(for 30 minutes twice per week for 4 weeks)				
Van Haitsma et al. (2013)	RCT (180)	-Ta: Individualized positive psychosocial intervention (IPPI) program matched to current leisure interests and abilities (n= 44) -Tb: Standardized one-on-on social interaction (conversation on a magazine they read through) (n= 43) -C: Usual care (n=93) -10 min, 3 days per week for 3 weeks	88.7; 82.2; moderate to severe; NHs, USA	Direct observations of affect, nonverbal and verbal behaviors	-Affect: Greater pleasure*** and alertness*** (Ta, Tb > C), more anger (Tb > Ta*, Tb > C**) -Nonverbal behaviors: Greater psychosocial task participation (Ta, Tb > C***), more general restlessness and eyes closed (C > Ta*, C > Tb**), more uncooperativeness (Tb > Ta*, Tb > C**), more aggression (Tb > C**), more positive touch behaviors (Ta, Tb > C***) -Verbal behaviors: more very negative verbal behaviors (Tb > Ta**, Tb > C***), more very positive verbal behaviors (Ta > Tb, C***), more positive verbal behaviors (Ta, Tb > C***, Tb > Ta**), more nonverbal responses (C > Ta, Tb***)	Moderate Yes
Leisure and social activities individualized based on self-identity						
Cohen-Mansfield et al. (2010a)	RMC (111)	-Individualized activities matched to self-identity and other non-individualized activities, involving engagement through live social stimuli, simulated social stimuli,	85.4; 80.2; severe; NHs, USA (participants with agitated behaviors among 193 participants)	Agitation (total, verbal, and physical agitation; ABMI)	-Decreased overall agitation in all stimuli** except for manipulative stimuli, decreased physical agitation in all stimuli** than baseline -Significantly less agitation : live	Moderate No

		manipulative stimuli (e.g., squeeze ball, puzzle, building blocks), work/task-related, music, and reading materials; 3 weeks -BL: usual care			social stimuli > self-identity stimuli > manipulative, simulated stimuli	
Cohen-Mansfield et al. (2010b)	RMC (193)	-Individualized activities related to past/ present interests in art, music, babies, pets, reading, television, and office work -3 weeks (four stimuli per day)	86; 78; moderate to severe; NHs, USA	Engagement (duration, attention, attitude ; OME)	<p><i>Past preference for music</i></p> <p>-Music stimuli > non-music stimuli: duration***, attention***, and attitude***</p> <p>-Participants with past preference for music > those without past preference for music: duration*, attention*, and attitude* when presented with music stimuli</p> <p><i>Present preference for music</i></p> <p>-Music stimuli > non-music stimuli: duration*, attention***, and attitude***</p> <p>-Participants with present preference for music > those without present preference for music: duration***, attention***, and attitude** when presented with music stimuli</p> <p><i>Present preference for art</i></p> <p>-Coloring stimuli > non-coloring stimuli: duration***</p> <p>-Participants with</p>	Weak No

					<p>present preference for art > those without present preference for art: duration***, attention*, and attitude** when presented with coloring stimuli</p> <p><i>Past preference for pets</i></p> <ul style="list-style-type: none"> -Pet stimuli (a real dog) > non-pet stimuli: attention*, and attitude*** -Participants with past preference for pets > those without past preference for pets: duration* when presented with pet stimuli <p><i>Present preference for pets</i></p> <ul style="list-style-type: none"> -Pet stimuli > non-pet stimuli: attention** and attitude*** -Participants with present preference for pets > those without present preference for pets: attention* when presented with pet stimuli <p>-Residents with current interests in music, art, and pets were more engaged by stimuli matched to interests than residents without these interests.</p>	
Cohen-Mansfield et al. (2010c)	RMC (193)	- Individualized activities matched to self-identity and other non-	86; 78; moderate to severe; NHs, USA	Engagement (duration, attention, attitude ;	Self-identity stimuli > non-individualized comparison stimuli	Weak No

		individualized activities (e.g., engagement through work-related, gender-related, and comparison stimuli) -3 weeks		OME)	in duration***, attention***, and attitude***	
Cohen-Mansfield et al. (2011)	RMC (193)	- Individualized activities matched to self-identity and other non-individualized activities (e.g., engagement through live social, simulated social, manipulative, work/task-related, music, and reading stimuli) -3 weeks	86; 78; moderate to severe; NHs, USA	Affect (pleasure, interest, negative affect; LMBS)	-Self-identity stimuli > non-individualized stimuli (except live social stimuli) in pleasure*** and interest*** -Non-individualized music stimuli > BL***, but lower levels of pleasure and interest than other stimuli	Moderate No
Leone et al. (2012)	RMC (40)	Engagement through objects (stimuli) tailored to interests in 4 categories of leisure, family, work-occupation and personal, and objects in "not interested" category, with and without guided interaction with a therapist; 15min per stimulus (n = 2) of each category (5×(15 min×2)) over 2 weeks	85.4; 72.5; mild to severe; NHs, France	Engagement (duration, attention, attitude ; OME)	-Significantly higher scores of duration, attention, and attitude in categories of interest compared to "non-interested" category - Guided > Non-guided: Duration of engagement in three categories of interest (leisure***, personal**, work**), but not in categories of family and "not-interested" -Guided > Non-guided in participants with apathy: Duration of engagement in	Strong Yes

					categories of leisure* and personal*	
Politis et al. (2004)	RCT (36)	-Ta: Standardized, structured activity in which a participant chooses an activity among five types of activity in the kit (geography, fun foods, animals, vegetables, and musical instrument) for mental stimulation/ reminiscence (n=18); 30 min. x 3 times per week x 4 weeks -C: Unstructured, personalized leisure and social activities based on interests (n=18)	84; 83.3; moderate to severe; dementia-specific LTC, USA	Apathy (NPI), behavioral disturbance (NPI-total), quality of life (ADQRL), participation, cueing, and enjoyment in routine daily activities (CRAI)	-T = C -Ta > BL in total NPI* -C > BL in NPI-apathy**, total NPI*, ADQRL*	Moderate No
Music listening activities individualized based on music preference						
Gerdner (2000)	RMC (39)	-T: Listening to recorded individualized music tailored to music preference (30 min. x twice per week x 6 weeks) -C: Listening to classical relaxation music	82.6; 76.9; severe; LTC, USA	Agitation (modified CMAI)	-T > C: Reduction in agitation*** during (for 30 minutes) and following intervention (for 30 minutes) -T > BL*** during and following intervention - C > BL only during the final 10 minutes of classical music** and during the first 10 minutes after classical music*	Moderate No
Gerdner (2005)	Mixed methods/ SSD (8)	Listening to recorded individualized music tailored to music preference (30 min. x daily x 4 weeks prior to peak	83.3; 100; moderate to severe; skilled care facility, USA	Agitation (modified CMAI, AVAS)	Significant reduction in agitation during the presentation of music*** compared to pre-intervention score,	Moderate No

		agitation time)			with an overall reduction in agitation on day shift during weeks 1-8*** and on evening shift during weeks 5-8*	
Guétin et al. (2009)	RCT (30)	-T: Listening to recorded individualized music tailored to music preference (n=15) ; 20 minutes per week for 16 weeks -C: Reading and rest (n=15)	86.1; 73.4; mild to moderate AD; NH, France	Anxiety (HAS), depression (GDS)	-T > C: Reduction in anxiety at week 4**, 8***, 16***, 24*** , in depression at week 4*, 8**, 16**, 24**	Strong Yes
Janata (2012)	RCT (38)	-T: Listening to recorded individualized music tailored to music preference, listening history, age, ADLs, where they grew up, and the time of day for appropriate tempo, instrumentation, and presence of vocals (n= 19); 4 times/ several hours per day for 12 weeks -C: Usual care (n= 19)	81.3; 65.8; severe; ALF, USA	Agitation (CMAI), depression (CSDD), behavioral disturbances (NPI)	-T = C -T, C > BL: Reduction in agitation***, depression***, and overall behavioral disturbances***	Moderate according to EPHPP Quality assessment tool, but weak due to bias No
Park & Pringle Specht (2009)	SSD (15)	T: Listening to individualized recorded music based on music preferences (30 min. x two times per week x 2 weeks prior to peak agitation time)	83.4; 73; severe; home, USA	Agitation (modified CMAI)	Significant reduction in agitation* during the intervention period compared to baseline and post-intervention periods	Moderate Yes
Sung et al. (2006)	QNC (57)	T: Listening to individualized recorded music based on music preferences (n=32); 30 min twice a	No info about age, gender, and stages; LTC, Taiwan	Agitation (CMAI)	T>C* in overall agitation, T>C*** in physically non-aggressive behaviors	Weak No

		week for 6 weeks C: Usual care (n=25)				
Sung et al. (2010)	QNC (52)	T: Listening to individualized recorded music based on music preferences (n=29); 30 min in mid-afternoon twice a week for 6 weeks C: Usual care (n=23)	80.1; 44.2; moderate to severe; LTC, Taiwan	Anxiety (RAID)	T > C** at 6 week	Moderate Yes
Social activities individualized based on life experiences and past memories:						
(a) Individualized simulated presence therapy						
Camberg et al. (1999)	RMC (54)	-SPT audiotaped by family member (75%) or staff -Placebo audiotape: a recording of a person reading emotionally neutral articles from the newspaper (non-individualized, non-interactive) -Usual care -At least twice a day whenever the person exhibited an agitated or withdrawn behavior, each continued for 17 days over a 4-wk period and a 10-day washout period)	82.7; 77.2; severe; NHs, USA	-Daily staff observation log by blinded staff (agitation, withdrawal), and weekly staff survey (agitation using the CMAI, mood and interest using the MOSES)	- Staff observation log: SPT > placebo, usual care in agitation*** and withdrawn behaviors*** -Staff survey: SPT > placebo**, usual care*** in interest (MOSES)	Strong No
Cheston et al. (2007)	SSD (6)	-SPT (B) audiotaped by spouse -Baseline conditions (no intervention/usual care): A1 (before intervention) and A2 (after the intervention) -21 periods of intervention and baseline conditions	83.3; 83.3; moderate to severe; NHs or hospital; England	Observation of distressed (e.g., asking or seeking to go home, hand-wringing) and pro-social (e.g., initiating positive interactions, talking	Significant reduction in distressed behaviors* during SPT(B) compared to A1 and A2	Weak No

		(No information on duration and content of the SPT)		calmly or happily) behaviors using the PRS		
Cohen-Mansfield & Werner (1997)	RMC (32)	- Ta: SPT videotaped by family member (87.5%) or surrogate person -Tb: Preferred music -Tc: One-to-on social interaction -C: Usual care (Each treatment: 30 min. for 2 weeks with a wash-out week)	86.8; 81.3; severe; NHs, Israel	Verbal agitation (tape recordings, standardized observations using the SBMI, and staff ratings using the CMAI)	Ta,Tb, Tc > C*** during intervention	Moderate No
Garland et al. (2007)	RMC (30)	- SPT audiotaped by family member -Preferred music -Placebo (neutral audiotape: a reading from a horticultural text) -Usual care (Each treatment : 15 min. once a day for three days over 3 weeks with a two-day washout period)	79; 63; severe; NHs, Australia	Observation of target behaviors (verbal and physical agitation categorized using the CMAI)	-Physical agitation: SPT > placebo**, usual care**; music > usual care* during intervention; improvements during SPT, placebo, music maintained after 15 minutes - Verbal agitation : SPT, placebo > usual care* during intervention; improvements during SPT and placebo maintained after 15 minutes	Strong No
Miller et al. (2001)	OPP (7)	-SPT audiotaped by family member when the resident displayed an agitated behavior (28 SPT sessions of 7 participants)	84; 85.7; moderate; LTC, USA	Observation of behaviors associated with agitation using 4 items of the HRS including language-conversation , social interaction,	Significant improvement* in two items of HRS (social interaction and attention awareness)	Weak No

				attention-awareness, and spatial orientation		
Peak & Cheston (2002)	SSD (4)	-SPT (B) audiotaped by spouse -Baseline conditions (no intervention/ usual care): A1 (before intervention) and A2 (after the intervention) -No information on duration of SPT, 23 SPT sessions of 4 participants	74.3; 75; moderate to severe; hospital, UK	Observation of positive and negative behaviors using a modified PRS with 'anger' added	Significant reduction in distressed behaviors and increase in positive behaviors during SPT(B) compared to A1 and A2 in two participants having a secure attachment history	Weak No
Woods & Ashley (1995)	OPP (9)	-SPT audiotaped by established caregiver (twice a day in the scheduled time when behavior problems of each participant were anticipated) -A total of 425 episodes of target behaviors over the 2-month observation period	82; 77.8; moderate; NHs, USA	Observation of target behaviors categorized using the DBRS, including two rating scales, one for disruptive behaviors (e.g., aggression, agitation, wandering), one for behaviors of affect (social isolation/wit hdrawal)	Significant reduction*** in disruptive behaviors and social isolation	Moderate No
Specific types of social activities individualized based on life experiences and past memories: (b) Individualized reminiscence therapy						
Chung (2009)	OPP (49)	Sharing positive and pleasurable life experiences from adolescence and adulthood with two to three youth volunteers and creating a	79; 80; mild; day care centers, Hong Kong	Quality of life (QoL-AD), cognition (MMSE), depression (GDS)	Significant improvement in QoL-AD (mean change = - 1.91; 95% CI = -3.18, - 0.64), GDS (mean change = 1.86; 95% CI = 0.92, 2.80)	Weak No

		personalized life story book (1.5 hours, weekly, 12 weeks)				
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OPP: one-group pretest-posttest design, QNC: quasi-experimental/non-equivalent control group design, RCT: randomized controlled trial, RMC: repeated measures with randomized crossover, SSD: single subject design AD: Alzheimer’s disease, ALF: assisted living facility, BL: baseline, BPSD: behavioral and psychological symptoms related to dementia, LTC: long term care facilities, NHs: nursing homes

ABMI: Agitation Behavior Mapping Instrument, ADQRL: Alzheimer’s Disease Related Quality of Life scale, AVAS: Agitation Visual Analog Scale, CMAI: Cohen-Mansfield Agitation Inventory, CRAI: Copper Ridge Activities Index, CSDD: Cornell Scale for Depression in Dementia, DBRS: Disruptive Behaviour Rating Scale, DMPT: Dementia Mood Picture Test, GDS: Geriatric Depression Scale, HAS: Hamilton Anxiety Scale, HRS; Haycox Rating Scale, LMBS: Lawton’s Modified Behavior Stream, MDS: Minimum Data Set, MMSE: Mini- Mental State Examination, MOSES: Multi-dimensional Observation Scale for Elderly Subjects, MPES: Menorah Park Engagement Scale, NPI: Neuropsychiatric Inventory, OME: Observational Measurement of Engagement, PGCARS: Philadelphia Geriatric Center Affect Rating Scale, PDS: Passivity in Dementia Scale, PRS: Positive Response Schedule for Severe Dementia, QoL-AD: Quality of Life-Alzheimer’s Disease, RAID: Rating Anxiety in Dementia, SBMI: Screaming Behavioral Mapping Instrument,

*p<0.05, **p<0.01, ***p<0.001, NS= not significant

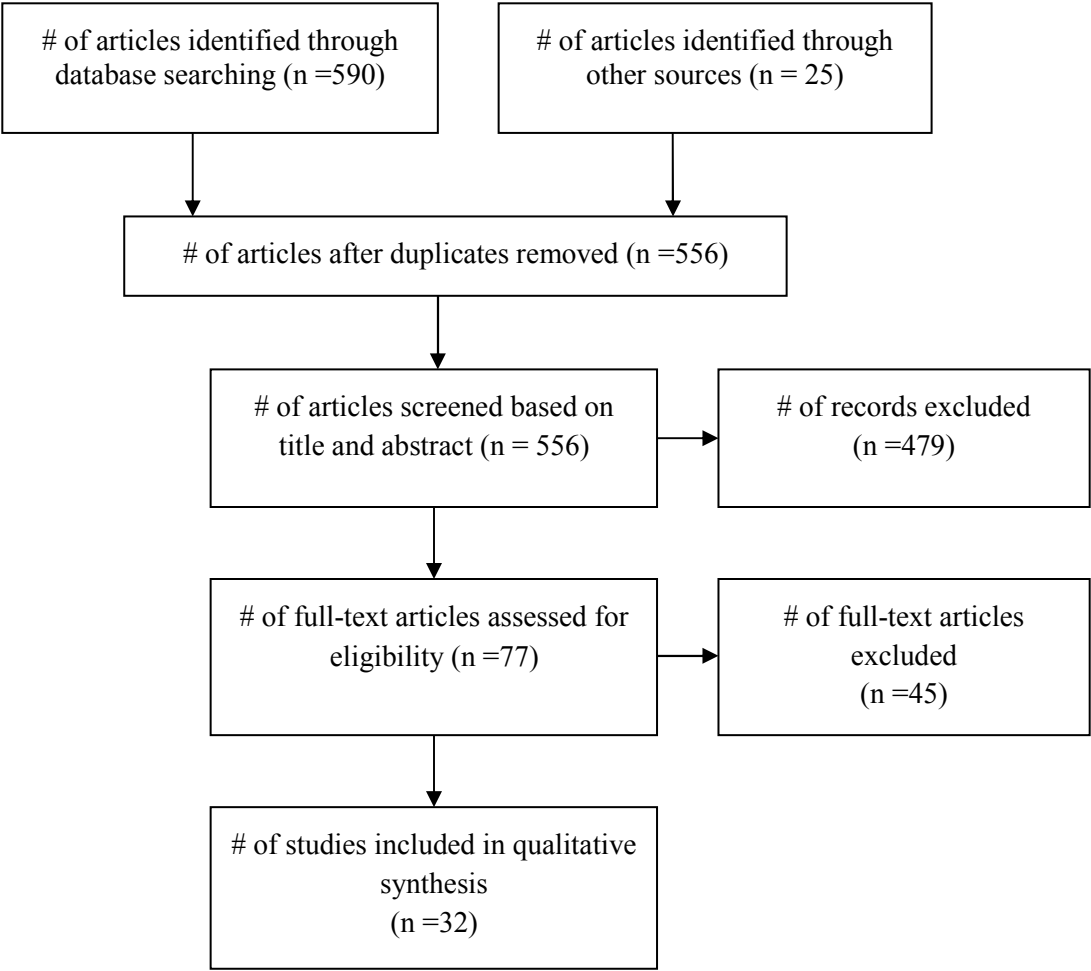
Table 3. Quality Assessment of the Included Studies

Authors	Selection Bias	Study Design	Confounders	Blinding	Data Collection Methods	Withdrawals & Dropouts	Global Rating
Cohen-Mansfield et al. (2007)	W	S	S	M	S	S	M
Cohen-Mansfield et al. (2012)	W	S	S	M	S	S	M
Cohen-Mansfield et al. (2006)	W	S	S	M	S	S	M
Gitlin et al. (2008)	M	S	S	M	S	S	S
Fitzsimmons & Buettner (2002)	M	S	W	M	S	S	M
Kolanowski et al. (2005)	M	S	S	M	S	S	S
Kolanowski et al. (2011)	M	S	S	S	S	S	S
Mowrey et al. (2013)	W	M	W	M	W	M	W
Richards et al. (2005)	M	S	W	M	S	S	M
van der Ploeg et al. (2013b)	M	S	S	M	S	M	S
Van Haitsma et al. (2013)	W	S	S	M	S	S	M
Cohen-Mansfield et al. (2010a)	W	S	S	M	S	M	M
Cohen-Mansfield et al. (2010b)	W	S	W	M	S	M	W
Cohen-Mansfield et al. (2010c)	W	S	W	M	S	M	W
Cohen-Mansfield et al. (2011)	W	S	S	M	S	M	M
Leone et al. (2012)	M	S	S	M	S	S	S
Politis et al. (2004)	M	S	W	M	S	S	M
Gerdner (2000)	M	S	S	M	S	W	M
Gerdner (2005)	M	M	W	M	S	S	M
Guétin et al. (2009)	M	S	S	S	S	M	S
Janata (2012)	W	S	S	S	S	S	M

Park & Pringle Specht (2009)	M	M	W	M	S	S	M
Sung et al. (2006)	M	S	W	M	S	W	W
Sung et al. (2010)	M	S	S	W	S	S	M
Camberg et al. (1999)	M	S	S	M	S	S	S
Cheston et al. (2007)	M	M	W	M	S	W	W
Cohen-Mansfield & Werner (1997)	M	S	S	M	S	W	M
Garland et al. (2007)	M	S	S	M	S	S	S
Miller et al. (2001)	M	M	W	M	S	W	W
Peak & Cheston (2002)	M	M	W	M	S	W	W
Woods & Ashley (1995)	M	M	W	M	S	S	M
Chung (2009)	M	M	W	W	S	S	W

*M: moderate, S: strong, W: weak

Figure 1. Flow of Studies through the Review Process



Appendix 4: Raw Data/ Coded Data

Interview 1

I: Interviewer

P: Person with dementia

S: Spouse of the person with dementia

- Descriptive comments: focused on describing the content of what the participant has said, the subject of the talk within the transcript (normal text)
- Linguistic comments: focused on exploring the specific use of language by the participant (italic)
- Conceptual comments: focused on engaging at a more interrogative and conceptual level (underlined)

Note: This couple tends to work as a team in the second part of the interview (alternating in talking most of the time)

Emergent Theme	Original Transcript	Exploratory Comments
	<p>I: I am a researcher of the PAIRS program that pairs people with early stage Alzheimer’s and medical students for social gatherings at the University of Kansas Medical Center. You participated in the PAIRS program from September, 2013 to April, 2014. I really appreciate that both of you agreed to participate in the study. Your responses are confidential and will not be shared with other participants in the program. Your name is not used for this audio recorded interview by assigning you a study number. This interview is to know about your experience of participation in the PAIRS program and your thoughts about its’ impacts on you and your daily life. There are no right or wrong answers. The interview will take about between 30 minutes to 1 hour. Before we start the interview, could you tell me activities you or your spouse did with the medical student during the PAIRS program period? We will talk about the details later, so I just... so please tell me activities briefly.</p>	
<p>Strategy of PwD in understanding questions</p>	<p>P: In overall, in overall view of the activities that the PAIRS... man, person in</p>	<p><u>He seems to understand my question pretty well already.</u></p>

<p>Participated by himself No involvement of spouse in activities Compatible</p>	<p>this case was a man... I: yeah P: and what we participated in? I: yeah, so for example, you went to bowling, for example, so act... any activities you did with the medical student. P: sure I: yeah</p> <p>S: uh. He participated by himself. I didn't participate in any group events because they were compatible and they were doing what each one...</p>	<p><u>To make sure if he understands the question? or</u> <u>His strategy to save the time for remembering things? His strategy to hide his difficulties in taking time in remembering things?</u></p> <p>He participated by himself No involvement in any activities They were compatible</p>
<p>No involvement of spouse in scheduling</p>	<p>I: Did you.. Did you drive him to any place? S: No. No. I: so he came to the house? S: They arranged whatever.</p>	<p>They arranged whatever (no involvement)</p>
<p>Sharing with spouse after meeting</p>	<p>I: So, you have no idea what they did. Okay. so S: He told me later. Whatsoever was... P: If you want an overview, sure.</p>	<p>He talked about what he did with the med student to his wife <u>To get the attention/attract the interviewer's attention to him rather than his wife?</u></p>
<p>Spouse's strategy</p>	<p>S: but the information all from him.</p>	<p><u>To show the interviewer her respect on him/his function or to help him get the attention?</u></p>
<p>I drive Comparison with other people in the group Going to meeting at AA twice a week</p>	<p>P: We did several things and I drive. Some Alzheimer's patients do not drive. I know my participation in programs now every Tuesday and Friday. It takes six hours from 9 to 3 and we do that twice a week on Tuesdays and Fridays. So I am in touch with other Alzheimer's patients. In this particular group there is about fifteen. And I would guess at least half of them do not drive. They have their caretaker..caregivers take care of them. Uh, with my pairs the individual who is a wonderful man named Scott. Scott couple and I went to the backstage tour of the art performing art center. We went to the Thomas Benton home it was a party there. The relationship to 125th anniversary of Tom Benton. uh,</p>	<p><u>Saying that he can still drive unlike the other people in his group seems to be important to him rather than answering the interviewer's question. Is it because that he wants to be looked differently from the people with Alzheimer's whose dementia progressed farther than him? Why does he make comparisons with them rather than saying that he can drive? Or, just to prevent a prejudice that people with Alzheimer's do not drive?</u></p>
<p>Explanation about group Wonderful man Remembers his pair's name and activities</p>	<p>to 125th anniversary of Tom Benton. uh,</p>	<p>Remembers his pair's name and activities/places they went to</p>

<p>Will for remembering things Strategy of PwD in remembering things</p> <p>Self-identity Past activities (volunteering)</p>	<p>we went to a couple of plays together. uh. a little theater, uh a little theater on Broadway, such as Unicorn theater. We went to a play rehearsal at a different theater possibly the Metropolitan also known as MET.. Let's see. I think we met to eat together a couple of times at restaurants. And I.. I try to recall. I will. We went to a concert. Yes. I have tickets to symphony. And the... I was invited. It was no cost involved for Scott nor myself for the symphony. Because I am a member of the symphony association...it's called Kansas City Symphony Association. I support if not financially was volunteer work. So I do volunteer. I did volunteer work until I found it I wanted spending time doing other things. So I dropped volunteer at the Kansas City Symphony. So that's a brief interview, overview. Okay?</p> <p>I: That's great! Thank you so much. So, for the first part of the interview, I would like to hear only from you [looking at the person with Alzheimer's]. And then I will give both of you time to talk later. And because the interview has to be done in the same way for everyone, I'd like to hear from. from him without your involvement or help in his talks for the first part. [looking at the spouse] It's up to you if you wanna stay here or but if you wanna stay here but you should not talk for the first part. [the spouse gestured like zipping her mouth with her fingers] If you want to do something else and come back later, it's okay. So...</p> <p>S: I will be here. I: yes. That would be perfect. P: None, whatsoever. I: Ready for the stu.. interview? P: Happy to be of, help.</p>	<p>Wonderful man Activities: Backstage tour of the art performing art center, anniversary at the Thomas Benton home, plays/theatre, eating out, symphony</p> <p>Will for remembering things (I try to recall. I will) Remembers that they went to a concert not by remembering that moment but by remembering tickets to symphony; <u>using cue, his strategy?</u> A member of the symphony association Used to volunteer at the symphony association but dropped volunteer to spend time doing other things</p>
<p>Happy to help research</p>	<p>I: Thank you so much. Could you tell me about your experience of participating in the PAIRS program?</p>	<p>Happy to help (by participating in the study)</p>
<p>Emotionally satisfying Personally interesting</p>	<p>P: um...I believe it was ...emotionally satisfying and um...personally interesting.</p>	<p>Emotionally satisfying, personally interesting</p>

<p>A fine companionship with his pair</p> <p>Enjoyed the sociability Easy to participate, to begin a new social relationship Easy</p> <p>Found sociability because his pair was extremely intelligent and interesting</p> <p>Interesting to meet a person who has academic training in medicine and experience (different from himself)</p> <p>Boost his pride/self-esteem: Being part of the experiment, nice and satisfying to be chosen, fascinating, so it was easy to adjust</p> <p>Pleased to feel that he was contributing to the medical student's learning</p>	<p>And I found...um... in addition to...a fine companionship... with Scott... I... found it the challenging...Let's say to... come up with some ideas with two of us to participate together...so um... it was no problem with me personally because I enjoyed the sociability... other people to begin with...So it was easy.</p> <p>I: So... you said that you found some emotionally satisfying feelings...</p> <p>P: Uh-huh. Yes. That I would think so.</p> <p>I: Because you found some sociability to begin with? Can you tell me more about that...what you mean by...</p> <p>P: I think because he...the person with whom I was paired with...was... extremely intelligent and um...most of I...I don't think to myself... um...how would you say? not intellectually but...from academic standpoint... from academic standpoint...um...it was interesting because I...I have no academic training...of the profession that for example you are into... you and I no... um...experience... so it was interesting because being part of the experiment... I kind of find...ha ha...um... so...egotistic...from ego standpoint...it was neat... it was kind of nice to be chosen...you know... so... it was satisfying to that sample...someone chose me to examine me...you know... who would find that... more than interesting... somewhat fascinating... so it was easy to adjust.</p> <p>I: so...from my understanding, you...um...you are saying that you had...because the...Scott was...you feel that Scott is more intelligent than you...you feel that you are...you feel that you are part of the area?</p> <p>P: I was...I was... I was pleased to feel that I was contributing...</p>	<p>A fine companionship with his pair</p> <p><u>Did he have difficulties/challenges in other social contexts, but not in this social context (PAIRS)?</u></p> <p>Enjoyed the sociability Easy to participate, to begin a new social relationship</p> <p>Found sociability because his pair was extremely intelligent and interesting</p> <p>Interesting to meet a person who has academic training in medicine and experience (different from himself)</p> <p>Boost his pride/self-esteem: Being part of the experiment, nice and satisfying to be chosen, fascinating, so it was easy to adjust</p> <p>Pleased to feel that he was contributing to the medical student's learning</p>
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<p>Very willing to participate in the program for any contribution whatever way he could and med student's learning (rounded education by hands-on experience)</p> <p>Pair's personality and attitude (So easy because the pair was so outgoing and the pair just knew what to say and respond; the pair made it so easy for him to establish that relationship to start with)</p> <p>A good person Hope he contributed to his pair's learning</p> <p>Expectation (to contribute to medical students' learning)</p> <p>A two way partnership Comfortable Shared personality</p>	<p>I: oh, so...contributing to what?</p> <p>P: from his knowledge of...what he was... what he was...um...supposedly... we were paired up... I presumed for him to learn...so from that standpoint I was very... willing...to participate... in the program and um... contributing whatever way I could...to giving him...um...rounded...you know...the impression... what kind of individuals he was dealing with...but it was so easy because he was so outgoing and um...he just knew...he just knew what to say and respond...and just a good person...He made it so easy for me to establish that relationship to start with...you know...it was Scott's fault...If it was succeeded in everything it was because of Scott.</p> <p>I: So... you...you said that... you were very happy to... contribute to... for his learning... process.</p> <p>P: I think so. I hope so. I hope so.</p> <p>I: Was it your expectation to...from the PAIRS program? So did you...did you decide to participate in the program because you wanna contribute to the medical students' learning?</p> <p>P: Uh-huh.</p> <p>I: Was there any other expectation for you?</p> <p>P: I think that's a nice...accurate way to put it... I was prepared and um... I was very happy to... and um...I think you covered it just fine...what you said... I agree with you.</p> <p>I: So you said that... you said that Scott was very outgoing and he knew that...what to...what to...how to respond... to you... so could you tell me more about him? How was the relationship with him? or...</p> <p>P: um...I pretty well mentioned it is... best I could... um...that um...it was a two way partnership...you know...and</p>	<p>Very willing to participate in the program for any contribution whatever way he could and med student's learning (rounded education by hands-on experience)</p> <p>So easy because the pair was so outgoing and the pair just knew what to say and respond; the pair made it so easy for him to establish that relationship to start with</p> <p><u>Did he have any experiences in which he had challenges in establishing new relationships due to his dementia?</u> <u>What does "he just knew what to say and respond" mean to him? Is this related to the pair's reaction and attitude about his diagnosis and symptoms or to the pair's sociable attitude (personality)</u> Just a good person</p> <p>Participated in the program for contributing to the medical students' learning</p> <p><u>Did he really have no other expectation?</u></p> <p>a two way partnership Comfortable Because both are outgoing</p>
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<p>(Because both are outgoing) Expression of self/ self-identity: an outgoing person</p> <p>Talks about others' experience in group</p>	<p>um...there was nothing uncomfortable about it at all. And um...I don't know it's because whether I am also an outgoing individual. We may have some participants in the PAIRS program... who are either less reluctant or less...um...eager to participate...but the people... I no longer to my group...one woman in particular...from North of the river and from a little what I learned about her...participant...when we exchange... some information ...um...she also had a very very wonderful African American lady...that... she was paired with... and she had enjoyable experience as well as I did.</p> <p>I: Sounds great. um.. before we start the actual interview, I asked some activities you did with the...with Scott. P: Sure. I: You mentioned that you went to...art center...and theaters... and some concerts... and you ate some foods at the restaurant. So... what was the best part? P: How was the best part of you? I: What was the best part of the program? You mentioned several activities and what was fun for you?</p>	<p>Expressing about self/ self-identity: an outgoing person</p> <p>Talks about some people in the PAIRS program who are less motivated</p> <p>Talks about one lady who had enjoyable experience as well as he did</p>
<p>Difficulty in understanding the question</p>	<p>P: I am not sure that I understand the question. S: What was fun... What did you like the best? P: Oh. S: of activities...</p>	<p>Difficulty in understanding the question</p>
<p>Enjoyed all the activities he did with his pair</p> <p>His strategy in checking his understanding of question</p> <p>Easy to participate Impact of dementia (I am missing the question again)</p>	<p>P: Oh. Everything I say. right? S: Yeah.</p> <p>P: I appreciate the question. I am just trying to... be sure that I knew in my head...that I could answer it accurately. um...no they...It was a...I mentioned...It was easy to participate... and...I am missing the question again... um...It was...the things we did that I mentioned...you mentioned that if I want to elaborate on them later, sure...It was... It was...It was my suggestions most of the</p>	<p>Enjoyed all the activities he did with his pair</p> <p><i>His strategy in making sure the question?</i></p> <p>Easy to participate Impact of dementia (I am missing the question again)</p> <p>He suggested activities most of the time for what they did</p>

<p>He suggested activities most of the time</p> <p>They did the things that he enjoys Did not go to the movie although he enjoys movies</p> <p>They did things that they could both participate in and get a reaction Impact of dementia (doesn't remember the artist's name) Frustrated when not remembering things? No hesitation in directly saying that he has Alzheimer's Consideration of his pair's interest (He chose and they went to an art gallery of an artist whom his pair is familiar with and who comes from the west-coast like his pair) Went to a theater that he is familiar with A play rehearsal which he enjoys: he thinks his pairs also found interesting</p> <p>Good memory</p> <p>Activities based on his interests His pair did not suggest activities Did normal things for him (his leisure and/or social activities he usually do or he likes to do)</p>	<p>time for what we did.</p> <p>I: Oh, yeah.</p> <p>P: It was...It was a...um...because he said. you know...spend time together...so, I did the things that I enjoy. We did not go to the movie, for example. Because it would be...not dull I enjoy motion pictures. We can discuss the pictures, but for some reason... we did things that we could both participate in...get a reaction. Now that I remember we went to another...it wasn't Salvador Dali, but it was a...a well-known artist, the name escapes me now... because of my Alzheimer's [an increasingly louder voice]. And um... we enjoyed...he was familiar with the artist and who's a traveling exhibit that was going to another city, then to the West-coast. He was going to alert his sister who lives in the West-coast. Scott is from the West-coast, my paired person. so...I am just...I selected the art gallery and... we went to a theater... that I am familiar with... and um...we went to a play rehearsal which I enjoy... and um... the background you can sit there the audience watch the director... of the play tell the... participants some of the play what to do. and um...Scott found that... interesting. You know...and same thing we had a tour of the performing art center which was at that time was still fairly new, year two only...having been established here in Kansas city. So...I was invited to a tour... I think that was from the Kansas City Association who offered this tour, background tour...the performing art center. So we did that...and um...and it was mostly my suggestion...what we did because we did things that I enjoyed. So, he didn't say we go to bowling... we go to a...what else people do...go to a movie or have dinner. you know. We just did normal...normal things...for me...That were normal things.</p> <p>I: So, these activities were chosen by you</p>	<p>They did the things that he enjoys Did not go to the movie although he enjoys movies</p> <p>They did things that they could both participate in and get a reaction</p> <p>Impact of dementia (don't remember the artist's name) <u>Feeling a little bit angry or frustrated about not remembering the name?</u> No hesitation in directly saying that he has Alzheimer's He chose and they went to an art gallery of an artist whom his pair is familiar with and who comes from the west-coast like his pair</p> <p>Went to a theater that he is familiar with A play rehearsal which he enjoys: he thinks his pairs also found interesting</p> <p>A tour of the performing art center Good memory (remembering details pretty well)</p> <p>They did things they he enjoys (his interests) The pair did not suggest activities Did normal things for him (his leisure and/or social activities he usually do or he likes to do)</p>
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<p>He likes looking at arts</p> <p>Likes photography and art gallery</p> <p>He go to the art gallery often</p> <p>Meet/socialize with other people at the galleries</p> <p>He has been told that people with Alzheimer's should keep busy and he use this as an excuse for his wife</p> <p>Does not like activities he does in sitting</p> <p>Belong to a leisure-based social group (He and his wife belong to a group of people who like movies)</p> <p>Good memory</p> <p>Thinks this gathering helps him to keep his mind busy</p> <p>Self-awareness of diagnosis and no hesitation in describing himself as a person with Alzheimer's</p>	<p>because you...</p> <p>P: interests</p> <p>I: Because you...you have interests in these activities. It sounds like you are a very artistic people...person. I guess. So...</p> <p>P: Thank you. I appreciate that.</p> <p>I: Did the activities have any special meaning to you?</p> <p>P: Yeah. I... We went to...we went to like this winery cheese opening, you know, on the first Friday. So, yes. I am...I am not an artist but I appreciate arts...looking at arts. You know. I cannot afford expensive arts. So...but I like photography....you know...and um...art gallery so I go to art gallery often Mrs. Miller can confirm. And um...also from social standpoint, I meet other people at the galleries. So, it keeps me...that I've been told Alzheimer's patients should keep busy and I use this as an excuse for Mrs. Miller. And say oh, I've got to, it will help my mind. you know. I need to be busy because it feels keep my mind fresh. I don't...do crossword puzzles, so... I don't like sitting...play cards, or, do bridge. I admire people who play bridge...and also chess. But if I guess if I really started it out earlier in my career eighty ninety years ago and if I had learned chess fifty years ago, I would be interested in chess. So...I belong to a group of motion picture people who like movies and we meet every month. And we enjoy, we pick someone the host. We meet at homes. And um...there...this has been going on for many years and the host picks a movie. It happened to be a Swedish movie last month. And um...we see the movies individually or together if we want to go with...a friend... Mrs. Miller and I would go. And then, we meet at someone's home. We have appetizers and we have...the dinner and then... we talk about the movie. And this is very nice... we criticize the movie or we complement it or we talk about the director or the</p>	<p>Based on his interests</p> <p><u>He seems to be very polite or sociable</u></p> <p>Went to winery cheese opening</p> <p>He appreciate arts; likes looking at arts</p> <p>Likes photography and art gallery</p> <p>He go to the art gallery often</p> <p>Meet/socialize with other people at the galleries</p> <p>He has been told that people with Alzheimer's should keep busy and he use this as an excuse for his wife</p> <p>Does not like activities he does in sitting</p> <p>He and his wife belong to a group of people who like movies (meet every month for many years to talk about movies and socialize)</p> <p>Good memory (remembers the movie chosen last month)</p> <p>Very nice</p> <p>Thinks this gathering helps him to</p>
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<p>Movies are great interests to him; loves going to the movies</p> <p>He never suggested going to the movie with his pair because of no active participation between two</p> <p>Preferred to go to the galleries and museum with the pair</p> <p>Happy to help research (doing his best)</p> <p>His strategy in understanding questions</p> <p>Enjoyed</p> <p>Easy to participate because of pure joy of certain things and feeling comfortable (not challenging because he chose activities that are familiar with him based on his interests)</p> <p>His pair was so accommodating Feelings of empowerment? His pair was the best person</p>	<p>people who in the film. So, it is another nice way to keep your mind busy...which we are supposed to do...we are patients...of Alzheimer's. So... motion pictures are great interests to me and I love to go to the movies. However, with Scott, I never picked film. I think we talked about film, but we didn't go to one. Because it's just two hours of static sitting there watching the film. So, we couldn't discuss after it so happened that I preferred to go to the galleries, or museum, on the case of Thomas Hart Benton, his home and his work on the wall...you know... things like that. So... I will be happy to ask if I can explain myself well. I will try. If I talk too much, it's your fault.</p> <p>I: Ha ha... It's okay. um...So, how do you feel about participating in the PAIRS program?</p> <p>P: How I feel about? I: Yeah.</p> <p>P: um... I enjoyed it. easy...easy to participate.</p> <p>I: What do you mean by it is easy to participate?</p> <p>P: Easy to participate? I didn't find it...I don't know. Mrs. Miller can possibly tell you... elaborate later because at certain times I can't express. um...the pure joy of certain things. [a louder voice] you know? But um...when I say easy, um...I don't know what else to say. I didn't find it uncomfortable...and um...it wasn't even challenging. Be nice to say, most challenging...I might say it was challenging because I was interested in what...where I go from here. But, he was so accommodating. You know? He was so easily...as a participant ... in the PAIRS program. They could have not chosen a better person in my opinion.</p> <p>I: So, do you mean that there... you</p>	<p>keep his mind busy Self-awareness of diagnosis and no hesitation in describing himself as a person with Alzheimer's Movies are great interests to him; loves going to the movies He never suggested going to the movies with his pair (they talked about film though) because of no active participation between each other while watching movies <u>He seems to like talking with the pair in particular; also because he already does in his movie club?</u> Preferred to go to the galleries and museum with the pair</p> <p><u>Recognize himself as a quite talkative person?</u></p> <p><u>Repeating/saying the question to save the time for thinking, help him understand the question better when repeating the question, or both?</u> Enjoyed</p> <p>Easy to participate because of pure joy of certain things and feeling comfortable (not challenging) – <u>not challenging because the activities are familiar with him?</u></p> <p>The pair was so accommodating (<u>Did he feel like that because the PAIRS program allows the person with Alzheimer's to choose the activities the person wants to do, so the pair did that way; respects opinions/thoughts of the person with Alzheimer's); empowerment</u></p>
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<p>A good match between him and his pair</p>	<p>mentioned that before he was...he knew that how to respond to your...to what you said? So, did you feel much comfortable because...this... Scott already know how to...?</p> <p>P: uh-huh. Yeah. I think they made a good choice with him and me.</p>	<p>Feels they were matched well; <u>They seem to be matched based on their personality based on what he said so far, but I wonder if he feels that they have shared interests.</u></p>
<p>Very comparable He thinks the pair seemed to sense the things that he was interested in doing and enjoys their time together (due to similar personality or the pair's attitude?) –not necessarily shared interests in arts A very pleasant relationship</p>	<p>I: Did you feel that Scott has a shared interest with you?</p> <p>P: Yes...Yes, he did. That's a nice question. um... yes... um...He is interested...seemed to...be very...comparable...and...he...he seemed to sense the things that I was interested in doing and...he certainly...we seemed to...he seemed to enjoy our time together. He would be best able to answer that question...you know... how he would find his relationship with me. You have to ask him. As far as I am concerned, it was a very pleasant relationship.</p> <p>I: I see. So, how do you think participation in the PAIRS program has affected you and your daily life?</p>	<p>He feels they are very comparable He thinks the pair seemed to sense the things that he was interested in doing and enjoy their time together; <u>It may be possible for him to think like that because of the pair's attitude or similar personality (not necessarily shared interests in arts)</u> A very pleasant relationship</p>
<p>No particularly significant effects on him and his life (Not particularly significant in the sense that there was no change)</p>	<p>P: Uh-huh...[a longer pause than before] I would say...that the...the affect as such... not particularly significant in the sense that...did anything to... um... change anything...um...all you can say...all I can say is it makes a person more aware that the risk such thing as Alzheimer's...and um...I am in what I call, what I've been told as early stage...um... and um... obviously I at the...my age...I learn something these meetings as I go to...this is the side...for you. You too already know. The older you are and you get this, the better off you are because you are not gonna live so long anyway. So, you don't have to suffer so many years if I were seventy years old...or sixty-five, and have Alzheimer's, you know, God knows... what my life would be like in ten years...but I don't project myself to living to a hundred, so chances are...my...my</p>	<p>Not particularly significant in the sense that there was no change</p> <p>It makes a person more aware that the risk of Alzheimer's: <u>Why is he saying like that? Is it because he talked about the risk of Alzheimer's with the med student?</u></p>
<p>His coping strategy</p>	<p>Learn something: this is the side for you – <u>seems to say like this in a positive way (accept the disease and enjoys the things he has and he can do now?)</u></p> <p>Feel relieved that he has got Alzheimer's in his old age (compared to seventy or sixty-five) and his disability with</p>	<p>Learn something: this is the side for you – <u>seems to say like this in a positive way (accept the disease and enjoys the things he has and he can do now?)</u></p> <p>Feel relieved that he has got Alzheimer's in his old age (compared to seventy or sixty-five) and his disability with</p>

<p>Such a natural event to participate in that he found it enjoyable and of interests because it was not challenging and the pair was so easily adaptable to anything he wanted to do</p> <p>A strong belief that the pair will be agreeable to anything he wants to do</p> <p>Not particular effects on his life because his life is basically continued, same way it was</p> <p>More aware of the fact that Alzheimer's is a growth industry</p> <p>My wife can tell you better</p> <p>Pleased that he was participating in the PAIRS program</p>	<p>disability with Alzheimer's will be limited by just how long the disease lasts and how long my physical...I may have a heart attack tomorrow and I am done. I am no longer interested to the PAIRS program. So, um...affected my life? is a good question. You know? I understand your questions... um...and... I don't mean to be difficult to find to answer them. But, um...it was...for me, such a natural...um... event to participate in... that I found it enjoyable...and um...of interests ...because... there was no...mental or... in my case no physical...thing to that I have to contend with...and the man was a... my pair was the... just so particularly...so...easily adaptable to anything I wanted to do. I think I even thought of going to a baseball game at one point and he would be agreeable to do that. I am interested in Kansas City Royal's fan. I don't know remember they were even playing at that time. But um...so, um...affected my life? ...I can't say either way. Another words of... my life is basically continued ...same way it was. Only I am more aware of the fact that it is a disease becoming... I call it... not popular but a um...growth...growth industry. I think Alzheimer's is a growth industry. You can put that down.</p> <p>I: Yep.</p> <p>P: ha ha.</p> <p>I: It sounds like Scott is... was...is a very nice person and you enjoyed talking with him and sharing your interests with him.</p> <p>P: Yeah.</p> <p>I: So, how did that make you feel?</p> <p>P: (Yeah~...) It's a... I understand the question. um... I can't say, maybe Mrs. Miller can tell you better... later when you want to...review some of things. I...I felt that...I felt rather...um...pleased... that the...I was participating in it...and um...I suppose you might say I was interested in learning...about it, but I don't know that</p>	<p>Alzheimer's will not be lasted so long</p> <p>No longer interested to the PAIRS program: <u>why is he saying like that because he thinks one time experience is enough for him?</u></p> <p>Such a natural event to participate in that he found it enjoyable and of interests because it was not challenging and the pair was so easily adaptable to anything he wanted to do</p> <p>A strong belief that the pair will be agreeable to anything he wants to do</p> <p>Not particular effects on his life because his life is basically continued, same way it was</p> <p>More aware of the fact that Alzheimer's is a growth industry <u>Based on what he said, he learns ways of living with Alzheimer's (coping through enjoying life while having Alzheimer's)? He feels self-growth as he go through the disease?</u></p> <p>I understand the question: <u>to make sure that what he says is from the total understanding about the question? (is he recognizing what the interviewer may anticipate from him but he does not think that way?)</u></p> <p>Pleased that he was participating</p>
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<p>Explanation about the PAIRS program</p> <p>We're: regarding himself as a part of the program/research (as a more active agent to discover the findings)</p> <p>We (people with dementia)</p> <p>Getting worse (the disease progression) is depressing Does not have signs of depression No negative effects on him (no depression or threatening feelings)</p> <p>Acknowledges that he can be eventually developing into a more severe case of the disease Disclosure to people and some friends about his diagnosis Coping (He realizes/accepts his changes in conversations due to Alzheimer's) Strategy: Thinks telling people his diagnosis helps people understand him better No hesitation in telling people his diagnosis, thinks there is no stigma about Alzheimer's</p>	<p>I...learned. I am trying to remember now because it's...I can blame Alzheimer's... to say that. What did I learned from the program...I have to think about that. Like I said, I learned it's...it's ongoing, and... many universities besides from Kansas... are involved in...in the research...and we're hoping to find some way of...of... not preventing it, but further less preventing it if that's possible, but lessening the...the effects of Alzheimer's... or... or... keeping it from... getting...you know what I am trying to say...um...the onset of Alzheimer's if you can delay the onset of Alzheimer's. I understand that that's good. Because we can all...you know... we...might have little dementia...quite... could...develop to something worse...and that depression...and things that nature. Fortunately, I haven't had any obvious signs of depression. But um... who knows? Maybe deep psychiatrist ...or Mrs. Miller to tell you. But um...certainly my experiences with the...Scott's... couple... had no signs of... leading me into depression about what we were doing... or the subject of the... of Alzheimer's. I didn't find it threatening...with me, it's not threatening at the moment, you know. I understand that I can be...eventually developing into a more severe case... of the disease. But um, I tell people and then some friends that I am an Alzheimer's patient. And I said that I want to tell you this in case I stop to talk off the wall and you wonder where I am going. You can understand I am an Alzheimer's patient, and I want you to be the first to know about it. So, I want to say to you that I have no qualms about telling people that I have Alzheimer's. It's no...no...no stigma... as far as I am concerned. I am happy to tell people. I know there are... from my meeting at this...the weekly meeting I go. There are people who are reluctant to bring the subject up...or bring it up with friends, or bring it up, you know, with whomever. And um... That's their...that's the way</p>	<p>in it Not sure if he learned from the program or not ; <u>He seems to think that I might expect for him to say that he feels differently (in a positive way) by participating in the program</u> <i>We're: regarding himself as a part of the program/research (as a more active agent to discover the findings)</i></p> <p><i>We (people with dementia)</i></p> <p>Getting worse (the disease progression) is depressing Does not have signs of depression</p> <p>No negative effects on him (no depression or threatening feelings)</p> <p>Acknowledges that he can be eventually developing into a more severe case of the disease He tells people and some friends that he has Alzheimer's He realizes/accepts his changes in conversations due to Alzheimer's Thinks telling people his diagnosis helps people understand him better No hesitation in telling people his diagnosis, thinks there is no stigma about Alzheimer's Happy to tell people</p>
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<p>Happy to tell people</p> <p>Understands/accepts why people in his group are reluctant to tell their diagnosis to friends or others ; disease as a process to cope with where each individual stands and feels differently</p> <p>Coping: He talks about what his group of people with Alzheimer's talked during the meeting: the positive side of Alzheimer's as a no communicable disease</p> <p>People shouldn't be afraid of associating with people with Alzheimer's because it is not like the flu, is it?</p> <p>A fear for his progression of disease?</p> <p>Hope for preventive cure of developing the process of Alzheimer's someday</p> <p>Strong hope for the cure</p> <p>No effect on participation/motivation for leisure and/or social activities</p> <p>Curious whether he is going to get any worse</p>	<p>they feel about it at this time in their life. You know. I guess everybody... meets the... subjects in different ways. And um...from what I learned in my meeting with my group, we meet twice a month evening for two hours. I was just there last night. Tuesday night we meet the first and third Tuesday so, second and fourth, whichever. And we meet for a whole hour. That's a group of 25 people and in that group I learn things... about other patients... who have Alzheimer's. And from what I understand... there is a great reluctance about divulging the affects to other people. But, as you have heard, I am sure...um...the positive side is many these of people have said in the meeting...um...that it is not like a...I grew up in the days of sickness or gonorrhoea or today a...or you know... that it isn't something... you can pass to some people with a shake of your hands... or kiss on the mouth isn't gonna give you Alzheimer's. So, it isn't communicable in that sense. So, people shouldn't be afraid of associating with people with Alzheimer's because it is not like the flu, is it? With the flu, you can get a shot. I understand. And with Alzheimer's, we don't have a shot yet. But, maybe there will be a shot, right? You can get it on the arm or buttock and they will say oh, that will stop it from developing any further. I presume...you... right there. You and you are nice guests here. Your associate... will find a... some preventive cure in your lifetime...in your lifetime. ...</p> <p>I: Yep. So...</p> <p>P: That would be nice. [Saying between his tears; with a small voice]</p> <p>I: So, how do you think participation in the PAIRS program has affected your motivation for or participation in any leisure or social activities?</p> <p>P: Um... not at all. Its make me curious... as to whether or not I am going to get any worse, but um...motivation-wise, or I</p>	<p>Understands/accepts why people in his group are reluctant to tell their diagnosis to friends or others ; disease as a process to cope with where each individual stands and feels differently</p> <p>Good memory (remembering details)</p> <p><u>Giving details is his way of talking or he became more like this after he has got Alzheimer's because being obsessed with remembering things or his symptom (getting off the subject in a moment)?</u></p> <p>Founds that people in his group have a great reluctance to telling the effects of Alzheimer's to other people</p> <p>He talks about what his group of people with Alzheimer's talked during the meeting: the positive side of Alzheimer's as a no communicable disease</p> <p>People shouldn't be afraid of associating with people with Alzheimer's because it is not like the flu, is it?</p> <p><u>He seems to have a fear for his progression of disease</u></p> <p>Hope for preventive cure of developing the process of Alzheimer's someday</p> <p><i>Saying between his tears (strong hope for the cure)</i></p> <p>Curious/unpredictability of the disease</p> <p><u>Misunderstands the question? (is he thinking the question is how Alzheimer's affected his</u></p>
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<p>in terms of motivation in leisure/social activities No effects on his motivation for leisure or social activities because he stills play part-time work Busy or pretend to be busy</p> <p>wife-a very intuitive about their life together can tell you</p> <p>Alzheimer's hasn't affected his participation in social activities</p> <p>Digressed from the main subject</p> <p>Expression of self-identity (A long talk about his profession and work experience)</p>	<p>still... play... part-time work. I am... busy or pretend to be busy. And um...it hasn't affected me that I know of...particularly...and so...Mrs. Miller who is very intuitive about our life together... can maybe tell you if it has had effects. Personally, your question is, has it, and I can't put my finger on anything. It hasn't slowed me up from a social standpoint...and because I am not a doctor, physician, or mathematician... I ...people in my group are gynecologists...two or three individuals who are in the medical field I know in the Alzheimer's program that I attend. And so, I often wonder... how has Alzheimer's affected their ability to examine a patient...medical...you know... patients. But, they participate and are seventy years old, and um...they are retired in most instances. And sometimes, I wonder if Alzheimer's has affected their ability to...participate in their chosen profession. My chosen profession has been... a weird....assessment of the... media. Mostly, so media individual. And um...so I haven't studied to be whatever I am. It is just the result of accumulation of circumstances. So, I don't have a profession... as such...I am in the industry of television and have been for a long time, but um...It hasn't kept me from doing what I really should be doing and that is...calling television stations around the world and see if they would like to lease products that I used to... that I used to...lease to television stations but the industry is left me behind technically...um...my business is sending physical print of a...of a motion picture, or a documentary or a television program...such as...the Golden Girls. When I was with the Columbia Picture, we leased... films like the Golden Girls...Bunny Miller. These are the things such as I love Lucy and um...things like a O'Conner or different actors I have known...who participated in half-hour situation comedies. My job was to re-lease...sublease again those things of</p>	<p><u>motivation and participation?</u> No effects on his motivation for leisure or social activities because he stills play part-time work Busy or pretend to be busy <u>-why?</u> wife-a very intuitive about their life together can tell you</p> <p>It hasn't slowed him up from a social standpoint (<u>it seems to mean Alzheimer's not the PAIRS program</u>)</p> <p><u>Digressed from the main subject</u></p> <p>Wonder if Alzheimer's would affect the ability to participate in medicine</p> <p>Starts to talk about his profession (a long talk without pause) <u>Why is he saying "a weird assessment of the media"?</u> <u>Because there is no academic training for his job and/or that job does not exist anymore?</u></p>
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<p>His job- old-fashioned because everything is satellite now</p> <p>Still have things upstairs in case he has clients in other countries (<u>hope for working again?</u>)</p>	<p>programs when they were through a network. My job was going into a... city, Saint Louis or Milwaukee, and say, I would like to lease you... I love Lucy or Golden Girls and they would say, Fine, Mr. Miller, when we get through with XYZ program, we would like to run Golden Girls at 6 O'clock at night. And when I was leading up to...that kind of a... a profession, I haven't point there not sure what it was...was something that um... I kind grew into it, something you don't...you don't go to school and you learn it, you just do it. I accidently... Oh, well, I remember it's a business of technology. So, I would supply in early days in a town like Springfield, Ohio. Let's say Springfield, Missouri. They would say what is Golden Girls, so we would...I am pretending it's now 1960, okay? And you would show them ...a sixty millimeter print... you put it on the wall, I've started it so early 1954... that um...you would physically have to show them the product and they would look at it and you would take the film in to show them, so...then later...this...then the... our studio, Columbia, would supply Golden Girls...physical...the physical prints to that station in Springfield, Missouri...and Topeka, Kansas. And um...it would be for 39 weeks or 52 weeks and each week they would get print of Golden Girls and run it and send back to Columbia Picture. Now it's all satellite, everything is satellite. And there is no such thing physical print, so...and... things like that that I have upstairs. My second floor prints...It's too expensive for me to put on satellites. I still have... I still... in a case of I have clients in Korea...and um...in the South Korea... for um...several years... among some of the programs might be interested in you. They were leasing some of my cartoons...American cartoons, animated films because they wanted to teach English to children in South Korea. And um... I had two or three wonderful people that I dealt with, I met them at the West-</p>	<p>He learned his work by just doing it (no academic training to do that job) Defines his job as a business of technology</p> <p>His job- old-fashioned because everything is satellite now</p> <p>Still have things upstairs in case he has clients in other countries (<u>hope for working?</u>)</p>
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<p>So having Alzheimer's hasn't slowed me up the technology as prevents me from doing I need</p> <p>There is no place for me up there because now I am 89, and I am too old to begin again...I cannot...on that level. So, technology left me behind and I don't think Alzheimer's left me behind, but the industry left me behind.</p> <p>It's a long answer. What was the question again?</p> <p>Delighted that this program exists and so grateful for research</p> <p>Enjoyed knowing that he is in it because he</p>	<p>coast at the convention. And um...they leased these from the standpoint of teaching the children the American words, you know, the English words I should say. So, that was one example. I leased films in Italy and I leased films in...in France not that many, unfortunately. But, there are other distributors that I am responsible for leasing those films in those areas so there were like my competition and they had Federal access... to those markets. I did it here a thousand miles away. So...having Alzheimer's hasn't slowed me up the technology as prevented me from doing... I need, I should be working for a New York City company or somewhere in the LA. Doing the marketing of other... motion pictures or product... from a satellite standpoint, and now there are these...satellite...that you and I know whether it is a Turner class movie or A&E or you know the art center entertainment so um... hem [clearing his voice]. They all have their own arms now and they buy each other's products. And it's a level of millions, millions of dollars and there is no place for me up there because now I am 89, and I am too old to begin again...I cannot...on that level. So, technology left me behind and I don't think Alzheimer's left me behind, but the industry left me behind. It's a long answer. What was the question again? Ha ha.[saying like this not because he wants to heard the question again but because as a joke on his long, broad answer?]</p> <p>I: I am ending the first part of the interview. I will stop the recording just for a moment. (35:21)</p> <p>I: I am starting the second part of the interview right now. ... So, how do you think about your spouse's participation in the PAIRS program?</p> <p>S: Well. I am delighted that this program exists and so grateful because a research</p>	<p>“So having Alzheimer's hasn't slowed me up the technology as prevents me from doing I need.” <u>Is he talking about his long story just to tell/prove that the technology prevented him from his work, not Alzheimer's? Is it because of the impact of dementia (difficulty in talking or thinking in a more organized way) or just his way of talking?</u> <u>I should be working (did he have to stop that job early in his career so he had to change his job?)</u></p> <p>“there is no place for me up there because now I am 89, and I am too old to begin again...I cannot...on that level. So, technology left me behind and I don't think Alzheimer's left me behind, but the industry left me behind. It's a long answer. What was the question again?”</p> <p>The second part of the interview starts</p> <p>Delighted that this program exists and so grateful for research</p>
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<p>was always enthusiastic about it and told me about things they did. A pleasant experience for him His pair was newer to the area and might not know the city as well. And he felt really good that he can expose elements of the city to his pair who wouldn't have time to go to otherwise. Doctors are busy They arranged their meetings considering each other's schedules</p>	<p>has been done and ...I enjoyed knowing that he is in it because he was always enthusiastic about it and told me about things they did. And um...You know, in general, it was a pleasant experience for him. um...I believe... the doctor was...newer to the area and might not know the city as well. And Herb felt really good that he can expose elements of the city to him he wouldn't have time to go to otherwise. Because, you know, doctors sometimes every minutes in a day is taken. And um...They arranged their times, meetings according to what appointments Herb had and what appointments he had.</p> <p>I: So, you said that you were delighted because you know that he is very enthusiastic to be involved in this particular environment. So, could you tell me more about that?</p>	<p>Enjoyed knowing that he is in it because he was always enthusiastic about it and told me about things they did.</p> <p>A pleasant experience for him</p> <p>His pair was newer to the area and might not know the city as well. And he felt really good that he can expose elements of the city to his pair who wouldn't have time to go to otherwise. Doctors are busy They arranged their meetings considering each other's schedules</p> <p><i>This particular environment (involving both the research and the PAIRS program itself)</i></p>
<p>Encouraging to think that there is always a future for the cure</p>	<p>S: Well. I think any with any disease that you have... um...It's encouraging to you to think that...um...maybe it won't be in time for you, but it would be in time for some who comes after. um...If research is done and things are discovered, cures... come to fruition. It's just a... I think it's a group thing...more than a personal thing. It's... not just for me, what's the matter with me. But, um... there is always a future.</p>	<p>Encouraging to think that there is always a future for the cure</p> <p>Hope for the cure not just for themselves but for the others in the future a group thing, more than a personal thing</p> <p>There is always a future</p>
<p>Both wanted to contribute to the society for future people with Alzheimer's and families</p> <p>Spouse's experiences as a family caregiver of her family members who had Alzheimer's</p>	<p>I: So, you...from my understanding, you also wanted to contribute to the society for future... people or families. S: Yeah. Either of us. Ha ha. I: Ha ha. That's great.</p> <p>S: My mother died with Alzheimer's, not from it. My uncle and brother died with it. um...My stepfather whom I cared for four years...he died from...not the Alzheimer's, but I took care of him through his illness. So, I have some acquaintance with it.</p> <p>P: Mrs. Miller has had some experiences</p>	<p>Member checking</p> <p>Experiences as a family caregiver of her family members who had Alzheimer's <u>Her experiences caused her to wish/want for her contribution to the society</u></p>

<p>Comparison people with Alzheimer's with people with cancer Less research for people with Alzheimer's No cure for people with Alzheimer's</p> <p>Need more research (never enough)</p> <p>One reason for her husband is so open with other people about his diagnosis They have been going to the movie group over 40 years</p> <p>Talks about how the couple joined in the movie group</p> <p>Both are interested in movies</p> <p>Talks about the story about his disclosure about his diagnosis to the movie group He wanted them to know He's been advocating</p> <p>Agrees with what his wife said We (the couple) want to get the word out</p> <p>Same meaning with the growth industry which he told before; so, the growth here means not only his growth but also the society's growth?</p>	<p>from a family standpoint.</p> <p>S: It's a...people with cancer... they know that there is a lot of research going on and they know...maybe...just maybe ...they can escape the ravages of the disease. Alzheimer's patients don't have that.</p> <p>I: So, did you feel that there are not... much research for people with Alzheimer's ?</p> <p>S: There is never enough. I: So, you feel that oh, we need more. S: Yes. I: That's great. That's wonderful.</p> <p>S: That's one reason for Herb is so open... like with our movie group of twelve, fifteen, twenty people. It varies. We've been going over 40 years. And the personnel have changed. Ha ha. Some people of died...some people of moved away because it's been a long period of time. And we were invited to join ... a friend of ours... Jack Kimberline. she is a fiber artist and I met her because I am working fiber. And um...We just thought that's a great idea, you know, before the group discussed the movies because we both are interested in movies. And um...so, he got up ...in front of the group one evening when we were meeting and he said I wanna tell you something and he expressed his condition and um...he was okay with it, wanted them to know. So, he's been advocating, I would say.</p> <p>P: Good..that's a good word, advocate, right. We want to get the word out. Like I said to you, it's a growth industry.</p> <p>I: So, what were your expectations...this is a similar question but, what were your expectations before your spouse participates in the PAIRS program?</p>	<p>Comparison people with Alzheimer's with people with cancer Less research for people with Alzheimer's No cure for people with Alzheimer's</p> <p>One reason for her husband is so open with other people about his diagnosis They have been going to the movie group over 40 years</p> <p>Talks about how the couple joined in the movie group</p> <p>Both are interested in movies</p> <p>Talks about the story about his disclosure about his diagnosis to the movie group</p> <p>He wanted them to know He's been advocating</p> <p>Agrees with what his wife said They want to get the word out Same meaning with the growth industry which he told before; <u>so, the growth here means not only his growth but also the society's growth?</u></p>
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<p>Curious to know what all was about Thinks the program is designed as much for the doctors</p> <p>He had mostly done things with younger people than him (doing stimulating things)</p> <p>Pursuing art things and mixing with groups Movie group of people with professional people Variety He learns so much by associating to people like that <u>It seems that he likes socializing with diverse people and enjoys learning from each different individual.</u> <u>The experience in the PAIRS program could be one of his interesting places he could share his interest and learn something.</u> Talks about his wife</p>	<p>S: Oh, I was curious to know what all was about. Also, it was some...I think designed as much for the doctors... should've been and probably was... because you have to have background. You can study all the medical conditions of what it does to the body, but he was interested in studying in the brain. So, it was...you know...what he was interested in...he has deep interest in that as a doctor. I: So, do you think that he was more interested in... knowing some about... some medical things and helping the student's learning... P: Yeah. I: than doing social things with a younger person?</p> <p>S: Um...Herb's mostly done things with younger people than him because um...they were doing stimulating things. I: What do you mean by...</p> <p>S: Pursuing art things and mixing with groups that the...our movie group is made up with professional people. And um... P: Variety...</p> <p>S: He learns so much by associating to people like that.</p> <p>P: Let me add to the... Mrs. Miller, however, is so good about medical...profession. She had a little psychiatric in college.</p> <p>S: No. I didn't have any Psychiatry. Ha ha. My major was Psychology... which was very helpful in raising a family.</p> <p>I: That's great.</p> <p>P: My relationship...I was gonna stress...she might could would been a</p>	<p>Curious to know what all was about Thinks the program is designed as much for the doctors</p> <p>He had mostly done things with younger people than him (doing stimulating things)</p> <p>Pursuing art things and mixing with groups Movie group of people with professional people Variety</p> <p>He learns so much by associating to people like that <u>It seems that he likes socializing with diverse people and enjoys learning from each different individual. The experience in the PAIRS program could be one of his interesting places he could share his interest and learn something.</u></p> <p>Wife major was psychology</p> <p>He starts talking about his wife She might could been a medical</p>
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<p>I am medically dumb</p> <p>She's a curious person</p> <p>Compliments her intelligence and memory</p> <p>She's never forgotten when he needs something (admires or envies her memory?)</p> <p>PAIRS program to help medical students to understand people who are in all the different stages better (this is a</p>	<p>medical... surgeon.</p> <p>S: I had no ambition on that dream.</p> <p>P: Whether it's a heart...whether it's a body. I mean she knows which bones attached to which bones. I have no idea. I am medically dumb about it...it is a...going through the moon... all the planets...beyond me in more ways than one. [clearing his throat] But, this woman has</p> <p>S: Well. time to spend to be very curious</p> <p>P: She's a curious person...and um...I always claim she's...her...expression of ...must bore her tears, but she started reading like the encyclopedia, botanical when she was 2 years old. And, she's never forgotten...</p> <p>S: No.</p> <p>P: She's never forgotten...</p> <p>S: Not so. You're exaggerating.</p> <p>P: When I need some...</p> <p>S: I grew up...</p> <p>P: ha ha...</p> <p>S: looking at the national geography before I can read.</p> <p>P: That's true.</p> <p>S: I can read, you know, I was devouring it. I am not terribly intelligent. My IQ is average, but um...that's kind of one reason why I pursued Psychology. I thought that would be very helpful to understand why people do what they do.</p> <p>I: So, you said that the program, the PAIRS program is designed for medical students' learning, helping medical students' learning. Why did you think that?</p> <p>S: Well. I would think... because um...either read stuff in the books or you can see something about people who have Alzheimer's um...or brain, any brain, brain problem... when they are in</p>	<p>surgeon</p> <p>Medically dumb</p> <p>She's a curious person</p> <p>Compliments her intelligence and memory</p> <p>She's never forgotten when he needs something; <u>admires or envies her memory?</u></p> <p>PAIRS program to help medical students to understand people who are in all the different stages better (this is a broader experience)</p>
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<p>broader experience)</p> <p>He took pleasure in it. He felt he was giving a service to upcoming doctors, and understanding something about the environment because his pair didn't grow up in it. His pair is not familiar with city. Time constraints would make him less knowledgeable. He felt like he was giving something to a (upcoming) doctor</p> <p>He went on his own merry way, as always, doing all the things he does. No difference</p> <p>He had pleasure every time. He looked forward to do it.</p> <p>He said that he looked forward to meeting with his pair He felt good about meeting him whatever they were doing</p> <p>That's the pleasure he got : One more opportunity to be out with somebody, intelligent for the future and being helpful</p>	<p>stressed. um...But, how do you, as you a doctor, um...understand people who are in all the different stages, is a broader experience. I think that's what they try to develop for doctors.</p> <p>I: How do you think participation in the PAIRS program has affected your spouse and your daily life?</p> <p>S: He took pleasure in it. He felt he was giving a service... to... upcoming doctors, and understanding something about his environment because he didn't grow up in it. He is not familiar with city. Time constraints would make him less knowledgeable. I am sure he had his group... because everybody does. He felt like, Herb felt like, he was... giving something to a doctor.</p> <p>I: Did you see any difference in his mood, or feelings, before he meets with Scott and after...?</p> <p>S: He went on his own merry way, as always, doing all the things he does.</p> <p>I: How did you feel that he had some pleasure in meeting him?</p> <p>S: Yeah. He did... every time. He looked forward to do it.</p> <p>I: How did you know that?</p> <p>S: He would say. He would...He feeling good about... meeting him... whatever they were doing. And um...it was one more opportunity to be out with somebody, intelligent...and um... for the future and being helpful.</p> <p>I: Do you think that this...?</p> <p>S: That's the pleasure he got.</p> <p>I: I feel that he is very enthusiastic in</p>	<p>He took pleasure in it. He felt he was giving a service to upcoming doctors, and understanding something about the environment because his pair didn't grow up in it. His pair is not familiar with city. Time constraints would make him less knowledgeable. He felt like he was giving something to a (upcoming) doctor</p> <p>He went on his own merry way, as always, doing all the things he does. No difference</p> <p>He had pleasure every time. He looked forward to do it.</p> <p>He felt good about meeting him whatever they were doing</p> <p>One more opportunity to be out with somebody, intelligent for the future and being helpful</p> <p>That's the pleasure he got</p>
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<p>The being an outlet, interesting people</p> <p>It fills a void in his life</p> <p>Enriches his life by having feelings of being a better self</p> <p>By associating with people who are successful by doing the things those people do. It's an encouraging thing</p> <p>He has not done volunteering work Working for the symphony was a part of the same pattern of being around people who are doing things. He likes socializing with people who are doing things in which he has some interests (no interests in helping activities necessarily)</p>	<p>helping some people, especially for future medical doctors. Did these activities have any special meaning to him, do you think? S: To him? I: Yes.</p> <p>S: It's all life. The being an outlet, interesting people. I: I see. Do you think...?</p> <p>S: It fills a void in his life. I: Could you tell me more about that?</p> <p>S: Well. I think everyone has some... feelings... a little trying to better yourself. And these things are enriching to his life. I think that's the main thing... I: By helping the future medical doctors...?</p> <p>S: By associating with people who are successful...um...by doing the things those people do...um... it's sort of a...it's an encouraging thing. I: Do you think he used to enjoy helping people before he got Alzheimer's or some volunteering work?</p> <p>S: No. I: But, he became more enthusiastic after he got...? S: um...He hasn't done volunteer work that I know of. Working for the symphony... it was a part of the same pattern of being around people who are doing things.</p> <p>I: Do you...How do you think participation in the PAIRS program has affected your spouse's participation in leisure or social activities?</p>	<p>The being an outlet, interesting people.</p> <p>It fills a void in his life</p> <p>Enriches his life by having feelings of being a better self</p> <p>By associating with people who are successful by doing the things those people do. It's an encouraging thing.</p> <p>He has not done volunteering work Working for the symphony... it was a part of the same pattern of being around people who are doing things. <u>So, he likes socializing with people who are doing things in which he has some interests (no interests in helping activities necessarily)</u></p>
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<p>No effect on his participation in leisure or social activities</p>	<p>S: It... really hasn't been visible. um... He would know better than I... how it affected him.</p>	
	<p>I: Do you think he...?</p>	
<p>He just continues his same lifestyle</p>	<p>S: But, he just continues his same lifestyle.</p>	<p>He just continues his same lifestyle</p>
	<p>I: So, he has many friends he normally goes out.</p>	
<p>He has many acquaintances he normally goes out. Is she correcting here because she doesn't feel that he has many friends?</p>	<p>S: Many acquaintances.</p>	<p>He has many acquaintances he normally goes out. <i>Is she correcting here because she doesn't feel that he has many friends?</i></p>
	<p>I: Oh, yeah. I see. How do you think participation in the PAIRS program has affected you and your daily life, not his point... not him?</p>	
<p>No change on her life except that she knew that he was enjoying himself (because he drives)</p>	<p>S: It hasn't changed my life at all, except that I knew he was enjoying himself.</p>	<p>No change on her life except that she knew that he was enjoying himself</p>
	<p>I: How about...did you do something else when he was going out or...?</p>	
	<p>S: I did the same things. I took care of the house and paid the bills...</p>	<p>She did the same things when she went out with his pair</p>
	<p>I: Because he drives.</p>	
	<p>S: He drives.</p>	<p>He drives</p>
<p>If I had been driving everywhere, then I would've said, oh, good! Somebody else is doing this.</p>	<p>I: So, it didn't make any change?</p>	
<p>Spouse's plan for the future: Prepared for the future when he cannot drive</p>	<p>S: Yeah. If I had been driving everywhere, then I would've said, oh, good! Somebody else is doing this. Because I know that's what comes eventually. ...So...I am sort of prepared for the future and he does...</p>	<p>If I had been driving everywhere, then I would've said, oh, good! Somebody else is doing this.</p>
	<p>I: Do you...It's been almost 8 months after the program is ended. It ended in April. So, I wonder how... after the program is ended, are you still contacting with Scott? Or, how do you...</p>	<p>Prepared for the future when he cannot drive</p>
	<p>S: I don't know. Whether he has or not.</p>	

<p>Contacted with his pair a couple of times after the program was ended</p> <p>We can meet again</p> <p>Another social occasion</p> <p>His pair said that he can call him [his pair] any time and do something together</p> <p>The couple goes to the support group at AA</p> <p>The spouse has been involved with the caregiver program a year long.</p> <p>He talks about the meeting at AA last night</p>	<p>P: Yes. I have a couple of times, yeah. In fact, probably should get to... reappear probably be gone for holidays, you know. And I forgot it about a month or more... If something came up, I will allude him to...and we could do it because he was tied up and it was...It was another social occasion or... it was something...</p> <p>S: [interrupting] Scott had made it clear that Herb can call him any time.</p> <p>P: Yes. Yes.</p> <p>S: and they can do something together if you want to...</p> <p>I: Do you do any similar...do you participate in any similar programs like...</p> <p>S: Myself?</p> <p>I: like the PAIRS? Does he participate in the programs like...?</p> <p>S: Oh, I go to the caregivers' meeting at the...main office over here... 75th mission. And there are about twenty of us and I think in my group...He goes to the patients' group and we go together. I didn't go... last time because I am probably contagious.</p> <p>P: She's involved with the caregiver program... has been a year long.</p> <p>S: Yeah. Ever since we were...made aware of it.</p> <p>P: Ever since...</p> <p>S: had him interviewed to see, you know, how he's doing.</p> <p>P: In fact told with a girl, Michelle last night, she goes around and asks everybody. It's a normal procedure at the evening meeting. Gives your name and how long you have been a patient and go</p>	<p>Contacted with his pair a couple of times after the program was ended</p> <p>We can meet again</p> <p>Another social occasion (<u>for the pair who is too busy to do social activities otherwise?</u>)</p> <p>The pair made it clear that he can call him any time</p> <p>And they can do something together; <u>belief based on trust on the pair?</u></p> <p>The couple goes to the support group at AA</p> <p>She has been involved with the caregiver program a year long.</p> <p>Ever since they were aware of it; <u>does "it" mean diagnosis or the support group?</u></p> <p>Talks about the meeting at AA last night</p>
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<p>He started going to the meeting a year ago</p> <p>Spouse's experience in support group for caregivers</p> <p>Coping strategy/accepting the disease (using humor for increasing resilience in dealing with distress) "Because there are things we discuss that you have to laugh about because there's nothing you can do about it. You know? It's a kind of a shared misery. And there is some crying." Benefits (getting information) of support groups and understanding about difference of each individual with Alzheimer's (same disease/shared misery but not same)</p>	<p>around and say my name is and I've been... you know, here for a year for two years, five years...and so when he came around me and say: I think I am about to first anniversary ...participating in her program at night. It's about Christmas year a year ago that I began in the evening program approximately.</p> <p>I: So, you go to the meetings for people with...</p> <p>S: Together.</p> <p>I: Yeah. You guys go to the meeting for people ...</p> <p>S: Once a month, for...</p> <p>I: for people with Alzheimer's and for families. So, do you think if there is any difference between that kind of program and with the PAIRS program? What do you think the difference between...?</p> <p>S: I think the program where we go... and um...we... meeting room so you can open a partition and comes one big room but it's partition with, you know, is kind of a flexible wall. And we don't hear them talking, but there is uproarious laughter on one side and a little later on our side uproarious. Because there are things we discuss that you have to laugh about because there's nothing you can do about it. You know? It's a kind of a shared misery. And there is some crying... and um...but the good that I get out of that...myself...I don't know what you get out...you know, specifically, um...I am forewarned...about how to handle certain things. Medication is discussed and any new developments. It's informational. And it's a...everybody there has the same problem, same...but it's not the same. There are... every patients is one patient, and every caregivers is one or more caregivers. Sometimes, it takes several people.</p> <p>I: How do you think about having some one-on-one interaction with one younger person compared to the meetings for</p>	<p>He started going to the meeting a year ago</p> <p>Difference between support group and the PAIRS program?</p> <p>A partition, a flexible wall in the meeting room "Because there are things we discuss that you have to laugh about because there's nothing you can do about it. You know? It's a kind of a shared misery. And there is some crying." <u>Coping strategy (using humor for increasing resilience in dealing with distress)</u></p> <p>"The good that I (his wife) get out of that I am forewarned...about how to handle certain things. Medication is discussed and any new developments. It's informational. And it's a...everybody there has the same problem, same...but it's not the same. There are... every patients is one patient, and every caregivers is one or more caregivers. Sometimes, it takes several people."</p>
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<p>The spouse belongs to a couple of quilts and I mostly go to the meeting when she is feeling up to it, less and less. (Less motivation simply due to aging?)</p> <p>Working together as a team in talking about her (his wife) He talks about his wife praises her about her talent) She is an artist for herself in many ways. She is a weaver... just beautiful things weaving. She will be spending into something. You know. And she's a great and she's got beautiful things in quilt</p> <p>She had to give up making pottery because of her arthritis</p> <p>We (PwD) vs. I (spouse)</p> <p>He starts talking about his grand-daughter who is interested in quilt like his wife</p>	<p>groups of people with the same Alzheimer's? How do you feel about participating one-on-one with younger people...? S: Like him I: yeah, for social gathering</p> <p>S: I have never thought of that. Everybody I know is much younger than I, and ...basically, that's true for Herb. Because they are doing things, I belong to a couple of quilts and I mostly go to the meeting when I am feeling up to it, less and less.</p> <p>I: Will you...um...will you be willing to participate in the programs like the PAIRS program in the future if you have any chance to?</p> <p>S: Me or him? I: Him. P: I might answer... Mrs. Miller just underlined what you are saying. She is an artist for herself in many ways. She is a weaver... just beautiful things weaving.</p> <p>S: A spinner..</p> <p>P: If you have any dogs...</p> <p>S: No more dog hair...</p> <p>P: No more, don't care. Right. She will be spending into something. You know. And she's a great and she's got beautiful things in quilt...</p> <p>S: I had to give up making pottery because of my arthritis.</p> <p>P: We have a pottery wheel. S: I have a pottery wheel and a kiln. P: and a kiln S: and a pottery room on the back wing. P: Fortunately, our grand-daughter is interested. She's 24, graduated from the New York...Kansas city Art Institute. She's some social worker by now, but she...And she was using the quilt near a couple of years ago when she was at the</p>	<p>She belongs to a couple of quilts and I mostly go to the meeting when she is feeling up to it, less and less. <u>Less motivation simply due to aging?</u></p> <p>He talks about his wife (praises her about her talent) She is an artist for herself in many ways. She is a weaver... just beautiful things weaving.</p> <p>Correcting weaving into a spinner</p> <p><u>What he was trying to say may be an old-fashioned way.</u></p> <p>She will be spending into something. You know. And she's a great and she's got beautiful things in quilt</p> <p>She had to give up making pottery because of her arthritis</p> <p><i>We vs. I</i></p> <p>He starts talking about his grand-daughter who is interested in quilt like his wife</p>
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<p>She misses doing the pottery She's a fine...she enjoys getting hands on the clay</p> <p>She's been part of her weaver's group who sell fiver at Renaissance fair for 36 years; it's a lot of fun; They feel proud of her contribution at the Renaissance fair</p> <p>Working as a team in talking</p>	<p>art institute. ...</p> <p>S: I miss doing the pottery.</p> <p>P: She's a fine...she enjoys getting hands on the clay</p> <p>S: A pot down there by the dog toy. That's one of mine.</p> <p>I: Wow. That's beautiful.</p> <p>P: She's got a couple of pots here. Nothing commercial in that...</p> <p>S: Oh, I sold a lot of my stuff.</p> <p>P: I mean you don't have a place where you are selling stuff...</p> <p>S: Not now.</p> <p>P: She is very sellable. Mostly, she is giving them to friends you know, gifts...[still talking]</p> <p>S: Wedding gifts. That got me out of a lot of expensive wedding gifts. [the person with dementia stopped talking] And then for thirty-six, thirty-seven years, I've been part of my weavers guild and we have a booth for Renaissance fair. You are familiar with Renaissance fair? And I sell my fiber out there with the weaver's group.</p> <p>P: Mrs. Miller is a weaver, Renaissance weaver...at the...at the Renaissance if you are ever out there.</p> <p>S: It's a lot of fun.</p> <p>P: Miller Jeanne has been a part of that for 35 years. And by that mean she's at the booth every... thirty...every...seven...</p> <p>S: And I managed that for ten years.</p> <p>P: Seven weekends of the year from labor day through Columbus day.</p> <p>S: ...weekend</p> <p>P: ...progress. That's what Jeanne is out there.</p> <p>S: So, my next birthday in March, which is coming up, I will be ninety. And I am glad to be able to done it that long.</p> <p>I: You look much younger than ninety.</p> <p>S: That's what everybody says.</p> <p>P: So far so good. But, if you are asking about one-on-one, sure, Mrs. Miller will be happy to visit with someone... whether</p>	<p>She misses doing the pottery She's a fine...she enjoys getting hands on the clay</p> <p>She's been part of her weaver's group who sell fiver at Renaissance fair for 36 years</p> <p>It's a lot of fun</p> <p>They feel proud of her contribution at the Renaissance fair</p>
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<p>Talks about his group leader/facilitator: excellent, very good leader, a bullet on fire, great little gall a lot of experience</p> <p>He talks about last night's meeting at AA</p> <p>Good balance in terms of gender in their group, but mostly women (caregivers)</p> <p>Fear of his future (by looking at other people at AA whose disease are progressed further than him)</p> <p>Spouse's support</p> <p>Caregivers are very important to people</p>	<p>it is related to PAIRS, or follow-up on Alzheimer's, you know, Mrs. Miller will be happy, I am sure to make herself available...um... whether they are youngsters or older people with... She's is a part of this caregiver, caregiver group, weaving, there is like twenty people on this side of the wall, and there is twenty-five over here. So, I am over here with people who are now patients and the next door at this 75th street here in Mission road where we just happen to be last night. um...Michelle um...Neiden is her last name. Jeanne leader is my...facilitator I call her. Jeanne is great. Jeanne leader ... has the same spelling with Mrs. Miller with the name Jeanne. And um...she is excellent, Jeanne leader, and she is...</p> <p>S: very good leader P: She is a bullet on fire, great little gall. She is five foot five or something, you know. S: a lot of experience P: and a lot of experience. She is very good. I wanted to say one more thing about her. um...She was there last night. um...there...um...so they...caregivers are... not youngsters. They are basically their... if they are not... live-in partners, they are wives or husbands...several husbands in the group. S: Oh, we have a...pretty good balance, but mostly women. Maybe... five of them are men.</p> <p>P: And my guys who in there are often very complementary saying they don't know where they will be without their caregiver. They are talking about their wives. And one fella in particular last night was saying either, where he would be if it wasn't for his wife... taking care. [became tearful at the end]</p> <p>S: so...that's what I am here for.</p> <p>P: They are...they are very important to patients... the caregiver... the great</p>	<p>Talks about his group leader/facilitator: excellent</p> <p>very good leader a bullet on fire, great little gall a lot of experience very good</p> <p>talks about last night's meeting</p> <p>Good balance in terms of gender in their group, but mostly women (caregivers)</p> <p><u>He seems to express his shared feeling by using what people in his group said in the meeting</u></p> <p><u>Because he is still independent, he may not need much help from his wife like the other people in his group, but he feels fear or sympathize what these people feel because he knows that his disease will progress ; became tearful at the end</u> <u>To express that she will be always there for him even his</u></p>
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<p>with Alzheimer's the great responsibility</p>	<p>responsibility... so...she...</p>	<p><u>disease progresses further?</u></p>
<p>She tried to open a conversation related to the couple's current issue</p>	<p>S: I don't know... how much I would get out of one other person... to talk to... because I am getting so much out of the group.</p>	<p>Caregivers are very important to people with Alzheimer's the great responsibility "because I am getting so much out of the group"</p>
<p>He explains his situation that is related to their current issue</p>	<p>I: What do you mean?</p>	<p><u>He seems to know what she is talking about, so he seems to try to defend himself by talking about his situation</u></p>
<p>He thinks his group meeting is too much for him (too much time)</p>	<p>P: So, it has a group and it's been...</p>	<p>The leader invited them to join in the support group a year ago The caregiver group meet twice a month, but his group meets twelve hours a week (twice a week, six hours each day) <i>Tone: Emphasizing to express the meeting is too much</i></p>
<p>The group involves twelve or thirteen people Very individualized thing They do music, artwork, and tell stories</p>	<p>S: same would...how I would feel about talking to somebody. I do...have requested in Jeanne... to talk to her one-on-one...about general things... so I kind of...I figured she is a fountain of information and um...so, we arranged that... coming for each others.</p>	<p>The group involves twelve or thirteen people Very individualized thing They do music, artwork, and tell stories</p>
<p>Activities for stimulation</p>	<p>P: So, group meetings you might say...Areum. Areum. I think valuable... my group of twenty five people usually and the caregivers on the other side of the wall. I might add, just for your records, that I am going also...the caregiver group is twice a month every other Tuesday. The one that I belong to that...Jeanne leader invited to us a year ago. We meet Tuesday, some Fridays for six hours... each day, twelve hours a week. And this is every week [a little bit emphasizing]. So, it's twelve hours this week, twelve hours last week, twelve hours every week. Where we meet anywhere from about twelve people...twelve or thirteen people...very individualized thing. You are probably aware of it. But,um... we do...we do music, we do artwork, we tell stories.</p>	<p>Activities for stimulation</p>
<p>He enjoys the activities at AA (Talks about word games he did with the group: a lot of fun, videotaped, historical, great fun)</p>	<p>S: Anything that will be stimulating</p> <p>P: Yeah, stimulating. We had word games the other day where she gives us words we have to work them into a conversation and I had a lot of fun of that. And um...and also some of these are videotaped. And then we will see it a week or two later, and this is historical. It's great fun! Yeah.</p>	<p>Talks about word games he did with the group: a lot of fun, videotaped, historical, great fun</p>
	<p>S: It really is.</p>	<p>Agrees</p>

<p>She tells that he was thinking about giving the group meeting up.</p> <p>Cannot understand why he wants to give up “That’s the only that that you do to exercise your mind.” (Talks the same thing at the same time: because of familiarity or because they already talked about this issue before?)</p> <p>Converts the topic to the word game story to discontinue talking about this issue</p> <p>He talks about yesterday’s meeting at AA (a game) A lot of fun</p> <p>“It is interesting because in this small group of talk people, um...some of them are fascinating to me because they are giving either script and they can...words are meaningless or they can’t quite comprehend</p>	<p>P: We had words. I asked after I was through...</p> <p>S: you were thinking that giving that up.</p> <p>P: Yeah. I... right.</p> <p>S: And why? I don’t know. That’s the only thing that you do that exercises</p> <p>P & S: your mind [saying together at the same time]</p> <p>P: So, wait... I was giving three words...so...new...it was only yesterday. Was yesterday Tuesday? What day was yesterday? Friday? Anyway. Tuesday. Um...One was masticate...one was odorless and the third one. And we were saying we were supposed to work, and we were giving them partner. They don’t know what words are. I have to come up with, you know. Later, when it’s all over, I said to somebody what is masticate. ha ha. So, I was so...but I had a lot of fun with words that I said...very dangerous she will mispronounce and you make me into a little... something... a little... other than...masticate...okay. But um...so we had fun with that too. And um...some of that...</p> <p>S: We hear ...laughter P: oh yeah. I told S: When their other group meet.</p> <p>P: So, this is our own group. It was challenging, so the facilitator, the woman who does videotaping, just gives us these words or she will give us situation... where we have to pretend to where...on television, we have to sell... some magic potion and that has to cure everything and it was a lot of fun. ...stimulate people in our group to try to work on their imagination. It is interesting because in this small group of talk people, um...some of them are fascinating to me because they</p>	<p>She tells that he was thinking about giving the group meeting up.</p> <p>Agrees Cannot understand why he wants to give up That’s the only that that you do to exercise your mind <i>Talks the same thing at the same time : because of familiarity or because they already talked about this issue before?</i></p> <p>Converts the topic to the word game story to discontinue talking about this issue</p> <p>He didn’t know the word’s meaning</p> <p>It was challenging, so the facilitator just gives us these words...(because the game can be done when the person knows the word) A lot of fun Activities using imagination</p> <p>“It is interesting because in this small group of talk people, um...some of them are fascinating to me because they are giving either script and they</p>
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<p>what they were supposed to be doing or they will speak as I am speaking [<i>slowly talking, voice with anger</i>]" . <u>He seems to be mad</u></p> <p>Spouse understands the behavior of other people at AA He is probably the least affected person in the group It takes so much time for people in his group to understand things</p> <p>Fear of future: And he feels like, "well. I'm...I'm not that far gone, and I don't really need to be here."</p> <p>The wife thinks that group is the most useful/helpful group that he is, but she also understands why he feels that way or wants to drop that group at the same time (sympathize). Depressing for him to see other people's progression</p> <p>Having fun vs depressing to see other people's progression</p> <p>The wife recognizes his profession in doing activities other than enjoying himself</p> <p>She regards what he does upstairs as a leisure activity (for fun) but he seems to think that as his work (his</p>	<p>are giving either script and they can... words are meaningless or they can't quite comprehend what they were supposed to be doing or they will speak as I am speaking [<i>slowly talking, voice with anger</i>].</p> <p>S: carefully... because the words are hard for them. The thing is that Herb is probably the least affected of this...um...group that he is talking about that takes so much time.</p> <p>P: uh-huh. S: And he feels like, well. I'm...I'm not that far gone. P: uh-huh. S: and I don't really need to be here. P: uh-huh.</p> <p>S: And he is thinking about dropping it which is probably the most useful group that he is in. um...but...I think it's depressing to him...to see or the other patients has gone to.</p> <p>P: uh-huh.</p> <p>S: And I think he is... wanting to avoid that feeling and...kind of...Jeanne turns to him...kind of ...in a leadership role almost... because he is more able... to hold his thoughts together and to... be something that the others can kind of hang on to it in that way he is kind of giving the service to the group.</p> <p>P: Jeanne... S: But it is taking his time...and...it's time more and more now...is a...not being taking...to do any work... but to enjoy himself. [Saying carefully]</p> <p>P: I grew up in the entertainment industry. What Jeanne was saying might want to confirm...she said very very well. It is twelve hours a week I have things to do</p>	<p>can... words are meaningless or they can't quite comprehend what they were supposed to be doing or they will speak as I am speaking [<i>slowly talking, voice with anger</i>]" . <u>He seems to be mad</u></p> <p>carefully... because the words are hard for them He is probably the least affected person in the group It takes so much time for people in his group to understand things</p> <p>And he feels like, "well. I'm...I'm not that far gone, and I don't really need to be here."</p> <p>"He is thinking about dropping it which is probably the most useful group that he is in. um...but...I think it's depressing to him...to see or the other patients has gone to." <u>The wife thinks that group is the most useful/helpful group that he is, but she also understands why he feels that way or wants to drop that group at the same time (sympathize).</u> Depressing for him to see other people's progression</p> <p>She thinks he wants to avoid that feeling (<u>depression and fear of his progression in the near future?</u>) He plays a leadership role in the group because he is more able to hold his thoughts together (he is kind of giving the service to the group)</p> <p>But it is taking his time more and more now not to do any work but to enjoy himself : <u>she seems to say this carefully because she regards what he does upstairs as a leisure activity (for fun) but he seems to think that as his work (his passion about his work)</u></p>
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<p>passion about his work)?</p> <p>I have things to do upstairs I worked at home</p> <p>Wife's praise/compliment about his past work/job</p> <p>The group meeting takes up a lot of time (he thinks no time or less time for doing things upstairs because of the group meetings?)</p> <p>But, you have not put it (<u>the time he spends at the meeting</u>) to work. You haven't used that time...when you weren't doing that</p> <p>that's a personal thing right now (<u>why is he thinking that this is a personal thing suddenly? Because he wants to show what he does good only?</u>) <u>internal in terms of family?</u></p> <p>Fine. Sure. I don't disagree. His contribution in the group Less participation of the group people (<u>due to less motivation or dementia?</u>) He always jumps in and</p>	<p>upstairs and it's a mess...my...I worked at home... last four years in my own business since 1976 when I established my own company in the cable television fields called cable films. And I...before I goes out in Columbia and D.C. worked for other people. Then I took by myself tried to work for myself ... it was not easy. My son...one of my sons helped it a great deal for many many years. It's a two person corporation. We covered the whole country and foreign markets.</p> <p>S: You did well.</p> <p>P: So, we did very well for a long time. So, now technology as I say, but what Jeanne was saying... there's still twelve hours a week ...every week, twelve hours...it takes going and coming. And let's say thirteen hours...it's a... what twenty-six...thirteen hours every week four weeks out of a month every month. That's a lot of time... and um.. she...</p> <p>S: But, you have not put it to work. You haven't used that time...when you weren't doing that...</p> <p>P: uh-huh.</p> <p>S: to do your work</p> <p>P: Any...well...that's a personal thing right now. so, that's...</p> <p>S: No, it pertains.</p> <p>P: Yeah. It's internal.</p> <p>S: It pertains what we are talking about.</p> <p>P: Fine. Sure. I don't disagree. What she said is interesting because...I find that... Jeanne leader knows that I can contribute because sometimes...the...the people in the group we are supposed to interchange...come to a point where it is a stand still and I will always jump in and say something just as I had here. And I think Jeanne appreciates, says because it</p>	<p>I have things to do upstairs I worked at home</p> <p>The group meeting takes up a lot of time (<u>he thinks no time or less time for doing things upstairs because of the group meetings?</u>)</p> <p>But, you have not put it (<u>the time he spends at the meeting</u>) to work. You haven't used that time...when you weren't doing that</p> <p>that's a personal thing right now (<u>why is he thinking that this is a personal thing suddenly? Because he wants to show what he does good only?</u>) <u>internal in terms of family?</u></p> <p>Fine. Sure. I don't disagree. His contribution in the group</p> <p>Less participation of the group people (<u>due to less motivation or dementia?</u>) He always jumps in and says something The leader appreciates his</p>
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<p>says something The leader appreciates his contribution</p> <p>“Loves the people in there ... they just can’t participate. [<i>Saying between his tears</i>]. And it’s...she said it’s almost depressing”</p> <p>He sees his future there. “What good I am doing here. Hey, I am not on that stage. I can use this time...”</p> <p>Talks about one guy in his group: What he says is always good, but he is just withdrawn</p> <p>His want to spend his time for himself because he thinks his life left is not that much</p> <p>His wife thinks what he does at home is not useful/helpful</p> <p>He tries to avoid this</p>	<p>moves us the long-lived...because it is easy I can see where the leader is going. And I will jump in if I can, so...now she...Jeanne says that it is true. I love the people in there, the sweet lovely one or two men. My heart goes out to them because... they just can’t participate. [<i>Saying between his tears</i>]. And it’s...she said it’s almost depressing...</p> <p>S: He sees his future there.</p> <p>P: What good I am doing here. Hey, I am not on that stage. I can use this time waiting until... Clark starts to contribute or one of our guys name is Charlie. He is such a sweet guy ...never...always sits there like this. He can’t...but he’s a...when he’s stimulated... when he has something to say. What he says is always good, but he is just withdrawn. You know? And I am thinking, do I need to be there twelve hours a week and watch a guy trying to say something? um...am I looking at it selfishly? Sure. I learn something about where I might go...down the...down the road...but I am not looking forward to sitting there like the dummy. So.. I’ve been selfish when I say listen, if I can use that time ...selfishly...even if to the extended that I am not getting done what I need to do. But, it’s not...it’s being waste of their...I don’t know. Jeanne has a better judge of that than I am because I am too close to...close to the trees for the forest. But, yes, I do enjoy some of time there... but it’s still six or eight hours out of my life...every...I am sorry, every day, you know, every week. And um...</p> <p>S: But when you are home, you are up on your computer sending messages out to...</p> <p>P :Wasting time, wasting time. S: everybody know, wasting time.</p>	<p>contribution Can see where the leader is going</p> <p>“Loves the people in there, the sweet lovely one or two men. My heart goes out to them because... they just can’t participate. [<i>Saying between his tears</i>]. And it’s...she said it’s almost depressing”</p> <p>He sees his future there.</p> <p>“What good I am doing here. Hey, I am not on that stage. I can use this time...”</p> <p>Talks about one guy in his group: What he says is always good, but he is just withdrawn</p> <p>“And I am thinking, do I need to be there twelve hours a week and watch a guy trying to say something? um...am I looking at it selfishly? Sure. I learn something about where I might go...down the...down the road...but I am not looking forward to sitting there like the dummy. So.. I’ve been selfish when I say listen, if I can use that time ...selfishly...even if to the extended that I am not getting done what I need to do. But, it’s not...it’s being waste of their...I don’t know. Jeanne (wife) has a better judge of that than I am because I am too close to...close to the trees for the forest. But, yes, I do enjoy some of time there... but it’s still six or eight hours out of my life...every...I am sorry, every day, you know, every week. And um...”</p> <p>But when you are home, you are up on your computer sending messages out to....</p> <p>Wasting time, wasting time</p>
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<p>conversation /argument</p> <p>Good experience for him and his pair</p> <p>She thinks he would in the long run get more out of the group at AA : Social workers with knowledge and experience</p> <p>He has enjoyed the things he does because he keeps on telling about it.</p> <p>Some new experience for him</p> <p>They are hilarious</p> <p>Talks about the dinner</p>	<p>P: That again. That's an internal thing. I am giving you the...</p> <p>S: Internal in what?</p> <p>P: that...</p> <p>S: It has to do with your... thoughts. Maybe you should drop out because you need the time</p> <p>P: involvement... I see. Sure.</p> <p>S: but you are not using that time with what you do that.</p> <p>P: Sure. That's a good...</p> <p>I: So...</p> <p>P: anyway...</p> <p>I: So, both of you agree that he has to do something when he has time, so um...but sometimes, both of you feel that that group may not be... for him, but how about the PAIRS program? Because he also mentioned that he is very enthusiastic in giving... he felt like that he gives services to the medical student.</p> <p>S: right. right. uh-huh.</p> <p>I: So, how do you feel that...do you think this is more for him, compared to being in that group?</p> <p>S: um...if it were likely first time...that was a good experience for... both... I think. I think he would in the long run get more out of staying with one he is in, personally for him. He would get more out of it. But, um...the social workers who are trained...and do their jobs beautifully. I met several of them. They have the knowledge and experience which takes to bring out whatever which person has, they know where they are at, of what level of at. And um...Herb has enjoyed the things he does because he keeps on telling about it. And um...some new experience for him, and they do videos of them doing skits or things. And um... you know, they are hilarious... we had... they gave a dinner ...just past...during this month.</p> <p>P: We could go</p> <p>S: um...for their caregivers and patients to be together and to explain to...you know, we don't all, I don't get together with all the caregivers, um...some, but not all. Some of them had their children or grandchildren, but...and... had some level of</p>	<p>That again. That's an internal thing. I am giving you the...</p> <p><u>He seems to tries to cover this issue when he feels that he is in a unfavorable position or he cannot be looked good.</u></p> <p><u>He doesn't seem to agree with his wife but pretends to agree with her simply to end this conversation/argument</u></p> <p>Good experience for him and the paired student</p> <p>She thinks he would in the long run get more out of the group</p> <p>Social workers with knowledge and experience</p> <p>He has enjoyed the things he does because he keeps on telling about it.</p> <p>Some new experience for him</p> <p>They are hilarious</p>
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<p>for the group (both people with Alzheimer's and caregivers) last week Very nice; showed the video Group meetings are usually separate Caregivers could see what their family members with Alzheimer's do during the group meeting by watching the videotape The chance to meet each other's caregivers Nice She expresses sympathy with his feeling: "So... um... probably that group is best thing to happen things so far... but I understand reluctance to... face up to... the future. I understand. It can be depressing and... he wants to be happy." "Right. Depressing is no fun." "No. It's no fun. He is dedicated to entirely...to having fun." "I am dedicated my life to entertainment." I might not be around forever and I'd better do what I can. "My brain is still functioning."</p>	<p>care for the patients. P: Last week, we had this dinner for our group. [still talking] Tuesday, Friday... S: It was very nice. And they showed the video. Ha ha. P: We can't get altogether. S: We would have never seen... P: So, we showed the video. S: Without...the things they do...during that... group meeting. P: We all had the chance to meet each other's caregivers. S: Yeah. That's nice. P: Like we sat with Norman, his wife and daughter who cared for... S: So... um...probably that group is best thing to happen things so far... but I understand reluctance to... face up to... the future. I understand. It can be depressing and... he wants to be happy. P: Right. Depressing is no fun. S: No. It's no fun. He is dedicated to entirely...to having fun. P: I am dedicated my life to entertainment. S: Yes. P: Right. I figured out why not now [a bigger voice]. I might not be around forever and I'd better do what I can... S: He just seem to be getting more desperate. P: My brain is still functioning. I: Yeah. I can see it. P: Right. S: functioning... pretty well I: So, I will just sum up what you said. So, I feel like you enjoyed participating in the PAIRS program because you are very</p>	<p>Talks about the dinner for the group (both people with Alzheimer's and caregivers) last week Very nice; showed the video Group meetings are usually separate Caregivers could see what their family members with Alzheimer's do during the group meeting by watching the videotape The chance to meet each other's caregivers Nice "So... um...probably that group is best thing to happen things so far... but I understand reluctance to... face up to... the future. I understand. It can be depressing and... he wants to be happy." <u>She expresses sympathy with his feeling</u> "Right. Depressing is no fun." "No. It's no fun. He is dedicated to entirely...to having fun." "I am dedicated my life to entertainment." <u>Does he decide not to drop out of his group meeting or the other way (to enjoy himself)?</u> "He just seem to be getting more desperate." <u>Is she saying like this because he decides to drop out of the group and find more enjoyment?</u> "My brain is still functioning."</p>
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<p>It was a happy experience for him.</p> <p>She respects his opinion (that's up to him) Separate herself from the PAIRS program participation (because she has no involvement in the program at all)</p> <p>Willing to participate in the programs like the PAISR program in the future "It's okay for me, because, you know, what else of I got to do." "You got it." Happy to participate in the program again and he recommends it to others</p>	<p>enthusiastic person to help medical...especially medical... future medical...students...medical doctors. And also, it was easy to participate to...with the medical student because he was...he knew that how to respond to him, so it was easy to participate. You [the spouse] can see how he different...he was different based on his feelings, so he was looking forward to meeting him.</p> <p>S: It was a happy experience for him. I: um...Is everything right, so far? S: Yeah. I: The last question is... I don't know I already asked about this but... do you want to participate in the programs similar to PAIRS, or would it be...it would be enough just for one? S: I wouldn't... at the moment because I am... I: For him? S: For him? That's up to him. ha ha...</p> <p>I: What do you think? Do you want to participate in the programs like PAIRS program in the future, if you have any chance?</p> <p>P: Me, yes, but she is busy with. What she is saying is... S: I got to. P: It's okay for me, because, you know, what else of I got to do. S: You got it.</p> <p>P: Ha ha. So, I will be happy to...but I will recommend it...is a follow-up if you are interested, sure. I think it's been a good program, you know, how can you say it wasn't...that one I was in. I understand it is ongoing now because someone just the other day said that people... at the meeting...someone I think it was last night. It doesn't matter, but um...I know this is an ongoing program that some of people in my group now participating . So, it is still functioning. That's good. They need funding, I presume. And um...I am gonna mention</p>	<p>Member checking</p> <p>Willing to participate in the programs like the PAISR program in the future "It's okay for me, because, you know, what else of I got to do." "You got it."</p> <p>I will be happy to (participate in the program again) and I will recommend it to (others)</p>
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<p>He feels proud of himself that his interview with his pair on the television will be used for fundraising</p>	<p>something that I don't think it's out of line to make sure for these two people because it happened that...Jeanne... Michelle brought it up... during my talk about my experience in the Washington...that was the honors program. She said that use my interview on the television... during the fundraising.</p>	<p>Tells that his interview on the television will be used for fundraising: <u>because he feels proud of himself?</u></p>
<p>Because you were very outspoken about it.</p>	<p>S: Right. Because you were...you were very outspoken about it. I: Yeah. I saw he was doing the... S: Did you see that? I: Yeah...at the end of the PAIRS party in... P: Did you see? ...Did you happen to see that? No? Scott couple...</p>	<p>Because you were very outspoken about it.</p>
<p>“I felt flattered.” <i>Tone of voice: Emphasizing because he feels proud of himself</i></p>	<p>S: He's been very enthusiastic about letting it be known that we all better be alert and supportive because it is going to affect people you know or you. P: So...my mention was that...I didn't know but I felt flattered because Michelle said that I know from what you just said. You've seen it. It was an interview of my friend, Scott at channel 4...taped. Michelle said she was using it at a fundraiser. [Emphasizing at the end]</p>	<p>“He's been very enthusiastic about letting it be known that we all better be alert and supportive because it is going to affect people you know or you.” “I felt flattered.” <i>Tone of voice: Emphasizing because he feels proud of himself</i></p>
<p>She feels proud of him too</p>	<p>S: Very good! I: Actually, the research is the only one...Our research is the only one for examining any impacts and your experience and any impacts on you and the family members. So, this is actually... we also have the other future...</p>	<p>Feeling proud of him too</p>
<p>He feels good when he was told that you contribute to the society through the interview/research</p>	<p>P: Ongoing... ongoing. I understand. S: Right. You learn from each thing you do. I: So, you are contributing to the society. I hope so. P: Now, I feel.... even better. S: Ha ha. I: Is there anything you want to add?</p>	

<p>His pair never let that impression although the pair (doctors) are very busy “it was a very giving about his(the pair) time It was a...he knew what he was doing.”</p> <p>Impressed with people who study the brain</p> <p>so fascinating because the brain controls everything you do</p> <p>his wife’s interests in medical things</p> <p>Joke Compliments his wife’s brilliance</p>	<p>Because we are...I think...if there is no adding thing... S: Oh, if this is an ongoing program, how many are involved now? I: Now, nine. S: How many doctors would be involved with the... another... session of the pairs? P: Good question. I: Right now, the ongoing program involves nine pairs as I know, but I don’t know about how many will be involved in the future... S: Uh-huh. I: right now. S: Well. It depends on the request from doctors’ point of view. Are...how many are studying the brain or the nervous system. It would depend on the need of doctors because they are hard-pressed for time. um...but doctor...with him...never...let that...impression...um...it was a very giving about his time It was a...he knew what he was doing..</p> <p>P: I’m...I’m impressed that...people who study the brain...I commend you all...I mean...it is...what other field of study I am sure there are others... S: ha ha...Because it controls everything in the body. P: so fascinating...it just is in your head and it controls everything you do. You know. S: Medical things has always been interesting to me. P: Wow. As I said, medical things are interesting. That’s why I personally... S: That’s what runs your life... P: ...surgeon, brain specialist...and I am gonna switch your brilliance from the encyclopedia to the National Geography. S: ha ha. That’s the story. P: That’s the story. I mean if it’s a picture or the copy S: Yeah. When you can read or look at the picture... P: National Geography and you don’t people who save them I’ve seen them you know stacks of them...They go back</p>	<p>His pair never let that impression although the pair (doctors) are very busy “it was a very giving about his(the pair) time It was a...he knew what he was doing.”</p> <p>Impressed with people who study the brain</p> <p>so fascinating because the brain controls everything you do</p> <p>his wife’s interests in medical things</p> <p>Joke Compliments his wife’s brilliance</p>
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<p>He thinks his disease may progress quickly. His willingness for participation in any follow-up research</p> <p>“I could deteriorate quickly.” <u>Does he want to drop out of the group also because he considers this possibility?</u> Willingness to participate in research Ongoing study is important</p> <p>She means she saw a pretty quick progression of the disease of her dad?</p> <p>Talks about his family history and divorced family</p>	<p>and...you can still pick up the subjects on Africa or you know the Middle East and it's all in the National Geography. And she had read these things like I said when she was two. So, how many of us read at two? You know. and...</p> <p>S: not to ...</p> <p>P: knowledgeably...so yes. I would hope that...Jeanne has a good question...how...what's the degree of interest here at Kansas University and what is the funding available. These always in need research you and I know.</p> <p>I: I actually tried to get more funds for my own research, but it is really hard to get to be funded. After I do my dissertation work based on this study, I will try to find more funds for...to... better develop the program.</p> <p>S: a lot of research</p> <p>P: So, just as a follow-up, you know, your study may include me a year from now... be feel, feel free in your note, just say, Miller is perfectly amenable to being looked again cause I may be... in bad shape six months from now.</p> <p>S: No, no. it's not that fast.</p> <p>P: You know...my age...and so on. I could deteriorate quickly. I am available anytime in your note and say anytime they want to check up on me. Feel free to do so because ongoing study is...I am sure are important.</p> <p>S: Very good for comparisons.</p> <p>P: Yeah. Comparisons where I was a year ago and where I will be in 2018? Anyway.</p> <p>S: I've done a lot of that. Because I got felt pretty soon after I saw my dad needed it. It was so helpful at that time...because I hadn't been around...except my mother had...but she didn't die from it a beautiful man just beautiful... an immigrant from Denmark. And Herb is from Estonia.</p> <p>P: I am from Estonia. I am kind of from broken...</p> <p>S: We are all mixed up.</p>	<p>“So, just as a follow-up, you know, your study may include me a year from now... be feel, feel free in your note, just say, Miller is perfectly amenable to being looked again cause I may be... in bad shape six months from now. “ “No, no. it's not that fast.”</p> <p>“I could deteriorate quickly.” <u>Does he want to drop out of the group also because he considers this possibility?</u> Willingness to participate in research Ongoing study is important</p> <p><u>She means she saw a pretty quick progression of the disease of her dad?</u></p> <p><u>Talks about his family history and divorced family</u></p>
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<p>Talks about perceptions about divorce and cancer a long time ago (hope for less stigma about Alzheimer's?)</p>	<p>P: She was from the divorced...family, and my mother left me when I was ten month old. And I grew up with a...I never considered her a step-mother, my dad remarried. But um...I was in Estonia when I was four years old. And that was 1929.</p> <p>S: Did you have a really good step-mother?</p> <p>P: And...she took care of me, so I only had one mother that I consider a mother not a step-mother. So...um...Today of course people are living in the combined families and they divorce two or three times. We have friends...Nancy has been divorced...</p> <p>S: Three times.</p> <p>P: three times. I have another friend of mine who has been divorced, remarried three times. And um...their combined families living together are just fine evidently. you know.</p> <p>S: as well as they can</p> <p>P: I grow up in 1940s when divorce was like a bad word. People...</p> <p>S: Oh if you had cancer, you didn't talk about. People avoided...</p> <p>P: I didn't hear the word cancer from my family because we are foreign people, foreign in 1930s. It's like you were...you were...ostracized. I mean it was terrible.</p> <p>S: You might be contagious.</p> <p>P: Yeah. yeah. and so... divorce was like...</p> <p>S: I'd better watch my step on that occasion to me.</p> <p>P: Ha ha... anyway, 40s, 50s and then suddenly 70s and 80s, people are divorcing and pairing again and kids are three from here and two from there. Well, you know, who's that semi-example...hate to mention her again, but our son's wife, Karren, brings up her other family. One of them is...woman has been in the service in... in the Iraq. You know her sister or whoever she is...</p> <p>S: Everybody has the mixed...crazy family things. ha ha..</p> <p>P: I am not familiar with that. We have enough... We have four children...</p>	<p>Talks about perceptions about divorce and cancer a long time ago</p> <p><u>To interrupt/discontinue his talking (not to speak behind someone's back)?</u></p>
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<p>“I always say we are also responsible for our own actions.”</p> <p>Answers are within themselves</p> <p>It seems that she says like this thinking about their issue in his want to drop out of the group</p>	<p>S: Every one of them are divorced. Bad choices when they were young. You see them head for the press. Don't go up that cliff and they just walk by the up there.</p> <p>P: We belong to our own cliffs.</p> <p>S: Yep. Make choices...</p> <p>P: I always say we are also responsible for our own actions.</p> <p>S: And the main trouble is ... keep going up the cliff.</p> <p>P: And their problems would people be answers within themselves.</p> <p>S: I am glad to hear that you say that.</p> <p>P: Absolutely.... It's another story.</p>	<p>Talks about their children's divorce</p> <p>“I always say we are also responsible for our own actions.”</p> <p>Answers are within themselves</p> <p><u>It seems that she says like this thinking about their issue in his want to drop out of the group</u></p>
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Themes –Interview 1 (P1: a person with with dementia, C1: wife, I: interviewer)

Themes	Quotes
<p>Supporting his new identity of playing an advocating, helping role</p>	<p>-He felt pleased and satisfied that he was contributing to medical students' learning (better understanding about people with Alzheimer's). One more opportunity to be out for the future and being helpful that enriches his life by feeling a better self.</p> <p>P1: ...so it was interesting because being part of the experiment... I kind of find...ha ha...um... so...egotistic...from ego standpoint...it was neat... it was kind of nice to be chosen...you know... so... it was satisfying to that sample...someone chose me to examine me...you know... who would find that... more than interesting... somewhat fascinating... so it was easy to adjust.</p> <p>P1: I was...I was... I was pleased to feel that I was contributing.</p> <p>I: Oh, so...contributing to what?</p> <p>P1: From his knowledge of...what he was... what he was...um...supposedly... we were paired up... I presumed for him to learn...so from that standpoint I was very... willing...to participate... in the program and um... contributing whatever way I could...to giving him...um...rounded...you know...the impression... what kind of individuals he was dealing with...</p> <p>I: So... you said that you were very happy to... contribute to... for his learning... process.</p> <p>P1: I think so. I hope so. I hope so.</p> <p>I: Was it your expectation to...from the PAIRS program? So did you...did you decide to participate in the program because you wanna contribute to the medical students' learning?</p> <p>P1: Uh-huh.</p> <p>I: Was there any other expectation for you?</p> <p>P1: I think that's a nice...accurate way to put it... I was prepared and um... I was</p>

very happy to... and um...I think you covered it just fine...what you said... I agree with you.

P1: ...I ...I felt that...I felt rather...um...pleased... that the...I was participating in it...

C1: ...And um...it was one more opportunity to be out with somebody, intelligent...and um... for the future and being helpful.

I: Do you think that this...?

C1: That's the pleasure he got.

C1: It's all life. The being an outlet, interesting people.

I: I see. Do you think...?

C1: It fills a void in his life.

I: Could you tell me more about that?

C1: Well. I think everyone has some... feelings...a little trying to better yourself. And these things are enriching to his life. I think that's the main thing...

C1: ...[his group facilitator's name] turns to him...kind of ...in a leadership role almost... because he is more able... to hold his thoughts together and to... be something that the others can kind of hang on to it in that way he is kind of giving the service to the group.

...

P1: ...What she [his wife] said is interesting because...I find that... [his group facilitator's name] leader knows that I can contribute because sometimes...the...the people in the group we are supposed to interchange...come to a point where it is a stand still and I will always jump in and say something just as I had here. And I think [his group facilitator's name] appreciates, says because it moves us the long-lived...because it is easy I can see where the leader is going. And I will jump in if I can, so...now she...[his wife's name] says that it is true. I love the people in there, the sweet lovely one or two men. My heart goes out to them because... they just can't participate. [Saying between his tears]. And it's...she said it's almost depressing...

P1: ... I understand it [the PAIRS program] is ongoing now because someone just the other day said that people... at the meeting...someone I think it was last night. It doesn't matter, but um...I know this is an ongoing program that some of people in my group now participating. So, it is still functioning. That's good. They need funding, I presume. And um...I am gonna mention something that I don't think it's out of line to make sure for these two people because it happened that...[his group facilitator's name]... [a social worker's name at Alzheimer's Association] brought it up... during my talk about my experience in the Washington...that was the honors program. She said that use my interview on the television... during the fundraising.

C1: Right. Because you were...you were very outspoken about it.

I: Yeah. I saw he was doing the...

C1: Did you see that?

I: Yeah...at the end of the PAIRS party in...

P1: Did you see? ...Did you happen to see that? No? [his pair's name] couple...

C1: He's been very enthusiastic about letting it be known that we all better be alert and supportive because it is going to affect people you know or you.

P1: So...my mention was that...I didn't know but I felt flattered because [the social worker's name at Alzheimer's Association] said that I know from what you just said. You've seen it. It was an interview of my friend, [his pair's name] at channel 4...taped. [The social worker's name at Alzheimer's Association] said she was using it at a fundraiser. [Emphasizing at the end]

C1: Very good!

I: So, you are contributing to the society.

P1: Now, I feel.... even better.

C1: Ha ha.

P1: So, just as a follow-up, you know, your study may include me a year from now... be feel, feel free in your note, just say, [his name] is perfectly amenable to being looked again cause I may be... in bad shape six months from now.

C1: No, no. it's not that fast.

P1: You know...my age...and so on. I could deteriorate quickly. I am available anytime in your note and say anytime they want to check up on me. Feel free to do so because ongoing study is...I am sure are important.

-He felt good that he could expose elements of the city to his pair who was not familiar with the city and would not have much time for being around the city otherwise.

C1: ...I believe... the doctor [his pair] was...newer to the area and might not know the city as well. And [her husband's name] felt really good that he can expose elements of the city to him he [his pair] wouldn't have time to go to otherwise. Because, you know, doctors sometimes every minutes in a day is taken. ...

I: How do you think participation in the PAIRS program has affected your spouse and his daily life?

C1: He [her husband] took pleasure in it. He felt he was giving a service... to... upcoming doctors, and understanding something about his environment because he [his pair] didn't grow up in it. He is not familiar with city. Time constraints would make him less knowledgeable. I am sure he had his group... because everybody does. He felt like, [her husband's name] felt like, he was... giving something to a doctor.

-His new identity as a person with Alzheimer's who advocates (I am telling people that I have Alzheimer's. People shouldn't be afraid of associating with people with Alzheimer's. Alzheimer's is a growth industry. We want to get the word out.)

P1: ...I understand that I can be...eventually developing into a more severe case... of the disease. But um, I tell people and then some friends that I am an Alzheimer's patient. And I said that I want to tell you this in case I stop to talk off the wall and you wonder where I am going. You can understand I am an Alzheimer's patient, and I want you to be the first to know about it. So, I want to say to you that I have no qualms about telling people that I have Alzheimer's. It's no...no...no stigma... as far as I am concerned. I am happy to tell people. I know there are... from my meeting at this...the weekly meeting I go. There are people who are reluctant to bring the subject up...or bring it up with friends, or bring it up, you know, with

whomever. And um... That's their... that's the way they feel about it at this time in their life. You know. I guess everybody... meets the... subjects in different ways. And um... from what I learned in my meeting with my group, we meet twice a month evening for two hours. I was just there last night. Tuesday night we meet the first and third Tuesday so, second and fourth, whichever. And we meet for a whole hour. That's a group of 25 people and in that group I learn things... about other patients... who have Alzheimer's. And from what I understand... there is a great reluctance about divulging the affects to other people. But, as you have heard, I am sure... um... the positive side is many these of people have said in the meeting... um... that it is not like a... I grew up in the days of sickness or gonorrhoea or today a... or you know... that it isn't something... you can pass to some people with a shake of your hands... or kiss on the mouth isn't gonna give you Alzheimer's. So, it isn't communicable in that sense. So, people shouldn't be afraid of associating with people with Alzheimer's because it is not like the flu, is it? With the flu, you can get a shot. I understand. And with Alzheimer's, we don't have a shot yet. But, maybe there will be a shot, right? You can get it on the arm or buttock and they will say oh, that will stop it from developing any further. I presume... you... right there. You and you are nice guests here. Your associate... will find a... some preventive cure in your lifetime... in your lifetime. ...

I: Yep. So...

P: That would be nice. [Saying between his tears; with a small voice]

P1: ...Only I am more aware of the fact that it is a disease becoming... I call it... not popular but a um... growth... growth industry. I think Alzheimer's is a growth industry. You can put that down.

I: Yep.

P1: ha ha.

C1: Well. I think any with any disease that you have... um... It's encouraging to you to think that... um... maybe it won't be in time for you, but it would be in time for some who comes after. um... If research is done and things are discovered, cures... come to fruition. It's just a... I think it's a group thing... more than a personal thing. It's... not just for me, what's the matter with me. But, um... there is always a future.

I: So, you... from my understanding, you also wanted to contribute to the society for future... people or families.

C1: Yeah. Either of us (she and his husband). Ha ha.

I: Ha ha. That's great.

C1: It's a... people with cancer... they know that there is a lot of research going on and they know... maybe... just maybe ... they can escape the ravages of the disease. Alzheimer's patients don't have that.

I: So, did you feel that there are not... much research for people with Alzheimer's?

C1: There is never enough.

I: So, you feel that oh, we need more.

C1: Yes.

I: That's great. That's wonderful.

C1: That's one reason for [her husband's name] is so open... like with our movie group of twelve, fifteen, twenty people. It varies. We've been going over 40 years.

...We just thought that's a great idea, you know, before the group discussed the

	<p>movies because we both are interested in movies. And um...so, he got up ...in front of the group one evening when we were meeting and he said I wanna tell you something and he expressed his condition and um...he was okay with it, wanted them to know. So, he's been advocating, I would say.</p> <p>P1: Good. That's a good word, advocate, right. We want to get the word out. Like I said to you, it's a growth industry.</p>
<p>Easy to participate</p>	<p>-Because he enjoyed the sociability and companionship with his pair</p> <p>P1: um...I believe it was ...emotionally satisfying and um...personally interesting. And I found...um... in addition to...a fine companionship... with [his pair's name]... I... found it the challenging...Let's say to... come up with some ideas with two of us to participate together...so um... it was no problem with me personally because I enjoyed the sociability... other people to begin with...So it was easy.</p> <p>-Because of his pair's personality and attitude (so outgoing like himself, so accommodating, and comparable; his pair never gave the impression that he is too busy)</p> <p>P1: ...but it was so easy because he [his pair] was so outgoing and um...he just knew...he just knew what to say and respond...and just a good person...He made it so easy for me to establish that relationship to start with...you know...it was [his pair's name]'s fault...If it was succeeded in everything it was because of [his pair's name].</p> <p>P1: um...I pretty well mentioned it is... best I could... um...that um...it [relationship with his pair] was a two way partnership...you know...and um...there was nothing uncomfortable about it at all. And um...I don't know it's because whether I am also an outgoing individual. ...</p> <p>P1: ...he was so accommodating. You know? He was so easily...as a participant ... in the PAIRS program. They could have not chosen a better person in my opinion.</p> <p>P1: ...it was...for me, such a natural...um... event to participate in... that I found it enjoyable...and um...of interests ...because... there was no...mental or... in my case no physical...thing to that I have to contend with...and the man was a... my pair was the... just so particularly...so...easily adaptable to anything I wanted to do. I think I even thought of going to a baseball game at one point and he would be agreeable to do that...</p> <p>I: Did you feel that [his pair's name] has a shared interest with you? P1: Yes...Yes, he did. That's a nice question. um... yes... um...He is interested...seemed to...be very...comparable...and...he...he seemed to sense the things that I was interested in doing and...he certainly...we seemed to...he seemed to enjoy our time together. He would be best able to answer that question...you know... how he would find his relationship with me. You have to ask him. As far as I am concerned, it was a very pleasant relationship.</p> <p>C1: ...It would depend on the need of doctors because they are hard-pressed for</p>

	<p>time. um...but doctor...with him...never...let that...impression...um...it was a very giving about his time It was a...he knew what he was doing..</p> <p>-Because of pure joy of certain things that he enjoys (he suggested most of the activities, so they did based on his interests)</p> <p>I: What was the best part of the program? You mentioned several activities and what was fun for you?</p> <p>...</p> <p>P1: It was... It was...It was my suggestions most of the time for what we did.</p> <p>I: Oh, yeah.</p> <p>P1: It was...It was a...um...because he said. you know...spend time together...so, I did the things that I enjoy. ...And um... we enjoyed...he was familiar with the artist and who's a traveling exhibit that was going to another city, then to the West-coast. He was going to alert his sister who lives in the West-coast. [his pair's name] is from the West-coast, my paired person. so...I am just...I selected the art gallery and... we went to a theater... that I am familiar with... and um...we went to a play rehearsal which I enjoy... and um... the background you can sit there the audience watch the director... of the play tell the... participants some of the play what to do. and um...[his pair's name]found that... interesting. You know...and same thing we had a tour of the performing art center which was at that time was still fairly new, year two only...having been established here in Kansas city. So...I was invited to a tour... I think that was from the Kansas City Association who offered this tour, background tour...the performing art center. So we did that...and um...and it was mostly my suggestion...what we did because we did things that I enjoyed. So, he didn't say we go to bowling... we go to a...what else people do...go to a movie or have dinner. you know. We just did normal...normal things...for me... That were normal things.</p> <p>I: So, these activities were chosen by you because you...</p> <p>P1: Interests</p> <p>I: Because you...you have interests in these activities.</p> <p>P1: um... I enjoyed it. easy...easy to participate.</p> <p>I: What do you mean by it is easy to participate?</p> <p>P: Easy to participate? I didn't find it...I don't know. [His wife's name] can possibly tell you... elaborate later because at certain times I can't express. um...the pure joy of certain things. [a louder voice] you know? But um...when I say easy, um...I don't know what else to say. I didn't find it uncomfortable...and um...it wasn't even challenging. Be nice to say, most challenging...I might say it was challenging because I was interested in what...where I go from here. But, he was so accommodating. You know? He was so easily...as a participant ... in the PAIRS program. They could have not chosen a better person in my opinion.</p>
<p>Personally interesting because his pair was interesting and different from himself</p>	<p>-Socializing with a medical student, who is intelligent and has knowledge in Medicine, was personally interesting to him because he has got new interest in the brain after he has got Alzheimer's. (He has socialized with people who are doing things he is interested in. Doing volunteering work at the symphony and going to the movie group are the same pattern of being around people who are doing things he is interested in.)</p>

	<p>P1: I think because he...the person with whom I was paired with...was... extremely intelligent and um...most of I...I don't think to myself... um...how would you say? not intellectually but...from academic standpoint... from academic standpoint...um...it was interesting because I...I have no academic training...of the profession that for example you are into... you and I no... um...experience...</p> <p>C1: Well. I think everyone has some... feelings...a little trying to better yourself. And these things are enriching to his life. I think that's the main thing...</p> <p>I: By helping the future medical doctors?</p> <p>C1: By associating with people who are successful...um...by doing the things those people do...um... it's sort of a...it's an encouraging thing.</p> <p>I: Do you think he used to enjoy helping people before he got Alzheimer's or some volunteering work?</p> <p>C1: No.</p> <p>I: But, he became more enthusiastic after he got...?</p> <p>C1: um...He hasn't done volunteer work that I know of. Working for the symphony... it was a part of the same pattern of being around people who are doing things.</p> <p>C1: Pursuing art things and mixing with groups that the...our movie group is made up with professional people. And um...</p> <p>P1: Variety...</p> <p>C1: He learns so much by associating to people like that.</p> <p>P1: I'm...I'm impressed that...people who study the brain...I commend you all...I mean...it is...what other field of study I am sure there are others...</p> <p>C1: Ha ha...Because it controls everything in the body.</p> <p>P1: So fascinating...it just is in your head and it controls everything you do. You know.</p> <p>C1: Medical things has always been interesting to me.</p> <p>P1: Wow. As I said, medical things are interesting. That's why I personally...</p> <p>P1: Whether it's a heart...whether it's a body. I mean she [his wife] knows which bones attached to which bones. I have no idea. I am medically dumb about it...it is a...going through the moon... all the planets...beyond me in more ways than one. ...</p>
<p>No involvement of her in scheduling and doing activities</p>	<p>C1: He [her husband] participated by himself. I didn't participate in any group events because they [he and his pair] were compatible and they were doing what each one...</p> <p>C1: They arranged whatever.</p> <p>C1: ...And um...They arranged their times, meetings according to what appointments [her husband's name] had and what appointments he [his pair] had.</p>
<p>Knowing that he enjoyed</p>	<p>C1: Well. I am delighted that this program exists and so grateful because a research has been done and ...I enjoyed knowing that he is in it because he was always enthusiastic about it and told me about things they did. And um... You know, in general, it was a pleasant experience for him. um...I believe... the doctor [his pair] was...newer to the area and might not know the city as well. And [her husband's</p>

	<p>name] felt really good that he can expose elements of the city to him he wouldn't have time to go to otherwise. Because, you know, doctors sometimes every minutes in a day is taken. ...</p> <p>C1: It hasn't changed my life at all, except that I knew he was enjoying himself.</p>
<p>Continued contacts with his pair after the program was ended</p>	<p>I: ...Are you still contacting with [his pair's name] after the program was ended?</p> <p>P1: Yes. I have a couple of times, yeah. In fact, probably should get to... reappear probably be gone for holidays, you know. And I forgot it about a month or more... If something came up, I will allude him to...and we could do it because he was tied up and it was...It was another social occasion or... it was something...</p> <p>C1: [His pair's name] had made it clear that [her husband's name] can call him [his pair] any time.</p> <p>P1: Yes. Yes.</p> <p>C1: and they can do something together if you want to...</p>
<p>His value and belief</p>	<p>-Keep mind busy as a person with Alzheimer's (learned/forced value?)</p> <p>P1: I've been told Alzheimer's patients should keep busy and I use this as an excuse [of going to art galleries] for my wife. And say oh, I've got to, it will help my mind. you know. I need to be busy because it feels keep my mind fresh.</p> <p>P1: So, it [going to his movie group] is another way to keep your mind busy... which we are supposed to do...we are patients...of Alzheimer's.</p> <p>P1: I am... busy or pretend to be busy.</p> <p>-That's a lot of fun but I don't know if I need to be there (I want to spend my time for myself to enjoy myself)</p> <p>P1: Yeah, stimulating. We had word games the other day where she gives us words we have to work them into a conversation and I had a lot of fun of that. And um...and also some of these are videotaped. And then we will see it a week or two later, and this is historical. It's great fun! Yeah.</p> <p>P1: So, this is our own group. It was challenging, so the facilitator, the woman who does videotaping, just gives us these words or she will give us situation... where we have to pretend to where...on television, we have to sell... some magic potion and that has to cure everything and it was a lot of fun...stimulate people in our group to try to work on their imagination. It is interesting because in this small group of talk people, um...some of them are fascinating to me because they are giving either script and they can...words are meaningless or they can't quite comprehend what they were supposed to be doing or they will speak as I am speaking [slowly talking, voice with anger].</p> <p>C1: carefully... because the words are hard for them. The thing is that my husband is probably the least affected of this...um...group that he is talking about that takes so much time.</p> <p>P1: uh-huh.</p> <p>C1: And he feels like, well. I'm...I'm not that far gone.</p>

P1: uh-huh.

C1: and I don't really need to be here.

P1: uh-huh.

C1: And he is thinking about dropping it which is probably the most useful group that he is in. um...but...I think it's depressing to him...to see or the other patients has gone to.

P1:uh-huh.

C1: And I think he is... wanting to avoid that feeling and...kind of...

P1: I love the people in there, the sweet lovely one or two men. My heart goes out to them because... they just can't participate. [Saying between his tears]. And it's...she said it's almost depressing...

C1: He sees his future there.

P1: What good I am doing here. Hey, I am not on that stage. I can use this time waiting until... clark starts to contribute or one of our guys name is [name]. He is such a sweet guy ...never...always sits there like this. He can't...but he's a...when he's stimulated... when he has something to say. What he says is always good, but he is just withdrawn. You know? And I am thinking, do I need to be there twelve hours a week and watch a guy trying to say something? um...am I looking at it selfishly? Sure. I learn something about where I might go...down the...down the road...but I am not looking forward to sitting there like the dummy. So.. I've been selfish when I say listen, if I can use that time ...selfishly...even if to the extended that I am not getting done what I need to do. But, it's not...it's being waste of their...I don't know. My wife has a better judge of that than I am because I am too close to...close to the trees for the forest. But, yes, I do enjoy some of time there... but it's still six or eight hours out of my life...every...I am sorry, every day, you know, every week. And um...

P1: I grew up in the entertainment industry. What my wife was saying might want to confirm...she said very very well. It is twelve hours a week I have things to do upstairs and it's a mess...my...I worked at home... last four years in my own business since 1976 when I established my own company in the cable television fields called cable films...

P1:...there's still twelve hours a week ...every week, twelve hours...it takes going and coming. And let's say thirteen hours...it's a... what twenty-six...thirteen hours every week four weeks out of a month every month. That's a lot of time... and um.. she...

-It's good that I got Alzheimer's in my old age, so I don't have to suffer so many years.

P1: I am in what I call, what I've been told as early stage...um... and um... obviously I at the...my age...I learn something these meetings as I go to...this is the side...for you. You too already know. The older you are and you get this, the better off you are because you are not gonna live so long anyway. So, you don't have to suffer so many years if I were seventy years old...or sixty-five, and have Alzheimer's, you know, God knows... what my life would be like in ten years...but I don't project myself to living to a hundred, so chances are...my...my disability with Alzheimer's will be limited by just how long the disease lasts and how long my physical...I may have a heart attack tomorrow and I am done.

-No need to hide my diagnosis to people around me

P1: I understand that I can be...eventually developing into a more severe case... of the disease. But um, I tell people and then some friends that I am an Alzheimer's patient. And I said that I want to tell you this in case I stop to talk off the wall and you wonder where I am going. You can understand I am an Alzheimer's patient, and I want you to be the first to know about it. So, I want to say to you that I have no qualms about telling people that I have Alzheimer's. It's no...no...no stigma... as far as I am concerned. I am happy to tell people. I know there are... from my meeting at this...the weekly meeting I go. There are people who are reluctant to bring the subject up...or bring it up with friends, or bring it up, you know, with whomever. And um...That's their...that's the way they feel about it at this time in their life. You know.

-Hope for the cure someday

P1: And with Alzheimer's, we don't have a shot yet. But, maybe there will be a shot, right? You can get it on the arm or buttock and they will say oh, that will stop it from developing any further. I presume...you... right there. You and you are nice guests here. Your associate... will find a... some preventive cure in your lifetime...in your lifetime. That would be nice. [Saying between his tears; with a small voice]

-Alzheimer's is a growth industry (self-growth and society's growth)

P1: Another words of... my life is basically continued ...same way it was. Only I am more aware of the fact that it is a disease becoming... I call it... not popular but a um...growth...growth industry. I think Alzheimer's is a growth industry. You can put that down.

P1: There are people who are reluctant to bring the subject up...or bring it up with friends, or bring it up, you know, with whomever. And um...That's their...that's the way they feel about it at this time in their life. You know. I guess everybody... meets the... subjects in different ways. And um...from what I learned in my meeting with my group, we meet twice a month evening for two hours. I was just there last night. Tuesday night we meet the first and third Tuesday so, second and fourth, whichever. And we meet for a whole hour. That's a group of 25 people and in that group I learn things... about other patients... who have Alzheimer's. And from what I understand... there is a great reluctance about divulging the affects to other people. But, as you have heard, I am sure...um...the positive side is many these of people have said in the meeting...um...that it is not like a...I grew up in the days of sickness or gonorrhoea or today a...or you know... that it isn't something... you can pass to some people with a shake of your hands... or kiss on the mouth isn't gonna give you Alzheimer's. So, it isn't communicable in that sense. So, people shouldn't be afraid of associating with people with Alzheimer's because it is not like the flu, is it? With the flu, you can get a shot. I understand. And with Alzheimer's, we don't have a shot yet. But, maybe there will be a shot, right? You can get it on the arm or buttock and they will say oh, that will stop it from developing any further. I presume...you... right there. You and you are nice guests here. Your associate... will find a... some preventive cure in your lifetime...in your lifetime. That would be nice. [Saying between his tears; with a small voice]

	<p>P1: Good..that's a good word, advocate, right. We want to get the word out. Like I said to you, it's a growth industry.</p>
<p>Her value and belief</p>	<p>-Keep mind busy as a person with Alzheimer's: She thinks the group activities at AA does anything that will be stimulating and his group is the most useful/helpful group to him.</p> <p>C1: Anything that will be stimulating.</p> <p>C1: And why? I don't know. That's [activities you do at the Alzheimer's Association] the only thing that you do that exercises your mind.</p> <p>C1: And he is thinking about dropping it which is probably the most useful group that he is in. um...but...I think it's depressing to him...to see or the other patients has gone to.</p> <p>C1: But it is taking his time...and... it's more and more now...is a...not being taking...to do any work... but to enjoy himself. [Saying carefully]</p> <p>C1: But, you have not put it to work. You haven't used that time...when you weren't doing that...to do your work.</p> <p>C1: But when you are home, you are up on your computer sending messages out to...</p> <p>P1: Wasting time, wasting time.</p> <p>C1: Everybody know, wasting time.</p> <p>C1: So... um...probably that group [group at Alzheimer's Association] is best thing to happen things so far... but I understand reluctance to... face up to... the future. I understand. It can be depressing and... he wants to be happy.</p> <p>P1: Right. Depressing is no fun.</p> <p>C1: No. It's no fun. He is dedicated to entirely...to having fun.</p> <p>P1: I am dedicated my life to entertainment.</p> <p>C1: Yes.</p> <p>P1: Right. I figured out why not now [a bigger voice]. I might not be around forever and I'd better do what I can...</p> <p>C1: He just seem to be getting more desperate.</p> <p>P1: My brain is still functioning.</p> <p>-Hope for the cure someday and being useful</p> <p>C1: Well. I think any with any disease that you have... um...It's encouraging to you to think that...um...maybe it won't be in time for you, but it would be in time for some who comes after. um...If research is done and things are discovered, cures... come to fruition. It's just a... I think it's a group thing...more than a personal thing. It's... not just for me, what's the matter with me. But, um... there is always a future.</p> <p>C1: My mother died with Alzheimer's, not from it. My uncle and brother died with</p>

	<p>it. um...My stepfather whom I cared for four years...he died from...not the Alzheimer's, but I took care of him through his illness. So, I have some acquaintance with it. It's a...people with cancer... they know that there is a lot of research going on and they know...maybe...just maybe ...they can escape the ravages of the disease. Alzheimer's patients don't have that.</p> <p>C1: He's been very enthusiastic about letting it be known that we all better be alert and supportive because it is going to affect people you know or you.</p>
<p>His strategy</p>	<p>-In understanding questions : Saying/repeating the question helps his understanding and saves time?; checking the question again to make sure if he understood the question correctly</p> <p>-In remembering things: Using cue ("Yes. I have tickets to symphony. And the...I was invited."), motivating/encouraging self ("I try to recall. I will.")</p> <p>-In accepting/coping with Alzheimer's</p> <ul style="list-style-type: none"> • He feels relieved that he has got Alzheimer's in his old age (compared to seventy or sixty-five) and his disability with Alzheimer's will not be lasted so long • He acknowledges that he can be eventually developing into a more severe case of the disease • He realizes/accepts his changes in conversations due to Alzheimer's • He discloses his diagnosis to people and some friends because telling people his diagnosis helps people understand him better • No hesitation in telling people his diagnosis, thinks there is no stigma about Alzheimer's • Happy to tell people • Understands/accepts why people in his group are reluctant to tell their diagnosis to friends or others ; disease as a process to cope with where each individual stands and feels differently • The positive side of Alzheimer's as a no communicable disease. People shouldn't be afraid of associating with people with Alzheimer's because it is not like the flu, is it? • I am busy or I pretend to be busy <p>-Working as team with his wife in talking <My wife can tell you better or can confirm> P1: I go to art gallery often. My wife can confirm. P1: I don't know. My wife can possibly tell you...elaborate later because at certain times I can't express. P1: I understand the question. um... I can't say, maybe my wife can tell you better... later when you want to...review some of things. P1: And um...it hasn't affected me that I know of...particularly...and so...my wife who is very intuitive about our life together... can maybe tell you if it has had effects.</p> <p><Agrees with what his wife said and adds his thoughts>. P1: Good...that's a good word, advocate, right. We want to get the word out. Like I</p>

	said to you, it's a growth industry.
Her strategy	<ul style="list-style-type: none"> -Help him to be an agent in talking ("the information is all from him"; to help him get the attention, respect his opinion, and expect the same respect to him from the interviewer?) -Help him understand the question better -She has a plan for the future: Prepared for the future when he cannot drive "Yeah. If I had been driving everywhere, then I would've said, oh, good! Somebody else is doing this. Because I know that's what comes eventually. ...So...I am sort of prepared for the future..." -She respects his opinion (that's up to him)
Impact of dementia	<ul style="list-style-type: none"> -Difficulty in understanding a question (one time) -Missing a question P1: I am missing the question again. -Difficulty in remembering P1: The name [an artist's name] escapes me now because of my Alzheimer's [a louder voice] (Frustrated or mad?) P1: I am trying to remember now because it's...I can blame Alzheimer's... to say that. -Takes time to think and express -Digressed from the main subject -Fear for his progression of disease and future? <Express his shared feeling by using what people in his group said in the meeting?> P1: And my guys who in there are often very complementary saying they don't know where they will be without their caregiver. They are talking about their wives. And one fella in particular last night was saying either, where he would be if it wasn't for his wife... taking care. [became tearful at the end]" "They are...they are very important to patients... the caregiver... the great responsibility... so...she... P1: What she said is interesting because...I find that... Jeanne leader knows that I can contribute because sometimes...the...the people in the group we are supposed to interchange...come to a point where it is a stand still and I will always jump in and say something just as I had here. And I think Jeanne appreciates, says because it moves us the long-lived...because it is easy I can see where the leader is going. And I will jump in if I can, so...now she...Jeanne says that it is true. I love the people in there, the sweet lovely one or two men. My heart goes out to them because... they just can't participate. [Saying between his tears]. And it's...she said it's almost depressing... P1: I could deteriorate quickly. -Alzheimer's hasn't affected his participation in/motivation for leisure and/or social activities
His expression of his self-identity and shared identity with his wife	<ul style="list-style-type: none"> -A member of the Kansas City Symphony Association -An outgoing person - I do not like activities in sitting -I belong to a group of motion picture people who like movies (for many years): a leisure-based social group

	<ul style="list-style-type: none"> -Motion pictures are great interests to me and I love to go to the movies -Still have things upstairs in case he has clients in other countries (hope for working again?) His work: old-fashioned; he had to stop working not due to Alzheimer's but due to outdated in terms of technology -A long talk about his past profession/work experiences without pause
Her expression of her self-identity and shared identity with her husband	<ul style="list-style-type: none"> -We are going to our movie group over 40 years we because we both are interested in movies -I belong to a couple of quilts and I mostly go to the meeting when I am feeling up to it, less and less. - I had to give up making pottery because of my arthritis. I miss doing the pottery. - And then for thirty-six, thirty-seven years, I've been part of my weavers guild and we have a booth for Renaissance fair. You are familiar with Renaissance fair? And I sell my fiber out there with the weaver's group. It's a lot of fun. And I am glad to be able to done it that long. -Her interests in medical things "Medical things has always been interesting to me." -Her experiences as a family caregiver of her family members who had Alzheimer's
His expression of his new identity (related to Alzheimer's)	<ul style="list-style-type: none"> -No hesitation in directly saying that he has Alzheimer's -No hesitation in describing himself as a person with Alzheimer's -“We (the couple) want to get the word out. Like I said to you, it's a growth industry.” -He feels proud of himself that his interview with his pair on the television will be used for fundraising. “I felt flattered.” -He feels good when he was told that he is contributing to the society through the interview/research “Now, I even feel better.” -His new interest in the brain: “I'm...I'm impressed that...people who study the brain...I commend you all...I mean...it is...what other field of study I am sure there are others...”so fascinating...it just is in your head and it controls everything you do. You know.” “Wow. As I said, medical things are interesting. That's why I personally...” -Happy to help research
Her expression of his new identity (related to Alzheimer's)	<ul style="list-style-type: none"> -She talks about the story about his disclosure about his diagnosis to the movie group. “And um...so, he got up ...in front of the group one evening when we were meeting and he said I wanna tell you something and he expressed his condition and um...he was okay with it, wanted them to know. So, he's been advocating, I would say.” -“He's been very enthusiastic about letting it be known that we all better be alert and supportive because it is going to affect people you know or you.” She feels proud of him too “Very good!”

Note

He remembers his pair's name and activities (good memory); “My brain is still functioning.”

Activities: Backstage tour of the art performing art center, anniversary at the Thomas Benton home, a play rehearsal, theatre, eating out, symphony

The way of talking in dyadic interview (second part): actively working as a team in talking (almost alternating talking/adding each other's talk)

A little bit of argument between the couple related to the issue (his want to drop off his group at AA)

The couple (both) likes talking (talkative). They talk a lot about other things not related to the PAIRS program (e.g., their divorced family history,)

He compliments her wife many times during the talk. His compliments often made the interview off the track.

Interview 2.

I: Interviewer

P: Person with dementia

S: Spouse of the person with dementia

- Descriptive comments: focused on describing the content of what the participant has said, the subject of the talk within the transcript (normal text)
- Linguistic comments: focused on exploring the specific use of language by the participant (*italic*)
- Conceptual comments: focused on engaging at a more interrogative and conceptual level (underlined)

Emergent Theme	Original Transcript	Exploratory Comments
	<p>I: I am a researcher of the PAIRS program that pairs people with early stage Alzheimer’s and medical students for social gatherings at the University of Kansas Medical Center. You participated in the PAIRS program from September, 2013 to April, 2014. I really appreciate that both of you agreed to do the interviews. Your responses are confidential and will not be shared with other people...participants in the program. Your name is not used for this audio recording by assigning you a study number. This interview is to know about your experience of participation in the PAIRS program and your thoughts about its’ impacts on you and your daily life. There are no right or wrong answers. The interview will take about between 30 minutes to 1 hour. Before we start the interview, could you tell me activities you or your spouse did with the</p>	

<p>Spouse's strategy (to help him understand and answer the question)</p> <p>Spouse is very aware of his cognition/language ability</p> <p>He doesn't say he cannot remember the activities and he lets his wife tell the activities instead of him</p> <p>Impact of dementia</p> <p>Use of "We" instead of "He" (because of her involvement in the program/activities)</p>	<p>medical student during the PAIRS program period? We will talk about the details later, so please tell me activities just briefly. Can you tell me any activities...you did...?</p> <p>S: Do you remember any special you did with Andrea?</p> <p>P: Um... you can pick up that.</p> <p>S: Well. We went to the Zoo...um...we went to some theatrical programs, one with the Coterie Theatre, the one act other... Romeo and Juliet at the Repertory Theatre. We went to a Kansas City Symphony and we went to the Nelson Gallery. I think that was everything.</p> <p>I: So, for the first part of the interview, I would like to hear only from you (<i>looking at the person with dementia</i>), and then I will give both of you time to talk later (<i>looking at the couple</i>). Because this interview has to be done in the same way for everyone, I'd like to hear from you without your help or involvement in his talks for the first part. It's up to you if you want to do something else and come back later for the second of the interview. If you want to stay for the first part of the interview, you are welcome to do that, but please do not talk during the first part of the interview. What would you like to do?</p> <p>S: Okay, but before we go on, we also went out for some meals.</p> <p>I: Uh-huh. Okay. Thank you so much. So, do you want to stay here?</p> <p>S: Okay.</p> <p>I: Do you have any questions before we start the interview?</p>	<p><u>Her voluntary involvement (she is very aware of his language ability)</u></p> <p><u>He doesn't say he cannot remember the activities and he lets his wife tell the activities instead of him (He does not remember the activities based on the other parts of the interview)</u></p> <p><i>Use of "We" instead of "He"</i> Activities: We went to the zoo, theatrical programs (twice), Kansas City symphony, Nelson Gallery</p> <p>She remembers one more activity (eating out) She chooses to stay for the first part of the interview</p> <p>She asks a question whether this interview is for the PAIRS program or</p>
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<p>He doesn't seem to remember anything related to the PAIRS program?</p> <p>This seems to be the way he usually does: When he doesn't remember, he does not express his difficulty in memory and he lets his wife do instead of him (to cover his memory difficulty?)</p> <p>He talks about his work before retirement (working as a pediatrician) Does he talk about his work experience because he cannot remember his pair /the things they did with his pair or because he forgets the question (assumption based on his short-term memory)?</p> <p>Self-identity related to his past work</p>	<p>S: No, no. Oh, yes. Is this for your PhD thesis or is this for the...study to the PAIRS program? I: um...both. S: Oh, both. Okay. I: So, this will be used for...I will use the data for my PhD dissertation, so... that helps me to complete my PhD also helps the development of a better PAIRS program. S: Okay. I: Do you have any questions before we start the interview? P: No I: Are you ready for the interview? S: Yes. Go ahead.</p> <p>I: So... could you tell me about your experience of participation in the PAIRS program? P: My...what...my practice? I: Oh, your experience of participation in the PAIRS program that you did with Andrea? S: Uh-huh. P: Oh yeah. Do you want to say something? S: Uh-uh [expressing no] I: This part is only for you...so...</p> <p>P: Okay. Well. I've been retired for sometime and my... my involvement ... has been... um... much less than I have been....my...um... before I retired...and my responsibilities in the past as a pediatrician working with the United States Federal...office of health and human service...I was giving with children and mothers. My title was a...um....originally I...as a pediatrician I was retired to be...working with a...um...Kennedy, the president Kennedy two or three time mental retardation problems in children. And then we focused broader on special needs children and then broader than that, mothers and</p>	<p>the interviewer's PhD dissertation</p> <p><u>Does he understand the question or does he remember who Andrea is?</u></p> <p><u>This seems to be the way he usually does: When he doesn't remember, he does not express his difficulty in memory and he lets his wife do instead of him (to cover his memory difficulty?)</u></p> <p>He talks about his work before retirement (working as a pediatrician) <u>Does he talk about his work experience because he cannot remember his pair /the things they did with his pair or because he forgets the question (assumption based on his short-term memory)?</u></p>
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<p>Expression of identity of himself and the couple: both are music-lovers, so they have been going to the Kansas City Symphony since 1960s</p> <p>He seems not to remember his pair and the experience with his pair</p> <p>Expression of identity related to family (families involved in medicine and music)</p> <p>Interrupting because he was excited to talk about their past experience/story he remembers well?</p>	<p>children, the health care. So, that's been my...my experience for a number of years when I retired a few years back.</p> <p>I: Yeah. Sounds interesting. And...so... your wife said that you went to...went to the zoo and you went to the theatres or you ate foods at the restaurant. And some...went to some gallery with Andrea. P: Uh-huh. I: So, do you have any...could you tell me any...any...any experience?</p> <p>P: Oh, we've been maintaining...um...both of us are music-lovers so that's why we did...Kansas City Symphony...and we've been doing that for...since... way back to the 60s.</p> <p>I: Oh, so...so...going to that symphony was...</p> <p>P: We were both...um...graduates of University of Minnesota. And um... my father was...is professional...was a professional musician, so...my wife...my father and I was very internal medicine, but he was very active in playing the music. So that...I think that got us together. Not Medicine... but um... liked, we liked each other because of things like music I remember that why I did I get marry to him...doctors, medical doctors...my...daughter ...then I...that's the...my friends...her brothers...my friends and me, we got to know each other very well from... um...where we met in the University of Minnesota and then following that. So, families have been involved with the...Medicine. And um...I am a pediatrician. My... brother-in-laws... three of them are internal Medicine people. A lot of Medicine in...in the family. My wife is a doctor...um...PhD in Mathematics. So, we have those kinds of</p>	<p>Mentions the activities to remind him of the activities</p> <p><u>He seems not to remember his pair and the experience with his pair</u> Talks about himself and his wife: both are music-lovers, so they have been going to the Kansas City Symphony since 1960s</p> <p><u>Interrupting because he was excited to talk about their past experience/story he remembers well?</u></p> <p>Talks about his father (who was involved in Medicine but very active in playing the music)</p> <p>He and his father liked each other not because of Medicine, but because of the same interest in music</p> <p>His family members (including himself, his father, brother-in-laws, daughters, son) have been involved in Medicine (Internal Medicine especially)</p> <p>“So we have those kinds of common things together”: his wife is a doctor (not a medical doctor but she has a PhD degree in Mathematics)</p>
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<p>Impact of dementia</p> <p>Expression of self-identity related to his past work and family</p>	<p>common...common... things together. And then, my son is a... a physician...Internal Medicine and um... my daughter...one of my daughters... my daughter is a...works for the Kansas City Star... as an author. And my grandkids are...one of the youngest has just got married and...our family is...everybody is married and then...I will see...I will see grand-grand children someday.</p> <p>I: Wow. All medical... people...</p> <p>P: Our family is a...taking...as I told others in the past ...we got...I got to meet... my wife and I met together...because of Medical School. So, I was invited over to... my wife's brother to parties for the medical students. She was...her dad was a prominent cardiologist... for the Medicine and Medicine and Medicine. So, it was, as I said earlier, that is a...my brother-in-laws and my wife's brother were all Internal Medicine doctors. I am a pediatrician also.</p> <p>I: But, at the same time, you have some interests. Did you have some interests in arts because you said that...</p> <p>P: Minneapolis, Minnesota, Minneapolis. We've been...it was a...in the Twin Cities of Minnesota...of the arts...and then of...I probably mentioned this for that...but there's a...my three brother-in-laws ...are all physicians. My father-in-law is a physician. So, we have all these physicians and I am...I've never went into to private practice like my brother-in-law. I worked...I got my first...first...responsibility after getting out of the medical school to be... working in public health. And then I became play for the federal department of health and human services. Let's call it back in...in</p>	<p>Talks about the other family members (daughter, grandkids)</p> <p><u>He seems to be talkative (likes talking) when he talks about things he remembers</u></p> <p>Talks about the story of how he and his wife met</p> <p>He met his wife because of Medical School (his wife's brother and father involved in the Medicine)</p> <p><u>Does he keep talk about his/his wife's family members' story because he feels proud of their family's involvement in Medicine?</u></p> <p><u>Interrupting because he is excited to talk about the past experiences he remembers well?</u></p> <p>"I probably mentioned this for that...": He is not sure whether he already talked this or not (short-term memory) Keep talking about his family's (his wife's family's) involvement in Medicine (three brother-in-laws and father-in-law)</p> <p>Talks about his work experiences (after he gets out of the medical school)</p>
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<p>She left</p> <p>Expression of self-identity related to his past work</p>	<p>the...Department of Health and Education Welfare. that's all. A few credits. I spent my life...with the...I work with the federal government.</p> <p>[The spouse left and started doing some house chores while he was talking]</p> <p>I: So, you are quite familiar with talking with some people who are in the medical area, right?</p> <p>P: Yeah. I've been...a consultant for the department of KU's Medical School and also a consultant of Children's Mercy Hospital with...involved with UMKC'S Medical...So, I had a...dealing with medical doctors in addition... because of my interests in the children and others...maternal and child health... federal program. Nutrition was a part of our lives and like a food pantry at Harvester's here's something I worked with. The university of Missouri's nutritional program I worked with them...and then KU and then University of Nebraska and then University of Iowa. And then for a while when I was a younger...consultant with University of Minnesota, and University of Iowa, University of Nebraska. So, I had all this...that's kind of responsibility being a federal employee, medical doctor in addition...to deal with the faculty...the medical schools. Then, with my interest...in a broader...children...I mean with programs like the nutrition and social work and...um...we had much broader thing given...when you care special needs children you can be dealing with physical therapy and occupational therapy. So, some of big change in the Kansas City area, for example, the Children's Mercy Hospital expanding greatly in the 60s and um... we worked with KU, as I</p>	<p>She left. <u>It may be hard for her to stay there because she had to see her husband's difficulty in answering the question.</u></p> <p><u>When considering his life experience and past environment (all medical people around him), meeting with/talking with a medical student (his pair) could be interesting to him.</u></p> <p>Talks about his past work experience (working as a consultant, dealing with medical doctors, his interests in children and maternal and child health, nutrition)</p> <p>responsibility being a federal employee, medical doctor</p> <p>Keeps talking about his broad work experience with several universities</p>
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<p>Feeling proud of himself in work?</p>	<p>mentioned earlier, at the medical school there and also um... University of Nebraska, University of Iowa, University of Minnesota...as a pediatrician trying to stimulate the...working with a training program... pediatricians and um related programs... special needs program let us into...dealing with the pediatric neurologist, dealing with a ...special education, nutrition, social work...</p> <p>I: Wow. That's a lot. P: A broad thing...maternal job...That's a... I: That's nice. P: My work when I was a...federal...still I have a strong advocacy because she was...any professions that were interested in mothers and children...and special needs kids. I: Wow. That's... P: My first job was titled... under the president of Kennedy of original program mental retardation. That was started way back in the ...50s. That was my first title and so... [The spouse was asked to come back for the interview] I: So, it's almost...um...it's winter time. So, do you do any specific things for fun or any... during the winter time?</p>	<p>and several disciplines</p> <p><u>Who is she?</u></p> <p>Talks about his first job title (<u>feeling proud of himself?</u>)</p> <p>I asked this question to divert his attention from talking about his work experience to talking about more casual, daily life</p>
<p>Impact of dementia (keep talking about his work experience regardless of question)</p> <p>Identity related to his past work</p> <p>Keep talking about what he did</p>	<p>P: Well. The one of the things I did for three years...it was with the Harvester's...a nutrition program and Kansas city and then we working with the...well, we had a food drive but um...the mission was food drive. What's the quality of the food? Is this appropriate? What's happening people with be taking...um... I use the word junk food...and the donation, so we...that made a committee of Harvester's here in Kansas city so I...do a... development of food... food...analysis food, food...for children and pregnant women. So, we</p>	<p>He keeps talking about his work experience/nutrition project (he does not answer/ignore my question) <u>is this because he wants to keep talking about his work experience or is he too focused/obsessed/excited to talk about his work experience? or because he feels comfortable in talking about his past experiences he remembers well (to cover his difficulty in remembering)?</u></p> <p>He keeps talking about what he did (<u>he does not talk about how he felt when he did these things</u>)- he is not an</p>

<p>Speaks with smile and joy because of feeling proud of his achievement in work?</p>	<p>scheduled of this. S: Excuse me. I have another visitor. P: we talked about the...getting nutritious food. I worked with a number of dietitians and nutritionists dealing with children and pregnant women. So, that was a big step getting involved with a set of people donating whatever they had... junk food in their kitchens because...we said you want to give something...food to poor people targeting at children, mothers...make sure they are nutritious, so to me... here in Kansas City. This is what the nutrition. Well, of course, but the big federal programs and state programs dealing with nutrition. You got involvement of the nutritionists from... who working at KU and at the Children's Mercy Hospital, but it was more...more getting the stimulus there...let's make sure babies and pregnant women are getting quality food and at the same time, that was happening the federal government came around us. Hey, let's sell...the nutritious program for children...woman, infant, child programs from the US. We were working, coordinating together the maternal child health...with the food people. Some people said...give them anything. Our committee...four state the nutrition. We said let's show...the public and the private sector what nutritious foods are... that's supposed to...here. That's called ... [Speaking with smile and joy at the end]</p> <p>I: Yeah. That's great.</p> <p>P: So, anyway. We...when we viewed this back in the middle 60s and oh my god, everybody is...throwing out their garbage. We went to the board. So, that was...that was a big change that happen dietitians nutritionists sitting with us and...helping a plan for nutritious food. So, we were handing</p>	<p><u>expressive person in terms of his emotions?</u></p> <p>Keeps talking about his nutrition project (giving healthy foods to children and pregnant women)</p> <p>Speaks with smile and joy at the end <u>because of being proud of his achievement?</u></p> <p>Keeps talking about his nutrition project</p>
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<p>Talks/ greets with a parcel delivery guy about weather</p> <p>Excited about upcoming Christmas holiday?</p> <p>Loves Christmas time because of happy memories with family?</p> <p>Keep talking his nutrition project</p> <p>That was part of my</p>	<p>out pamphlets to...to various food banks and say here's a what you were going to be having for... if you had...pretty much tight for mothers and children but at the same time...um...we were...flying a lot of ... in quality became important instead. That's good. Let me empty my kitchen... that junk... we stopped the junk food.</p> <p>I: That's hard. That's hard. Ha ha.</p> <p>P: quality is such a thing for pediatricians and nutritionists.</p> <p>I: So, I will start the second part of the interview.</p> <p>S: I found it.</p> <p>I: Thank you so much. I will see it after we finish the interview.</p> <p>[door bell]</p> <p>S: Oh. Excuse me.</p> <p>P: Popular today. Where are we?</p> <p>I: Yeah. We...</p> <p>A parcel delivery guy: Hi, sir.</p> <p>P: Hello</p> <p>A parcel delivery guy: How are you?</p> <p>P: I am fine today. Are you warming up?</p> <p>A parcel delivery guy: Oh, well. You know. We are actually starting to be warming up.</p> <p>P: Well. This is a...a day or two before the coldest...shown as... day of the year. Then, become to the coldest of the year.</p> <p>I: Yeah.</p> <p>A parcel delivery guy: That was supposed to snow I think.</p> <p>P: That's because it's a...I use it...because of Christmas. We would not have any cold in. [speaking with a higher voice because of joy?]</p> <p>A parcel delivery guy: Oh.</p> <p>P: But have you got all your presents already waiting for the... I love this time because I will say oh, here's something nice for children, candy?</p> <p>No... well, anyway. Was that giving you advice to um...people who want to give children and pregnant women quality foods, not just a school's from</p>	<p>Because she came back</p> <p>Another visitor (a parcel delivery guy)</p> <p>Talks with the parcel delivery guy (greeting)</p> <p>Tells that today is a day or two before the coldest day of the year. <u>Does he check the calendar every day? or just knowing that today is very close to the Christmas holiday?</u></p> <p><u>He seems to be excited about the upcoming Christmas holiday.</u></p> <p>"I love this time (Christmas) because I will say oh, here's something nice for children, candy? No" <u>Is he saying like this because he enjoys spending the family time (children)? or happy memory?</u></p> <p>Keeps talking about his nutrition</p>
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<p>life : stimulate quality food</p>	<p>what's in the trash can. That was...that was my part of my life... stimulate...quality food...and that came from a number of excellent...public health and nutritionists...hospital nutritionists...about here something If you are pregnant and your baby is born, what fit programs like the women and child and nutrition programs for pregnant women and their infants. I worked for that and then I...we quickly got the experts...nutrition and...people helping with the... [The spouse talked with the delivery guy for a second and the guy left] P: Where are we? I: We are waiting for her to do the second part of the interview. S: Yeah. Sorry. He was supposed to come between 1:30 and 2, so I said that would be okay. I: This will be busy time because it's around Christmas. S: Okay. All right. So, where are we? I: So... this time, I will involve you...both of you to...for the interview. So, you can talk, you can talk. S: Okay. (19:42)</p> <p>I: So, first...I will ask you how do you think about your spouse's participation in the PAIRS program.</p>	<p>project (giving children and pregnant women quality foods) "That was my part of my life... stimulate...quality food..."</p> <p>"I worked for that (finding/developing nutrition programs for pregnant women and their infants) and then I...we got quickly got the experts..."</p> <p>He stopped talking because of interruption</p> <p>She joins the interview</p>
<p>A lot of fun "It encourages us to do some wonderful things that we just don't get around doing like going to the Zoo. I haven't been in the zoo for years." Description of his pair: such a pleasant, wonderful person His spirits were lifted by being with his pair</p>	<p>S: Oh, it was a lot of fun. Yeah. It forces... to...not forces, but encourages us to do some wonderful things that we just don't get around doing like going to the Zoo. I haven't been in the zoo for years. And then Andrea was such a pleasant... wonderful person, and I've known Bradley's spirits were lifted by being with her. I: So, you mentioned several activities you and...you went to that activities with...</p>	<p>A lot of fun "It encourages us to do some wonderful things that we just don't get around doing like going to the Zoo. I haven't been in the zoo for years." <u>more motivated?</u> His pair: such a pleasant, wonderful person She found that his spirits were lifted by being with his pair</p>

<p>She went to all the activities but participated separately (by herself or with her friend)</p> <p>Aware of the protocol</p> <p>A nice opportunity for socializing with her friend “it encouraged me to do things with my friend, which was nice.”</p> <p>She chose every activities based on his interests, but they talked it over before making decisions</p> <p>Pretty familiar with all the cultural activities in KC</p> <p>Base on his interest: He’s always enjoyed the theater and he loves classical music</p> <p>Working as a team in talks (his little participation) “I like penguins and children.” Likes going to the zoo?</p>	<p>S: I went to everything. I went to everything, but um...the protocol was that I was not supposed to be doing with them. So, at the zoo, I just was at the zoo by myself. And... went to the theatre I...with the Coterie Theatre by a friend coming be with me. I bought four tickets and Bradley and Andrea sat separately from my friend and me. [a small laugh] And um...we also went out to lunch before then. There again, we sat at a separate table, so...it encouraged me to do things with my friend, which was nice. [a small laugh]</p> <p>I: Do you think...do you know how they decided...these activities?</p> <p>S: I chose. I chose everything. [a small laugh]</p> <p>I: How did you choose activities based on what?</p> <p>S: We’ve lived for 65 years. I am pretty familiar with all the cultural activities in the area.</p> <p>I: Did these activities have any special meaning to him do you think?</p> <p>S: We talked it over before...he’s always enjoyed the theatre and he loves classical music. You are not a big fan of the zoo, but um...</p> <p>P: Oh, I like penguins and I like children.</p> <p>S: I wanted to see the polar bears and penguins. There was a new exhibit.</p> <p>P: She is a good pediatrician’s wife.</p> <p>I: So, from my understanding, you</p>	<p><u>She went to all the activities (to drive him to that places or she wanted to do activities?)</u></p> <p>She was aware of the protocol (the spouse is not supposed to be doing with them), so she looked around by herself at the zoo and she invited her friend and sat with her friend at the theatre (also sat a separate table at the restaurant)</p> <p>A nice opportunity for socializing with her friend “it encouraged me to do things with my friend, which was nice.”</p> <p>She chose every activities on behalf of him</p> <p><u>Based on his interests and her knowledge in cultural activities?</u></p> <p>“We’ve lived for 65 years. I am pretty familiar with all the cultural activities in the area.”</p> <p><u>“We talked it over before...” Although she said that she chose the activities, it seems that she asked his opinion before they actually went for the activity (she suggested activities?)</u></p> <p>Based on his interest in music and theater “He’s always enjoyed the theatre and he loves classical music.”</p> <p>He disagrees with her and expresses his like in penguins and children (<u>so, he liked going to the zoo?</u>)</p> <p>She chose one activity based on her interest (for herself) rather than his interests because she wanted to see the polar bears and penguins at the zoo. <u>She used the program to have fun for herself too (she also was an active participant of the program?)</u></p> <p><u>He may mean that she deserves as a</u></p>
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<p>She chose one activity (zoo) based on her interest She chose activities based on the couple's interest (shared interest in music and theater) His joke?</p> <p>Relationship is not good (the couple is really...many times not getting along very well) He is very very upset with my driving</p> <p>He feels very bitter that he doesn't drive Lots of fight about her driving Being with his pair was like being on a date Really perked him up and lifted his spirits</p> <p>Nice for her to do something little one with her friend Even had fun going around by myself</p>	<p>chose these activities because you think he will like it based on his interests. S: Because I like them too. Yeah. Ha ha. I: So, both of you had shared interests. S: Yes. P: I can count to one two three and my wife can count to one two three.</p> <p>S: They gave us a list of suggested activities with about 30 places in it.</p> <p>I: So...um...I can see you also had some interests in these activities, so I wonder if you found any differences between when you...when you only went to that activities only two of you or how was that different from involving another...medical student?</p> <p>S: It was very different. It was very different. Yeah, very different.</p> <p>I: Could you tell me more about that? S: Bradley and I are really... many times not getting along very well. So, we go to some place and um...he is very unhappy with it. He is very very upset with my driving.</p> <p>I: Why?</p> <p>S: He doesn't drive and feels very bitter about that. And... lots of fight about my driving...and...um...um... [Saying with hesitation]. Well, with Andrea was like being on a date. I mean it really perked him up and...that lifted his spirits. It was nice for me to do something little one with my friend. I even had fun going around by myself.</p> <p>I: So, do you feel that his participation in the PAIRS program has affected</p>	<p><u>pediatrician's wife because she is a caring person. (not meaning that he is a good pediatrician)</u></p> <p>She chose activities not only based on his interest but also based on her interest (the couple's interest) The couple has shared interests <u>Why is he saying like this? His joke?</u></p> <p>Help each pair find activities based on interests of the person with Alzheimer's by giving a list of 30 activities "They gave us a list of suggested activities with about 30 places in it." <u>I asked this question because some of the chosen activities seemed to be activities the couple has been doing for a long time (e.g., going to a theater, symphony)</u> <i>Very different; repeated "very different" three times because she strongly felt that way?</i></p> <p><i>Really, many times, very (to emphasize)</i> Relationship is not good (He and I are really...many times not getting along very well.) "He is very unhappy with it" (<u>going to some places together?</u>) "He is very very upset with my driving." <u>Is he unhappy with going to some places together or this is just because of the driving issue?</u> He feels very bitter that he doesn't drive. <u>Because he says that he will drive or he is just upset?</u> Lots of fight about her driving <i>Hesitation in talking about the fight; she did not talk about the fight</i> Being with his pair was like being on a date; it really perked him up and lifted his spirits "It was nice for me to do something little one with my friend. I even had fun going around by myself." <u>he is not independent enough for her to be with</u></p>
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<p>A happy time for her Wonderful cultural resources in the community More time for socialization with her friend</p> <p>Her expectations: he enjoys being with someone... intelligent, charming, young lady. Ha ha. And I would enjoy seeing all these wonderful sites.”</p> <p>Met her expectations</p> <p>Four hours is too long for PwD, so twice for two hours sometimes</p> <p>The best part was a long conversation with someone other than her</p> <p>Change in their social life/ limited social life (friends lift away) She also suffer from</p>	<p>you as well?</p> <p>S: Oh, yeah. Well. It was a happy time. This community has wonderful cultural resources.</p> <p>I: So, you had some... more time for socialization with your friend.</p> <p>S: Yeah, felt like...yeah.</p> <p>I: What were your expectations before he participates in the PAIRS program?</p> <p>S: Well that was my expectation he enjoys being with someone... intelligent, charming, young lady. Ha ha. And I would enjoy seeing all these wonderful sites.</p> <p>I: So, do you think... the program met your expectations?</p> <p>S: Oh, yeah yeah. right. It was...it was some demanding for time. The program...most of that was...they said...a four hour segment, but I thought...maybe that...a lot of times that was little long... over times. So, we did two two hours sometimes. Yeah. I would say that...better...looking to that...I think a lot of people with Alzheimer’s are not ready for a four hour program.</p> <p>I: What do you think to be the best part of the PAIRS program for him...you think?</p> <p>S: I think the best part was a long conversation with someone other than me. [a small laugh]</p> <p>I: What do you mean by someone other than you?</p> <p>S: I mean we are together most of the time and our social life isn’t so great. When you have Alzheimer’s, your friends... can...lift away. And also I</p>	<p><u>him all the time? She has less time for herself because she has to take care of him?</u></p> <p>“Oh, yeah. Well. It was a happy time. This community has wonderful cultural resources.” Member checking (She had some more time for socialization with her friend)</p> <p>Her expectations: “he enjoys being with someone... intelligent, charming, young lady. Ha ha. And I would enjoy seeing all these wonderful sites.”</p> <p>The PAIRS program met her expectations</p> <p>Demanding for time because a four hour segment is too long for people with Alzheimer’s , so they did two two hours sometimes (rather than meeting once a month for 4 hours)</p> <p>“I think the best part was a long conversation with someone other than me.”</p> <p>Change in their social life/ limited social life (friends lift away) She also suffer from depression like he does (hard to force herself to arrange</p>
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<p>depression like he does (hard to force herself to arrange things)</p> <p>Glad to have the pressure to do (encouraged her to arrange activities)</p> <p>Beneficial for both</p> <p>No permanent improvement</p> <p>Certainly he enjoyed all the time (a smile on his face)</p> <p>No effect on the couple's relationship "But it gave him some happy time. That was important to me."</p> <p>It (knowing that he enjoys himself/having happy time with his pair) was a load off my back. He has depression too.</p>	<p>suffer from depression and I don't feel like arranging much. [a small laugh] It's hard to force myself to arrange things.</p> <p>I: So, from my understanding, you had some difficulties in arranging activities.</p> <p>S: No. My point was I was glad to have the pressure to do it. Ha ha.</p> <p>I: Okay. I see.</p> <p>S: Because they were very beneficial for both of us.</p> <p>I: How do you think participation in the PAIRS program has affected your spouse and his daily life?</p> <p>S: Well. um...I really can't say whether there was permanent improvements, but certainly he enjoyed all the time.</p> <p>I: How did you know that he enjoyed?</p> <p>S: There was a smile on his face.</p> <p>I: Pardon?</p> <p>S: A smile. A smile on his face.</p> <p>I: Oh, yeah. So, you could see his smiles on his face. Did you see... any difference in his...any...relationship with you because he had some...new happy relationship with another person? Did you see any difference between...?</p> <p>S: No. I wouldn't say that, but it gave him some happy times. That was important to me.</p> <p>I: So, how did you feel when you found that he was so enjoying that participation... that program?</p> <p>S: Yeah...it was a load off my back. ha ha. Yeah. He has depression too. I mean how would you not be depressed. This is a fatal... incurable illness. Think about it and then would be depressed. Ha ha.</p>	<p>things)</p> <p>Having the pressure (things that she must do) by participating in the program encouraged her to arrange activities (more motivated?)</p> <p>Beneficial for both of us</p> <p>No permanent improvement Certainly he enjoyed all the time (a smile on his face)</p> <p>No effect on their relationship "But it gave him some happy time. That was important to me."</p> <p>It (knowing that he enjoys himself/having happy time with his pair) was a load off my back. He has depression too.</p>
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<p>Her coping strategy/belief : do everything you can do and enjoy life even with Alzheimer's (you can be happy and enjoy your life with Alzheimer's)</p> <p>His involvement in talk (family visits make him happy and support them a lot?)</p> <p>Encouraged her to be more active in engaging fun things for themselves</p> <p>They visited the Nelson gallery recently again</p> <p>They go to the symphony and concert versions of musicals</p> <p>She invites him to the conversation</p> <p>He enjoyed the concert</p>	<p>I: I totally understand that.</p> <p>S: But...you are not going to die tomorrow because there are many happy years I think. I think I would advise anybody, don't take the illness lying down, do everything you can do to fight it, like exercises, socialization, and volunteer work everything you can do. There is no reason just to say: Oh, I have Alzheimer's I will die tomorrow. You don't have to say that.</p> <p>P: What about family visits? S: What about? P: Our supports. S: Yeah. We have good kids and grand kids. [a small laugh]</p> <p>I: So...how do you think participation in the PAIRS program has affected your strategy for helping him in any way?</p> <p>S: Well. I am trying to...be more active about engaging fun things like going to the Nelson Gallery...um...all those things...get out of the house and get out of your shell.</p> <p>I: So, do you...do you arrange some similar activities after the program is ended? S: Well we went to the Nelson just recently. We haven't been back to the zoo. Um...</p> <p>I: Do you go to some gallery or theatre? S: Well. We already have season tickets for several events. We go to the Quality Hill, Symphony and there is a place for musical theatre heritage that does concert versions of musicals. So... we just last week we went to a concert by the Kansas City Chamber Orchestra...all Bach. I am a Bach's fan, so that was a...that was an upper and you enjoyed that too, didn't you?</p> <p>P: Yes, ma'am. Building of</p>	<p>Her coping strategy/belief : do everything you can do and enjoy life even with Alzheimer's (you can be happy and enjoy your life with Alzheimer's)</p> <p><u>He seems to say like that because he thinks family visits make him happy and support them a lot.</u></p> <p>Effects on her strategy for helping him?</p> <p>Encouraged her to be more active in engaging fun things for themselves "I am trying to...be more active about engaging fun things like going to the Nelson Gallery...um...all those things...get out of the house and get out of your shell."</p> <p>They visited the Nelson gallery recently again</p> <p>They go to the symphony and concert versions of musicals</p> <p>He enjoyed the concert too</p>
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<p>too His happy memory in music and themselves</p> <p>Wants/efforts to keep in touch with his pair but didn't work out due to his pair's schedules Understands his pair's busy life She thinks his pair felt very close to them</p> <p>Very happy for his relationship with his pair. It was really rejuvenating for him to be with his pair. Sometimes they ate all together for him "I will just eat together because we all enjoyed each other's company." She enjoyed socializing with his pair too.</p>	<p>that...music...I think that's one of the reasons we fell in love each other. It was because I was the medical doctor and her brother, older brother was a medical doctor... because...would you like to go to the symphony? I got some extra tickets and my problems are... that way...music...my father was a professional musician, so that tie was what I am kind of...</p> <p>S: I intended to keep our relationship with Andrea too. We saw her at the Alzheimer's walk in October. And I intended to invite her over but... medical students are so overscheduled. I know we won't be able to see her very often. I think she felt very close to us.</p> <p>I: So, you met Andrea in October after the program is ended.</p> <p>S: Last...right. The program was over. We met at the Alzheimer's walk. You know about Alzheimer's walk?</p> <p>I: Yeah, I've heard about it, but I wasn't there.</p> <p>S: It was...a fundraiser.</p> <p>I: Yeah, fundraising thing.</p> <p>S: Yeah.</p> <p>I: That's great. How do you think about the relationship with...his relationship with Andrea?</p> <p>S: His?</p> <p>I: Yeah, his relationship with Andrea.</p> <p>S: I was very happy for them. I mean it was really rejuvenating for him to be with her. And we cheated a little bit. Sometimes we ate all together for him and me...ha ha...because we thought well, it's becoming the end of the program, I will just eat together because we...we all enjoyed each other's company.</p> <p>I: I feel like you guys have both shared interests in music.</p> <p>S: uh-huh.</p> <p>I: And how do you think about her...Andrea's...did Andrea</p>	<p>Music was one of the reasons they fell in love each other</p> <p>He asked her out for the symphony</p> <p>She intended to keep their relationship with his pair and tried to invite his pair over, but the pair couldn't come over because of her schedules "I know we won't be able to see her very often. I think she felt very close to us." <u>Past tense (felt); She seems to be very willing to keep in touch with his pair but she hesitates because she understands how busy the pair is.</u></p> <p>Very happy for his relationship with his pair. It was really rejuvenating for him to be with his pair. Sometimes they ate all together for him "I will just eat together because we all enjoyed each other's company." <u>She seems to enjoy socializing with his pair too.</u></p>
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<p>They have something in common in terms of family's involvement in medicine (His pair's father is a physician) His pair was deprived in terms of cultural experience His pair enjoyed. It opened her eyes</p> <p>Related his pair to their own son</p> <p>No personal life for med students, but everybody needs personal life "So, this was good for her (his pair) and... I would say this was good for us."</p>	<p>have...do you think Andrea has some interests in music too? S: Oh, this is really curious. Her father is a physician, and ...so she did not come from a deprived background, but she was deprived. I mean she has never been to the zoo, never been to the Nelson, never been to the symphony, all these wonderful things we go to. And she was not familiar with them. Yeah. And she enjoyed every minute of it. It opened her eyes even though she didn't have much experience with them. I: So, I guess she learned from...learned a lot of these...experience... S: I really think medical students are abused...with such an intensive program...and...my son told me the story before he started the medical school. There was an orientation and the faculty members said "Now, if you have any per....", this was Friday, " If you have any personal problems, solve them by Monday." Ha ha. So, I know he was not supposed to have any personal life, but everybody needs personal life. So, this was good for her and... I would say this was good for us. I: um... S: Oh, I will tell you sometimes, a couple of times, Bradley said that I never want to see you again. P: ha ha I: Oh, really? S: Yeah. He said that a couple of times because it's just...he gets mad at me so much. I think I shouldn't gloss over ... some things went wrong. But, I bet he liked the program, right? P: Yes. S: He just said that. I don't think...at that time I've just dismissed that...I didn't think he meant that. I: So, what do you think to be the important features of the PAIRS</p>	<p>They have something in common in terms of family's involvement in medicine (His pair's father is a physician) His pair was deprived in terms of cultural experience (the pair has never been to these places they go to and the pair is not familiar with them) His pair enjoyed. It opened her eyes</p> <p>Really think medical student are abused with such an intensive program Talks about a story of his son when he started the medical school</p> <p>No personal life for med students, but everybody needs personal life. "So, this was good for her (his pair) and... I would say this was good for us."</p> <p>Sometimes he said that he never want to see you (his pair?) again.</p> <p>She thinks he liked the program, and he didn't truly meant that.</p>
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<p>The good thing was going some places interesting that give you something to talk about and thing about</p> <p>Take you out of your petty concerns</p> <p>It gives him something to talk about with his pair. It gives us something to think about other than our usual concerns</p> <p>The couple belongs to the support group at the AA (twice a month)</p> <p>A huge difference between the support group and the PAIRS program</p> <p>At least at the caregiver's meeting, the atmosphere is usually pretty somber (talking about very heavy problems. Crying sometimes) The PAIRS program-</p>	<p>program?</p> <p>S: Oh, well. The good thing was...go some place interesting. You don't just sit and talk. Go some place and they give you something to talk about and think about, like the Nelson and Zoo. Take you out of your... petty concerns and...</p> <p>I: So, from my understanding, because you go to some place, it brings up your...something to talk about...together.</p> <p>S: Well. It gives him something to talk about with Andrea...my point was...and it gives us something to think about other than our usual concerns.</p> <p>I: I know the people...the families are also involved in other programs... something like caregiver for...some meetings for caregivers. Do you do?</p> <p>S: Oh, yeah. We belong to. Alzheimer's...The Alzheimer's Association sponsors a support group, one for the patients, one for the caregivers, which mean simultaneously twice a month we've been going to that.</p> <p>I: Do you see any difference between that program and the programs like PAIRS program?</p> <p>S: Oh, yeah...night and day... There is a huge difference. Ha ha.</p> <p>I: Could you tell me more about?</p> <p>S: Oh, well. Because at this meeting, at least the caregivers' meeting, the atmosphere is usually pretty somber. People are talking about very heavy problems. They don't seem to have much of solutions. Sometimes...they are ready to cry. This...yeah. I admire</p>	<p>Te good thing was going some places interesting that give you something to talk about and thing about</p> <p>Take you out of your petty concerns</p> <p>It gives him something to talk about with his pair. It gives us something to think about other than our usual concerns</p> <p>The couple belongs to the support group at the AA (twice a month)</p> <p>A huge difference between the support group and the PAIRS program</p> <p>At least at the caregiver's meeting, the atmosphere is usually pretty somber (talking about very heavy problems. Crying sometimes) The PAIRS program- escapism (not thinking about disease and arguments; takes you away from yourself)</p>
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<p>escapism (not thinking about disease and arguments; takes you away from yourself)</p> <p>Most contacts with elderly people Less contact with their children than they wish and they do not like going to places with them</p> <p>Go to places with his pair who sees everything with fresh eyes; mood elevator</p>	<p>the people, they are brave, they are making best of things... and um...but...the PAIRS program is a escapism. You are not thinking about...your memory is gone to hell. You are not thinking about the arguments. You are thinking about, oh, look at the polar bears swimming in the water. It just takes you away from yourself. Escapism is the best sense of the word... what I am saying. And then...um...most of our contacts now are elderly people. We don't even see our children as much as I would like and they are usually that crazy to go places with us. So um...we go to places with someone like Andrea who sees everything with fresh eyes. And...it was a... mood elevator I would say. [a small laugh]</p> <p>I: That sounds so great. um...before you mentioned that you could see his smile while he was having the relationship with Andrea. S: Yeah. I: So...um... S: By the way, did you interview her too? I: No, we are not interviewing the medical students. We only interview the families. S: They are supposed to write a report. I: Yeah. I know that's another study. So, it's already done. But, this research is to... only for the families who were in the program. S: Okay. But, somebody will look at up everything, right? Somebody will look at both your report and the medical students' reports, right? I: um...If it is published, that would be. Yeah. But, there will be two separate publications. S: Okay. Okay. Yeah.</p> <p>I: So, you said that...when you were in the zoo, you were not thinking about...he had the dementia. You were just enjoying that moment.</p>	<p>Most contacts with elderly people Less contact with their children than they wish and they do not like going to places with them</p> <p>Go to places with his pair who sees everything with fresh eyes; mood elevator</p> <p>Asks if I interview the medical students too</p> <p>Knows the medical student write a report</p> <p>Asks if somebody will look at up everything <u>why is she curious about this? Is she worried if somebody will see how different what she thinks /says is from his pair's report?</u></p> <p>Member checking (just enjoying that moment)</p>
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<p>Much more calm and cheerful when he was participating in activities with his pair</p> <p>Both music lovers since the couple met and that's continued We like symphony and we used to go to the operas Still go to some plays</p> <p>Spouse's strategy</p> <p>Spouse's strategy</p> <p>Impact of dementia</p> <p>Talks about happy memories (how they met and how much they love music) Expression of self-identity related to his past work, music, and family</p> <p>Talks about his family's involvement in Medicine</p>	<p>S: Right. Right.</p> <p>I: Could you tell me more about that? how...Did you see any difference between his motivation or his participation in these kinds of activities when he was with Andrea rather than when he was...in...daily life or...?</p> <p>S: well...much more calm and cheerful. Yeah. What did you say? P: Yes. I: Do you like looking at the polar bears and what did you most like...in the zoo? [Asking to the person with dementia]</p> <p>P: We are both music lovers since we met each other. So, that's continued. So, we are crazy people in symphony and used to go to the operas. And um...we still go to the...some plays... S: I think she is speaking of what we do with Andrea. We went to...saw the Wiz remember the...at the Coterie Theatre? P: Yeah. S: We saw Romeo and Juliet... and the Nelson. Anything special that stands out in your mind?</p> <p>P: Oh, that's always been...as long as we met each other...in a way... students... Minnesota... we met each other...there was always some extra tickets...my wife's parents...would you like to go to the play at the University of Minnesota? Would you like to go to the symphony? We had some tickets ...would you like to once in a while? My father was a professor musician, so... I: So, you have some blood in musical... P: Yes. I: That's great. P: Well, then the other thing that's going on with is that...our children grew up. Medicine was in my wife's</p>	<p>Much more calm and cheerful when he was participating in activities with his pair</p> <p>Invited him to conversation</p> <p>Both music lovers since the couple met and that's continued They like symphony and they used to go to the operas Still go to some plays Helps him understand the question by giving specific examples</p> <p>She tries to remind him of activities they did with his pair together</p> <p><u>He also seems to like talking about how they met and how much they love music. He repeatedly mentions that his father was a professional musician.</u></p> <p>Talks about his family's involvement in Medicine</p>
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<p>Spouse's strategy</p> <p>I have to be stimulated from my wife. So, we've been doing things together</p> <p>That's wonderful that I have a family</p> <p>We love kids We have a large family</p> <p>They meet their children/grandchildren a couple times a month; she'd like to see them more often "They like us." Supportive</p>	<p>family when we got married. As a medical doctor, pediatrician, and then the next thing I know was my son is a neurologist... copycats.</p> <p>S: but...um...would you...any those of activities stand out in your mind we did with Andrea like Romeo and Juliet or...? P: Yeah. S: The penguins... any of that? P: Getting out...doing things I did with young adults...things just slow down I am doing ... and um...but that shouldn't have to happen S: uh-huh. P: So...I have to stimulate from... my wife...as you already hear...and um...so we've been doing things together. And then... I back to my kids. Now, my grandchildren... we are going out with the young-married couple...next next generation. Ha ha. So, that's been... thrilling...for me and of course I think my wife. I think it spins off, oh how nice. So, that's wonderful that I have a family. I: Yes. um... P: Almost it's as good as my cat. We love kids. I am a pediatrician I think that was a beginning I think. I love kids. My wife has got...six children in her family, five am I. we are both the oldest. And so I used to get kicked in the shins by my brother-in-law. And I...how nice.</p> <p>I: Do you see your children and grandchildren very often or... do they visit you? S: A couple times a month. Yeah. um...I'd like to see them more, but um...yeah.. always... P: They like us. They like us. S: They are supportive.</p> <p>I: So, did you feel that having Andrea with you... give some feelings of being with your children or grandchildren, something like that?</p>	<p>She tries to remind him of activities they did with his pair together</p> <p>"So...I have to stimulate from... my wife...as you already hear...and um...so we've been doing things together."</p> <p>"So, that's wonderful that I have a family."</p> <p>Loves kids The couple has a large family</p> <p>And so I used to get kicked in the shins by my brother-in-law.: <u>why did he say this? What meaning?</u></p> <p>They meet their children/grandchildren a couple times a month; she'd like to see them more often</p> <p>"They like us." Supportive</p>
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<p>Happy close relationship with his pair</p> <p>Spouse: Over-involved in activities</p> <p>They go to the meetings for the Democratic Party once a month and they are voters of Blue Cross</p> <p>Working as a team in talking (He adds exercises)</p> <p>They exercise five days a week and have some chance for conversation there. (Conversation with other people or between them?)</p> <p>She is involved in many activities She doesn't want to give up anything because they are all fun.</p> <p>Help in home management: a domestic worker who cleans their house once a week and Jewish man service (repairs around the house, moving heavy objects)</p> <p>Kids suggested</p>	<p>S: Well. It was...just happy close relationship, sure.</p> <p>I: Do you involve in any activities?</p> <p>S: I am over-involved...over-involved. Ha ha.</p> <p>I: Are you being involved in any similar programs like the PAIRS program? Is he...is he involved in any similar programs?</p> <p>S: No, I don't think. I've never heard of similar programs, but we are. We go to the meetings for the Democratic Party once a month. And um...we are voters of...Blue Cross...seniors who like computers.</p> <p>P: And exercises</p> <p>S: Oh, yeah. We exercise...we try to do it five days a week. Have some chance for conversation there. And I am...involved...I play in a band I play the flute. I am in a bridge group. I am in a book club. And I run a volunteer program...a mathematics club. Ha ha. Also, I do...I've been tutoring, so I really...</p> <p>I: Wow, you are so busy.</p> <p>S: I have too many activities. I don't want to give up anything because they are all fun. Ha ha.</p> <p>I: How did you...how do you manage all the activities while you are caring for him?</p> <p>S: Oh...my slumpy housekeeping. Ha ha.</p> <p>I: Do you have anybody who...?</p> <p>S: Oh, yeah. We have a domestic worker who comes once a week and cleans the house. And...</p> <p>P: We have a cat that takes care of us too.</p> <p>S: Jewish man service has a nice program. You pay a flat fee and you get unlimited service from...that man was with them. He fixed that...it's called a glider chair. He fixed that for me. All the things...minor repairs... around the house they can do. Or,</p>	<p>Happy close relationship with his pair</p> <p>Over-involved in activities</p> <p>They go to the meetings for the Democratic Party once a month and they are voters of Blue Cross</p> <p>He adds exercises</p> <p>They exercise five days a week and have some chance for conversation there. <u>Conversation with other people or between them?</u></p> <p>She is involved in many activities</p> <p>She doesn't want to give up anything because they are all fun.</p> <p>They have a domestic worker who cleans their house once a week <u>We have a cat that we take care of?</u></p> <p>They use Jewish man service (repairs around the house, moving heavy objects)</p> <p>The goal of the Jewish man service</p>
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<p>moving him to the retired home</p> <p>Doesn't want to move him there because move is dramatic (die in six months)</p> <p>"We will do it if we have to do. But I don't want to do it before we have to."</p> <p>A future plan</p> <p>Would like to involved in similar programs like the PAISR program</p> <p>The PAIRS program gives preference to people who have not been in the program</p> <p>More families than available medical students</p> <p>She expressed her interest for participation in the PAISR program again</p> <p>Use friendly visiting</p>	<p>even moving furniture...or moving heavy objects...so that's...the goal is to keep the patients in their homes as long as possible. Because...our kids saying why don't you move him to the retired home, but...some people move and die in six months. The move is dramatic. So, I don't want to move.</p> <p>We will do it if we have to do. But I don't want to do it before we have to.</p> <p>I: Right.</p> <p>P: There is somebody between us to somebody watching the other one, so... we are...If I am with by myself, I don't think I will be at home.</p> <p>S: No. No. If Bradley dies before I do it, I will ask for going to the assisted living sometime though .Then, I will sell the house and get something to smaller one. We don't need four bedrooms. We don't need this big lot, and we don't need this continual...spending money. Ha ha.</p> <p>I: So, if there is any similar program like the PAIRS program in the near future, do you...would you like to be involved in that kind of program again?</p> <p>S: I would. But um...at the Alzheimer's Association, they are giving the preference to people who have not been in it. I mean the PAIRS program is going on now, but they hadn't given the preference to...not to us because we were already in it.</p> <p>There is more people who want it than there are medical students are available.</p> <p>I: So, did you... So, you wanted to participate in the program again, but you couldn't because they give the priority to the new people?</p> <p>S: Well. Yeah. If we could have?, I would've urged Bradley to do it. But...I think we did formally express the interest, but they explained no that...I understand that.</p> <p>I: Right. um...</p> <p>S: Our temple has a program where</p>	<p>program is to keep the patients in their homes as long as possible</p> <p>Kids suggested moving him to the retired home</p> <p>She doesn't want to move him there because she thinks the move is dramatic (some people die in six months)</p> <p>"We will do it if we have to do. But I don't want to do it before we have to."</p> <p>"If I am with by myself, I don't think I will be at home."</p> <p>She has a plan (what she would do if he dies before she does)</p> <p>No need for this big house / spending money if he dies and she lives alone</p> <p>Would like to involved in similar programs like the PAISR program</p> <p>The PAIRS program gives preference to people who have not been in the program</p> <p>More families than available medical students</p> <p><i>We</i></p> <p>She expressed her interest for participation in the PAISR program again ; <u>maybe she wants more than he does?</u></p> <p>Their temple has a friendly visiting</p>
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<p>program for caregiving</p> <p>He doesn't want to go out with the friendly visitor</p> <p>A maximum of two hours; hard to go to some places (e.g., can't go to the movie)</p> <p>They went out for a snack once but he didn't seem to be interested in doing that again.</p> <p>The friendly visiting program has helped her when she went to the rehearsal for the band Monday night.</p> <p>She just left him alone some of the time</p> <p>Setup "You must go some place, so we did. With this, it's optional and you opt to not to go anyplace. ha ha."</p> <p>Yes (good) it was great to get out of the house and do something different.</p>	<p>they send out the friendly visitor. And I... use them for caregiving. Bradley hasn't wanted to go to any place with them though. They would be glad to take you some place but you haven't really wanted to.</p> <p>P: No.</p> <p>S: And also they usually just come for a maximum of two hours. It's pretty hard...you really can't go...you can't...window...you couldn't go to the movie...you could go out for a snack. They did that once, but he didn't seem to be interested in that... and doing that again.</p> <p>I: So, you mentioned that the friendly visiting program has...were shorter time...</p> <p>S: Yeah. Only..two hours in total. That's been helped me out because...like when I went to the rehearsal for the band Monday night, somebody was here.</p> <p>I: Is it once a month or...?</p> <p>S: Oh, they come out maybe three times a month.</p> <p>I: But, they only have two hours.</p> <p>S: But, never more than two hours. Yeah.</p> <p>I: So, it is hard to go out to some place...</p> <p>S: Well. I just left him alone some of the time. I maybe be taking a chance, but um...I think...you function pretty well for short periods.</p> <p>I: Did you have any differences between that program and the PAIRS program other than the time?</p> <p>S: Well. The thing is that the PAIRS program was setup. You must go some place, so we did. With this, it's optional and you opt to not to go anyplace. ha ha.</p> <p>I: So, was it good? Was it good or bad?</p> <p>S: Oh, yes. From my point of view, like I said, it was great to get out of the house and do something different.</p>	<p>program and she uses the program for caregiving</p> <p>"He hasn't wanted to go to any place with them through. They would be glad to take you some place but you haven't really wanted to." <u>Why?</u> <u>Because she is not going together?</u></p> <p>A maximum of two hours; hard to go to some places (e.g., can't go to the movie)</p> <p>They went out for a snack once but he didn't seem to be interested in doing that again.</p> <p>The friendly visiting program has helped her when she went to the rehearsal for the band Monday night.</p> <p>Come three times a month (a maximum of two hours each visit)</p> <p>She just left him alone some of the time</p> <p>"The thing is that the PAIRS program was setup. You must go some place, so we did. With this, it's optional and you opt to not to go anyplace. ha ha."</p> <p>Yes (good) it was great to get out of the house and do something different.</p>
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<p>His involvement in talks</p> <p>We've been very active in supporting the arts and music (musicians in families)</p> <p>Music is so common to the couple</p> <p>He's always been encouraging anybody to get a hobby</p> <p>We like to have /find something else to love</p> <p>He feels good that his children are supportive.</p> <p>He is still very active</p> <p>More opportunities for going out and being active?</p> <p>"Definitely. We haven't been to the zoo in thirty years. This was a motivation to go to the zoo."</p>	<p>I: So, going out to somewhere was good because as you said before, it brings up some interesting topics to talk, but do you... is there any other thing you found that going out to somewhere was good for you and your husband?</p> <p>P: We've been...we've been very active in...supporting...the arts and um... music. My father was a professional musician. Her whole family is a bunch of musicians. I think that's one of the reasons we got married because music is... so common...two of us...and um...it's something that I've always been...encouraging anybody to get...you get a hobby. And somebody likes to play the flute and somebody likes to listen to the flute....My father was a professional pianist, so that's...my wife...we are dating ever since then we have music. It was a kind of. We like cats too. I think that is another thing in common. We both agree with each other... We like to have something to...something else to love. Our kids are grown-up. Our grand-grand children are...grown-up. And um...we have a little bit of fun. And um...I think we both are fortunate to see our kids all the time. They want to know how we are. Oh, I feel good.</p> <p>I: So, he used to be very active and right?</p> <p>S: He is still very active.</p> <p>I: So, he likes going out and...Do you think the PAIRS program gave more opportunities for going out and being active?</p> <p>S: Well, definitely. We haven't been to the zoo in thirty years. This was a motivation to go to the zoo.</p> <p>I: You didn't go to the zoo for a while because you were not motivated? Or... Was it because of your driving like you said before? Or...What was the reason for not going for a while to</p>	<p>"We've been very active in supporting the arts and music."</p> <p>His father and her family has musicians</p> <p>"That's one of the reasons we got married because music is... so common...two of us...and um...it's something that I've always been...encouraging anybody to get...you get a hobby."</p> <p>They both like music and cats</p> <p>"We like to have something to...something else to love."</p> <p>Feel good that his children are supportive. "Our kids are grown-up. Our grand-grand children are...grown-up. And um...we have a little bit of fun. And um...I think we both are fortunate to see our kids all the time. They want to know how we are. Oh, I feel good."</p> <p>"He is still very active."</p> <p>More opportunities for going out and being active?</p> <p>"Definitely. We haven't been to the zoo in thirty years. This was a motivation to go to the zoo."</p>
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<p>His involvement in talks</p> <p>Memory in Nelson Galley and Kansas City Symphony</p> <p>We love music</p> <p>Slowed down going to symphony some time period (due to driving issue): decreased her desire to go around places</p> <p>“It was a commitment to do this, so we did it.”</p>	<p>the zoo?</p> <p>S: Well.um... I cannot answer that. We just didn't do it... ha ha.</p> <p>P: I will bring it up.</p> <p>S: Okay. ha ha.</p> <p>P: We were very...We've always been very busy people. And so...some things are... secondary, and others are primary. We both love arts. We went to the symphony, went to the operas. We have amateur musicians in the family. So...the arts have always been important. We used to go over a little more regularly to the Nelson Gallery. We've just been there and that kind of thing. I wasn't involved until I married and I found ...I like to go too, which wasn't going to be too expensive as a new couple, but we found ways to getting into the... then we moved here. But...one of the early things we did...and I first moved here and working in Kansas City. Was finding the Nelson Gallery...we...we used to get tickets for the Kansas City Symphony still. It's been last year that we slow down somewhat but we have still been going in...I love music but my...amateur musician is over here. We always say I don't think we got married if it wasn't for...music.</p> <p>S: The fighting about the driving... really has a...taken away my desire to go around places.</p> <p>I: But, Andrea drove... because Andrea drove to that place every time?</p> <p>S: Well. I still had to drive rarely, but the point was...it was...it was a commitment to do this, so we did it. [a small laugh]</p> <p>I: So, you found that...from my understanding, you found that it was a little forcing to...for you to do that was helpful, to go out even though you were a little bit less desired at the beginning?</p>	<p>“We've always been very busy people. And so...some things are... secondary, and others are primary. We both love arts. We went to the symphony, went to the operas. We have amateur musicians in the family. So...the arts have always been important. We used to go over a little more regularly to the Nelson Gallery. We've just been there and that kind of thing.”</p> <p>“One of the early things we did...and I first moved here and working in Kansas City...was finding the Nelson Gallery. We...we used to get tickets for the Kansas City Symphony still. It's been last year that we slow down somewhat but we have still been going in...I love music but my...amateur musician is over here. We always say I don't think we got married if it wasn't for...music.”</p> <p>“The fighting about the driving... really has a...taken away my desire to go around places.”</p> <p>“It was a commitment to do this, so we did it.”</p>
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<p>Due to the commitment in the program, she could encourage herself to go out to places</p> <p>“I don’t drive any more. I can’t drive anymore.”</p> <p>Very hard to going to places due to unwillingness to do driving Used to be the lead driver She does all the driving and that is not fair We tried to find that that we can do together like exercises We still go to the symphony Music has been part of our lives since I was born Transportation becomes a barrier</p> <p>Disagrees (not a barrier); willing to drive for symphony; Jewish family service provides transportation</p>	<p>S: Well. Well. Once you have a commitment, if you are a decent person, you want to honor the commitment, so we did it. But, if I just say Bradley how about going to the zoo tomorrow and he says No I don’t think so. I am not going to fight him about it.</p> <p>I: So, you said that you chose these activities but do you think he liked all the activities you chose?</p> <p>S: Yeah, he liked all the activities, didn’t you?</p> <p>P: Oh...to like things...and to be able to participate in different things...I don’t drive any more. I can’t drive any more.</p> <p>S: But, the things we went to... with Andrea.</p> <p>P: went...we went to...</p> <p>S: You liked time when we met at the zoo.</p> <p>P: Yeah.</p> <p>I: Theatres...going to the theatres...and</p> <p>P: It’s been very hard to going to places... when... um... there is a...unwillingness to be in...doing in much driving. And that’s a real life. I used to be the lead driver when we did something. So, I thought it was...then...my wife has had to get stuck with ...um...doing all the driving. That is not the fair. We tried to find things that we can do together... like exercises Friday and weekend at the community center. And we do...we have been still going to the symphony. That’s a pain. Music has been part of our lives since I was born. And ...so...transportation becomes a barrier.</p> <p>S: Oh, main thing. It’s really not a barrier. I am perfectly willing to drive... off for the symphony. Jewish family service will provide a round transportation for 20 dollars.</p>	<p>“Once you have a commitment, if you are a decent person, you want to honor the commitment, so we did it. But, if I just say Bradley how about going to the zoo tomorrow and he says No I don’t think so. I am not going to fight him about it.”</p> <p>He liked all the activities.</p> <p>“I don’t drive any more. I can’t drive anymore.”</p> <p>“It’s been very hard to going to places... when... um... there is a...unwillingness to be in...doing in much driving. And that’s a real life. I used to be the lead driver when we did something. So, I thought it was...then...my wife has had to get stuck with ...um...doing all the driving. That is not the fair. We tried to find things that we can do together... like exercises Friday and weekend at the community center. And we do...we have been still going to the symphony. That’s a pain. Music has been part of our lives since I was born. And ...so...transportation becomes a barrier.”</p> <p>She disagrees. “Oh, main thing. It’s really not a barrier. I am perfectly willing to drive... off for the symphony. Jewish family service will provide a round transportation for 20 dollars.”</p>
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<p>He's so upset and bitter that she drives. Not a burden for me to drive but the burden for him to watch her drive</p>	<p>I: That's good. S: That's reasonable considering it's fifteen miles a round trip?. But um...he's so upset and bitter about it. That's the...not the...burden for me to drive. That's the burden for you to watch me drive. That's the problem.</p> <p>I: Yeah. It's hard to see someone...I feel when I drive...sometimes some people feel a little bit unsafe when the other person is driving. I think it's a natural thing when we are driving we don't feel that it's safe or unsafe. [Saying to try to ease the tension about the driving issue]</p>	<p>“But um...he's so upset and bitter about it. That's the...not the...burden for me to drive. That's the burden for you to watch me drive. That's the problem.”</p>
<p>Her understanding about driving issue (self-identity especially for man) Coping strategy: It really isn't big deal to have to deal with driving</p>	<p>S: Yeah. Well. It's um...talking about it in the support group. Driving is not just a method from getting to point A to point B. It's a self-identity, and worth are tied up with that especially for men. So...it really isn't big deal to have to deal with driving.</p> <p>I: Right. It's been almost eight months after the program is ended. I feel like...you are going to some symphony still together. I don't know whether you found any difference between his moods between that...when he was involved in the program or...now he is not involved in the program? Do you see any difference between his feelings...?</p>	<p>“Driving is not just a method from getting to point A to point B. It's a self-identity, and worth are tied up with that especially for men. So...it really isn't big deal to have to deal with driving.”</p> <p>Affected his feelings?</p>
<p>He was happy with his pair Might stay happy for a day after meeting his pair No effect on his basic mood</p>	<p>S: Well. When you were with Andrea, you were happy and you might stay happy for a day afterwards. But I can't...I really can't say they affected his basic mood. I: So, his basic mood is stable. S: Yeah. I: But, at that time when he was with Andrea, he seemed to be happier?</p>	<p>“Well. When you were with Andrea, you were happy and you might stay happy for a day afterwards. But I can't...I really can't say they affected his basic mood.”</p>
<p>It affected his short-term mood and that was good. Coping strategy: Short</p>	<p>S: Yeah. Well. Don't despair short-term memory. Ha ha. I mean...short-term memories can... they are very blissful. ha ha. Yeah. Short-term</p>	<p>“Short-term memories can... they are very blissful. ha ha. Yeah. Short-term memories may be the best thing you</p>

<p>term memories: very blissful and may be the best thing you have going for you.</p>	<p>memories may be the best thing you have going for you. I don't think it affected long-term mood, but I think it affected short-term mood, that was good.</p>	<p>have going for you. I don't think it affected long-term mood, but I think it affected short-term mood, that was good. .”</p>
<p>Good for both</p>	<p>I: That was good for you, right? S: Yeah. Good for him. I: Good for him and good for you? S: Yeah. Right. Yeah. I: Because you know he is happier. S: Yeah. I: Is there anything you want to add... before we...? S: I would like to thank all the people involved in the program. I know it was work to set it up.</p>	<p>Good for him</p> <p>Good for both</p>
<p>Suggestions: Get more medical students or volunteers in the community to do something like this (it doesn't matter whether they are med students or not)</p>	<p>I: Do you have any suggestions for the PAIRS program? S: No. I mean actually they get more medical students... involved as no way we do that. Of course maybe somebody could get volunteers in the community to do something like this. I don't know. I: Right. So, I am ending the recording right now.</p>	<p>Suggestions for the program?</p> <p>Get more medical students or volunteers in the community to do something like this (it doesn't matter whether they are med students or not)</p>

Themes –Interview 2 (P2: person with dementia, C2: wife, I: interviewer)

Themes	Quotes
<p>Lifted his spirits by being with his pair</p> <p>(Being with his pair was like being on a date; rejuvenating; much more calm and cheerful; short-term mood)</p>	<p>C2: ...I've known [her husband's name]'s spirits were lifted by being with her [his pair].</p> <p>C2: ...Well, with [his pair's name] was like being on a date. I mean it really perked him up and...that lifted his spirits.</p> <p>C2: I was very happy for them. I mean it was really rejuvenating for him to be with her.</p> <p>C2: Well...much more calm and cheerful.</p> <p>C2: Well. When you [her husband] were with [his pair's name], you were happy and you might stay happy for a day afterwards. But I can't...I really can't say they</p>

	<p>affected his basic mood.</p> <p>C2: Well. Don't despair short-term memory. Ha ha. I mean...short-term memories can... they are very blissful. ha ha. Yeah. Short-term memories may be the best thing you have going for you. I don't think it affected long-term mood, but I think it affected short-term mood, that was good.</p> <p>C2: Well. um...I really can't say whether there was permanent improvements, but certainly he enjoyed all the time.</p> <p>I: How did you know that he enjoyed?</p> <p>C2: There was a smile on his face.</p> <p>C2: It gave him some happy times.</p>
<p>Having a friend (Having an opportunity to socialize with someone other than family)</p>	<p>C2: I think the best part was a long conversation with someone other than me. [a small laugh]</p> <p>I: What do you mean by someone other than you?</p> <p>C2: I mean we are together most of the time and our social life isn't so great. When you have Alzheimer's, your friends... can...lift away.</p> <p>C2: Well that was my expectation he enjoys being with someone... intelligent, charming, young lady. Ha ha. And I would enjoy seeing all these wonderful sites.</p> <p>I: So, do you think the program met your expectations?</p> <p>C2: Oh, yeah yeah. right.</p>
<p>Encouraged the couple to go to some interesting places (It gave him something to talk about with his pair and it gave the couple something to think about other than their usual concerns)</p>	<p><u>-A lot of fun and it encouraged the couple to do wonderful things that they haven't done for years</u></p> <p>C2: Oh, it was a lot of fun. Yeah. It forces... to...not forces, but encourages us to do some wonderful things that we just don't get around doing like going to the Zoo. I haven't been in the zoo for years.</p> <p>I: So, he likes going out and...Do you think the PAIRS program gave more opportunities for going out and being active?</p> <p>C2: Well, definitely. We haven't been to the zoo in thirty years. This was a motivation to go to the zoo.</p> <p><u>-Encouraged the couple to go places by being with his pair (he is upset/ unhappy that she drives when they go to some places; they are not getting along well many times, a lot of fight about her driving; a mood elevator)</u></p> <p>I: So...um...I can see you also had some interests in these activities, so I wonder if you found any differences between when you...when you only went to that activities only two of you or how was that different from involving another...medical student?</p> <p>C2: It was very different. It was very different. Yeah, very different.</p> <p>I: Could you tell me more about that?</p> <p>C2: [Her husband's name] and I are really... many times not getting along very well. So, we go to some place and um...he is very unhappy with it. He is very very upset with my driving.</p>

	<p>I: Why?</p> <p>C2: He doesn't drive and feels very bitter about that. And...lots of fight about my driving...and...um...um... [Saying with hesitation]. Well, with [his pair's name] was like being on a date. I mean it really perked him up and...that lifted his spirits. It was nice for me to do something little one with my friend. I even had fun going around by myself.</p> <p>C2: ...And then...um...most of our contacts now are elderly people. We don't even see our children as much as I would like and they are usually that crazy to go places with us. So um...we go to places with someone like [his pair's name] who sees everything with fresh eyes. And...it was a... mood elevator I would say. [a small laugh]</p> <p>C2: Well that was my expectation he enjoys being with someone... intelligent, charming, young lady. Ha ha. And I would enjoy seeing all these wonderful sites.</p> <p>I: So, do you think... the program met your expectations?</p> <p>C2: Oh, yeah yeah. right.</p> <p><u>-Going to some places interesting gave them something to talk about and think about other than their usual concerns.</u></p> <p>C2: Oh, well. The good thing was...go some place interesting. You don't just sit and talk. Go some place and they give you something to talk about and think about, like the Nelson and Zoo. Take you out of your... petty concerns and...</p> <p>I: So, from my understanding, because you go to some place, it brings up your...something to talk about...together.</p> <p>C2: Well. It gives him something to talk about with [his pair's name] ...my point was...and it gives us something to think about other than our usual concerns.</p> <p><u>- The PAIRS program is escapism by not thinking about disease and arguments.</u></p> <p>C2: The PAIRS program is a escapism. You are not thinking about...your memory is gone to hell. You are not thinking about the arguments. You are thinking about, oh, look at the polar bears swimming in the water. It just takes you away from yourself. Escapism is the best sense of the word... what I am saying.</p>
<p>Encouraged her to arrange activities</p>	<p><u>-It encouraged her to arrange activities during the PAIRS period. She was glad to have the pressure/the commitment to do it</u> (She suffers from depression and the fight about driving has taken away her desire to go around places)</p> <p>C2: And also I suffer from depression and I don't feel like arranging much. [a small laugh] It's hard to force myself to arrange things. ...I was glad to have the pressure to do it. Ha ha. Because they were very beneficial for both of us.</p> <p>C2: The fighting about the driving... really has a...taken away my desire to go around places.</p> <p>C2: Well. I still had to drive rarely, but the point was...it was...it was a commitment to do this, so we did it. [a small laugh]</p>

	<p>C2: Well. Well. Once you have a commitment, if you are a decent person, you want to honor the commitment, so we did it. But, if I just say [her husband's name] how about going to the zoo tomorrow and he says "No I don't think so." I am not going to fight him about it.</p> <p>C2: Well. The thing is that the PAIRS program was setup. You must go some place, so we did. With this [friendly visitor program], it's optional and you opt to not to go anyplace. ha ha.</p> <p>I: So, was it good?</p> <p>C2: Oh, yes. From my point of view, like I said, it was great to get out of the house and do something different.</p> <p><u>-It has encouraged her to be more active in arranging fun activities for themselves after the PAIRS program was ended.</u></p> <p>I: So...how do you think participation in the PAIRS program has affected your strategy for helping him in any way?</p> <p>C2: Well. I am trying to...be more active about engaging fun things like going to the Nelson Gallery...um...all those things...get out of the house and get out of your shell.</p> <p>I: So, do you...do you arrange some similar activities after the program was ended?</p> <p>C2: Well we went to the Nelson just recently. We haven't been back to the zoo.</p> <p>Um...</p> <p>I: Do you go to some gallery or theatre?</p> <p>C2: Well. We already have season tickets for several events. We go to the Quality Hill, Symphony and there is a place for musical theatre heritage that does concert versions of musicals. So... we just last week we went to a concert by the Kansas City Chamber Orchestra...all Bach. I am a Bach's fan, so that was a...that was an upper and you enjoyed that too, didn't you?[looking at her husband]</p> <p>P2: Yes, ma'am. Building of that...music...I think that's one of the reasons we fell in love each other. It was because I was the medical doctor and her brother, older brother was a medical doctor... because...would you like to go to the symphony? I got some extra tickets and my problems are... that way...music...my father was a professional musician, so that tie was what I am kind of...</p>
<p>A nice, fun opportunity for her to do things with her friend or by herself</p>	<p>C2: I went to everything. I went to everything, but um...the protocol was that I was not supposed to be doing with them. So, at the zoo, I just was at the zoo by myself. And... went to the theatre I...with the Coterie Theatre by a friend coming be with me. I bought four tickets and [her husband name] and [his pair's name] sat separately from my friend and me. [a small laugh] And um...we also went out to lunch before then. There again, we sat at a separate table, so...it encouraged me to do things with my friend, which was nice. [a small laugh]</p> <p>C2: ... It was nice for me to do something little one with my friend. I even had fun going around by myself.</p> <p>I: So, do you feel that his participation in the PAIRS program has affected you as well?</p> <p>C2: Oh, yeah. Well. It was a happy time. This community has wonderful cultural resources.</p> <p>I: So, you had some... more time for socialization with your friend.</p>

	C2: Yeah, felt like...yeah.
Knowing that he had some happy times	<p><u>-Knowing that he had some happy times was important to her (A load off her back)</u></p> <p>C2: ...It gave him some happy times. That was important to me.</p> <p>C2: It was a load off my back. ha ha. Yeah. He has depression too. I mean how would you not be depressed. This is a fatal... incurable illness. Think about it and then would be depressed. Ha ha.</p> <p>C2: I was very happy for them. I mean it was really rejuvenating for him to be with her. And we cheated a little bit. Sometimes we ate all together for him and me...ha ha...because we thought well, it's becoming the end of the program, I will just eat together because we...we all enjoyed each other's company.</p>
Activities chosen based on the couple's shared interests	<p>I: Do you know how they decided these activities?</p> <p>C2: I chose. I chose everything. [a small laugh]</p> <p>I: How did you choose activities based on what?</p> <p>C2: We've lived for 65 years. I am pretty familiar with all the cultural activities in the area.</p> <p>I: Did these activities have any special meaning to him do you think?</p> <p>C2: We talked it over before...he's always enjoyed the theatre and he loves classical music. You are not a big fan of the zoo, but um...</p> <p>P2: Oh, I like penguins and I like children.</p> <p>C2: I wanted to see the polar bears and penguins. There was a new exhibit.</p> <p>P2: She is a good pediatrician's wife.</p> <p>I: So, from my understanding, you chose these activities because you thought he would like them based on his interests.</p> <p>C2: Because I like them too. Yeah. Ha ha.</p> <p>I: So, both of you have shared interests.</p> <p>C2: Yes.</p>
Her little involvement in doing activities	<p><u>-She went to all the activities but participated separately (by herself or with her friend; aware of the protocol)</u></p> <p>C2: I went to everything. I went to everything, but um...the protocol was that I was not supposed to be doing with them. So, at the zoo, I just was at the zoo by myself. And... went to the theatre I...with the Coterie Theatre by a friend coming be with me. I bought four tickets and [her husband name] and [his pair's name] sat separately from my friend and me. [a small laugh] And um...we also went out to lunch before then. There again, we sat at a separate table, so...it encouraged me to do things with my friend, which was nice. [a small laugh]</p> <p><u>-She joined in him and his pair sometimes (eating together).</u></p> <p>C2: ...And we cheated a little bit. Sometimes we ate all together for him and me...ha ha...because we thought well, it's becoming the end of the program, I will just eat together because we...we all enjoyed each other's company.</p>

<p>Her description of his pair</p>	<p><u>-A pleasant, wonderful person</u></p> <p>C2: ...And then [his pair's name] was such a pleasant... wonderful person. ...</p> <p>C2: Well that was my expectation he enjoys being with someone... intelligent, charming, young lady. Ha ha. ...</p> <p><u>-Not much experience in cultural activities, so sees everything with fresh eyes</u></p> <p>C2: ...Her father is a physician, and ...so she did not come from a deprived background, but she was deprived. I mean she has never been to the zoo, never been to the Nelson, never been to the symphony, all these wonderful things we go to. And she was not familiar with them. Yeah. And she enjoyed every minute of it. It opened her eyes even though she didn't have much experience with them.</p> <p>C2: ...And then...um...most of our contacts now are elderly people. We don't even see our children as much as I would like and they are usually that crazy to go places with us. So um...we go to places with someone like [his pair's name] who sees everything with fresh eyes. And...it was a... mood elevator I would say. [a small laugh]</p>
<p>Her thoughts about relationship with his pair</p>	<p><u>-Happy close relationship</u></p> <p>C2: ...I think she [his pair] felt very close to us.</p> <p>C2: Well. It was...just happy close relationship.</p> <p>C2: I was very happy for them. I mean it was really rejuvenating for him to be with her. And we cheated a little bit. Sometimes we ate all together for him and me...ha ha...because we thought well, it's becoming the end of the program, I will just eat together because we...we all enjoyed each other's company.</p> <p><u>-She tried to keep in touch with his pair after the program was ended, but it didn't work out.</u> (She invited her to come over to their place, but it didn't work out due to his pair's busy schedules. She understands how busy medical students are.)</p> <p>C2: I intended to keep our relationship with [his pair's name] too. We saw her at the Alzheimer's walk in October. And I intended to invite her over but... medical students are so overscheduled. I know we won't be able to see her very often. I think she felt very close to us.</p>
<p>Shared family's involvement in Medicine (between the couple and his pair)</p>	<p><u>-The couple and his pair have something in common in terms of family's involvement in Medicine.</u> His pair was deprived in terms of cultural experience. She thinks his pair enjoyed every activity because it opened her [his pair] eyes. It was good to her who does not have any personal life due to busy schedules as a medical student (she talks about her son's experience when he was a medical student).</p> <p>I: I feel like you guys have both shared interests in music.</p> <p>C2: Uh-huh.</p>

	<p>I: And how do you think about her [his pair's name]'s... do you think [his pair's name] has some interests in music too?</p> <p>C2: Oh, this is really curious. Her father is a physician, and ...so she did not come from a deprived background, but she was deprived. I mean she has never been to the zoo, never been to the Nelson, never been to the symphony, all these wonderful things we go to. And she was not familiar with them. Yeah. And she enjoyed every minute of it. It opened her eyes even though she didn't have much experience with them.</p> <p>I: So, I guess she learned from...learned a lot of these...experience...</p> <p>C2: I really think medical students are abused...with such an intensive program...and...my son told me the story before he started the medical school. There was an orientation and the faculty members said "Now, if you have any per.... this was Friday, if you have any personal problems, solve them by Monday." Ha ha. So, I know he was not supposed to have any personal life, but everybody needs personal life. So, this was good for her and... I would say this was good for us.</p>
<p>Her belief and value</p>	<p><u>-Her belief and value that everybody including busy medical students needs personal life.</u> (Her family's involvement in Medicine and music and her active involvement in Music and arts; This belief might affect arranging activities and scheduling with his pair. They met twice a month for two hours each time sometimes because she thinks meeting for four hours is too long for a person with Alzheimer's. Meeting twice a month could be demanding to medical students who are very busy and scheduling could be challenging, based on what other participants said. Her belief and value in the important of having personal time might influence that they met twice a month for two hours each time rather than meeting once a month for four hours)</p> <p>C2: Her [his pair] father is a physician, and ...so she did not come from a deprived background, but she was deprived. I mean she has never been to the zoo, never been to the Nelson, never been to the symphony, all these wonderful things we go to. And she was not familiar with them. Yeah. And she enjoyed every minute of it. It opened her eyes even though she didn't have much experience with them.</p> <p>C2: I really think medical students are abused...with such an intensive program...and...my son told me the story before he started the medical school. There was an orientation and the faculty members said "Now, if you have any per... this was Friday, if you have any personal problems, solve them by Monday." Ha ha. So, I know he was not supposed to have any personal life, but everybody needs personal life. So, this was good for her [his pair] and... I would say this was good for us.</p> <p>C2: It was...it was some demanding for time. The program...most of that was...they said...a four hour segment, but I thought...maybe that...a lot of times that was little long... over times. So, we did two two hours sometimes. Yeah. I would say that...better...looking to that...I think a lot of people with Alzheimer's are not ready for a four hour program.</p> <p><u>-Keeping him at home as long as possible</u> (She doesn't want to move him to the retired home until they have to do because she thinks the move is dramatic. She</p>

	<p>already has a future plan for herself if he dies before he moves to the retired home).</p> <p>C2: ...so that's...the goal is to keep the patients in their homes as long as possible. Because...our kids saying why don't you move him to the retired home, but...some people move and die in six months. The move is dramatic. So, I don't want to move. We will do it if we have to do. But I don't want to do it before we have to.</p> <p>P2: There is somebody between us to somebody watching the other one, so... we are...If I am with by myself, I don't think I will be at home.</p> <p>C2: No. No. If [her husband's name] dies before I do it, I will ask for going to the assisted living sometime though. Then, I will sell the house and get something to smaller one. We don't need four bedrooms. We don't need this big lot, and we don't need this continual...spending money. Ha ha.</p> <p><u>-Short-term mood and memories are very blissful.</u></p> <p>C2: Yeah. Well. Don't despair short-term memory. Ha ha. I mean...short-term memories can... they are very blissful. ha ha. Yeah. Short-term memories may be the best thing you have going for you. I don't think it affected long-term mood, but I think it affected short-term mood, that was good.</p>
His strategy	<p><u>-Working as a team with his wife in talking when he cannot remember:</u> He doesn't say he cannot remember and he lets his wife tell instead of him (possible not only for the need but also for his self-esteem?)</p> <p>C2: Do you remember any special you did with [his pair's name]?</p> <p>P2: Um... you can pick up that.</p> <p>I: Oh, your experience of participation in the PAIRS program that you did with [his pair's name].</p> <p>P2: Oh yeah. Do you want to say something? [looking at his wife]</p> <p><u>-His voluntary involvement in talking when he can do</u> (to disagree with what his wife said and to add his thoughts)</p> <p>P2: We talked it over before...he's always enjoyed the theatre and he loves classical music. You are not a big fan of the zoo, but um...</p> <p>P2: Oh, I like penguins and I like children.</p> <p>C2: I wanted to see the polar bears and penguins. There was a new exhibit.</p> <p>P2: She is a good pediatrician's wife.</p> <p>C2: But...you are not going to die tomorrow because there are many happy years I think. I think I would advise anybody, don't take the illness lying down, do everything you can do to fight it, like exercises, socialization, and volunteer work everything you can do. There is no reason just to say: Oh, I have Alzheimer's I will die tomorrow. You don't have to say that.</p> <p>P2: What about family visits?</p> <p>C2: What about?</p> <p>P2: Our supports.</p> <p>C2: Yeah. We have good kids and grand kids. [a small laugh]</p> <p>C2: We go to the meetings for the Democratic Party once a month. And um...we</p>

	<p>are voters of...Blue Cross...seniors who like computers. P2: And exercises</p> <p>C2: Well.um... I cannot answer that. We just didn't do it... ha ha. P2: I will bring it up. C2: Okay. ha ha.</p>
Her strategy	<p><u>-She helps him understand and answer the question</u> (rather than answering the question by herself), so he can still be an agent in talking, but his self-esteem is not hurt in front of another person (interviewer) before he can feel embarrassed (as soon as the interviewer asks about activities because she is very aware of his cognition).</p> <p>C2: Do you remember any special you did with [his pair's name]?</p> <p><u>-She tries to remind him of activities they did with his pair by giving specific examples</u></p> <p>C2: I think she [the interviewer] is speaking of what we do with [his pair's name]. We went to...saw the Wiz remember the...at the Coterie Theatre? P2: Yeah. C2: We saw Romeo and Juliet... and the Nelson. Anything special that stands out in your mind?</p> <p><u>-Her coping strategy/belief: Do everything you can do to fight it and enjoy life even with Alzheimer's</u> (you can be happy and enjoy your life with Alzheimer's).</p> <p>C2: But...you are not going to die tomorrow because there are many happy years I think. I think I would advise anybody, don't take the illness lying down, do everything you can do to fight it, like exercises, socialization, and volunteer work everything you can do. There is no reason just to say: Oh, I have Alzheimer's I will die tomorrow. You don't have to say that.</p>
The couple's strategy (doing things together)	<p><u>-Working as a team in doing</u></p> <p>P2: So...I have to stimulate from... my wife...as you already hear...and um...so we've been doing things together. And then... I back to my kids. Now, my grandchildren... we are going out with the young-married couple...next next generation. Ha ha. So, that's been... thrilling...for me and of course I think my wife. I think it spins off, oh how nice. So, that's wonderful that I have a family.</p>
Impact of dementia	<p><u>-He doesn't remember anything related to PAIRS program including activities he did with his pair.</u></p> <p><u>-He keeps talking about his past work experience, his and her family involvement in Medicine, his and the couple's shared interests in music, and the story of when the couple met each other regardless of question</u> (Because he wants to talk about these experiences that help him feel proud of himself and happy, because he cannot remember anything relate to the PAIRS, or because he forgets the question? assumption based on his short-term memory)</p>

<A few examples>

I: So, it's almost...um...it's winter time. So, do you do any specific things for fun or any... during the winter time? [asked this question to divert his attention from talking about his work experience to talking about more casual, daily life]

P2: Well. The one of the things I did for three years...it was with the Harvester's...a nutrition program and Kansas city and then we working with the...well, we had a food drive but um...the mission was food drive. What's the quality of the food? ...

I: Do you like looking at the polar bears and what did you most like...in the zoo?
[Asking to the person with dementia]

P2: We are both music lovers since we met each other. So, that's continued. So, we are crazy people in symphony and used to go to the operas. And um...we still go to the...some plays...

C2: I think she [the interviewer] is speaking of what we do with [his pair's name]. We went to...saw the Wiz remember the...at the Coterie Theatre?

P2: Yeah.

C2: We saw Romeo and Juliet... and the Nelson. Anything special that stands out in your mind?

P2: Oh, that's always been...as long as we met each other...in a way... students... Minnesota... we met each other...there was always some extra tickets...my wife's parents...would you like to go to the play at the University of Minnesota? Would you like to go to the symphony? We had some tickets ...would you like to once in a while? My father was a professor musician, so...

-He has to do things together with his wife because he cannot do it by himself

P2: So...I have to stimulate from... my wife...as you already hear...and um...so we've been doing things together.

-Driving issue (he is upset that he cannot drive any more. This affected their leisure lives that they have done together for a long time. She uses Jewish family service for transportation sometimes. She understands that driving is related to his self-identity, so she regards this issue as a natural thing to deal with.)

P2: I don't drive any more. I can't drive any more.

P2: It's been very hard to going to places... when... um... there is a...unwillingness to be in...doing in much driving. And that's a real life. I used to be the lead driver when we did something. So, I thought it was...then...my wife has had to get stuck with ...um...doing all the driving. That is not the fair. We tried to find things that we can do together... like exercises Friday and weekend at the community center. And we do...we have been still going to the symphony. That's a pain. Music has been part of our lives since I was born. And ...so...transportation becomes a barrier.

C2: Oh, main thing. It's really not a barrier. I am perfectly willing to drive... off for the symphony. Jewish family service will provide a round transportation for 20 dollars.

I: That's good.

C2: That's reasonable considering it's fifteen miles a round trip?. But um...he's so upset and bitter about it. That's the...not the...burden for me to drive. That's the burden for you to watch me drive. That's the problem.

	<p>C2: Yeah. Well. It's um... talking about it in the support group. Driving is not just a method from getting to point A to point B. It's a self-identity, and worth are tied up with that especially for men. So... it really isn't big deal to have to deal with driving.</p> <p>-<u>Change in social life/ limited social life</u> (friends lift away)</p> <p>C2: I mean we are together most of the time and our social life isn't so great. When you have Alzheimer's, your friends... can... lift away.</p> <p>-<u>The couple has depression</u>. (he has got depression after his diagnosis but it's not sure her depression was due to his diagnosis)</p> <p>C2: ...He has depression too. I mean how would you not be depressed. This is a fatal... incurable illness. Think about it and then would be depressed. Ha ha.</p> <p>C2: And also I suffer from depression and I don't feel like arranging much.</p>
<p>His expression of his self-identity and shared identity with his wife</p>	<p>-<u>Identity related to his past work</u></p> <p><Summary: Working as a pediatrician with the federal government for children and mothers></p> <p>P2: Okay. Well. I've been retired for sometime and my... my involvement ... has been... um... much less than I have been... my... um... before I retired... and my responsibilities in the past as a pediatrician working with the United States Federal... office of health and human service... I was giving with children and mothers. My title was a... um... originally I... as a pediatrician I was retired to be... working with a... um... Kennedy, the president Kennedy two or three time mental retardation problems in children. And then we focused broader on special needs children and then broader than that, mothers and children, the health care. So, that's been my... my experience for a number of years when I retired a few years back.</p> <p><Summary: He talks about his involvement in public health by working with the federal government after he graduates from medical school></p> <p>P2: Minneapolis, Minnesota, Minneapolis. We've been... it was a... in the Twin Cities of Minnesota... of the arts... and then of... I probably mentioned this for that... but there's a... my three brother-in-laws ... are all physicians. My father-in-law is a physician. So, we have all these physicians and I am... I've never went into to private practice like my brother-in-law. I worked... I got my first... first... responsibility after getting out of the medical school to be... working in public health. And then I became play for the federal department of health and human services. Let's call it back in... in the... Department of Health and Education Welfare. that's all. A few credits. I spent my life... with the... I work with the federal government.</p> <p><Summary: He talks about his working experience as a consultant and his interests in children, maternal and child health, and nutrition; his responsibility as a federal employee and a medical doctor; working with several universities and several disciplines></p>

P2: Yeah. I've been... a consultant for the department of KU's Medical School and also a consultant of Children's Mercy Hospital with... involved with UMKC'S Medical... So, I had a... dealing with medical doctors in addition... because of my interests in the children and others... maternal and child health... federal program. Nutrition was a part of our lives and like a food pantry at Harvester's here's something I worked with. The university of Missouri's nutritional program I worked with them... and then KU and then University of Nebraska and then University of Iowa. And then for a while when I was a younger... consultant with University of Minnesota, and University of Iowa, University of Nebraska. So, I had all this... that's kind of responsibility being a federal employee, medical doctor in addition... to deal with the faculty... the medical schools. Then, with my interest... in a broader... children... I mean with programs like the nutrition and social work and... um... we had much broader thing given... when you care special needs children you can be dealing with physical therapy and occupational therapy. So, some of big change in the Kansas City area, for example, the Children's Mercy Hospital expanding greatly in the 60s and um... we worked with KU, as I mentioned earlier, at the medical school there and also um... University of Nebraska, University of Iowa, University of Minnesota... as a pediatrician trying to stimulate the... working with a training program... pediatricians and um related programs... special needs program let us into... dealing with the pediatric neurologist, dealing with aspecial education, nutrition, social work...

<Summary: He talks about his first job title (feeling proud of himself?)>

P2: My first job was titled... under the president of Kennedy of original program mental retardation. That was started way back in the ...50s. That was my first title and so...

<Summary: He talks about his nutrition program that aims to give healthy foods to children and pregnant women>

P2: Well. The one of the things I did for three years... it was with the Harvester's... a nutrition program and Kansas city and then we working with the... well, we had a food drive but um... the mission was food drive. What's the quality of the food? Is this appropriate? What's happening people with be taking?... um... I use the word junk food... and the donation, so we... that made a committee of Harvester's here in Kansas city so I... do a... development of food... food... analysis food, food... for children and pregnant women. So, we scheduled of this. We talked about the... getting nutritious food. I worked with a number of dietitians and nutritionists dealing with children and pregnant women. So, that was a big step getting involved with a set of people donating whatever they had... junk food in their kitchens because... we said you want to give something... food to poor people targeting at children, mothers... make sure they are nutritious, so to me... here in Kansas City. This is what the nutrition. Well, of course, but the big federal programs and state programs dealing with nutrition. You got involvement of the nutritionists from... who working at KU and at the Children's Mercy Hospital, but it was more... more getting the stimulus there... let's make sure babies and pregnant women are getting quality food and at the same time, that was happening the federal government came around us. Hey, let's sell... the nutritious program for children... woman, infant, child programs from the US. We were working, coordinating together the maternal child health... with the food people. Some people said... give them anything. Our committee... four state the nutrition. We said let's show... the public and the private

sector what nutritious foods are... that's supposed to...here. That's called ...
[Speaking with smile and joy at the end] (because he feels proud of what he did?)

I: Yeah. That's great.

P2: So, anyway. We...when we viewed this back in the middle 60s and oh my god, everybody is...throwing out their garbage. We went to the board. So, that was...that was a big change that happen dietitians nutritionists sitting with us and...helping a plan for nutritious food. So, we were handing out pamphlets to...to various food banks and say here's a what you were going to be having for... if you had...pretty much tight for mothers and children but at the same time...um...we were...flying a lot of ... in quality became important instead. That's good. Let me empty my kitchen... that junk... we stopped the junk food.

I: That's hard. That's hard. Ha ha.

P2: Quality is such a thing for pediatricians and nutritionists.

<Summary: He talks about his work experience related to nutrition. Stimulating quality food was my part of life.>

P2: But have you got all your presents already waiting for the... I love this time [Christmas] because I will say oh, here's something nice for children, candy? No... well, anyway. Was that giving you advice to um...people who want to give children and pregnant women quality foods, not just a school's from what's in the trash can. That was...that was my part of my life... stimulate...quality food...and that came from a number of excellent...public health and nutritionists...hospital nutritionists...about here something If you are pregnant and your baby is born, what fit programs like the women and child and nutrition programs for pregnant women and their infants. I worked for that and then I...we quickly got the experts...nutrition and...people helping with the...

-Shared identity with his wife as music and arts lovers (happy memories; He thinks music is one of the reasons they fell in love each other. He asked her out for the symphony)

P2: Oh, we've been maintaining...um...both of us are music-lovers so that's why we did...Kansas City Symphony...and we've been doing that for...since... way back to the 60s.

P2: Yes, ma'am. Building of that...music...I think that's one of the reasons we fell in love each other. It was because I was the medical doctor and her brother, older brother was a medical doctor... because...would you like to go to the symphony? I got some extra tickets and my problems are... that way...music...my father was a professional musician, so that tie was what I am kind of...

P2: We are both music lovers since we met each other. So, that's continued. So, we are crazy people in symphony and used to go to the operas. And um...we still go to the...some plays...

P2: We've been...we've been very active in...supporting...the arts and um... music. My father was a professional musician. Her whole family is a bunch of musicians. I think that's one of the reasons we got married because music is... so common...two of us...and um...it's something that I've always been...encouraging anybody to get...you get a hobby. And somebody likes to play the flute and

somebody likes to listen to the flute....My father was a professional pianist, so that's...my wife...we are dating ever since then we have music. It was a kind of. We like cats too. I think that is another thing in common. We both agree with each other...We like to have something to...something else to love.

P2: We both love arts. We went to the symphony, went to the operas. We have amateur musicians in the family. So...the arts have always been important. We used to go over a little more regularly to the Nelson Gallery. We've just been there and that kind of thing. I wasn't involved until I married and I found ...I like to go too, which wasn't going to be too expensive as a new couple, but we found ways to getting into the... then we moved here. But...one of the early things we did...and I first moved here and working in Kansas City. Was finding the Nelson Gallery...we...we used to get tickets for the Kansas City Symphony still. It's been last year that we slow down somewhat but we have still been going in...I love music but my...amateur musician is over here. We always say I don't think we got married if it wasn't for...music.

-Identity related to his family (family's involvement in Medicine and music- things in common)

<Summary: He talks about his father who was involved in Medicine but very active in playing the music. He and his father liked each other not because of Medicine, but because of the same interest in music. His family members (including himself, his father, brother-in-laws, daughters, son) have been involved in Medicine (Internal Medicine especially). He talks about other family members (daughter and grandkids).>

P2: We were both...um...graduates of University of Minnesota. And um... my father was...is professional...was a professional musician, so...my wife...my father and I was very internal medicine, but he was very active in playing the music. So that...I think that got us together. Not Medicine... but um... liked, we liked each other because of things like music I remember that why I did I get marry to him...doctors, medical doctors...my...daughter ...then I...that's the...my friends...her brothers...my friends and me, we got to know each other very well from... um...where we met in the University of Minnesota and then following that. So, families have been involved with the...Medicine. And um...I am a pediatrician. My... brother-in-laws... three of them are internal Medicine people. A lot of Medicine in...in the family. My wife is a doctor...um...PhD in Mathematics. So, we have those kinds of common...common... things together. And then, my son is a... a physician...Internal Medicine and um... my daughter...one of my daughters... my daughter is a...works for the Kansas City Star... as an author. And my grandkids are...one of the youngest has just got married and...our family is...everybody is married and then...I will see...I will see grand-grand children someday.

P2: Well, then the other thing that's going on with is is that...our children grew up. Medicine was in my wife's family when we got married. As a medical doctor, pediatrician, and then the next thing I know was my son is a neurologist... copycats.

<Summary: He talks about how he and his wife met>

P2: Our family is a...taking...as I told others in the past ...we got...I got to meet...

	<p>my wife and I met together...because of Medical School. So, I was invited over to... my wife's brother to parties for the medical students. She was...her dad was a prominent cardiologist... for the Medicine and Medicine and Medicine. So, it was, as I said earlier, that is a...my brother-in-laws and my wife's brother were all Internal Medicine doctors. I am a pediatrician also.</p> <p>P2: Oh, that's always been...as long as we met each other...in a way... students... Minnesota... we met each other...there was always some extra tickets...my wife's parents...would you like to go to the play at the University of Minnesota? Would you like to go to the symphony? We had some tickets ...would you like to once in a while? My father was a professor musician, so...</p> <p><u>-His interests in animals, children, Christmas time</u> P2: Oh, I like penguins and I like children. P2: Almost it's as good as my cat. We love kids. I am a pediatrician I think that was a beginning I think. I love kids. P2: We like cats too. I think that is another thing in common. P2: I love this time [Christmas] because I will say oh, here's something nice for children, candy? No... well, anyway.</p> <p><u>-His family's support (He feels good about his family's support)</u> P: So...I have to stimulate from... my wife...as you already hear...and um...so we've been doing things together. And then... I back to my kids. Now, my grandchildren... we are going out with the young-married couple...next next generation. Ha ha. So, that's been... thrilling...for me and of course I think my wife. I think it spins off, oh how nice. So, that's wonderful that I have a family. I: Yes. um... P2: Almost it's as good as my cat. We love kids. I am a pediatrician I think that was a beginning I think. I love kids. My wife has got...six children in her family, five am I. we are both the oldest. And so I used to get kicked in the shins by my brother-in-law. And I...how nice. I: Do you see your children and grandchildren very often or... do they visit you? C2: A couple times a month. Yeah. um...I'd like to see them more, but um...yeah.. always... P2: They like us. They like us. C2: They are supportive.</p> <p>P2: ...Our kids are grown-up. Our grand-grand children are...grown-up. And um...we have a little bit of fun. And um...I think we both are fortunate to see our kids all the time. They want to know how we are. Oh, I feel good.</p>
<p>Her expression of his identity and the couple's shared identity</p>	<p><u>-His interests in classical music and theatre</u> C2: He's always enjoyed the theatre and he loves classical music.</p> <p><u>- He is very active</u> C2: He is still very active.</p> <p><u>-Shared identity (participation in activities)</u> C2: We go to the meetings for the Democratic Party once a month. And um...we are voters of...Blue Cross...seniors who like computers.</p>

	<p>P2: And exercises C2: Oh, yeah. We exercise...we try to do it five days a week. Have some chance for conversation there.</p>
<p>Her expression of her self-identity</p>	<p><u>-Her participation in varied leisure and social activities:</u> She does not want to give up anything because they are all fun. She uses home management services and a friendly visitor program to participate in her activities and have somebody with him.</p> <p>I: Do you involve in any activities? C2: I am over-involved...over-involved. Ha ha.</p> <p>C2: ...And I am...involved...I play in a band I play the flute. I am in a bridge group. I am in a book club. And I run a volunteer program...a mathematics club. Ha ha. Also, I do...I've been tutoring, so I really...</p> <p>I: Wow, you are so busy. C2: I have too many activities. I don't want to give up anything because they are all fun. Ha ha.</p> <p>I: How did you...how do you manage all the activities while you are caring for him? C2: Oh...my slumpy housekeeping. Ha ha.</p> <p>I: Do you have anybody who...? C2: Oh, yeah. We have a domestic worker who comes once a week and cleans the house. And...Jewish man service has a nice program. You pay a flat fee and you get unlimited service from...that man was with them. He fixed that...it's called a glider chair. He fixed that for me. All the things...minor repairs... around the house they can do. Or, even moving furniture...or moving heavy objects...so that's...the goal is to keep the patients in their homes as long as possible. Because...our kids saying why don't you move him to the retired home, but...some people move and die in six months. The move is dramatic. So, I don't want to move. We will do it if we have to do. But I don't want to do it before we have to.</p> <p>C2: Our temple has a program where they send out the friendly visitor. And I... use them for caregiving. Bradley hasn't wanted to go to any place with them though. They would be glad to take you some place but you haven't really wanted to. P2: No. C2: And also they usually just come for a maximum of two hours. It's pretty hard...you really can't go...you can't...window...you couldn't go to the movie...you could go out for a snack. They did that once, but he didn't seem to be interested in that... and doing that again. I: So, you mentioned that the friendly visiting program has...were shorter time... C2: Yeah. Only..two hours in total. That's been helped me out because...like when I went to the rehearsal for the band Monday night, somebody was here. I: Is it once a month or...? C2: Oh, they come out maybe three times a month. I: But, they only have two hours. C2: But, never more than two hours. Yeah. I: So, it is hard to go out to some place... C2: Well. I just left him alone some of the time. I maybe be taking a chance, but um...I think...you function pretty well for short periods.</p>
<p>Suggestions for</p>	<p><u>-Having more medical students or volunteers involved in the program (it doesn't</u></p>

<p>the PAIRS program</p>	<p>matter whether they are med students or not)</p> <p>C2: I mean actually they get more medical students... involved as no way we do that. Of course maybe somebody could get volunteers in the community to do something like this. I don't know.</p> <p>C2: Um...at the Alzheimer's Association, they are giving the preference to people who have not been in it. I mean the PAIRS program is going on now, but they hadn't given the preference to...not to us because we were already in it. There is more people who want it than there are medical students are available.</p> <p>I: So, did you... So, you wanted to participate in the program again, but you couldn't because they gave the priority to the new people?</p> <p>C2: Well. Yeah. If we could have, I would've urged [her husband's name] to do it. But...I think we did formally express the interest, but they explained no that...I understand that.</p>
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Note

-Activities: Going to the zoo, theatrical programs (twice), Kansas City symphony, Nelson Gallery, and eating out

-He became talkative when he talks about things he can remember and he is interested in (when talking about his past work experiences and shared interests in music with his family and wife). He talked at length without any pause and didn't let the interviewer talk. He frequently interrupted while the interviewers said as a response to his talk. (Because he was so excited to talk about what he remembers well or is this a sign/symptom of dementia?)

-His wife left in the middle of the first part of the interview. It may be hard for her to stay there because she had to see her husband who talks what is not related to the PAIRS program.

-There was a visitor (a parcel delivery guy) between the first part and second part of the interview. He greeted with the visitor and say that today is a day or two before the coldest day of the year. P2: Well. This is a...a day or two before the coldest...shown as... day of the year. Then, become to the coldest of the year.

Interview 3.

I: Interviewer

P: Person with dementia

S: Spouse of the person with dementia

- Descriptive comments: focused on describing the content of what the participant has said, the subject of the talk within the transcript (normal text)
- Linguistic comments: focused on exploring the specific use of language by the participant (italic)
- Conceptual comments: focused on engaging at a more interrogative and conceptual level (underlined)

Emergent Theme	Original Transcript	Exploratory Comments
<p>Impact of dementia (difficulty in remembering the activities) Sigh, hesitation and laughter</p> <p>Impact of dementia (memory loss) Self-awareness of memory loss Impact of dementia (can't remember the name but can describe it)</p>	<p>I: I am a researcher of the PAIRS program that pairs people with early stage Alzheimer's and medical students for social gatherings at the University of Kansas Medical Center. You participated in the PAIRS program from September, 2013 to April, 2014. I really appreciate that both of you agreed to do interviews today. Thank you so much. And then, your responses are confidential and will not be shared with other participants in the program. Your name is not used for this audio recorded interview by assigning you a study number. This interview is to know about your experience of participation in the PAIRS program and your thoughts about its' impacts on you and your daily life. There are no right or wrong answers. And the interview will take about 1 hour. Before we start the interview, could you tell me activities you or your spouse did with the medical student during the PAIRS program period? We will talk about the details later, so please tell me activities briefly.</p> <p>P: Oh. [Sigh] That's been a while. ha ha. Well. We went out...had lunch together. um... I ...you know. ha ha. My... my</p> <p>I: I know it's been... for a while.</p> <p>P: my memory is a... so far... gone. I just remember we go after lunch and visit. um.. We went over to my son's house at one point and there she and her husband and a little boy. um.. We went over and they had dinner with us over there... um... visited and um... We went down to a.. a lunch at the ... the... um... historic</p>	<p><i>Sigh, hesitation and laughter</i> <u>Is she laughing to cover her embarrassment of not remembering the activities (memory loss)?</u> <u>Why does she remember having lunch together first?</u> <i>Expressed sympathy</i></p> <p>Impact of dementia (memory loss) Self-awareness of memory loss <i>Hesitation</i> Impact of dementia (can't remember the name but can describe it) <i>Repetition of one event: visiting</i></p>

<p>Repetition of one event: visiting her son's house with the medical student, her (the medical student) husband, and her little boy</p> <p>Little involvement of her spouse in activities (except one time)</p> <p>Lucky that her sister lives very close</p> <p>It's been a while</p> <p>She feels like it's been longer than 8 months since she did not meet her pair (no contact after the program was ended)</p> <p>Did a lot of things and always enjoyed Her pair: delightful Meeting with her family and the little boy was really nice (repeat again)</p>	<p>home... down by a... the a Kauffman center. Can't think of the name of it now, but it's...it's a... what used to be a school and they remodeled and that looks just beautiful and have all kinds of unique presence and things. We um...she and her husband and a little boy came over to my... with us to our son's and had dinner during the holiday... time. um... I think we went to a show...a movie... one time and she was with me. um...</p> <p>I: Were you with her when she and...? S: No. I: Oh, so the... S: We had one. One session where I was with them. P: um...A couple of my sisters went along with us too. My...she lives across the street from me, how lucky is that? [smile]</p> <p>S: Ha ha ha.</p> <p>P: and I... I seem...I...you know. It's been a while, so...</p> <p>I: I know. It's been almost... ya...8 months. Ya...</p> <p>P: Seems like longer than that, but...</p> <p>I: Yeah, we can talk the later.</p> <p>P: We did a lot of things and we always enjoyed it. She was delightful, and.. getting to meet her family and a little one was really nice.</p>	<p><i>her son's house with the medical student, her (the medical student) husband, and her little boy</i></p> <p><u>Why does she mention visiting her son's house with the medical student, her (the medical student) husband, and her little boy twice?</u></p> <p><u>Is this event important or impressive to her? Why?</u></p> <p>Asked to the husband to better know about activities Her husband was with them one time Her sister accompanied them several times She thinks she is lucky that her sister lives very close to her. <u>Does she have a close relationship with her sister? Why the sister accompanied them? Does she usually spend time with her sister for fun?</u> <i>Laughter</i> <i>Hesitant repetitions (I...I seem...I)</i> <u>She is not saying that she can't remember because of her dementia. She is saying that it's been a while. Does she say like this to protect her self-esteem?</u> <i>Expressed sympathy</i> She feels like it's been longer than 8 months since she did not meet the medical student. <u>Is this because she remembers earlier times when they met better than the later times?</u></p> <p>She always enjoyed the meetings She said the medical student was delightful and meeting with her family and the little boy was really nice. <u>She did a lot of things with the medical student, but she talked about meeting with the medical student's family again because it</u></p>
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<p>Impact of dementia (memory loss: she can't remember her pair's name) Her spouse doesn't know about any activities which she did with her pair except the family dinner with her pair's family</p> <p>He or her sister dropped off her to the places. The spouse couldn't stay on their gathering except one family dinner</p> <p>Impact of dementia (she can't drive) Impact of dementia: memory loss (She can't remember whether her sister engaged in the activities together or drove them only)</p>	<p>I: Do you know any activities your wife did with the medical student? S: with what? I: With the medical student? P: was...um...I can't ...can't remember her name. S: I don't know it either; we had one dinner with her. I: So, the... she [the medical student] came to the house to drive to somewhere with her [the person with Alzheimer's]? P: Well. No, I think that's why somebody went else went to be... 'cause I think she had... I don't think she had to take me to somebody by herself or something. I: Uh...So, how did she go to the...? S: We dropped off them or something. Either that or her sister... 'er go with them, so not always... I wouldn't I couldn't stay on the meeting but we did have one individual... P: yes. either...either ... S: dinner P: who was Lesley or.... or...my sister. You know. Usually went... was with us. I: So, your sister drove her... S: Could have. P: Well. I think she wasn't... she can drive me in her car or something. S: Yes. P: and so I couldn't drive. So...I think it was my sister more than anybody. It was...uh...see... and I can't remember if Lesley did any of that... too. S: I don't know. I dropped her... too...but not very many times like the downtown thing. I think somebody else drove her. I: I see. So for the first part of the interview, I would like to hear only from you (<i>looking at the person with dementia</i>), and then I will give both of you time to talk later (<i>looking at the couple</i>). Because the interview has to be done in the same way for everyone, I'd like to hear from her without your involvement or help in her talks for the</p>	<p><u>was really nice. Why is she feeling like that?</u></p> <p><i>I asked the spouse the activities assuming that the spouse might ask her what she did with the medical student on that day.</i></p> <p>Impact of dementia (memory loss: she can't remember the medical student's name) The spouse doesn't know about any activities which she did with the medical student except the family dinner with the medical student's family <u>Is he not interested in what his wife did with the medical student? Does he usually not talk with her about how she spends a day? Is this a continued pattern during their marriage years or is this after her diagnosis (memory loss)?</u></p> <p>The spouse said that he or her sister dropped off her to the places. The spouse couldn't stay on their gathering except one family dinner.</p> <p>She said that her sister usually drove them to places.</p> <p>Impact of dementia (she can't drive) Impact of dementia: memory loss (She can't remember whether her sister engaged in the activities together or drove them only.) The spouse said he dropped her a few times (not many times).</p>
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<p>My memory is bad</p> <p>Concerned about being helpful because of bad memory</p> <p>Her strategy? Doing her best within her abilities</p> <p>Enjoyed her pair Laugh because she can't remember her pair's name Nice girl; Enjoyed hearing about her family, her little boy, and her husband Expression of self-identify: Family-oriented; so matched for me because she could hear about her pair's life Pleasant time Enjoyed having her pair meet her family (coming over to her son's house) A nice couple and a cute little boy Going to a movie together Feels it's been a long time since she has seen her would like to see her pair again Always nice We always enjoyed whatever we were doing Looked forward to going with her</p>	<p>first part. Do you have any questions before we start the interview? P: ha ha... Other than my memory is so bad, I don't know how helpful this is the... I: no no no. P: Okay. I: You are the expert. I am just here to learn about your experience. It's okay if you cannot remember. It doesn't matter. P: I will do what I can. Ha ha... I: Are you ready for the interview? P: Yes.</p> <p>I: Could you tell me about your experience of participation in the PAIRS program?</p> <p>P: Well... um... I enjoyed the pair the girl I was... was my pair. Ha ha...um... She was just really nice and I enjoyed hearing about her family and her little boy and her husband. I'm very family-oriented and it is so me...matched for me because... hear about her life and she...um...um... you know I am not exactly sure what you are needing to hear. I just...she...made a great...this was always a pleasant...um...time. I enjoy having her meet some of my family which is what I am saying...um...being at our son's because they were just, such a nice couple and a cute little boy. ...I went to a movie I think one time. We went to a movie together I think. ... and I... maybe...My memory is...is...something well I am...you know.... It is just hard for me to pull up because it's been. It seems like it's been forever. I can I guess it is over in May or something. I don't know it seems like it's been a long time since I've seen her, and I would like to see her again too. But...um...It does...It was always nice I just remember. We always seemed to enjoy whatever it was we were doing... and I...I look forward to going...going with her. You know... I: It sounds like you enjoyed having P: (interrupting, agreeing) Oh, yeah.</p>	<p>Concerned about being helpful because of bad memory <u>Need and want for being helpful but not so confident because of her memory loss?</u> <i>I reassured her that she is the expert and it's okay if she cannot remember.</i> <u>Her strategy? Doing her best within her abilities</u></p> <p>Enjoyed; <i>Laughter(because she can't remember the medical student's name)</i> Nice girl; Enjoyed hearing about her family, her little boy, and her husband Family-oriented; so matched for me because she could hear about the medical student's life <i>Hesitation because she can't remember</i> Pleasant time Enjoyed having the medical student meet her family (coming over to her son's house) A nice couple and a cute little boy Going to a movie together Hesitation <i>Hesitation because she can't remember</i> Feels it's been a long time since she has seen her I would like to see the medical student again Always nice We always enjoyed whatever they were doing Look forward to going with her</p> <p><i>Expressed sympathy</i> <i>Tone: Excited, interrupting</i></p>
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<p>Enjoyed getting to know her family A big family gathering (with her son's family and her sister together) Expressed the joy of living closer to her sister again</p> <p>Enjoyed seeing her pair once a month</p> <p>Liked her pair I could make her another daughter Interested in her pair's family Wanted to make her pair a part of her family, so that they did (gathering with her son's family and her sister altogether) Pleasurable experience Her pair's attitude: Pleased to be able to take part of it because her pair was very easy to talk to Feeling like her pair had looked forward to seeing her; <i>past tense</i></p>	<p>very... I: some time with her and...</p> <p>P: Yeah. And knowing kind of getting to her family and...she...and then as I say, I know I had our son's and my sister was with us on some occasions too. She lives across the street. How great is that? Ha ha...</p> <p>I: Yes. That's nice.</p> <p>P: So... It was just...I enjoyed the experience. You know. I mean. I enjoyed getting the...see her once a month I think it was ... and I... um...you know... I don't know what...I just don't know what else to say that going to...</p> <p>I: So... I feel like you are... You said that you are a family-oriented person, so it was... From my understanding, it was good time to meet... You said that it was good time to meet her... her...</p> <p>P: family I: family P: uh huh. I: So, could you tell me more about that? What do you mean by...um...so, could you tell me...um... how does it make you feel at that time because you are...</p> <p>P: Well. I just liked... she...I could make her another daughter. I mean I just...I just thought she was...I was interested in her family and um... kind of wanted to make her a part of my family... so that we did... in her mingled with my son and...and my sister went along too. um... It just made a...a pleasurable experience... and I... you know. I just was pleased that I was able to take part of it with her because she just was very easy to talk to and...um...you know she... she...I felt like she had looked forward to seeing me and I certainly look forward to seeing her and I... just kind of adopting her into my family... as far as some family gatherings and things...</p>	<p><i>because she couldn't wait for strongly agreeing that she enjoyed the meetings very much</i> Getting to know her family A big family gathering (with her son's family and her sister together) Expressed the joy of living closer to her sister again</p> <p>Enjoyed Enjoyed seeing her once a month <i>Hesitation because she doesn't know what else to say (difficulty in talking about events in details because of memory loss)</i></p> <p>Liked the med student ; making the med student another daughter Interested in the med student's family Wanted to make the med student a part of her family, so that they did (gathering with her son's family and her sister altogether) Pleasurable experience Pleased to be able to take part of it because the medical student was very easy to talk to Feeling like the medical student had looked forward to seeing her; <i>past tense because of no further contact with the med student</i> Certainly looking forward to seeing the medical student; <i>present tense (missing the med student)</i></p>
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<p><i>because of no further contact with the med student</i> Certainly looking forward to seeing her pair; <i>present tense (missing her pair)</i> Adopting her pair into her family (family gatherings)</p> <p>Expressing of self-identity: a talker and very much a touch feely person Likes to get hugs Her pair's Attitude: Her pair was amenable to her hugs She adores and feels close to her two daughters, but they live far; She misses them so much Regarding her pair as another little daughter; having her pair come was really an added bonus for her Conversations with her pair were comfortable and easy Liked hearing about her pair's son Impact of dementia (memory loss; cannot remember what the her pair's husband's job is but remember her feelings when she heard about it) Likes to be connected Expressing her friends and neighbors are very important to her; Nurturing relationship with them is what she wants Being close to her family (<i>present tense</i>:</p>	<p>I: so, you said that it was easy to talk with her. So, how did you know that... how did you know that she was so easy to talk?</p> <p>P: Well...I am a talker. Ha ha...I am also a person who is very much...um... I am a touchy feely person. I like to get hugs... and she was... she was amenable to my giving her a hug. I...I have my two daughters I adore who living California and Ohio. So, she was my other... ha ha... little one... I mean. You know. I just... I am very close to my daughters and I miss them so much...so having her come was really an added bonus for me... and I... I had no problems. We had no problems in talking how we... I mean our... our conversations were not strained. They were very easy... liked to hear about her son. Her husband is involved in some really spectacular...um...amazing kind of... scientific things at the university... and I... you know. It was just interesting to hear a little bit about... what findings they...we are going to discover... what this...not going to remember what it was but... I just I liked to be connected... I... um... My friends are very important to me. My neighbors...um... I am just that, that's just what I... nurture. I mean that's what I want because I am close to my family...and I... I was close to my children... and...it's been a very hard thing for me that I have...neither of my daughters...um...close... I mean Ohio and California.</p> <p>I: so, you have three daughters? P: Two daughters and a son. I: Two daughters and... but she [looking at her daughter behind us] P: my daughter.</p>	<p>Adopting the med student into her family (family gatherings)</p> <p>Expressing about self/ self-identity; a talker and very much a touch feely person Likes to get hugs The med student was amenable to her hugs She adores and feels close to her two daughters, but they live far; She misses them so much Regarding the med student as another little daughter; having the med student come was really an added bonus for her Conversations with the med student were comfortable and easy Liked hearing about the med student's son Impact of dementia (memory loss; cannot remember what the med student's husband's job is but remember her feelings when she heard about it) Likes to be connected Expressing her friends and neighbors are very important to her; Nurturing relationship with them is what she wants Being close to her family (<i>present tense: emotional closeness</i>) <i>I was close to my children (past tense)</i> Living far from her daughters has been very hard for her <u>She talks about not living close with her daughters; when she mentioned that she was close to her children, does this only mean closeness in terms of distance?</u></p>
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<p><i>emotional closeness</i> <i>I was close to my children (past tense)</i> Living far from her daughters has been very hard for her</p> <p>Feeling close with her sister (in terms of distance and relationship) Her sister moved and live very near; how's that? she mentions and brags about this again Her sister's move helped her because her daughters live far Difficulty in spending time together with her son and daughter-in-law (her daughter-in-law is a lawyer and very busy; Her son travels a lot) Expressing herself as a very family-oriented person Living far from her daughters is hard because they are her back-up</p> <p>Having a small family Enjoying the holidays with her family Spending time together/ being together means what a family is to her? physical closeness seems to be important to her because she expressed herself as a touchy-feely person and she talks about closeness in terms of physical distance a lot</p> <p>Being close to her neighbors (regarding one neighbor as another</p>	<p>I: yeah. so, one daughter lives in California? P: That's one who lives in California. I: I thought you live in near...</p> <p>P: no. no. My sister... my sister... who... We are really close and three years ago she remarried her first husband and they live across the street. Now how's that? We've always been very close and are and so... it's been wonderful for me... and they have... It's really been helpful because my girls are long-distance... and I... and I love my daughter-in-law, but she is a lawyer and she is very busy. You know. so... I mean I love her to death but it's... and my son... um...he travels a lot...so... it's hard for...for my girls... both are far and...since it's been my... back-up because I am very family-oriented...and I...</p> <p>I: Can you...um...can you tell me more about being... what it means to you to be family-oriented? Can you give me some stories of... your...about yourself to be family-oriented and....</p> <p>P: Well. We...we have a small family. We only have two first cousins and they are both male and neither one of them live here now. And I... so...It's a small family... and we...um...we enjoy the holidays together... um... Mark's wife's parents were from here but they live...um...down close to Booneville, Missouri now most of the time but they are here a lot. And they just have two children, my daughter in law and her brother. So it's a small group and um...and her brother lives in California....so...her folks are splitting their time between Kansas City and California. But family...but...um...we do a lot of family. And it's... I've got really great neighbors on this side of us too. I</p>	<p><u>Does she also mean closeness in terms of relationship?</u></p> <p>Feeling close with her sister (in terms of distance and relationship) Her sister moved and live very near; <i>how's that? she mentions and brags about this again</i> Her sister's move helped her because her daughters live far Difficulty in spending time together with her son and daughter-in-law (her daughter-in-law is a lawyer and very busy; Her son travels a lot) Expressing herself as a very family-oriented person Living far from her daughters is hard because they are her back-up <u>No mention about her husband is because her husband is present?</u></p> <p>Having a small family Enjoying the holidays with her family <u>Spending time together/ being together means what a family is to her? physical closeness seems to be important to her because she expressed herself as a touchy-feely person and she talks about closeness in terms of physical distance a lot</u></p> <p>Being close to her neighbors (regarding one neighbor as another sister/a family) ; having great neighbors She has a small family but she</p>
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<p>sister/a family) ; having great neighbors She has a small family but she feels she has a bigger family by regarding neighbors as her family too</p> <p>Feeling one neighbor as another part of the family</p> <p>Expressed being family-oriented is the big part of herself (that's what I am all about) ; family includes her real families and people whom she likes (neighbors and the med student) Seeing them (actual contact/meeting seems to be very important to her)</p> <p>Keeping touch with her high school mates (getting together)</p> <p>Meeting with the high school mates two or three times a year</p> <p>Impact of dementia (I can't remember their names always)</p> <p>Feels frustrated when</p>	<p>just... I love her just like another sister. She's a little older, she's 82? Ha ha...</p> <p>S: yeah.</p> <p>P: but she and her husband are just like an adopted them another part of the family and that's kind of a ... Missy, could you find me some Kleenex?</p> <p>S: yeah. yeah. yeah. yeah.</p> <p>P: That's the big... That's what I am all about. It's just family and...seeing them and being proud of them.</p> <p>I: being connected to them...</p> <p>P: Oh, yeah.</p> <p>I: people around you. so...</p> <p>P: yeah.</p> <p>I: I feel like you are really a family-oriented person and you are so nice person I think... so...</p> <p>P: It's even like my high school class where... oh...I've been in high school in 1956... but...uh... there is a group of us... still get together.</p> <p>I: Wow. That's great.</p> <p>P: Two or three times a year some of us. Now our last meeting was pretty small for only twelve but they've been about twenty to thirty... about two to three times a year. So that's been kind of my... I rarely mentalize a couple of names... I am very... I don't have my names. You know.</p> <p>I: What do you mean by.. when you don't have your name.</p> <p>P: I can't remember their names always. You know. I mean... my...Remembering name is a real problem for me and it's</p>	<p>feels she has a bigger family by regarding neighbors as her family too; <u>her strategy?</u></p> <p>Feeling one neighbor as another part of the family</p> <p>Expressed being family-oriented is the big part of herself (that's what I am all about) ; family includes her real families and people whom she likes (neighbors and the med student) Seeing them (<u>actual contact/meeting seems to be very important to her</u>)</p> <p>Keeping touch with her high school mates (getting together)</p> <p>Meeting with the high school mates two or three times a year</p> <p>Impact of dementia (I can't remember their names always) Feels frustrated when she cannot remember their names (a real</p>
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<p>she cannot remember their names (a real problem for her)</p> <p>Not remembering her high school friends' names and telephone numbers is irritating and provoking Feeling a lot faster deterioration in her memory last year Feeling like losing ground (losing more abilities to remember)</p> <p>Frustrated when she cannot remember numbers/ages of people (her frustration increases in the social context?)</p> <p>Laughter when she mentions having this problem; rather than directly say the problem as dementia or Alzheimer's (feeling ashamed of saying that she has dementia?)</p> <p>Feels frustrated in social context (because social gathering /being connected to people is very important to her?) Friends are very understanding about her memory loss Self-awareness of her memory loss/dementia</p> <p>Friends and families are very supportive and patient (wonderful in</p>	<p>frustrating. I: so, how do you...how does it make you feel when you cannot remember their names.</p> <p>P: Well, it's just irritating to me... um...[shaky voice] ...I feel... like well why can't I, but... It's just like my telephone number. I can't remember that most of the time. [shaky voice/saying between her tears] um... these those little things get very provoking in it. um...I can't just...and the last year...has really...deteriorated a lot faster I think. I mean I feel like I am losing ground. I: What do you mean by losing... P: Well. I am losing more abilities to remember. I: Why did you feel that? did you... P: I don't know how... I mean... It just a... It frustrates me. I can't... you know... um...and I... numbers... ages of people...and...</p> <p>I: Do you think not remembering their names or numbers has affected your leisure life or social life?</p> <p>P: Well. Those my friends know I am having this problem. [giggling] so they understand it when I...you know... I look at somebody or I got something I want to tell them...just like...well...you know. I think they can pull the names, or the age, or the... place... you know. It's frustrating... because I forget. um... They all are very understanding realizing... that's one of the problems with this disease. It affects your... your memory. I: So, it's... Your close friends or family already understand you... P: Oh, yeah. I: You have the Alzheimer's. P: right. I: so they can... they can make some efforts to help you. P: Oh, they do. They are all very wonderful about it. They realize that I just... you know... cannot always come</p>	<p>problem for her)</p> <p>Not remembering her high school friends' names and telephone numbers is irritating and provoking <i>Shaky voice and saying between her tears: became emotional</i> Feeling a lot faster deterioration in her memory last year Feeling like losing ground</p> <p>Losing more abilities to remember</p> <p>Frustrated when she cannot remember numbers/ages of people <u>her frustration increases in the social context?</u></p> <p><i>Laughter when she mentions having this problem; rather than directly say the problem as dementia or Alzheimer's (feeling ashamed of saying that she has dementia?)</i> Feels frustrated in social context (<u>because social gathering /being connected to people is very important to her?</u>) Friends are very understanding about her memory loss Self-awareness of her memory loss/dementia</p> <p>Friends and families are very supportive and patient (wonderful in supporting her)</p>
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<p>supporting her) Cannot ask for a better environment Being close with friends at church Seeing people at church and cannot remember their names Impact of dementia: Difficulties in remembering and saying the answers, names, and things that fast Appreciate that her high school friends still keep her in relationships Appreciate her husband (very helpful and so sweet) Losing abilities in daily activities (like dressing) so need her husband's help (he's right there) Her husband helps in driving Does her husband give more practical help (dressing and driving)? Her husband seems not to be an expressive person as much as her</p> <p>Invited her pair to her family gathering because she felt close to her like another family</p> <p>She has had a helper (a lady) for almost one year and she feels very close to the helper (a little energizer bunny; dearly love her) like another daughter by spending time together (workout at the gym and getting into the hot tub)</p> <p>Keeps from being disappointed about self.</p>	<p>up with the answer... very patient with me... very supportive... I mean I couldn't ask for a better environment than I have because of friends at church. We go to church, see people and I won't be able to pull the names up you know but if I am out some place that I went to a high school with they know that I'm not ignoring them. I mean they understand that I can't pull out answers, names, and things that fast. They still keep me in the loop and I... I couldn't ask more for my husband who is... he is wonderful. We've been married... fifty-six? ... fifty-five? fifty-six years? Somewhere in that... [giggling] He's very helpful and he's been so sweet as I... lost... um... some abilities... like getting on clothes... I need help and he's... he's right there.</p> <p>I: He's always been right there for you.</p> <p>P: Yeah. He's really great. And drives me here, there and wherever I have to go. [giggling]</p> <p>I: How about the relationship with the medical student you met in the PAIRS program?</p> <p>P: Well. It was great. I just could've adopted... my little pair. She was wonderful and that's why I said to her... come to my... you know... come to our family things. um... I have a... helper now that I had since, it... would be a year in January and she... um... She is a nursing... well... not a nursing-nursing, but she's got some training... all that training. She comes three times a week and she is a little energizer bunny and I dearly love her. She is love her like my own and... um... She just keeps me from getting down on myself. She takes me three times a week weekly go to the gym and get in the pool. We just really good</p>	<p>Cannot ask for a better environment Being close with friends at church Seeing people at church and cannot remember their names <u>People whom she closes with at church and her close high school friends are very understandable and supportive but people who are not that close with her at church may misunderstand her that she is ignoring them?</u> Impact of dementia: Difficulties in remembering and saying the answers, names, and things that fast Appreciate that her high school friends still keep her in relationships</p> <p>Appreciate her husband (very helpful and so sweet) Losing abilities in daily activities (like dressing) so need her husband's help (he's right there) Her husband helps in driving <u>Does her husband give more practical help (dressing and driving)? Her husband seems not to be an expressive person as much as her</u></p> <p>Invited the med student to her family gathering because she felt close to her like another family</p> <p>She has had a helper (a lady) for almost one year and she feels very close to the helper (a little energizer bunny; dearly love her) like another daughter by spending time together (workout at the gym and getting into the hot tub)</p> <p>Keeps from being disappointed about self. <u>Does the helper's support impact her self-esteem by being active and improving her mood?</u></p>
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<p>(Does the helper's support impact her self-esteem by being active and improving her mood?) Boasting about the helper's cooking skills The helper makes her mood improved (she doesn't let me depressed) Expressed a wish for the interviewer to meet her helper because the helper is wonderful (being proud of her helper)</p> <p>The helper is so special to her and depends on the helper emotionally (emotionally supportive as substitute for her daughters) <i>Strong expression: I can't do without her</i> The helper is the one who currently meet/satisfy her needs in emotional support</p> <p>Her pair was really sweet-heart and she just loved her pair</p> <p>Wants to keep in touch with her pair</p> <p>Family is the biggest thing and most important Her families are supportive and keep her from sad or bad feelings</p>	<p>workout for thirty minutes and then we get in the hot tub for about ten... kind of...you know. I: That's great. P: and it is and um... she is also...she...she was a cater. I mean she is the best cook because she makes us best foods and they are all healthy... and she doesn't let me get down and um...hopefully she will be here before you leave and you will meet her because she is wonderful.</p> <p>I: yeah. I hope so. Oh. [I saw the helper waiving her hand behind]. Ha ha.. P: Is she here? Ha ha... but she is just so special to me and I don't know what I do without her. and...particularly since both my daughters are gone. It's just...I... can't do without her.</p> <p>I: You said that the medical who was paired with you was more like your adopted daughter.</p> <p>P: I mean I just loved her too. She was real...really sweet-heart and her husband and her son... you know. They were so nice. um...so... I am hoping best things for her and... I hope not to totally lose contact with her.</p> <p>I: You said that... um.. you had some lunches together and you went to some historical place and you visited your son's house with her family. so... these activities have any special meaning to you and what was...?</p> <p>P: Well. Yeah....because family is my biggest thing. That's the most important do. um... so having them involved in... they know what I am going through. They are also supportive and just um... It brings me out any kind of sad feelings or</p>	<p>Boasting about the helper's cooking skills The helper makes her mood improved (she doesn't let me depressed) Expressed a wish for the interviewer to meet her helper because the helper is wonderful (being proud of her helper)</p> <p>The helper is so special to her and depends on the helper emotionally (emotionally supportive as substitute for her daughters) <i>Strong expression: I can't do without her</i> The helper is the one who currently meet/satisfy her needs in emotional support</p> <p>The med student was really sweet-heart and she loved the med student</p> <p>Wants to keep in touch with the med student</p> <p>Family is the biggest thing and most important Her family and the med student are supportive and keeps her from sad or bad feelings Wants to keep track of people</p>
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<p>Wants to keep track of people whom she cares about (want to remember people whom she cares about) Impact of dementia (not sure what she was talking about and if she digressed) <u>her strategy (checking)?</u> <i>Laughter</i></p> <p>Her sister is her anchor (why not her husband?)</p> <p>Consider her sister as a part of her family (made by marriage) Loves her daughters so much Living far from her daughters is hard for her Fills her empty heart (because of living far from her daughters) with her sister Her sisters visits her and helps her Loves her sister if she were mine Her sister keeps her going Feels loved by her sister Feels proud of her sister who takes a good care of her daughter that had problems at birth Describes her sister as a spectacular and caring person with full of love Her sister is the kind of person that she needs</p> <p>Liked all of the activities that she did with her pair</p>	<p>something when I am bad because... they are part of it and um... don't wanna lose track of them. so... um... I don't know if I am got off track or where I am. Ha ha...</p> <p>I: That's okay. ha ha...</p> <p>P: but Lesley is... is my anchor.</p> <p>I: so, you invited her to your son's house because you felt like she is a part of the family. so...</p> <p>P: Right. Right. yes. and two daughters that I have.</p> <p>I: Could you tell me some stories about that dinner? or... that time you had...spent time together.</p> <p>P: Well. It's been more than one occasion. I don't know exactly... I mean. um...well...They just fit in like they are family. I consider Lesley, my little sister, I mean I just and because my daughters... aren't here [voice: emphasizing]. I love them so much and it's hard for me. Lesley comes in and makes that work for me because I love her dearly and I couldn't love her any more if she were mine and um... she keeps me going... and she's a spectacular person and she is very loving me. She has a daughter that had problems at birth... so she had some problems all along. and ...she's doing so well because she has a momma like she does. You know, she works at KU med as a helper... you know. Lesley is just full of love and caring... the kind of person that I need.</p> <p>I: um... so you mentioned several activities you did with the medical student... eating at the restaurant, or visiting your son's house, and visiting some historical place. What was the best part? What did you like the most among these activities?</p> <p>P: Well. I guess I am not really...</p>	<p>whom she cares about</p> <p>Impact of dementia (not sure what she was talking about and if she digressed) <u>her strategy (checking)?</u> <i>Laughter</i> Her sister is her anchor (<u>why not her husband?</u>)</p> <p>Consider her sister as a part of her family (made by marriage) Loves her daughters so much Living far from her daughters is hard for her Fills her empty heart (because of living far from her daughters) with her sister Her sisters visits her and helps her Loves her sister if she were mine Her sister keeps her going Feels loved by her sister Feels proud of her sister who takes a good care of her daughter that had problems at birth Describes her sister as a spectacular and caring person with full of love Her sister is the kind of person that she needs</p> <p>Liked all of the activities that she did with the med student Expressing about self/ self-identity: a social person (likes</p>
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<p>Expressing of self-identity: a social person (likes people)</p> <p>Being able to be active enough to have her friends over or she goes over there is matter to her</p> <p>Her friends understand that she is having memory problems and so they are very supportive</p> <p>Her high school friends calls to check to see how she is doing It makes her feel good that she has got these girl friends that will see her Her friend came over and gave her a hug; her friends know where she is and they are very supportive when they see her Past tense when describing her pair because there is no further contact after the program is ended (I just thought, she was sweet) Considering her pair as another little daughter A cute baby and sweet husband</p> <p>She mentions about her pair's baby and her husband quite often. She seemed to meet them in person just one time but she seems to be very close to her pair's family because they talked a lot. Did she feel comfortable in talking</p>	<p>figuring what I'm not saying, I mean I loved all of them. I just... I am a social person because I like people... and I... so...being a... being able to be active enough to have my friends over or I go over there and they understand that I am having memory problems and so they are very supportive... even make it hard for me. and um... even my high school group... several of them calling to check to see how I am doing... and um... so it's...my...my one friend that was in my wedding party lives in Saint Louis. And she tries to come back for our high school old school thing and usually she stays here. And she came back this past month to our Christmas party and um...it just makes me feel good that I've got these gals that will see me. We were...Lesley and I were shopping the other day and she came to the store we were in. She came over and gave me a hug. so... they know where I am and... I mean... they are really supportive when they see me.</p> <p>I: You said that it was easy to talk with the medical student you were paired with.</p> <p>P: Yeah. She was sweet as she could be, I just thought she was like another little daughter. She had a cute baby and sweet husband... um...</p> <p>I: You said that your close friends is very supportive because... and you felt so comfortable because you... they know where you are...</p> <p>P: Yeah.</p> <p>I: They understand about your... about having the... Alzheimer's.</p>	<p>people) Being able to be active enough to have her friends over or she goes over there is matter to her Her friends understand that she is having memory problems and so they are very supportive Her high school friends calls to check to see how she is doing One of her high school friends visited her and spent time together last month for her family's Christmas party It makes her feel good that she has got these girl friends that will see her She ran into her high school friend by chance when she and her sister were shopping; her friend came over and gave her a hug; her friends know where she is and they are very supportive when they see her</p> <p><i>Past tense when describing the med student because there is no further contact after the program is ended (I just thought, she was sweet)</i> Considering the med student as another little daughter A cute baby and sweet husband <u>Did she and the med student talk a lot about the med student's own family? She mentions about the med student's baby and her husband quite often. She seemed to meet them in person just one time but she seems to be very close to the med student's family because they talked a lot. Did she feel comfortable in talking with the med student because they could talk about something she likes to talk (family, friends, etc.)?</u></p>
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<p>with her pair because they could talk about something she likes to talk (family, friends, etc.)?</p> <p>Accepts the disease (God gives use what he gives us and I ended up with this) Feels frustrated (it's frustrating) but feels so happy because of people around her who are very understandable and supportive (I couldn't be as happy as I am) Children and grand-children are so important Happy because I didn't have a husband that is <i>eldest-old (oldest-old)</i> Appreciate for her family's support (such a small family but each individual's support) Her daughter is her support (<i>Saying between her tear</i>) Seems to get more emotional support from her daughters (living far) than her son (living close).</p> <p>Impact of dementia (She doesn't remember her expectations before participation in the program) ; Really happy with that and it worked They (personnel at AA) can keep her from getting worse in terms of memory</p>	<p>P: Right. Right. I: Do you think meeting with the medical student... because she knew that...because she already knew that you had the Alzheimer's, so do you think it makes your relationship better? Feel more comfortable? or...</p> <p>P: Well yeah. I mean. God gives us what he gives us. I ended up with this. I will just assume that I have that problem. It's frustrating... but... everybody I work with me is very understanding and um...supportive...and um...I couldn't get...I couldn't be here and be as happy as I am because I didn't have a husband that is eldest-old and my children and grand-children are so important. And it's not that that big of family so makes easier too... Missy comes in from California and Cindy is coming tomorrow from Ohio and my son is here, so we are... It's not such a big family that we can get together at least once a year and more...Missy is so wonderful to come back from California... and um... she is ... my... support...[saying between her tears] and then Lesley comes.</p> <p>I: What were your expectations before you participate in the PAIRS program?</p> <p>P: I can't really know what to expect...so, I mean. It's a... whatever...however it came about and it worked it worked and I was really happy with that. And um...I've been... you know... They can keep me from not. I mean...going down hills as far as my memories but... they are also supportive and it just helps and I know they are gonna be there for me.</p>	<p>Accepts the disease (God gives use what he gives us and I ended up with this) Feels frustrated (it's frustrating) but feels so happy because of people around her who are very understandable and supportive (I couldn't be as happy as I am) Children and grand-children are so important Happy because I didn't have a husband that is <i>eldest-old (oldest-old)</i> <u>why is she saying like that? She may know friends or sisters who take care of their oldest-old husbands and she feels relieved that her husband doesn't need care because of aging.</u> Appreciate for her family's support (such a small family but each individual's support) Her daughter is her support (<i>Saying between her tear</i>) <u>Seems to get more emotional support from her daughters (living far) than her son (living close).</u></p> <p>Impact of dementia (don't remember her expectations before participation in the program) ; <i>Hesitation</i> Really happy with that and it worked <i>Go down the hills (-> go downhill)</i> <u>Who are they? They seem to be the personnel at the Alzheimer's Association who are involved in the PAIRS program.</u></p>
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<p>They are supportive Knowing that they are going to be there for her helps her</p> <p>Visiting the Alzheimer's Association less often than before She is not missing the programs at the Alzheimer's Association because she has got the support close by Driving issue may be a minor issue? The major reason for not going to the Alzheimer's Association is because she did not get the support which she wants from there?</p> <p>Impact of dementia (Can't remember how she decided what to do with her pair) No further contact with her pair Talked about different things but cannot remember the details of the talks They went to the museum and it was fun Hesitation and Sigh because she can't remember things; frustrated Looked forward to meeting with her pair Always had a good time</p> <p>Likes going to museums but she hasn't done it</p>	<p>I: I know this program is from the Alzheimer's Association and I know there are many programs from the Association, so... from my understanding, you trust the people in the Alzheimer's Association? That's why you thought the program from them will be...</p> <p>P: Yeah.</p> <p>I: good for you?</p> <p>P: I don't... We don't go to those as much now because... it's kind of a long way down there... and I... [Hesitating] I do better with just... the way it is now... people... I mean. We go once a while but it's... it's not easy to drive clear down to the 75th and night. You know, doing that way. I'm... People are talking, but... um... I... I just I don't miss that as much as because I've got the support... close by... my neighbors and my family and my kids. And um... That's... my husband and I... love dearly and... loves me back ha ha... sometimes. ha ha...</p> <p>I: ha ha... um... Could you tell me how you decided what to do with the medical student?</p> <p>P: [sigh]...you know. I can't really remember how it was set up. I haven't seen her now for several months when we met in ... um...we just we talked about different things and came up with them but I can't really remember the details of that. I know we went to the museum down there...by... the... downtown... which was really fun... and we...and um...[sigh] I am trying to pull these up. They are not just popping up for me... but I looked forward to it. We always had a good time.</p> <p>I: Do you like to going to some...going to museums...some arts or historical places?</p> <p>P: yeah. but...um...we just haven't done it lately. I'm...I'm... slowed down as far</p>	<p>They can keep her from getting worse in terms of memory They are supportive Knowing that they are going to be there for her helps her</p> <p>Visiting the Alzheimer's Association less often than before She is not missing the programs at the Alzheimer's Association because she has got the support close by <i>Hesitation to be polite</i> <u>Driving issue may be a minor issue? The major reason for not going to the Alzheimer's Association is because she did not get the support which she wants from there? Why did she feel that way? Sharing each other's story and feelings were not supportive to her?</u></p> <p>Impact of dementia (Can't remember how she decided what to do with the med student) No further contact with the med student Talked about different things but cannot remember the details of the talks They went to the museum and it was fun <i>Hesitation and Sigh because she can't remember things; frustrated</i> Looked forward to meeting with the med student Always had a good time</p> <p>Likes going to museums but she hasn't done it lately</p>
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<p>lately Physical health issue? Her sister helps her go to the pool and workout Her sister doesn't let her be lazy (helps her to be active) I don't know what I do without her (her sister)</p> <p>No problem in participating in the PAIRS program. Great/Willing to help if she can A very big shock at the time of diagnosis It took a while for her to accept the disease because it's frustrating and scary to know that she is losing parts of her memory and orientation She could feel eased after she heard from her family saying that they are not going to leave her Appreciate that her family and people are her has been so supportive</p> <p>The program at AA including the PAIRS program opened her mind to see there are other people and the ways that can help her accept her disease and the strategies for remembering things Wonderful and</p>	<p>as I am not walking real far, where...Lesley and I are...She helping me go to the pool and workout and I am getting... better...on... on that. She doesn't let be lazy. She is, she's always let's get up and go so I don't know what I do without her, she's...</p> <p>I: yeah. That's great. [I think I expressed it just naturally/automatically because I didn't get it]. um... How do you feel about participating in the PAIRS program?</p> <p>P: I had no problems doing it. I mean if I can be of some help, that's great. I never expected to be here it was a very big shock when the doctor... ha ha... says ...yeah... Alzheimer's. It was like.. oh...okay. ha ha... so... it was a shock and it was a...something I don't... it took me a while that... you know now I have to see it and I see as I continue... it lose parts of my... where I am... what I am doing... um...It's frustrating. It's scary. um...I just got some promises from some people that they're not going to leave me, and my family... and a lot of... you know...everybody has been so supportive.</p> <p>I: So, I know... from my understanding, you have such a nice people and very supportive people around you and ...the medical student who was paired with you was kind of another supportive person</p> <p>P: uh-huh.</p> <p>I: other than... in addition to the very supportive people around you.</p> <p>P: Right. Right.</p> <p>I: so... how do you think participation in the PAIRS program has affected you and or your daily life?</p> <p>P: Well. I think it opened my mind... or eyes, to see that there are other people and the ways that they can help me... as far as.... accepting... that I am losing my... memory...and um...they can make easy for... help me...remember, you know. Without saying "I told you that". They are also wonderful and it makes me feel better and... know I that I have care.</p>	<p><u>I am slowed down as far as I am not walking real far: does she have any physical health issue?</u> Her sister helps her go to the pool and workout Her sister doesn't let her be lazy (helps her to be active) I don't know what I do without her (her sister)</p> <p>No problem in participating in the PAIRS program. Great/Willing to help if she can A very big shock at the time of diagnosis It took a while for her to accept the disease because it's frustrating and scary to know that she is losing parts of her memory and orientation She could feel eased after she heard from her family saying that they are not going to leave her Appreciate that her family and people are her has been so supportive</p> <p><u>It seems that she regards the PAIRS program as the whole program at the Alzheimer's Association including the PAIRS program here.</u> Opened her mind to see there are other people and the ways that can help her accept her disease and the strategies for remembering things <u>Who are they? They seem to be the staff at the Alzheimer's association or the people with Alzheimer's</u> Wonderful and uncritical</p>
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<p>uncritical (Without saying “I told you that”) Makes her feel better and feel supportive Doesn’t like to become a burden to anybody Sigh and fear to become a burden</p> <p>Fear of not remembering her family at some point</p> <p>Her pair was really sweet and she really loved her pair</p> <p>Loved easy: seeing and</p>	<p>They are gonna be with me. I just... don’t like having... become a burden to anybody. And so... That’s the only thing that I... [sigh] I don’t want to have...</p> <p>I: So you said that you became... you felt like you became more open-minded to have another supportive person... to get to know another supportive person and realizing that there are people who are willing to support you but you don’t feel as a burden because you are just socializing with them.</p> <p>P: Yeah.</p> <p>I: Do you think participation in the PAIRS program has affected any your motivation or participation in other leisure or social activities?</p> <p>P: Well. I really haven’t thought about it at whole a lot. Frankly I had... you know. I have gone into with the idea this one. You know, thing... um... This had made a big difference and I feel like I know it’s there and I know... what my family support and all... has done that help me and um...I ... the thing I fear is that I get to the point where I can’t remember... my family...and I don’t want to go there. ha ha... I don’t wanna be here and not know my family.</p> <p>I: You said that ... so the medical student was... You felt that the medical student was more like another ...daughter.</p> <p>P: Yeah.</p> <p>I: because your daughters are... living far from here.</p> <p>P: Yeah.</p> <p>I: so I wonder...because you are such a family-oriented person, so I wonder at that time when you were with the adopted daughter, the medical student, how did that make you feel as yourself? Because you are such a...</p> <p>P: Well. She was really sweet. I really loved her. You know. I loved easy. I mean I.. see people I know oh that’s person with a good heart and then I... as I</p>	<p>(Without saying “I told you that”) Makes her feel better and feel supportive Doesn’t like to become a burden to anybody <i>Sigh and fear to become a burden</i></p> <p><u>It seems that she regards the PAIRS program as the whole program at the Alzheimer’s Association including the PAIRS program.</u> Hasn’t thought about it at whole a lot Knowing the support around her helps her</p> <p>Fear of not remembering her family at some point</p> <p>The med student was really sweet and she really loved her Loved easy: seeing and knowing people with a good heart (including husband, neighbors,</p>
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<p>Thinks knowing the diagnosis of Alzheimer's is tough Talking with people at the AA was good</p> <p>Her pair: Very sharp, young lady, very good, nice person The gathering with her pair was very good and very healthy for his wife</p> <p>Learning from people who had been diagnosed earlier than his wife helped the couple grow; very good</p> <p>Her husband have experience of the process of dementia by his brother who died 2 years ago with Alzheimer's Each person is different / different stages Feels that his wife made a very good progress It was a challenge but the support group was good</p> <p>The group helped the couple see the reality and positive aspects of living even with Alzheimer's at the same time His wife has got some good verbal discussions</p>	<p>I: Could you.. What do you mean by being an outlet for her? Could you tell me more about that? S: Well. First of all, you got... hit side of a head... with the thought that you got Alzheimer's. It's tough. So... I think by have.. being able to...you know... ten to couple of meetings and talk with people there. It was good. And the extra program where she worked with... very sharp, young lady...um...very good, nice person. It was very good. very healthy... so... this is a sort of step-by-step progression that was a very important step... um...as where some of conversations from the people who have been in it for... ten or twelve years something like that. I am hearing some of their experiences. so... but as far as the program itself, that was part...I think Barbara's growth. Very good.</p> <p>I: What were your expectations before she participates in the PAIRS program? S: For her? I: Yeah.</p> <p>S: Well. I have a brother who died 2 years before with Alzheimer's. so... I have experiences of little of that...process. And um...this...each person is different and um...different stages. so...um...I think... I think Barbara's progress she's made... during this period of time... actually very good. I don't mean that it was not a challenge but um... I think the PAIRS group was a good support...support group.</p> <p>I: Why do you think it was good... the program was good? S: Well... I think... first year that the group was...people... understand it and they've seen it...different other people. so... I think they just...reinforced...positive aspects of it and the reality. um... We've been realistic?... Barbara's got some</p>	<p>Thinks knowing the diagnosis of Alzheimer's is tough Talking with people at the AA was good</p> <p><i>Repeated use of very</i> The med student: Very sharp, young lady, very good, nice person The gathering with the med student was very good and very healthy for his wife</p> <p>Learning from people who had been diagnosed earlier than his wife helped the couple grow; very good <u>Her husband talks about the whole program at the Alzheimer's Association including the PAIRS program.</u></p> <p>Her husband have experience of the process of dementia by his brother who died 2 years ago with Alzheimer's Each person is different / different stages Feels that his wife made a very good progress It was a challenge but the support group was good</p> <p><u>Her husband talks about the whole program at the Alzheimer's Association including the PAIRS program here.</u></p> <p>The group helped the couple see the reality and positive aspects of living even with Alzheimer's at the same time His wife has got some good verbal discussions <u>about what?</u></p>
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<p>Very positive</p> <p>Agrees with what his wife said about her relationship with the med student: very good relationship, very strong</p> <p>Expression of self-identity: people person (loves people)</p> <p>When people are part of her life, she feels that they are just like part of her family Her pair and her whole family were just sweet (her feeling); they are in her heart She shares with her sister about her close feeling with her pair Important to her</p> <p>Her husband and she met her pair for eating out and at their son's house (family gathering)</p>	<p>good...verbal discussions... because... after coming back from one of functions with the individual... I can't pull out her name by myself... at this point...but um... very positive...and...Nothing...nothing negative... no harm. Any suggestions... from group I think it was ... for Barbara... in this case... good situation.</p> <p>I: How about...how do you think about the relationship, her relationship with the paired medical student? S: How was it? I: Yeah. how was... How do you think the ... her relationship with the medical student? S: I think... her... like what she said about is exactly what it was... yeah...very good relationship... very strong. um...</p> <p>P: I tend the love people</p> <p>S: huh? P: I mean... When they are part of my life, they are just like part of my family.</p> <p>I: I see. P: I mean... she was just sweet... she and her whole family. so...I...I...That's how I feel about. They are in my heart. I couldn't be any closer, I've already told Lesley she's came as close as... ha ha... I mean it's just...They are just important to me. I: I see. Did you meet the medical student when she was with her? [Looking at her spouse]</p> <p>S: Oh, yeah. and um... yeah so if I would drive Barbara to it and we had dinner out one time and we had it over at Mark's place and his this family. so... yeah...</p> <p>I: Do you think it's... S: And I met her husband and um...got him committed to showing space program he's got his basement. P: ha ha.. S: He is connected to space expo in</p>	<p>Very positive</p> <p><u>Does he talk about the PAIRS program or just talk at AA?</u></p> <p>Agrees with what his wife said about her relationship with the med student: very good relationship, very strong</p> <p>She loves people</p> <p>When people are part of her life, she feels that they are just like part of her family</p> <p>The med student and her whole family were just sweet (her feeling); they are in her heart She shares with her sister about her close feeling with the med student Important to her</p> <p>Her husband and she met the med student for eating out and at their son's house (family gathering)</p> <p><u>Her husband seems to talk more</u></p>
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<p>Going out for fun with her pair was another outlet for his wife to interact with other people He think it's very positive situation Very nice young lady, very supportive A more social outlet that support his wife</p> <p>Very supportive Can't measure No negative</p>	<p>Houston so he transferred up here... with his wife who's going to Med school. You know about space expo? I: No. S: It's a free enterprise system. It's a corporation is sending the space shuttles up to... space on... When we had dinner with him, he mentioned that he... when he moved up here, they move in and set...um...filled their basement with computers here in Kansas City. So he's been connected to it because he is still employed by. I'd like my grand-children over to show them. He said "Yeah, I'd be glad to show them." I: I feel that she is really a family-oriented person and she is a very nice lady. I can...I can feel it...and... it feels... to me...it feels like that the activities she did with the paired student were very just usual things what families usually do, normally do. So, how do you think about what...how do you think what these activities have the meaning to...what meanings these activities are...to her?</p> <p>S: Well. I think it's another outlet for her to interact with other people...and um...so I think it's very positive situation. And um...very nice young lady... and um...very supportive...and...so...a more social outlet in a sense...um...that...shows supporting her...so that's good....that's good.</p> <p>I: How do you think participation in the PAIRS program has affected your wife?</p> <p>S: I think it...I don't think you can define it anything. Let's say it was very supportive... and um...You can't measure... this too much. You can say this was helping and this was good, but um... As far as I am concerned there was no negative. And um... I think...</p> <p>I: Do you see any difference...Did you see any difference between...um... in</p>	<p><u>with the med student's husband when they met altogether</u></p> <p>Going out for fun with the med student was another outlet for his wife to interact with other people He think it's very positive situation Very nice young lady, very supportive A more social outlet that support his wife</p> <p>Very supportive Can't measure No negative</p>
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<p>Very positive Not negative His wife always looked forward to meeting with her pair</p> <p>He describes his wife as a pretty positive gal (lady)</p> <p>Another avenue for support</p>	<p>terms of her feelings after she met with her [the medical student] or before she met with the medical student? Any difference in her...?</p> <p>S: Oh, she is good. She is a tough old lady. Ha ha...</p> <p>P: Ha ha...</p> <p>I: Was she looking forward to meeting with her because she was excited?</p> <p>S: Yeah. It was...it was a very... just a positive situation. It wasn't a negative thing. And she was always wanting to go...she looked forward to it. so... it wasn't a...</p> <p>I: How did you know she looked forward to meeting?</p> <p>S: You will know pretty well after fifty years. You can...interpret a person.</p> <p>I: Did you see any smiles...or any... happy...?</p> <p>S: Well. She's a pretty positive gal Yeah...anyway, so...but again, just reinforced it... because no one can interpret what a person feels when this type of things comes into it...but...um... there was no expression saying that "well. I don't wanna go" there was always... she was looking forward to it.</p> <p>I: How do you think participation in the PAIRS program has affected you or your daily life? Is there any...?</p> <p>S: I... Yeah. It's more of a... another avenue for support...and um...</p> <p>I: How did that make you feel?</p> <p>She...knowing...just knowing that she has another support? How did that make you feel?</p> <p>S: Well. I...I just...you can't measure it... but...as I say...you can't measure it, what the negatives are. I don't see any negatives...for...</p> <p>I: So... not seeing any negative effects was good for you?</p> <p>S: huh?</p> <p>I: Not seeing any negative...oh... so... this program didn't affect her in a negative way...so was it just good to know that? or...because you said that you had some positive... things there was no</p>	<p>Very positive Not negative His wife always looked forward to meeting with the med student</p> <p>He describes his wife as a pretty positive gal (lady) <u>Reinforced it what does "it" mean? He means promoted her feelings/mood?</u></p> <p>Another avenue for support</p> <p>Can't measure it but no negatives <u>Her husband is a very accurate person or he just misunderstands the questions or he is not very expressive person?</u></p>
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<p>His wife was enjoying her experience The meetings at the association were good during that period time, nice to see the support, see different people, good experience</p> <p>Regards the PAIRS program as still a support element A good experience</p> <p>They are not going that much now to the meetings at AA Driving issue Setting in there with people who talk about their Alzheimer's; the people are great</p> <p>She usually learned</p>	<p>negatives...so... S: Well. I think...I think...it's a...I can't say it any other way. Yeah. It was just very...I felt... she was enjoying her experience. And um... That's about it. yeah...you know, when you have any type of measurable challenge. It's nice to see it, the support situation. so...even the meetings at the association were good during that period time. ...seeing different people. Barbara has some good experiences as well.</p> <p>I: From my understanding, you were involved in other programs at the Alzheimer's Association. So... I wonder... Is there any difference between these kinds of programs and programs like PAIRS program? Do you see any difference between...? P: I don't think I know what you are talking about as far as...differences as far as...I thought these are all ...?stuffs connected with the fact that we said yes we are glad to sign up for it. and um... I: I know there are support... P: I can't see a difference between... I: I know there are support groups for people with Alzheimer's and also there is a support group for caregivers, families. Do you think...Is there any difference between that kind of support groups compared to the PAIRS program? S: You are defining the PAIRS program you are talking about just your group... I: Yeah. Pairing the medical students for social gatherings. S: I don't...I don't see it...um...I see it still a support element. And it was a good experience. um...</p> <p>P: We are not going... that much now to the... meetings. First place is a drive...quite a drive over there. and it's at night...um...That's when you are sitting in there with people who are... I have Alzheimer's. I think the gal that runs is great. I usually found something that I...Oh, yeah. That's good to know. um...But I think ...that is not...</p>	<p>His wife was enjoying her experience The meetings at the association were good during that period time, nice to see the support, see different people, good experience <u>Her husband might feel helpless or accept/know the reality (no cure for Alzheimer's anyway and the progress will continue)</u></p> <p>Regards the PAIRS program as still a support element A good experience</p> <p>They are not going that much now to the meetings at AA Driving issue Setting in there with people who talk about their Alzheimer's; the people are great</p> <p>She usually learned something that is good to know, but she thinks to continue going there is</p>
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<p>something that is good to know, but she thinks to continue going there is not important to her because she feels that she is getting the support and need in the way she is doing now</p> <p>There are dominantly more males than females in the meetings at AA <u>Difference between males and females?</u></p> <p>She doesn't feel like that's really what she needs</p> <p>Impact of dementia : Can't remember her pair's name The PAIRS program was a different type of thing from the meetings at AA Being with her family and her caregivers is more important to her than going to the meetings (fulfill her psychosocial needs and wants)</p> <p>Daughter-backbone</p> <p>Her son and daughter-in-law: so busy</p>	<p>imperative to me to continue going at this point to be...to continue going... that far... um...down there. I just feel like I am getting the support and stuff I need...now...the way I am...the way we are doing it.</p> <p>I: From my understanding...It can be... the reason why you are not going to the Alzheimer's Association very much, very often is because... you already have a support you need... from...around... some your families and...so when you visit the Alzheimer's Association for some programs, you...did you feel like oh, I am getting some information, not very much support like the family's support something like that?</p> <p>P: Yeah. I don't see it as much...when I was going down there...um...mostly... there are dominantly more males than females anyway. And...here is the guy's story and bad things. I don't know...I ...I just don't feel like that's really what I need. And um...now when...when I had the PAIRS deal with well I can't pull the name out now. um...it was a different type of thing...and now...It's with...the...my family and...um...and my caregiver. That's what...This is what's... more important to me... than really going to meetings... down there. I mean, I don't...I just don't feel like get as much out of that as I do... just... having Lesley here...and...um.. my family, my sister across the street...and...um...you know that's...That's what I am...That's what I am...my...my...my grand-children over here get to see...more often my... the other three are in Ohio. But they are all... we manage to be together...and they are coming ...they get here tomorrow... and um...Missy is here until after the first of the year. That's really important to me. She's...she's my backbone.</p> <p>I: Backbone? Wow...</p> <p>P: Ha ha... um...My son's just...bless his heart, his business has been so busy...and</p>	<p>not important to her because she feels that she is getting the support and need in the way she is doing now</p> <p>There are dominantly more males than females in the meetings at AA <u>Difference between males and females?</u></p> <p>She doesn't feel like that's really what she needs</p> <p>Impact of dementia : Can't remember the med student's name The PAIRS program was a different type of thing from the meetings at AA</p> <p>Being with her family and her caregivers is more important to her than going to the meetings (fulfill her psychosocial needs and wants)</p> <p><u>Why she can't feel the emotional closeness or support from the support groups at the AA? Is it because the topic they share usually is dark (difficulties) or is it because there were more males than females (who may be family-oriented as much as she is)?</u> Daughter-backbone</p> <p><i>Pity about her son's busy life?</i> Her son and daughter-in-law: so</p>
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<p>Feels frustrated when she can't remember things, but family support helps her overcome her frustration</p>	<p>gone a lot... and he's wife is working full-time and...their oldest is getting ready to go to the college and the one is gonna be senior high school and... the little one is 7th grade...and my daughter-in-law is a lawyer and she is busy. Ha ha.. But it's having the family here and close by...and ...hopely we are going together trip after to California? and ...</p> <p>I: During the holiday or?</p> <p>P: No no. Missy is here.. ha ha... but after...you know... sometime after she gets back. We will go out for... a little bit... see our grand-daughter out there...</p> <p>I: Sounds great.</p> <p>P: and then... Cindy will be here so she'll be great.</p> <p>I: That's good.</p> <p>P: I just feel like I got a family that's... 100 percent behind me...and...I am feeling like...That's good as I can get I think....because I get very frustrated when I can't remember stuff, but...</p> <p>I: so, I will... summarize the interview. From my understanding, you are really a family-oriented person, and the things you want is just... the support and to be connected to people, the important people, meaningful people in your life and...your life having very family-oriented time... so, maybe the activities what you do with them are not very important, just being with them...</p> <p>P: Right.</p> <p>I: Being with them and having the very family-oriented time is important to you from my understanding.</p> <p>P: Uh-huh.</p> <p>I: You enjoyed time with the medical student because you felt like she is the part of your family, so...</p> <p>P: uh-huh.</p> <p>I: it was a kind of another support....another person you can feel like oh, she is my family.</p> <p>P: Yeah.</p> <p>I: because you live a little bit...quite far away from...far from your daughters...so it was hard to meet them very often. so...</p>	<p>busy</p> <p><i>Wants for spending more time together with her son's family?</i></p> <p>Feels frustrated when she can't remember things, but family support helps her overcome her frustration</p> <p>Member checking</p>
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<p>Being honest with the interview</p> <p>Feels lucky and fortunate thanks to her family and supportive people around her;</p> <p>Darn disease Belief that people around her are going to help her go through the disease</p> <p>Good for the young people (students) who haven't experienced before about the disease</p> <p>Also good for the person with Alzheimer's and the caregiver</p>	<p>It was a...Meeting with her gave you a feeling of being connected...kind of being connected to your own family. P: Uh-huh. I: um...so...Is there anything you want to add to our conversation? or... P: Well. I don't really. I talked a lot. so.. ha ha... I: Thank you so much. You were...yeah... P: ha ha... I don't really. I think I pretty much said where I...I feel very very lucky...[emphasizing] very fortunate...and well loved by all of my family and the support group... and I know that ... they're there for Bill and ... um...so it's ... If I am in this place and I have this darn disease and it's gone away goes... at least I got a... a whole group of people that are going to help me go through it. I: I think you really expressed your feelings and your thoughts very well. I think... how I can appreciate your time and your time for the interview...and... P: No no... I will do what you need to do for you too...so... I: That was really helpful... and thank you so much and I will... S: One thing that I want to add I: Yeah. Sorry. S: I think a... the importance of the PAIRS program is good... um... because you don't know how people are gonna interpret...having students come in and...the person who hasn't experienced before...wouldn't know whether she will have it or not. So we are saying that it's a plus situation for a person who has Alzheimer's or caregiver... and um...you... pull out of it but it's a solid... it's a solid thing for the young person coming in...in a phase with the older person...so...I think it's a...from the side issue...is very plus. I: So... do you think that...meeting with...the families... who have Alzheimer's were... could be helpful for young people who... may not have experience?</p>	<p>Being honest with the interview</p> <p>Feels lucky and fortunate thanks to her family and supportive people around her; <i>repeated use of very to emphasize Darn disease</i> Belief that people around her are going to help her go through the disease</p> <p>Good for the young people (students) who haven't experienced before about the disease</p> <p>Also good for the person with Alzheimer's and the caregiver</p>
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<p>Very good, another avenue</p> <p>Wants for the PAIRS program to be continued for others</p>	<p>S: I would think so. I would think so. I don't know. They have to interpret that. but um...as far as the experiences from the adults... person's avenue... very good... it's another avenue. It maybe a short-period... but it may not get anything out of it, may think it's worthless. But from our standpoint...I will voice what Barbara saying there it's good. so... rather continue it... you should continue it. I am not talking about from us but from...</p> <p>I: others?</p> <p>P: yeah.</p> <p>S: So... That's all.</p>	<p>Very good, another avenue</p> <p>Wants for the PAIRS program to be continued for others</p>
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Themes –Interview 3 (P3: person with dementia, C3: husband, I: interviewer)

Themes	Quotes
<p>Enjoyed having family-oriented time that is aligned with her self-identity as a family-oriented person and who likes being connected with people like a family</p>	<p><u>-Hearing about her pair's family and meeting each other's family were really nice because she is very family-oriented and it is matched for her self-identity and what she nurtures (being connected like a family)</u></p> <p>P3: We did a lot of things and we always enjoyed it. She [her pair] was delightful, and... getting to meet her family and a little one [her pair's child] was really nice.</p> <p>P3: Well... um... I enjoyed the pair the girl I was... was my pair. Ha ha...um... She [her pair] was just really nice and I enjoyed hearing about her family and her little boy and her husband. I'm very family-oriented and it is so me...matched for me because... hear about her life and she...um...um... you know I am not exactly sure what you are needing to hear. I just...she...made a great...this was always a pleasant...um...time. I enjoy having her meet some of my family which is what I am saying...um...being at our son's because they were just, such a nice couple and a cute little boy. ...</p> <p>I: It sounds like you enjoyed having</p> <p>P3: (Interrupting and agreeing strongly) Oh, yeah. very</p> <p>I: Some time with her and</p> <p>P3: Yeah. And knowing kind of getting to her family and...she...and then as I say, I know I had our son's and my sister was with us on some occasions too.</p> <p>P3: Well...I am a talker. Ha ha...I am also a person who is very much...um... I am a touchy feely person. I like to get hugs... and she [her pair] was... she was amenable to my giving her a hug. I...I have my two daughters I adore who living California and Ohio. So, she [her pair] was my other... ha ha... little one... I mean. You know. I just... I am very close to my daughters and I miss them so much...so having her [her pair] come was really an added bonus for me... and I... I had no problems. We had no problems in talking how we... I mean our... our conversations were not strained. They were very easy... liked to hear about her son. Her husband is involved in some really spectacular...um...amazing kind of...</p>

	<p>scientific things at the university... and I... you know. It was just interesting to hear a little bit about... what findings they...we are going to discover... what this...not going to remember what it was but... I just I liked to be connected... I... um... My friends are very important to me. My neighbors...um... I am just that, that's just what I... nurture. I mean that's what I want because I am close to my family...and I... I was close to my children... and...it's been a very hard thing for me that I have...neither of my daughters...um...close... I mean Ohio and California.</p> <p>I: ...so... these activities have any special meaning to you and what was...?</p> <p>P3: Well. Yeah...because family is my biggest thing. That's the most important do. um... so having them involved in... they know what I am going through. They are also supportive and just um... It brings me out any kind of sad feelings or something when I am bad because... they are part of it and um... don't wanna lose track of them. so... um... I don't know if I am got off track or where I am. Ha ha...</p> <p>(* She mentioned having a big family gathering of each family of her and her pair many times throughout the interview, much more than any other activities)</p> <p><u>-She thinks PAIRS program was different from the meetings at AA because she was with her family (doing more family things and talking about families with her pair)</u></p> <p>P3: Yeah. I don't see it as much...when I was going down there...um...mostly... there are dominantly more males than females anyway. And...here is the guy's story and bad things. I don't know...I ...I just don't feel like that's really what I need. And um...now when...when I had the PAIRS deal with well I can't pull the name out now. um...it was a different type of thing...and now...It's with...the...my family and...um...and my caregiver. That's what...This is what's... more important to me... than really going to meetings... down there. I mean, I don't...I just don't feel like get as much out of that as I do... just... having [her helper's name] here...and...um.. .my family, my sister across the street...and...um...you know that's...That's what I am...That's what I am...my...my...my grand-children over here get to see...more often my... the other three are in Ohio. But they are all... we manage to be together...and they are coming ...they get here tomorrow... and um...[one of her daughter's name] is here until after the first of the year. That's really important to me. She's...she's my backbone.</p> <p><u>-Always enjoyed every activities with her pair because she is a social person and likes to be connected with people like a family</u></p> <p>P3: ...But...um...It does...It was always nice I just remember. We always seemed to enjoy whatever it was we were doing... and I...I look forward to going...going with her.</p> <p>P3: Well. I guess I am not really... figuring what I'm not saying, I mean I loved all of them [all of the activities she did with her pair]. I just... I am a social person because I like people... and I... so...being a... being able to be active enough to have my friends over or I go over there and they understand that I am having memory problems and so they are very supportive...</p>
Her pair like	<u>- Having her pair was an added bonus for her who misses her daughters living far</u>

<p>another daughter (A part of her family)</p>	<p>P3: Well. I just liked... she...I could make her another daughter. I mean I just...I just thought she was...I was interested in her family and um... kind of wanted to make her a part of my family... so that we did... in her mingled with my son and...and my sister went along too. um... It just made a...a pleasurable experience... and I... you know. I just was pleased that I was able to take part of it with her because she just was very easy to talk to and...um...you know she... she...I felt like she had looked forward to seeing me and I certainly look forward to seeing her and I... just kind of adopting her into my family... as far as some family gatherings and things...</p> <p>P3: Well...I am a talker. Ha ha...I am also a person who is very much...um... I am a touchy feely person. I like to get hugs... and she was... she was amenable to my giving her a hug. I...I have my two daughters I adore who living California and Ohio. So, she was my other... ha ha... little one... I mean. You know. I just... I am very close to my daughters and I miss them so much...so having her [her pair] come was really an added bonus for me... and I... I had no problems. We had no problems in talking how we... I mean our... our conversations were not strained. They were very easy... liked to hear about her son.</p> <p>P3: Well. It [relationship with her pair] was great. I just could've adopted... my little pair. She was wonderful and that's why I said to her... come to my... you know...come to our family things.</p> <p>P3: I mean I just loved her [her pair] too. She was real...really sweet-heart and her husband and her son... you know. They were so nice. um...so... I am hoping best things for her and... I hope not to totally lose contact with her.</p> <p>C3: I think... her... like what she said about is exactly what it was... yeah...very good relationship... very strong. um...</p> <p>P3: I tend the love people</p> <p>C3: huh?</p> <p>P3: I mean...When they are part of my life, they are just like part of my family.</p> <p>I: I see.</p> <p>P3: I mean... she was just sweet... she and her whole family. so...I...I...That's how I feel about. They are in my heart. I couldn't be any closer, I've already told [her helper's name] she's [her pair] came as close as... ha ha... I mean it's just...They are just important to me.</p>
<p>Description of her pair</p>	<p><u>-Nice, sweet, and delightful</u></p> <p>P3: She [her pair] was delightful, and.. getting to meet her family and a little one [her pair's child] was really nice.</p> <p>P3: Well... um... I enjoyed the pair the girl I was... was my pair. Ha ha...um... She was just really nice and I enjoyed hearing about her family and her little boy and her husband.</p> <p>P3: I mean I just loved her [her pair] too. She was real...really sweet-heart and her husband and her son... you know. They were so nice. um...so... I am hoping best</p>

	<p>things for her and... I hope not to totally lose contact with her.</p> <p>P3: Yeah. She was sweet as she could be, I just thought she was like another little daughter. She had a cute baby and sweet husband... um...</p> <p>P3: Well. She was really sweet. I really loved her. You know. I loved easy. I mean I.. see people I know oh that's person with a good heart and then I...</p> <p>C3: very sharp, young lady...um...very good, nice person</p> <p>C3: very nice young lady... and um...very supportive...</p> <p><u>-Very easy to talk to (because she liked to hear about her pair's family and she felt like her pair had looked forward to seeing her)</u></p> <p>P3: I just was pleased that I was able to take part of it with her because she just was very easy to talk to and...um...you know she... she...I felt like she [her pair] had looked forward to seeing me and I certainly look forward to seeing her and I... just kind of adopting her into my family... as far as some family gatherings and things.</p> <p>I: so, you said that it was easy to talk with her. So, how did you know that... how did you know that she was so easy to talk?</p> <p>P3: Well...I am a talker. Ha ha...I am also a person who is very much...um... I am a touchy feely person. I like to get hugs... and she was... she was amenable to my giving her a hug. I...I have my two daughters I adore who living California and Ohio. So, she was my other... ha ha... little one... I mean. You know. I just... I am very close to my daughters and I miss them so much...so having her come was really an added bonus for me... and I... I had no problems. We had no problems in talking how we... I mean our... our conversations were not strained. They were very easy... liked to hear about her son. Her husband is involved in some really spectacular...um...amazing kind of... scientific things at the university... and I... you know. It was just interesting to hear a little bit about... what findings they...we are going to discover... what this...not going to remember what it was but... I just I liked to be connected... I... um... My friends are very important to me. My neighbors...um... I am just that, that's just what I... nurture. I mean that's what I want because I am close to my family...and I... I was close to my children... and...it's been a very hard thing for me that I have...neither of my daughters...um...close... I mean Ohio and California.</p>
<p>Another very supportive social outlet for his wife</p>	<p><u>-Another very supportive social outlet for his wife</u></p> <p>C3: ...So... we were going weekly basis type of thing and tied up with the PAIRS thing. It was...the University student...It was very good. And ...it was another outlet for her and...very supportive.</p> <p>C3: Well. I think it's another outlet for her to interact with other people...and um...so I think it's very positive situation. And um...very nice young lady... and um...very supportive...and...so...a more social outlet in a sense...um...that...shows supporting her...so that's good....that's good.</p> <p>C3: It was...it was a very... just a positive situation. It wasn't a negative thing. And</p>

	<p>she was always wanting to go...she looked forward to it. so... it wasn't a... I: How did you know she looked forward to meeting? C3: You will know pretty well after fifty years. You can...interpret a person. I: Did you see any smiles...or any... happy...? C3: Well. She's a pretty positive gal. Yeah...anyway, so...but again, just reinforced it... because no one can interpret what a person feels when this type of things comes into it...but...um... there was no expression saying that "well. I don't wanna go" there was always... she was looking forward to it.</p> <p>C3: I think a... the importance of the PAIRS program is good... um... because you don't know how people are gonna interpret...having students come in and...the person who hasn't experienced before...wouldn't know whether she will have it or not. So we are saying that it's a plus situation for a person who has Alzheimer's or caregiver... and um...you... pull out of it but it's a solid... it's a solid thing for the young person coming in...in a phase with the older person...so...I think it's a...from the side issue...is very plus.</p> <p>C3: um...as far as the experiences from the adults... person's avenue... very good... it's another avenue. It maybe a short-period... but it may not get anything out of it, may think it's worthless. But from our standpoint...I will voice what [his wife's name] saying there it's good. so... rather continue it... you should continue it. I am not talking about from us but from...</p> <p>I: Others? P3: Yeah.</p> <p><u>-He thinks the PAIRS program and the support groups at AA are same as support elements</u></p> <p>C3: I don't...I don't see it...um...I see it still a support element. And it was a good experience. um...</p> <p><u>-It was nice for him to know that she was enjoying time with her pair</u> C3: It was just very...I felt... she was enjoying her experience. And um... That's about it. yeah...you know, when you have any type of measurable challenge. It's nice to see it, the support situation. ...</p>
<p>Still feels close to her pair and her family (They are in my heart)</p>	<p><u>-No contact after the program was ended, but she looks forward to meeting her pair again. She still feels close to her pair and her whole family. They are in her heart.</u></p> <p>P3: I mean... she [her pair] was just sweet... she and her whole family. so...I...I...That's how I feel about. They are in my heart. I couldn't be any closer, I've already told [her helper's name] she's [her pair] came as close as... ha ha... I mean it's just...They are just important to me.</p> <p>P3: ...I don't know it seems like it's been a long time since I've seen her, and I would like to see her again too. But...um...It does...It was always nice I just remember. We always seemed to enjoy whatever it was we were doing... and I...I look forward to going...going with her. You know...</p> <p>P3: ...I certainly look forward to seeing her.</p>

	<p>P3: ...um... so... I am hoping best things for her [her pair] and... I hope not to totally lose contact with her.</p> <p>P3: so...I really... I really haven't kept...because I knew she is a student with a little one...and...I ... you know...not that I wouldn't love to see her again and I just haven't gotten to the... gotten on the phone done anything about it, and I...but I'd love to see her again. She is a really really sweet girl and really nice family.</p>
<p>Little involvement of her family in doing activities</p>	<p><u>-Only one family dinner:</u> She cannot drive, so her sister or her husband drove her to the meeting place. He did not participate in any activities together except one family dinner (aware of the program's requirement).</p> <p>I: Uh...So, how did she go to the...?</p> <p>C3: We [He or her sister] dropped off them or something. Either that or her sister... 'er go with them, so not always... I wouldn't I couldn't stay on the meeting but we did have one individual...</p> <p>P3: Yes. either...either ...</p> <p>C3: Dinner</p> <p>P3: Who was [her helper's name] or.... or...my sister. You know. Usually went... was with us.</p> <p>I: So, your sister drove her...</p> <p>C3: Could have.</p> <p>P3: Well. I think she wasn't... she can drive me in her car or something.</p> <p>C3: Yes.</p> <p>P3: And so I couldn't drive. So...I think it was my sister more than anybody. It was...uh...see... and I can't remember if [her helper's name] did any of that... too.</p> <p>C3: I don't know. I dropped her... too...but not very many times like the downtown thing. I think somebody else drove her.</p> <p>I: Were you with her when she and...?</p> <p>C3: No.</p> <p>I: Oh, so the...</p> <p>C3: We had one. One session where I was with them.</p> <p>C3: We had dinner out one time and we had it over at [their son's name]'s place and his this family. so... yeah...And I met her husband and um...got him committed to showing space program he's got his basement.</p> <p>P3: ha ha..</p> <p>C3: He is connected to space expo in Houston so he transferred up here... with his wife who's going to Med school. You know about space expo?</p> <p>I: No.</p> <p>C3: It's a free enterprise system. It's a corporation is sending the space shuttles up to... space on... When we had dinner with him, he mentioned that he... when he moved up here, they move in and set...um...filled their basement with computers here in Kansas City. So he's been connected to it because he is still employed by. I'd like my grand-children over to show them. He said "Yeah, I'd be glad to show them."</p>

<p>Her value and belief</p>	<p><u>-Being connected to her own family and people she feels close to like a part of her family (family-oriented)</u></p> <p>P3: I'm very family-oriented.</p> <p>P3: Well. Yeah...because family is my biggest thing. That's the most important do. um... so having them involved in... they know what I am going through. They are also supportive and just um... It brings me out any kind of sad feelings or something when I am bad because... they are part of it and um... don't wanna lose track of them. so... um... I don't know if I am got off track or where I am. Ha ha...</p> <p>P3: And um...now when...when I had the PAIRS deal with well I can't pull the name out now. um...it was a different type of thing...and now...It's with...the...my family and...um...and my caregiver. That's what...This is what's... more important to me... than really going to meetings... down there. I mean, I don't...I just don't feel like get as much out of that as I do... just... having [her helper's name] here...and...um... my family, my sister across the street...and...um...you know that's...That's what I am...That's what I am...my...my...my grand-children over here get to see...more often my... the other three are in Ohio. But they are all... we manage to be together...and they are coming ...they get here tomorrow... and um...[one of her daughter's name] is here until after the first of the year. That's really important to me. She's...she's my backbone.</p> <p>I: Backbone? Wow...</p> <p>P3: Ha ha... um...My son's just...bless his heart, his business has been so busy...and gone a lot... and he's wife is working full-time and...their oldest is getting ready to go to the college and the one is gonna be senior high school and... the little one is 7th grade...and my daughter-in-law is a lawyer and she is busy. Ha ha.. But it's having the family here and close by...and ...hopefully we are going together trip after to California and ...</p> <p>P3: I...I have my two daughters I adore who living California and Ohio.</p> <p>P3: I just I liked to be connected... I... um... My friends are very important to me. My neighbors...um... I am just that, that's just what I... nurture. I mean that's what I want because I am close to my family... and I... I was close to my children... and...it's been a very hard thing for me that I have...neither of my daughters...um...close... I mean Ohio and California.</p> <p>P3: ...because my girls are long-distance... and I... and I love my daughter-in-law, but she is a lawyer and she is very busy. You know. so... I mean I love her to death but it's... and my son... um...he travels a lot...so... it's hard for...for my girls... both are far and...since it's been my... back-up because I am very family-oriented...and I...</p> <p>P3: ...My...she [her sister] lives across the street from me, how lucky is that? [smile]</p> <p>P3: She [her sister] lives across the street. How great is that? Ha ha...</p> <p>P3: My sister... my sister... who...we are really close and three years ago she</p>
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	<p>remarried her first husband and they live across the street. Now how's that? [with joy] We've always been very close and are and so... it's been wonderful for me... and they have... It's really been helpful because my girls are long-distance... and I... and I love my daughter-in-law, but she is a lawyer and she is very busy. You know. so... I mean I love her to death but it's... and my son... um...he travels a lot...so... it's hard for...for my girls... both are far and...since it's been my... back-up because I am very family-oriented...and I...</p> <p><u>-Meaning of being family-oriented to her:</u> Spending time together and doing family things & Being connected to people around her (physical closeness is important to her and she regards people who feels close as a part of family)</p> <p>I: Can you...um...can you tell me more about being... what it means to you to be family-oriented? Can you give me some stories of... your...about yourself to be family-oriented and....</p> <p>P3: Well. We...we have a small family. We only have two first cousins and they are both male and neither one of them live here now. And I... so...It's a small family... and we...um...we enjoy the holidays together... um... [her son's name]'s wife's parents were from here but they live...um...down close to Booneville, Missouri now most of the time but they are here a lot. And they just have two children, my daughter in law and her brother. So it's a small group and um...and her brother lives in California...so...her folks are splitting their time between Kansas City and California. But family...but...um...we do a lot of family. And it's... I've got really great neighbors on this side of us too. I just... I love her just like another sister. She's a little older, she's 82? Ha ha...</p> <p>C3: yeah.</p> <p>P3: but she and her husband are just like an adopted them another part of the family and that's kind of a ... That's the big... That's what I am all about. It's just family and...seeing them and being proud of them.</p> <p>I: being connected to them...</p> <p>P3: Oh, yeah.</p> <p>I: people around you. so...</p> <p>P3: yeah.</p> <p><u>-Being active enough to socialize with others who she feels close</u></p> <p>P3: I just... I am a social person because I like people... and I... so...being a... being able to be active enough to have my friends over or I go over there and they understand that I am having memory problems and so they are very supportive...</p> <p><u>-Not being a burden to anybody</u></p> <p>P3: I just... don't like having... become a burden to anybody. And so...That's the only thing that I... [sigh] I don't want to have...</p>
<p>Her expression of her self-identity and shared identity</p>	<p><u>-Being family-oriented is the big part of herself</u> (To her, family includes her own family and people who she feels close to and does family things together)</p> <p>P3: Well. Yeah...because family is my biggest thing. That's the most important do. um... so having them involved in... they know what I am going through. They are also supportive and just um... It brings me out any kind of sad feelings or something when I am bad because... they are part of it and um... don't wanna lose</p>

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P3: I...I have my two daughters I adore who living California and Ohio.

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I: Can you...um...can you tell me more about being... what it means to you to be family-oriented? Can you give me some stories of... your...about yourself to be family-oriented and....

P3: Well. We...we have a small family. We only have two first cousins and they are both male and neither one of them live here now. And I... so...It's a small family... and we...um...we enjoy the holidays together... um... [her son's name]'s wife's parents were from here but they live...um...down close to Booneville, Missouri now most of the time but they are here a lot. And they just have two children, my daughter in law and her brother. So it's a small group and um...and her brother lives in California...so...her folks are splitting their time between Kansas City and California. But family...but...um...we do a lot of family. And it's... I've got really great neighbors on this side of us too. I just... I love her just like another sister. She's a little older, she's 82? Ha ha...

C3: yeah.

P3: but she and her husband are just like an adopted them another part of the family and that's kind of a ... That's the big... That's what I am all about. It's just family and...seeing them and being proud of them.

I: being connected to them...

P3: Oh, yeah.

I: people around you. so...

P3: yeah.

I: How do you think the ... her relationship with the medical student?

C3: I think... her... like what she said about is exactly what it was... yeah...very good relationship... very strong. um...

P3: I tend the love people

C3: huh?

P3: I mean...When they are part of my life, they are just like part of my family.

-A social person / A people person

P3: I just... I am a social person because I like people... and I... so...being a... being able to be active enough to have my friends over or I go over there and they understand that I am having memory problems and so they are very supportive...

P3: I am a talker. Ha ha...I am also a person who is very much...um... I am a

	<p>touchy feely person. I like to get hugs...</p> <p>P3: I tend the love people</p>
<p>Her participation and experience in the meetings for people with Alzheimer's at the Alzheimer's Association</p>	<p><u>-She does not go to the meetings because she thinks she has got the support she wants from her family (going to AA was not important to her and what really she wanted)</u></p> <p>P3: I don't... We don't go to those [meetings at AA] as much now because... it's kind of a long way down there... and I... [Hesitating] I do better with just... the way it is now... people... I mean. We go once a while but it's... it's not easy to drive clear down to the 75th and night. You know, doing that way. I'm... People are talking, but... um... I... I just I don't miss that as much as because I've got the support... close by... my neighbors and my family and my kids. And um... That's... my husband and I... love dearly and... loves me back ha ha... sometimes. ha ha...</p> <p>P3: We are not going... that much now to the... meetings. First place is a drive... quite a drive over there. and it's at night... um... That's when you are sitting in there with people who are... I have Alzheimer's. I think the gal that runs is great. I usually found something that I... Oh, yeah. That's good to know. um... But I think ... that is not... imperative to me to continue going at this point to be... to continue going... that far... um... down there. I just feel like I am getting the support and stuff I need... now... the way I am... the way we are doing it.</p> <p>P3: Yeah. I don't see it as much... when I was going down there... um... mostly... there are dominantly more males than females anyway. And... here is the guy's story and bad things. I don't know... I ... I just don't feel like that's really what I need. And um... now when... when I had the PAIRS deal with well I can't pull the name out now. um... it was a different type of thing... and now... It's with... the... my family and... um... and my caregiver. That's what... This is what's... more important to me... than really going to meetings... down there. I mean, I don't... I just don't feel like get as much out of that as I do... just... having [her pair's name] here... and... um... my family, my sister across the street... and... um... you know that's... That's what I am... That's what I am... my... my... my grand-children over here get to see... more often my... the other three are in Ohio. But they are all... we manage to be together... and they are coming ... they get here tomorrow... and um... [one of her daughter's name] is here until after the first of the year. That's really important to me. She's... she's my backbone.</p> <p><u>-Opened her mind to see there are other people and the ways that can help her accept her disease and learn the strategies for remembering things (wonderful, uncritical people)</u></p> <p>P3: Well. I think it opened my mind... or eyes, to see that there are other people and the ways that they can help me... as far as... accepting... that I am losing my... memory... and um... they can make easy for... help me... remember, you know. Without saying "I told you that". They are also wonderful and it makes me feel better and... know I that I have care.</p>
<p>His thoughts about</p>	<p><u>-A great outlet for his wife and helped the couple grow: Very good, supportive</u></p>

<p>her participation in the meetings for people with Alzheimer's at the Alzheimer's Association</p>	<p>people; Knowing the diagnosis of Alzheimer's is tough, so talking with/learning from other people at the AA, who had been diagnosed earlier than her, was good and healthy; helped the couple grow because dealing with Alzheimer's is a sort of step-by-step progression</p> <p>C3: Well. I think it was a great outlet for her. Particularly, it was the beginning of her experience that must be going through. And I... I thought people who were... the Alzheimer's group that was very good, very supportive and I... this is early and... after... that I found out about... and the... this is one place where they recommended... the doctors recommended...my connect with the association. So... we were going weekly basis type of thing and tied up with the PAIRS thing. It was...the University student...It was very good. And ...it was another outlet for her and...very supportive.</p> <p>I: Could you.. What do you mean by being an outlet for her? Could you tell me more about that?</p> <p>C3: Well. First of all, you got... hit side of a head... with the thought that you got Alzheimer's. It's tough. So... I think by have.. being able to...you know... ten to couple of meetings and talk with people there. It was good. And the extra program where she worked with... very sharp, young lady...um...very good, nice person. It was very good. very healthy... so... this is a sort of step-by-step progression that was a very important step... um...as where some of conversations from the people who have been in it for... ten or twelve years something like that. I am hearing some of their experiences. so... but as far as the program itself, that was part...I think [his wife's name]'s growth. Very good.</p>
<p>Her strategy</p>	<p><u>-Describing thing (a place) when she cannot remember the name</u></p> <p>P3: ...We went down to a.. a lunch at the ... the... um... historic home... down by a... the a Kauffman center. Can't think of the name of it now, but it's...it's a... what used to be a school and they remodeled and that looks just beautiful and have all kinds of unique presence and things. ...</p> <p><u>-Use of humor/ laughter when she cannot remember or she talks about her memory</u></p> <p>P3: Oh. [Sigh] That's been a while. ha ha. Well. We went out...had lunch together. um... I ...you know. ha ha. My... my</p> <p>P3: ha ha... Other than my memory is so bad, I don't know how helpful this is the...</p> <p>P3: Well. Those my friends know I am having this problem. [Giggling] so they understand it when I...you know... I look at somebody or I got something I want to tell them...just like...well...you know.</p> <p>P3: so... um... I don't know if I am got off track or where I am. Ha ha...</p> <p>P3: ...I never expected to be here it was a very big shock when the doctor... ha ha... says ...yeah... Alzheimer's. It was like.. oh...okay. ha ha... so... it was a shock and it was a...something I don't... it took me a while that... you know now I have to see it and I see as I continue... it lose parts of my... where I am... what I am doing...</p>

-Doing her best within her abilities (Low confidence in her memory, but I will do what I can)

P3: ha ha... Other than my memory is so bad, I don't know how helpful this is the...

I: no no no.

P3: Okay.

I: You are the expert. I am just here to learn about your experience. It's okay if you cannot remember. It doesn't matter.

P3: I will do what I can. Ha ha...

-She accepts her disease and deals with it /feels happy through her supportive people (her family support helps her overcome her frustration)

P3: Well yeah. I mean. God gives us what he gives us. I ended up with this [Alzheimer's]. I will just assume that I have that problem. It's frustrating... but... everybody I work with me is very understanding and um...supportive...and um...I couldn't get...I couldn't be here and be as happy as I am because I didn't have a husband that is eldest-old and my children and grand-children are so important. And it's not that that big of family so makes easier too... [One of her daughter's name] comes in from California and [One of her daughter's name] is coming tomorrow from Ohio and my son is here, so we are... It's not such a big family that we can get together at least once a year and more...[One of her daughter's name] is so wonderful to come back from California... and um... she is ... my... support...[saying between her tears] and then [her helper's name] comes.

P3: ...I never expected to be here it was a very big shock when the doctor... ha ha... says ...yeah... Alzheimer's. It was like.. oh...okay. ha ha... so... it was a shock and it was a...something I don't... it took me a while that... you know now I have to see it and I see as I continue... it lose parts of my... where I am... what I am doing... um...It's frustrating. It's scary. um...I just got some promises from some people that they're not going to leave me, and my family... and a lot of... you know...everybody has been so supportive.

P3: I just feel like I got a family that's... 100 percent behind me...and...I am feeling like...That's good as I can get I think...because I get very frustrated when I can't remember stuff, but...

P: ha ha... I don't really. I think I pretty much said where I...I feel very very lucky...[emphasizing] very fortunate...and well loved by all of my family and the support group... and I know that ... they're there for [her husband's name] and ... um...so it's ... If I am in this place and I have this darn disease and it's gone away goes... at least I got a... a whole group of people that are going to help me go through it.

-She has supportive people who give her emotional and practical supports.

<Her friends who understand her difficulty in remembering things and figure out what she tries to say /very patient. She feels good that she has these supports.>

P3: I don't know how... I mean... It just a... It frustrates me. I can't... you know... um...and I... numbers... ages of people...and...

I: Do you think not remembering their names or numbers has affected your leisure life or social life?

P3: Well. Those my friends know I am having this problem. [Giggling] so they understand it when I...you know... I look at somebody or I got something I want to tell them...just like...well...you know. I think they can pull the names, or the age, or the... place... you know. It's frustrating... because I forget. um... They all are very understanding realizing... that's one of the problems with this disease. It affects your... your memory.

I: So, it's... Your close friends or family already understand you...

P3: Oh, yeah.

I: You have the Alzheimer's.

P3: right.

I: so they can... they can make some efforts to help you.

P3: Oh, they do. They are all very wonderful about it. They realize that I just.... you know... cannot always come up with the answer... very patient with me... very supportive... I mean I couldn't ask for a better environment than I have because of friends at church. We go to church, see people and I won't be able to pull the names up you know but if I am out some place that I went to a high school with they know that I'm not ignoring them. I mean they understand that I can't pull out answers, names, and things that fast. They still keep me in the loop and I...

P3: I just... I am a social person because I like people... and I... so...being a... being able to be active enough to have my friends over or I go over there and they understand that I am having memory problems and so they are very supportive... even make it hard for me. and um... even my high school group... several of them calling to check to see how I am doing... and um... so it's...my...my one friend that was in my wedding party lives in Saint Louis. And she tries to come back for our high school old school thing and usually she stays here. And she came back this past month to our Christmas party and um... it just makes me feel good that I've got these gals that will see me. We were...[her helper's name] and I were shopping the other day and she came to the store we were in. She came over and gave me a hug. so... they know where I am and... I mean... they are really supportive when they see me.

<her husband who gives more practical help (dressing and driving, and overall planning for activities)>

P3: ...and I... I couldn't ask more for my husband who is... he is wonderful. We've been married... fifty-six? ... Fifty-five? Fifty-six years? Somewhere in that... [giggling] He's very helpful and he's been so sweet as I... lost... um... some abilities... like getting on clothes... I need help and he's... he's right there.

I: He's always been right there for you.

P3: Yeah. He's really great. And drives me here, there and wherever I have to go. [giggling]

<Her helper who she feels very close to by spending time together' a little energizer bunny; dearly love her like another daughter; Her helper keeps her from getting

	<p>down on herself; She seems to get emotional supports from her helper now as substitute for her daughters></p> <p>P3: um... I have a...helper now that I had since, it...would be a year in January and she... um...She is a nursing... well... not a nursing-nursing, but she's got some training... all that training. She comes three times a week and she is a little energizer bunny and I dearly love her. She is love her like my own and... um...She just keeps me from getting down on myself. She takes me three times a week weekly go to the gym and get in the pool. We just really good workout for thirty minutes and then we get in the hot tub for about ten... kind of...you know.</p> <p>I: That's great.</p> <p>P3: And it is and um... she is also...she...she was a cater. I mean she is the best cook because she makes us best foods and they are all healthy... and she doesn't let me get down and um...hopefully she will be here before you leave and you will meet her because she is wonderful.</p> <p>I: Yeah. I hope so. Oh. [I saw the helper waiving her hand behind]. Ha ha..</p> <p>P3: Is she here? Ha ha... but she is just so special to me and I don't know what I do without her. and...particularly since both my daughters are gone. It's just...I... can't do without her.</p> <p>P3: but [her helper's name] is... is my anchor.</p> <p>P3: They [her sister and helper] just fit in like they are family. I consider [her helper's name], my little sister, I mean I just and because my daughters... aren't here [voice: emphasizing]. I love them so much and it's hard for me. [Her helper's name] comes in and makes that work for me because I love her dearly and I couldn't love her any more if she were mine and um... she keeps me going... and she's a spectacular person and she is very loving me. She has a daughter that had problems at birth... so she had some problems all along. and ...she's doing so well because she has a momma like she does. You know, she works at KU med as a helper... you know. [Her helper's name] is just full of love and caring... <u>the kind of person that I need.</u></p> <p>P3: ...as I say... I am with my husband, with my neighbors, with my sister and [her helper's name] is my little God Ha ha... She keeps me... she keeps me balanced and helps...and...um...so...<u>I feel supported all the way around.</u></p>
Working as a team in talking	<p>-Her voluntary involvement in his talk to add</p> <p>I: Yeah. how was... How do you think the ... her relationship with the medical student?</p> <p>C3: I think... her... like what she said about is exactly what it was... yeah...very good relationship... very strong. um...</p> <p>P3: I tend the love people</p> <p>C3: huh?</p> <p>P3: I mean...When they are part of my life, they are just like part of my family.</p> <p>I: I see.</p> <p>P3: I mean... she was just sweet... she and her whole family. so...I...I...That's how I feel about. They are in my heart. I couldn't be any closer, I've already told [her helper's name] she's [her pair] came as close as... ha ha... I mean it's just...They are just important to me.</p>

Impact of dementia	<p><u>-Difficulty in remembering the activities and how she and her pair decided the activities [Sigh, hesitation and laughter] (takes time to recall the activities and she is not so sure)</u></p> <p>P3: Oh. [Sigh] That's been a while. ha ha. Well. We went out...had lunch together. um... Iyou know. ha ha. My... my</p> <p>I: I know it's been... for a while.</p> <p>P3: my memory is a... so far... gone. I just remember we go after lunch and visit. um.. We went over to my son's house at one point and there she and her husband and a little boy. um..We went over and they had dinner with us over there... um... visited and um...We went down to a.. a lunch at the ... the... um... historic home... down by a... the a Kauffman center. ...</p> <p>P3: We went to a movie together I think. ... and I... maybe...My memory is...is...something well I am...you know.... It is just hard for me to pull up because it's been. It seems like it's been forever. I can I guess it is over in May or something.</p> <p>I: Could you tell me how you decided what to do with the medical student?</p> <p>P3: [sigh]...you know. I can't really remember how it was set up. I haven't seen her now for several months when we met in ... um...we just we talked about different things and came up with them but I can't really remember the details of that. I know we went to the museum down there...by... the... downtown... which was really fun... and we...and um...[sigh] I am trying to pull these up. They are not just popping up for me... but I looked forward to it. We always had a good time.</p> <p><u>-Difficulty in remembering names of her friends is a real problem for her and it's frustrating and irritating. She feels like she is losing more abilities to remember.</u></p> <p>P3: ...So that's been kind of my... I rarely mentalize a couple of names... I am very... I don't have my names. You know.</p> <p>I: What do you mean by.. when you don't have your name.</p> <p>P3: I can't remember their names always. You know. I mean... my...Remembering name is a real problem for me and it's frustrating.</p> <p>I: so, how do you...how does it make you feel when you cannot remember their names.</p> <p>P3: Well, it's just irritating to me... um...[shaky voice] ...I feel... like well why can't I, but... It's just like my telephone number. I can't remember that most of the time. [Shaky voice/saying between her tears] um... these those little things get very provoking in it. um...I can't just...and the last year...has really...deteriorated a lot faster I think. I mean I feel like I am losing ground.</p> <p>I: What do you mean by losing...</p> <p>P3: Well. I am losing more abilities to remember.</p> <p>I: Why did you feel that? did you...</p> <p>P3: I don't know how... I mean... It just a... It frustrates me. I can't... you know... um...and I... numbers... ages of people...and...</p> <p>I: Do you think not remembering their names or numbers has affected your leisure life or social life?</p> <p>P: Well. Those my friends know I am having this problem. [giggling] so they</p>

understand it when I...you know... I look at somebody or I got something I want to tell them...just like...well...you know. I think they can pull the names, or the age, or the... place... you know. It's frustrating... because I forget. um... They all are very understanding realizing... that's one of the problems with this disease. It affects your... your memory.

P3: ...We go to church, see people and I won't be able to pull the names up you know but if I am out some place that I went to a high school with they know that I'm not ignoring them. I mean they understand that I can't pull out answers, names, and things that fast.

- She needs help in daily activities like dressing

P3: He's [her husband] very helpful and he's been so sweet as I... lost... um... some abilities... like getting on clothes... I need help and he's... he's right there.

- Losing train of thoughts

P3: so... um... I don't know if I am got off track or where I am. Ha ha...

-Low confidence in her memory

P3: my memory is a... so far... gone.

P3: ha ha... Other than my memory is so bad, I don't know how helpful this is the...

I: no no no.

P3: Okay.

I: You are the expert. I am just here to learn about your experience. It's okay if you cannot remember. It doesn't matter.

P3: I will do what I can. Ha ha...

-She (and her husband) doesn't remember her pair's name

P3: was...um...I can't ...can't remember her name.

C3: I don't know it either; we had one dinner with her.

-She can't drive.

P3: And so I couldn't drive.

-A very big shock at the time of diagnosis (took time to accept the disease); She feels frustrating and scary to lose part of her memory

P3: ...I never expected to be here it was a very big shock when the doctor... ha ha... says ...yeah... Alzheimer's. It was like.. oh...okay. ha ha... so... it was a shock and it was a...something I don't... it took me a while that... you know now I have to see it and I see as I continue... it lose parts of my... where I am... what I am doing... um...It's frustrating. It's scary. um...I just got some promises from some people that they're not going to leave me, and my family... and a lot of... you know...everybody has been so supportive.

- Her fear of not remembering her family at some point

	<p>P3: ... I know... what my family support and all... has done that help me and um... I ... the thing I fear is that I get to the point where I can't remember... my family... and I don't want to go there. ha ha... I don't wanna be here and not know my family.</p> <p><u>-Her feeling about Alzheimer's: She calls Alzheimer's as "this darn disease"</u></p>
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Note

- Activities (based on her memory): Having lunch and visiting a museum, going to a movie, and inviting her pair's husband and son to her son's house during the holiday.

-Based on what she talked, she seems to get more emotional support from her sister living close, her daughter living far, and her helper. Her husband gives more practical help (dressing and driving, and overall planning for activities)

-Her husband doesn't remember her pair's name and activities she did with her pair except for the family dinner. Based on the interview and observation in overall, he seems not to have good memory. He is not an expressive person, while his wife is a very expressive person. He might not ask and talk with her about things she did with her pair and how the meeting was after she came back from her meeting with her pair. He might forget it although they talked about the gathering a little bit. He is the one who forgets sending back the completed questionnaire so many times (very different from the other spouses who sent back the completed questionnaires within two weeks).

Interview 4.

I: Interviewer

P: Person with dementia

S: Spouse of the person with dementia

- Descriptive comments: focused on describing the content of what the participant has said, the subject of the talk within the transcript (normal text)
- Linguistic comments: focused on exploring the specific use of language by the participant (italic)
- Conceptual comments: focused on engaging at a more interrogative and conceptual level (underlined)

Emergent Theme	Original Transcript	Exploratory Comments
	<p>I: I am a researcher of the PAIRS program that pairs people with Alzheimer's and medical students for social gatherings at the University of Kansas Medical Center. You participated in the PAIRS program from September, 2013 to April, 2014. I really appreciate that both of you agreed to do</p>	

<p>Spouse's strategy</p>	<p>interviews. Thank you so much. And, this interview is to know about your experience of participation in the PAIRS program and your thoughts about its' impacts on you and your daily life. There are no right or wrong answers. And... so... you are the expert of the experience and I am just hear to learn about your experience. And this will take about 1 hour. Before we start the interview, could you tell me activities you did with the medical student during the PAIRS program period? You can talk about the details later, so could you...so please tell me activities briefly?</p>	<p>Spouse's involvement to help him understand the question easier/ better and remember better (rather than answering the question by herself)</p>
<p>Impact of dementia (remembering that he went out t to see something but not remembering what he did with his pair exactly)</p>	<p>S: What did you do with Kyle?</p> <p>P: We went out and um...and look at...we went to the lawyer ...not to the lawyer. [Saying with hesitation because of difficulty in remembering activities] I: Take your time. Yeah. P: We went to... to see something. [Saying with hesitation because of difficulty in remembering activities]</p>	<p>Impact of dementia (remembering that he went out but not remembering what he did with his pair exactly); <i>Saying with hesitation because of difficulty in remembering activities</i></p>
<p>Spouse's strategy (asking him if she can help)</p>	<p>S: May I assist? P: You are going to have to. S: Okay. P: [Cleared his throat]</p> <p>S: They went to the movies and after eat afterwards. And that was basically what they did. I: Oh, so movie...watching movie and eating out after watching the movies? S: Yes. Yes. Yes. Yes. I: And...is there any other activities they... S: Pardon me? I: Is there any other activities they did? S: No. P: No. S: The first time he just...</p>	<p>Spouse asks him if she can help (<u>does she do this way in daily lives (let him do by himself as much as he can and then help)?</u> <u>Because of embarrassment of not remembering?</u>)</p> <p>Activities: Going to the movies and eating out after watching the movies</p> <p>No other activities</p>
<p>Working as a team in talking (he tries to engage in the talk and she recognizes what</p>	<p>P: Well. S: He just...stayed with him [the medical student]. P: We went to the thing in the end.</p>	<p>He is trying to engage in the talk (efforts to engage in the talk together) He remembers the last meeting</p>

<p>he tries to say and organizes it in a clear way by adding what she knows too)</p>	<p>S: Oh. P: And um... S: Well the beginning too. P: He got something. I don't want to..., so... S: That parties at the Alzheimer's Association... at the beginning and at the end. I: Yeah. I was there at the end of the PAIRS party. So, for the first part of the interview, I would like to hear only from you [looking at the person with Alzheimer's], and then I will give both of you time to talk later [looking at the couple]. And because the interview has to be done in the same way for everyone, I'd like to hear only from him for the first of the interview without your help or involvement. But...so...it's up to you if you want to do something else and come back later. But...you are so welcome to stay here, but for the first part of the interview...</p>	<p>(the end of the PAIRS party) The couple works together in talking (the spouse recognize what he tries to say and organize it in a clear way by adding what she knows too)</p>
<p>Low confidence in his memory</p>	<p>P: She's got to stay here because I don't talk very... S: Well. He wants me... She doesn't want me to talk. This is like the PAIRS program. They want your participation, not mine. I: No. No. No. No. [Meaning that I want the spouse participation as well] S: No. Well. I: Yeah. [I found out that the spouse was talking about the PAIRS program only]. S: This was the major requirement. We [the PAIRS program] don't want you [the spouse] to go. We want one-on-one. I: Uh-huh. Right. S: which...you know...because you end up talking to the one person. I: So, for the first part of the interview, I'd like to hear only from you [looking at the person with Alzheimer's]. But after that, for the second part I'd like to hear from both of you. So...do you have any questions before we start the interview? No? Are you ready for the interview?</p>	<p>He wants his wife to stay for the first part of the interview; <u>low confidence?</u> She likens the interview style to the PAIRS program ("want participation of the person with dementia); She has a good understanding about the PAIRS program : about the major requirement (one-one-one) and reasons for doing one-on-one</p>
<p>Spouse's good understanding about the program</p>	<p>I: So, for the first part of the interview, I'd like to hear only from you [looking at the person with Alzheimer's]. But after that, for the second part I'd like to hear from both of you. So...do you have any questions before we start the interview? No? Are you ready for the interview?</p>	<p>His joke</p>
<p>His joke</p>	<p>P: I may be asked about from the start of the interview. I: Ha ha. So, could you tell me about your experience of participation in the PAIRS</p>	<p>His joke</p>

<p>I don't remember Apologize that he cannot remember the details</p> <p>Impact of dementia: Uncertainty and difficulty in remembering things</p> <p>He remembers a specific topic he talked with his pair (related to his past profession)</p> <p>Watching movie: no special meaning to him His pair chose the activity (He didn't</p>	<p>program? P: In what program? I: PAIRS program that... pairs you with the medical student for social gathering. What was his name [the medical student's name]? Kai? [I tried to say/remember the medical student's name to help him remember the experience with the medical student] P: I don't understand. Things doing with those students? I: Yeah. The medical student. P: Okay. And what I was doing with him [his paired medical student]? I: uh-huh. Your experience. Just your experience.</p> <p>P: Well. We would go. We went many many times to the... theater and um... we... and I cannot tell you what date. I don't remember. I: That's okay.</p> <p>P: I am sorry. I: That's okay.</p> <p>P: Um... We went to the... theaters. And we saw them. And um... then we came back and we went over to... places we can eat. And um... we talked there about what we ended up seeing and doing and um... all of those things. We stayed together probably after the... movie. We stayed probably... um... two hours... at least. And he's talking about things that he wanted to hear and things I wanted to hear. And um... that was it. I had... I was a professor at the University of Missouri and um... he knew that I was that. And so, we talked about some of the things I worked with over there and... things like that. And um... I don't know. Any something else you'd like... you'd like to hear? I don't know. [the spouse left to the kitchen] I: Yeah. So, you said that you went to the theater to watch the movies. P: Yes, ma'am. I: And ... is there any reason you went to the theater? Did this activity have any special meaning to you? P: Um... I don't think it's a... I think... he chose them. I: Oh, the medical student chose watching</p>	<p>He seems to not remember the exact name of the PAIRS program</p> <p>Need to give explanation about the PAIRS program again</p> <p>He apologizes that he cannot remember the details (what date) <u>Do people think that knowing the exact date is very important when they are asked about talking their experience? Why does he apologize not remembering the date? The date might mean details including the date.</u></p> <p><i>Hesitation in talking and use of "probably" because of uncertainty and difficulty in remembering things</i> Not very specific explanation (because he does not remember or because the topics are broad?) He remembers a specific topic he talked with his pair (related to his past profession)</p> <p>His pair chose the activity (going to the theater to watch movies). He didn't like some of the</p>
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<p>like some of the movies his pair chose)</p> <p>Passive in voicing his opinion (deciding activities): accepts what his pair suggests His personality or learned behavior?</p> <p>Like watching movie (subject matter)</p> <p>Impact of dementia (not remembering details: specific things)</p> <p>His pair as “my friend”</p> <p>His pair chose movies</p>	<p>the movie? P: Yeah. And um...some I liked some I didn't. He liked them all...very well. I: So, you said that he...the medical student chose watching the movie. I wonder if he chose what movie you were going to see, or did he choose going to the theater, the idea of going to the theater? P: He chose them...at the theaters. And then, we went to the theater and saw it. I: So, he chose the theater, right? P: Yes. I: Was there any reason why you wanted to watch the movie with him? P: I just told him that I would be very happy to do take that....to... I: watch the movie? P: Yes. It really made difference to me. I: Do you like watching movies? P: Some of them. [Laughing] I: What do you mean some of? [Laughing] P: But, I didn't look back. Well. Some of them I don't think are very interesting... at all. I: Oh, could you tell me more about that? P: Well. If I am going to see somebody in there, I want to see them... doing things I think are important...um...I cannot give you specific things right now because I...but I...I...I like them, but I...I will just assume not to see them... the ones that I don't see. I will get to that I do see. And I didn't say this to... I: Oh, so... P: my friend [the medical student] I: From my understanding, you...you watched the movies together, and then...maybe you didn't like some of them. You were not interested in some of the movies but you didn't say that I didn't like it. P: You are absolutely right. You are absolutely right. I: So... um...so you only... P: Don't you go to the movie sometime and say “Yeah. It's okay.” R: We all like different subject matters. P: Yeah. Yeah. I: So... um... P: And he chose them. I: Oh. So, he suggested some movies?</p>	<p>movies his pair chose.</p> <p>He seems to be very passive in voicing his opinion (depending on his pair in choosing the movie) or he accepts what his pair suggests; <u>his personality (who accepts and respects others' opinion first?) or learned behavior (after diagnosis)?</u></p> <p>Impact of dementia (not remembering details: specific things)</p> <p>Saying his pair as “my friend”</p> <p>He says that his pair was the boss</p>
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<p>His pair was the boss and he is just an old man standing there</p> <p>He did not tell his pair what he likes to watch</p> <p>Rather passive attitude in the relationship and talking with his pair (because he lost confidence due to his memory loss? Learned behavior after having dementia?)</p> <p>Impact of dementia (I can't remember; He remembers one activity he did with his pair other than going to the movie. He does not remember what the activity was.)</p>	<p>P: He was the boss. I was just an old man standing at a...</p> <p>I: But I guess you may like some genres. You may have some genres of your...your favorite genres such as...you may like action movies or comedy movies or...something like that. So, did you give him any suggestion? Or, did you talk about that to him? or...</p> <p>P: Just talked to him. Yes. These are his.</p> <p>R: Did you tell him what you like?</p> <p>I: uh-huh.</p> <p>P: um... I don't know that was terrible. But um...No. I don't think so. I take that I just went along with him listen to what he was saying. I would. You know. Even though something... you'd like to keep...you know. go out and say it "blah blah blah" you just...I don't know what thinking about what I am saying.</p> <p>I: So, I feel like...you...you may like any other activities...you wanted to do with him other than watching movie. Was there any other thing you...?</p> <p>P: He and I went to a...um...I can't remember...What was it... he and I watched? [Asking to his wife] [Coughing] Excuse me. um...It was at some animal we went out and saw. we went to the...you know... go out and see it and...see things going on and...all those things.</p> <p>I: Do you mean the museums? or any arts...?</p> <p>P: Well. I...there are museums I guess you can call it. There are a lot of here in the...</p> <p>I: Kansas City.</p> <p>P: Yeah. Kansas City. And we went to one of those. Just... just one. Then we went back to the...</p> <p>I: So, you went to some place...something like museum at one time and then the other...for the most of the time, you went to...</p> <p>P: the most of the time we went to...</p> <p>I: you went to the theater with him?</p> <p>P: Yes. Yes, ma'am.</p> <p>I: I am...</p> <p>P: And I talked to him over the phone</p>	<p>and he is just an old man standing there. <u>Was it because he chose to be like that or his pair was bossy? Does he feel less control in daily life?</u></p> <p>He did not tell his pair what he likes to watch.</p> <p>Rather passive attitude in the relationship and talking with his pair (<u>because he lost confidence due to his memory loss? Learned behavior after having dementia?</u>)</p> <p>Impact of dementia</p> <p>He remembers one activity he did with his pair other than going to the movie. He does not remember what the activity was. They went to the movies for the most of the time.</p>
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<p>His pair decided the movies because his pair wanted to see the movies</p>	<p>what... I: So...did he suggest watching the movie every time? because and then you agreed to do that. because he said that let's go to... P: He was the one who decided the movies. Yes. If you want to do something for me, I don't have something to add something different. but um...he wanted to see the movies. He is really...do you know him? I: No.</p>	<p>His pair decided the movies because his pair wanted to see the movies. <u>(Who said that "if you...different." He or his pair?)</u></p>
<p>Impression that his pair is really busy</p>	<p>P: He is really busy. [Emphasizing] And he...had to take..., you know, time...when he could... liked it and to listen to do things with it ...and if he didn't feel like he can do that he would call and tell me that we will have to go some other time. And I said "fine. We can do that." and um...because he was very very good at the university.</p>	<p>He got some impression that his pair is really busy because his pair changed the meeting time. He accepted the changed schedule.</p>
<p>Changes in schedules</p>	<p>I: Okay. How was the relationship with him? P: I am sorry? I: How was the relationship with him...with the medical student? P: I thought very good. um... it took a year I haven't seen him since. I: Oh, yeah.</p>	<p>He thought his relationship with his pair was very good. Use of past tense (<i>thought</i>) because he hasn't seen his pair after the program was ended.</p>
<p>He thought the relationship was very good (past tense)</p>	<p>P: Like I said...he was... in his first year at the university. And um...since then...and we went through all that... went through the...um...I think we even went through here...he was staying here at the...his first year... because he was working some place here at the university...and it was that he just got so busy that he....</p>	<p>I asked this question because he mentioned that the medical student knew that he worked at the University of Missouri and they talked about his work experience over there</p>
<p>No further contact</p>	<p>I: You also said that after watching the movie, you went to some restaurants to eat out. You told that... your...the place you worked...you worked in the past...he knew the place...how to say? P: He knew it... I: He knew the place where you worked before as a professor in the University of Minnesota or Missouri? P: No. No. I: So, you talked about some...about your major, your interest area. P: Yes Yes. I: With him. Could you tell me more about</p>	<p>Because he mentioned that he also talked about his experience as a professor (work experience at the university of Missouri)</p>
<p>His pair just got so busy</p>	<p>I: You also said that after watching the movie, you went to some restaurants to eat out. You told that... your...the place you worked...you worked in the past...he knew the place...how to say? P: He knew it... I: He knew the place where you worked before as a professor in the University of Minnesota or Missouri? P: No. No. I: So, you talked about some...about your major, your interest area. P: Yes Yes. I: With him. Could you tell me more about</p>	<p>I asked this question because he mentioned that the medical student knew that he worked at the University of Missouri and they talked about his work experience over there</p>

<p>Impact of dementia (not remembering what he talked about with his pair)</p> <p>We talked about things we were interested in each other</p> <p>We talked about medicine, things, and that I've gone through and he's gone through</p> <p>Description of his pair: a really very interesting young man</p> <p>We were very kind each other</p> <p>Enjoyed talking to his pair</p> <p>I think he enjoys talking to me</p> <p>All of them are very interesting to me.</p> <p>Happy to take his pair as a partner</p> <p>He remembers the first meeting with his pair</p> <p>Impact of dementia (forgetting the exact word)</p>	<p>that...what you usually talked with him while you were eating out with him?</p> <p>R: What kinds of things you talked about during your meal?</p> <p>P: (pause). You are asking something... It's gone away. Ha ha. Um... We were talking about that because...that was I worked with at the university. And um... so I...we talked about things we were going on and I cannot tell you exactly what they are. But...the things we were interested in each other...and he is a really very interesting young man. [Emphasizing] He is going to be something I would say very very good. um...But we talked about...medicine, things, and that I've gone through and he's gone through. And um... That's all I can tell you. We...we were very kind each other and I enjoyed talking to him. And I think he enjoy talking to him.</p> <p>I: So, you said that you enjoyed talking with him and you... mostly talked about your interest in medicine. So...</p> <p>P: Oh, yeah. Right. Things ever going on. Yeah.</p> <p>I: So...talking about the medicine...both of your interest in... made the conversation more interesting to you? How was the conversation with him? How do you think about...?</p> <p>P: I don't know if there was more interesting. I think all of them are very interesting to me... a long time ago. But um...I was happy to take him...as a partner from the place....I don't remember... we were heading a meeting and put it and finding people to...work with each other.</p> <p>I: Do you mean some internship program?</p> <p>P: I am sorry?</p> <p>I: Internship...internship program or...?</p> <p>P: They call all of...a lot of people and...I think one of them are in the um...Al...zheim...but I am not sure. But, we went there and we chose people that we were going to work with them for the rest of the year and um...I think the people had look at it and had done it too. And ... they came</p>	<p>Impact of dementia (not remembering what he talked about with his pair)</p> <p><u>They seemed to talk about their past and current experiences</u></p> <p>We talked about things we were interested in each other</p> <p>We talked about medicine, things, and that I've gone through and he's gone through</p> <p>Description of his pair: a really very interesting young man</p> <p>We were very kind each other</p> <p>Enjoyed talking to his pair</p> <p>I think he enjoys talking to me</p> <p>I asked this question because I thought that he talked with the medical student about his work experience that the medical student could be interesting or could be familiar with because medical students take some class of microbiology</p> <p>All of them are very interesting to me.</p> <p>Happy to take his pair as a partner</p> <p>He remembers the first meeting with his pair</p> <p>Impact of dementia (forgetting the exact word)</p> <p><u>He seems to try to say Alzheimer's but forgets the exact word</u></p>
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<p>I knew a lot of the things he was interested in...the feature of...(Alzheimer's)?</p> <p>Shared interest in microbiology (his past occupation as a professor in medical school)</p> <p>They may talk about medicine in general (things going on in medicine)</p> <p>He felt that they didn't have much time to talk (because they watched movie before eating and talking)</p> <p>Description of his pair (a really nice young man)</p>	<p>over at the beginning and said that you know they would like to...if it was possible for us to get together and...</p> <p>I: Was it job fair?</p> <p>P: I am sorry?</p> <p>I: Job fair? Job fair?</p> <p>R: Were you talking about just when you were matched with your pair for this program?</p> <p>P: Yeah.</p> <p>I: Oh, I see.</p> <p>R: So you were matched with your pair.</p> <p>P: Yeah. yeah.</p> <p>R: Okay.</p> <p>I: At that time, you talked about the activities you were going to do together, right?</p> <p>P: Yeah. Yeah. He knew that I had.... He was coming in for the first year and he knew that I had...I was...um...with the school... that um...I knew a lot of the things he was interested in...the features of ...</p> <p>I: Do you mean your major, microbiology?</p> <p>P: Yes Yes.</p> <p>I: So, he is interested in microbiology, Right?</p> <p>P: Yeah, but he wants to be a doctor.</p> <p>I: Uh-huh. Right.</p> <p>P: yeah.</p> <p>I: But he is interested in...hearing about your major. Right?</p> <p>P: Yeah yeah yeah yeah. But we also heard about other people's majors too. So...that's how we worked.</p> <p>I: Did you talk about other things other than your shared interest in your major?</p> <p>P: You know. We actually we didn't, no. We were interested in what we were talking about. We knew that we didn't have more than four hours...Ha ha... to talk...so we'd better to get it all done before...and fours with also eating...</p> <p>I: Right.</p> <p>P: Do you know him? [Asking to the research assistant]</p> <p>R: No.</p> <p>P: He is really a nice young man.</p>	<p>Impact of dementia (forgetting the exact word)</p> <p><u>he seems to try to say Alzheimer's but he forgets the word Alzheimer's</u></p> <p>He remembers the first meeting with his pair</p> <p>Shared interest in microbiology or Alzheimer's? ("I knew a lot of the things he was interested in...the feature of...")</p> <p>Shared interest in microbiology (his past occupation as a professor in medical school)</p> <p>They may talk about medicine in general (things going on in medicine)</p> <p>He felt that they didn't have much time to talk (because they watched movie before eating and talking)</p> <p><u>[Based on what he talked so far, he and his pair talked basically about his daily experience and/or features of Alzheimer's. They also talked about his past work experience to get to know each other, but they seem to talk about</u></p>
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<p>Felt good when he socialized with his pair Wants to help medical student in general</p> <p>Lucky to know each other and start talking</p> <p>“He and I talked quite a bit. I talked quite a bit.” “I haven’t talked to for a while.”</p> <p>What enjoyed him is that his pair was a very honest young man His pair trying to talk very wazzy</p> <p>It was good to hear and be with his past profession (belonging to his past profession/self-identity)</p>	<p>I: How did you feel when you socialized with the medical student? P: I am sorry? I: How did you feel when you socialized with the medical student? [Talking slowly] P: I thought good. Is that what you want to? I: Yeah. Thoughts or feelings. P: Yeah. I like them all. I mean...yeah. I...knew mine the best. But um...yeah...it’s nice to know them and try to help them if they had a question. I: So...from my understanding, you feel that you help the medical student because you were telling the student who is interested in your major? So...</p> <p>P: I don’t see...No. I...it’s not a problem with that. They all have to find me to...you know like that. It’s just we were lucky enough to rather cross each other and start talking...except for the man that I was working with. He and I...talked quite a bit. I talked [emphasizing] quite a bit. I haven’t talked to for a while. I: I think you enjoyed the time with him, but could you tell me why... the specific reasons...what was enjoyable to you? P: What enjoyed to me? I: Yeah...of the participation in the PAIRS program. P: The fact that he was...he was a very honest young man. And he liked to talk ... the things. He was trying to talk very wazzy. He worked through his first year... the thing. And um...there were things that...I had worked for...but I had worked for those about... 15 years ago, so there were a lot of changes for me. And um...I learned a lot about what was going on... that I didn’t know the things in...so much more than I had when I was there. So, it was good for</p>	<p><u>their daily life mostly (His daily life as a person with Alzheimer’s and his pair’s life as a medical student). Talking about his work experience doesn’t seem to happen often, maybe at the beginning only. As a medical student, his pair would be more interesting to hear about his daily life as a person with Alzheimer’s.</u> His pair: a really nice young man</p> <p>Felt good when he socialized with his pair Wants to help medical student in general “It’s nice to know them [medical students] and try to help them if they had a question.” <u>I said this way because I thought they talked about his work experience and microbiology as a shared interest or shared knowledge</u></p> <p>Lucky to know each other and start talking</p> <p>“He and I talked quite a bit. I talked quite a bit.” “I haven’t talked to for a while.”</p> <p>What enjoyed him? The fact that he was a very honest young man. He was trying to talk very wazzy. <u>[based on what he talked so far, they talked about things related to his profession (the area of his major: microbiology) and he enjoyed talking about it because that’s been his interest and he could learn more current knowledge (changes after his retirement) and have a feel of</u></p>
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<p>Description of his pair: A very nice young man</p> <p>The best part was being with his pair (and talking with his pair about various thing that were going on and what his pair was doing)</p> <p>Because he wanted to help students and because the medical students were doing things that he had done before(shared profession)</p>	<p>me...um...get to...get to be with it.</p> <p>I: So, was it kind of information exchange? P: Yeah. [Answering at the same time when I said "so..."] I: So, you learn from him, and he learns from you. P: Yeah. We asked questions, asked questions or say "Oh, I wonder how they did that.", and maybe neither one of us knew, so we got together and found out what was happening. He...he is a very nice young man.</p> <p>I :What was...what did you like the most? P: (pause) I don't what you mean. I: I mean what was fun for you during the PAIRS program period? What was the...what did you like the most? What was the best part of the... P: Being with him. Being with him. Talking with him about various things that were going on and what he was doing. He is really a sharp young man. I: What were your expectations before you participate in the PAIRS program? P: What was...I am sorry? I: What were your expectations before you participate in the PAIRS program? [Talking slowly] P: I hoped that that were going to be he and he was...is what you...I don't...</p> <p>I: Do you...why did you decide to participate in the PAIRS program? P: Because I wanted to help the...you did...any of the students. They were doing it...from things I had done before. And I... There were things that I had done before that I could do. And I am sorry that this time is going by... just time.... shoo shoo shoo (and sounds of fingers walking on the table) [Making sounds with his mouth and fingers to express that time goes fast]</p> <p>I: Was there any other expectation other than helping the medical students' learning? P: I don't know.</p> <p>I: Okay. And how do you think participation</p>	<p><u>belonging to his profession/self identity. The medical student seems to be more interested in knowing about his life or history related to Alzheimer's, so the medical student asked questions related to this. At the same time, the medical student could share things related to his (the person with Alzheimer's) interest in microbiology because the medical student has some knowledge in medicine including microbiology.]</u></p> <p>What was the best part of the program?</p> <p>Being with his pair, talking with his pair about various thing that were going on and what his pair was doing</p> <p>He decided to participate in the PAISR program because he wanted to help students. Also because the medical students were doing things that he had done before. (shared profession)</p>
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<p>He moved to Kansas one and a half years ago. Impact of dementia (not remembering where he moved to Kansas from) He wanted to get hold of some young man He had never been around Kansas. May hear a lot of things out of that... Plus for him Very happy when his pair said that he wanted to be a friend We had a very good time.</p> <p>He recalls where he moved from (Columbia)</p> <p>Friends and more acquaintance are in Columbia; Less friends and acquaintance are in Kansas.</p> <p>He still likes his pair even though he hasn't met his pair since the program was ended.</p>	<p>in the PAIRS program has affected you and your daily life? [Ringing of the telephone] [The spouse answers the phone and talks over the phone in the kitchen]</p> <p>P: Well. We had moved up here...from...um...no...we moved up from some place else. And we've been here for about an hour...a year and a half. And um...I was...I wanted to get hold of some young man. I had never been to the Kansas...um...place. And...I got to hear him and um...you know...picked up a lot of things out of that...that I may be heard a lot of the...um. And it was just...a plus for me, okay? And I...I was very happy when he said that to...he wanted to be...a friend. And...I think we had a very good time. Is that answering your question?</p> <p>I: Yeah. Yeah. Absolutely. From my understanding, you moved in the Kansas City a year and a half years ago?</p> <p>P: We moved into this house from...from Columbia. That was it. I: So... maybe your friends or more acquaintance...friends... are in Columbia. So, you were...</p> <p>P: Yes. You are absolutely right. You are absolutely right. Yes.</p> <p>I: From my understanding, you were happy to have a friend in Kansas City because you had been...</p> <p>P: Oh, I liked him a lot. Yes. I did. I do. Yes.</p> <p>I: So, do you think having that relationship with him has affected your feeling or mood...or...in any way? [a little bit of noise from the spouse's talk on the phone] P: Would you say it again? I: So...um...has participation in the PAIRS program...do you think participation in the PAIRS program has affected your mood or</p>	<p>He moved to Kansas one and a half years ago. Impact of dementia (not remembering where he moved to Kansas from) He wanted to get hold of some young man. He had never been around Kansas. May hear a lot of things out of that... Plus for him Very happy when his pair said that he wanted to be a friend We had a very good time. <i>Hesitation</i> because of difficulty in remembering where he moved from and saying "hour" instead of year at the beginning; <u>disrupted by the noise from his wife's phone talk?</u></p> <p>He recalls where he moved from (Columbia)</p> <p>Friends and more acquaintance are in Columbia; <u>Less friends and acquaintance are in Kansas.</u></p> <p><i>Past and present tense</i>; He still likes his pair even though he hasn't met his pair since the program was ended.</p>
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<p>He feels that he has become very attached to Alzheimer's (more affected) after he moved to Kansas</p> <p>Social workers in the AA are wonderful.</p> <p>He appreciates that he was partnered up (participation in the PAIRS program) Great and entertaining He wants to see his pair again and hear what he has been doing. His pair- very smart He thinks that the PAIRS program helped him and his pair.</p> <p>Happy working with his pair His pair never made him angry His pair had lots of things he wanted to do and they tried to do. He Just enjoyed and he hopes his pair enjoyed him too.</p> <p>He goes to AA all the time. (His participation in leisure or social</p>	<p>feeling?</p> <p>P: Oh, yeah. um...Alzheimer's. I don't know... Alzheimer's...I become... very attached to Alzheimer's...since I've been here. I started with it when I was in Columbia, but I...we were leaving and I really didn't. (pause) I don't know. um... it's much more effected here. I don't know if you know the ladies in and there or not. I: in the Alzheimer's Association?</p> <p>P: Yeah. Alzheimer's. Yes. They are wonderful. They are wonderful. And they are...something that I've been rather doing this year. They are doing another one, but thanks I was partnered up...at first time. And um...that was great and um...it's just been kind of entertaining. If I ever ran across my friend [his pair], um...I'd like to much see him and find out what he has been doing. And...I know he's very smart and getting high grades. I don't know that answered your question but...yeah...um...it helped me and as far as I know helped him.</p> <p>I: Could you tell me more about how... the participation helped you? It sounds like you...because you enjoyed having time with him and have a friend...but...did this affect your feeling or...? You feel like oh, I am happier or...I am...</p> <p>P: Oh, I was certainly happy working with him. Yes. Yes. He had never made me angry...never made me angry. Um...and he had lots of things he wanted to do, and... we tried to do. Well... I just enjoyed. And I hope he enjoyed me. I: Yes. Sure. How do you think participation in the PAIRS program has affected your participation or motivation for the leisure or social activities? [A louder voice of the spouse talking on the phone in the other room]</p> <p>P: I go to... Alzheimer's all the time. [Alzheimer's -> Alzheimer's Association] Um...and I guess they had started another one this year and I didn't know that.</p>	<p><u>It seems that he recalls the word "Alzheimer's" suddenly and he starts saying "Alzheimer's"</u> He feels that he has become very attached to Alzheimer's (more affected) after he moved to Kansas. <u>Why? Because his disease has progressed more after moving to Kansas or just his is feeling like that (due to fewer social life/ less active daily life) ?</u> Social workers in the AA are wonderful. He appreciates that he was partnered up (participation in the PAIRS program) Great and entertaining He wants to see his pair again and hear what he has been doing. His pair- very smart He thinks that the PAIRS program helped him and his pair.</p> <p>Happy working with his pair His pair never made him angry His pair had lots of things he wanted to do and they tried to do. <u>Maybe they did many things but he just doesn't remember them?</u> He Just enjoyed and he hopes his pair enjoyed him too.</p> <p>He goes to AA all the time. <u>His participation in leisure or social activities seems to be through AA now.</u></p>
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<p>activities seems to be through AA now).</p> <p>Looking forward to meeting with his pair again.</p> <p>He thinks his less participation in leisure or social activities is not just because of dementia. (also aging)</p> <p>He goes to the meetings at AA twice a week.</p> <p>Impact of dementia (difficulty in finding the right word)</p> <p>He wanted to participate in the PAIRS program again</p> <p>He says that other participants also enjoyed participation in the PAIRS program very much</p> <p>He thinks there is no</p>	<p>um...And a lot of them...Alzheimer's going trying to find places out in the Kansas...places. Um...if I had the opportunity and... and if um... my boy would call me back... um...I would...go immediately. You know. That's what you are asking. I don't know.</p> <p>I: How do you...um...</p> <p>P: I am getting older. Ha ha.</p> <p>I: Are there any...um...Do you participate in leisure or social activities during the day or...?</p> <p>P: Um...</p> <p>I: You said that you go to the meeting...</p> <p>P: with Alzheimer's. Yes I do. Yes. Yes. I go there twice a... twice a...day...um...Ugh. [because he cannot remember the word "week"]</p> <p>I: Week?</p> <p>P: A week.</p> <p>I: Six hours?</p> <p>P: um...six hours each day. Yeah. Have you been over?</p> <p>I: Yes. Sure.</p> <p>P: Oh, good. I didn't see you.</p> <p>I: Actually, I was at the end of the PAIRS party in...last April. I saw the medical students and families over there and...</p> <p>P: Okay.</p> <p>I: Yeah. I think that's good. That's good...good program.</p> <p>P: Well. See. I wasn't invited back...next time and I don't know why.</p> <p>I: Oh, I heard that because they want to give the priority to the new people.</p> <p>P: Yes.</p> <p>I: Did you want to...?</p> <p>P: Oh, yes, I did. Very much. If... I could...I would've done it.</p> <p>I: Okay. um...So...</p> <p>P: Because I think they do well. They really do. A lot of people from my...my Alzheimer's...has same thing I had with my friend [his pair]. And um...they really are enjoying it.</p> <p>I: Do you think...do you see any difference between the PAIRS program and the meetings at the Alzheimer's Association?</p> <p>P: For who?</p>	<p>If he participated in the PAIRS program again/ if his pair would call him, he would go immediately. He is looking forward to meeting with his pair again.</p> <p>I am getting older. He thinks his less participation in leisure or social activities is not just because of dementia. (also aging)</p> <p>He wanted to participate in the PAIRS program again because he thinks they (med students?) do well.</p> <p>He says that other participants also enjoyed participation in the PAIRS program very much. <u>Who are they? They: med students? or the entire program?</u></p> <p>He thinks there is no difference</p>
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<p>difference between the PAIRS program and the meetings (support groups) at the AA because he thinks they are together (he doesn't think one is better than the other)</p> <p>No difference because we are all on the same track (we are all interested in Alzheimer's)</p> <p>He says that AA is trying to help people with Alzheimer's to be involved/ engaged in the community more.</p>	<p>I: For you. I mean do you feel differently... um...the PAIRS program is different from the meetings at the Alzheimer's Association. Do you see any difference between those two programs? P: They...they are together. I: Yeah. P: Yeah. Um...I don't think one is better than the other. I think...I don't know. I: Yeah. I don't... P: If I had my choice and if somebody asks me...you know jump and say "I will do it." um...I think I will do it. um...I just don't think there is any difference. We are...all on the same track. I: So...um...what do you mean by you are on the...in the same track. P: We all are interested in Alzheimer's. And... I mean...I have go from Alzheimer's because that's I am so actively... now. And see what the other people are doing and because...I mean they are doing a lot of things at Alzheimer's aren't doing. And they keep going together all the time...Alzheimer's and um...um...Kansas. I: Kansas? P: The people in Kansas. I: Um...do you mean that people in the Kansas? P: They know a lot about Alzheimer's. I: Oh, do you mean that the social workers? P: I am sorry? I: Social workers at the Alzheimer's Association? P: I don't know what you are talking about. I: Do you mean Michelle and the other facilitators in...at the Association? Or, what do you mean by people in the Kansas City? R: Are you saying the people in the Kansas City Alzheimer's Association know a lot? And...is that what you were saying? P: I was saying that they...No. No. The people...Alzheimer's do not... pay as much attention as Kansas people do. I: Oh, so...do you mean that people with Alzheimer's should get more attention from the Kansas City? or... P: I think it would help them. Yes. I: um...so... P: All of the...got plenty...they got a lot of</p>	<p>between the PAIRS program and the meetings (support groups) at the AA.</p> <p>They are together</p> <p>We are all on the same track.</p> <p>Shared interest in Alzheimer's (actively involved/engaged now)</p> <p>He says that AA is trying to help people with Alzheimer's to be involved/ engaged in the community more.</p>
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<p>He likes both (the PAIRS program and support group meetings at AA)</p> <p>He let his pair do whatever his pair wanted to do because he felt his pair was very busy and did his best in school. He was very happy to help his pair and his pair wanted to know about Alzheimer's. So, he tried to help his pair know about Alzheimer's.</p> <p>He didn't ask his pair to choose the activity (going to the movies), and his pair wanted to do so (It seems that his pair suggested going to the movies</p>	<p>help. A lot more help...very helpful. R: Okay. So, he is saying that like um...the Kansas City Alzheimer's Association it would be more beneficial if they were reached out to the community more and have more involvement with people with Alzheimer's. Is that what you are saying? P: Yeah. Yeah. Yeah. R: Okay. So, do you more to get them involved...the people with Alzheimer's are involved and... I: Oh, in the community? R: Yeah. I: Do you...Because as I know these meetings at the Alzheimer's Association are group meetings, so you meet other people with Alzheimer's and their family members. The PAIRS program is a one-on-on interaction with...one-on-one social engagement, so do you see any...do you feel any difference when you are with one person and you do the thing just both of you like to do? At the Alzheimer's Association, you do some fun things together with other people. P: I like too down there. I: Do you mean that you like better in group? P: I don't say I like it better, but I like it down as well. I: Okay. P: But I had to take care of my boy [the medical student] first. I: Oh, your boy? P: He [his pair] was very busy. Some of those guys who are working over there [other medical students?] are really busy. And he was really trying to the...at the top of the...people. And um...so I...at least this is why I had thought about ...I wanted him let him do whatever he wanted to do and um...I would be very happy to help him and he wanted to know about Alzheimer's. And I tried to help him with Alzheimer's. I: So, from my understanding, you wanted to give him...because you know that he is too busy, so you wanted...give him.... to feel free more...to feel free? P: I wanted him to feel as free as he to feel . I: That's why you let him choose the activities to do? P: I didn't let him do. He wanted to. Ha Ha.</p>	<p>He likes both (the PAIRS program and support group meetings at AA)</p> <p><u>Did he feel more responsibility (feel more as active agent) in the PAIRS program?</u></p> <p>He let his pair do whatever his pair wanted to do because he felt his pair was very busy and did his best in school. He was very happy to help his pair and his pair wanted to know about Alzheimer's. So, he tried to help his pair know about Alzheimer's.</p> <p>He didn't ask his pair to choose the activity (going to the movies), and his pair wanted to do so. <u>It seems that his pair suggested</u></p>
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<p>and he accepted his suggestion.)</p> <p>He wanted to have more time with his pair, but his pair didn't have much time to do so.</p> <p>He did not want to go to the movies all the time. He wanted to go out to different places in Kansas</p> <p>Difficulty in remembering the word</p> <p>He was interested in going out for different cultural activities in Kansas, but he didn't voice his opinion because he thought his pair didn't have much time to go there.</p> <p>Description of his pair as a very bright young man.</p> <p>His misunderstanding about the program (He thought that the medical students have to choose activities)</p>	<p>So...I...I mean...I did. But no. I didn't ask him to do it.</p> <p>I: But he just...</p> <p>P: Yes.</p> <p>I: chose watching the movie is good for me.</p> <p>P: Oh, yeah. Oh, yeah.</p> <p>I: I see. Do you...um... Was there any other activities you wanted to do with him other than watching the movie?</p> <p>P: I would like to have more time with him but he didn't have it to do.</p> <p>I: Oh, I see.</p> <p>P: um...</p> <p>I: What would be...is there any...um...could you tell me the activities you wanted to do with him?</p> <p>P: Well, if I can remember though. Um... you know. There are a lot of places here in Kansas that you can go and you can find out very interesting things. And I would like have done that...</p> <p>I: more cultural activities</p> <p>P: rather than going to movie all the time...to go out there and see the...the... the... [sigh] I don't know.</p> <p>R: Museums and different things there.</p> <p>P: Thank you.</p> <p>I: art theaters, art galleries, symphony...</p> <p>P: animals too.</p> <p>R: zoo.</p> <p>P: There are a lot of interesting animals. There are a lot of things you can do, but for me there was not that much time because he didn't have that much time. And I didn't want to say that "Well. if you are not going to do, I am not going to do these." Ha ha.</p> <p>I: Do you think it would be more enjoyable if you could do that kinds of activities with him?</p> <p>P: I imagine. I really don't know. He is a very bright young man. And he knew what he was doing. And um...I didn't want to say "Well. You should do what I wanted to do." because that's not what I was told at the very beginning. I was not to...you know, force myself into their...people who were accepting us. They were the ones who were supposed to tell me and tell you things about what they were doing as far as</p>	<p><u>going to the movies and he accepted his suggestion.</u></p> <p>He wanted to have more time with his pair, but his pair didn't have much time to do so.</p> <p>He did not want to go to the movies all the time. He wanted to go out to different places in Kansas.</p> <p><i>Sigh because of difficulty in remembering the words\</i></p> <p>It seems that he wanted to the zoo to see interesting animals. He was interested in going out for different cultural activities in Kansas, but his pair didn't have much time to go there. <u>He might suggest other activities to his pair, but it seems that his pair did not accept his suggestion and rather suggested going to the movies because of his busy schedule.</u></p> <p><u>Maybe he heard that each pair should consider each other's schedule to choose the activities because the students have their own schedules. (He misunderstood or forgot the details? He would not be heard that medical students have to choose the activities). It seems that he felt that his pair was</u></p>
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<p>Impact of dementia (difficulty in finding words)</p>	<p>...um...Alzheimer's does. I: Actually, as I know...I heard that the person with Alzheimer's should choose the activities, not the students. Actually, that's my understanding about the program. P: You heard that they should...? I: You should choose...you should choose the activities whatever you want, not by the medical student. P: Well, that wasn't the way I understood. My person [his pair]...my person told me that...[he tapped on the table; to help him say/remember what he is trying to say] I: The medical students have to choose activities? P: Yeah. Yeah. I: Really? P: Yeah. R: Hmm. I & P: Ha ha P: There are a whole bunch of us. It isn't... there are just a few people there are a lot of people there working. I can't remember how many. Did you go to the...? I: The end of the meeting? P: Yeah. I: I saw. Maybe...as I know there were thirteen...thirteen pairs. P: Yeah. Yeah. Yeah. I: Oh, interesting. P: Did you have somebody working for...with you? I: I was not paired with anyone, but I am doing the...because I am doing the interviews. I already did several interviews with the other people and they did whatever they wanted to do. So...actually, it is interesting to hear from you because you know that the medical... P: Oh, I thought that was too bad too that that...you know. We had a bunch of people and we could've gone together...you know... maybe not... once a month maybe once every two months something like that. We can make ourselves...you know... aware...and we didn't do it. Some of them did...I found out later on...some of them did, but it was just a few people. I: So, do you mean that just a few of them</p>	<p><u>really busy and/or his pair might give him too much impression that the medical student was too busy and/or he did not voice his opinion when his pair asked him about what he wanted to do, so his pair thought he has no interest in the other activities and his pair chose watching the movie and eating out together?</u></p> <p>He thought that the medical students have to choose activities.</p>
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<p>Wants for more people with Alzheimer's at AA to be able to participate in the PAIRS program (at least giving them a chance to meet with medical students)</p>	<p>did...did activities... the things they wanted to do during the PAIRS period? P: Yeah. Yeah. Yeah. I: So, the other people in that program...they just had to follow what the medical students told? P: yes yes yes yes. I: That's weird. That's really weird. I don't know why. So, how did you... because you said that you found that a few people could do the things they wanted to do, and the other person did whatever they wanted. P: But I found out... I: later. P: after I was out. I: So, how did you feel that? P: Going out? I: No, I mean when you found out that you could choose activities. Some people chose whatever they wanted to do with the medical students and the other people just... P: I thought I was doing...I thought I was doing what I was supposed to be doing. I: When you found out these, did you...how did you feel? P: Well. I...I thought it would...I...I didn't... do a lot because I wasn't still there. I...I thought it would be nice to have a whole bunch of us together... not all the time but um...period of times. And I thought it would help them as well as it helped us. I don't know if that makes any sense to you. And I am sorry that if I am not making any sense to you I: No. You are perfectly okay. Yeah. [He cleared his throat] I: So, what do you think to be the important features of the PAIRS program? P: Things are what? I: What do you think to be the important features of the PAIRS program? P: (pause) I don't know. R: What stuck out as important parts of the program. I: Purpose or something like that. P: How are they going to do it? uh-huh? If you... I mean when you said the problem...if I had a problem, it's just gonna be and whoever is with me.</p>	<p>It seems that he misunderstood my question and I misunderstood what he meant. I was talking about the issue of who chose the activities (by the person with Alzheimer's or by the medical student) still, but he was telling me that it would be nice if more people with Alzheimer's in his group could participate in the PAIRS program because he found that only a few people with Alzheimer's could participate in the PAIRS program. He thinks that it would be nice for those who were not in the PAIRS program to get together with them (those who were paired with medical students) once every two months. <u>Why does he feel this way? Because he thinks engaging in the PAIRS program was good, so he wanted to have more people with Alzheimer's to participate in the PAIRS program?</u></p>
<p>Difficulty in understanding the question</p>		<p>Difficulty in understanding the question</p>

<p>His wants that all PAIRS groups could get together and talk how and what they are doing and what they need to be helped with during the PAIRS program period (because he needed some help /explanation? Difficulty due to no involvement of his wife?)</p>	<p>I: The program that pairs people with Alzheimer's and medical students. What do you think to be... the purpose or the important thing about the program?</p> <p>P: Oh, I think it would be wonderful if the people who are... taking... charge of... what they... you know... that... I can say well... you know it just needs to be me and my boy or my girl, whatever it is. It would be good if we can say...I feel like once every month...I don't know how they do it now. um...Kyle and I think we...I think we went twice a month... um...and I think that if... um...if other people I found out and a very few of them...would go for...once a month...once a...a week. And it's very helpful that way with them and if they would take... a bunch of them say once every...um...month... and all the groups would be together and see if that things have been...you know... passed about each other and what are they doing and what they need to be helped with...I think that would be wonderful, but it didn't happen that way.</p> <p>I: So, you think it would be...it would be better if you can get together and talk about each other's experience during that time...so you can get how the other people are doing...</p> <p>P: I think...in my mind...that would be good...very good. Yeah. I don't know what the other people are thinking about that.</p> <p>R: Okay. Can I add some? He also thinks another important part of the program would be how often you meet.</p> <p>I: Yeah, other than once a month.</p> <p>P:Don't wait until the end. It would help them if they meet each other. And that I mean they are not together all the time. They may think they are. But they are not. And it would help them have somebody to...to be there and explain different things.</p> <p>(48:42)</p> <p>I: So...now I will start the second part of the interview. Are you ready for...? [Looking at his spouse]</p> <p>S: Are you ready for me?</p>	<p>He thinks it would be good if all PAIRS groups could get together and talk how what they are doing and what they need to be helped with during the PAIRS program period rather than meeting at the end one time. <u>Did he feel some need to get help during the PAIRS program period? Based on what he said so far, he didn't like going to the movies all the time and he was not sure about what to do. He seems to think that if they had some meetings during the PAIRS program period, he and his PAIR could do more diverse activities he was interested in?</u></p>
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<p>His joke</p> <p>Good, very positive He is unique to the program He was a professor in a med school He was very involved with students An active member of a church A close relationship with med students (not just as a professor but also as a friend)</p> <p>Successful with him because no involvement of her (family) in activities and shared interest in terms of profession</p> <p>Followed program's rules/criteria strictly by understanding the features of program</p> <p>It was very good, excellent. She was delighted that he was able to participate in the</p>	<p>I: Yes. S: Okay. That I've just got a call from Cathy Lou and I just took advantage of mine, not being mean. Ha ha. I: So, I will start the second part of the interview. So, for this part, you can talk...both of you can talk. Feel please to talk. P: I can't talk. [Pretending that his voice sounds hoarse] I: Ha ha. So, how do you think about your spouse, his participation in the PAIRS program? P: (coughing) S: how do I think he...? I: his participation in the PAIRS program. S: Oh, in...I thought it was good. I think the thing that's...unique about him though is a fact that he was a professor in a medical school. He was very involved with students. He was on the Missions committee for years. He had a close relationship with these medical students and there quite a few of them are still...not only...when we lived in Columbia...not only whether they were his doctors but they were his friends. So...he is almost a...unique... person to be involved in something like that. I thought that was very positive, of course.</p> <p>I: So, from my understanding, maybe this experience was the things he used to do or he still do... S: I think the things that he used to do influence how successful it was with him. It would...but then I heard when we went to the final meeting and heard the other people talking about it. And it seems to me the family was much more involved than I. I was...I was informed at the beginning this is one-on-one. They don't want you to go to the movie with them. You know. They don't want you to go to the museum with them. You know. They don't want you to go to...out to eat with them because the medical student is going to end up talking to you. But, some of them had a closer tie...some of the families had closer ties and we've never done that. And this again might be a function of what is...his professional life was too</p>	<p>His joke</p> <p>It was good, very positive He is a unique person to be involved in the PAIRS program because... He was a professor in a medical school He was very involved with students He was on the Missions committee for years (a very active member of a church; active engagement in church) He had a close relationship with medical students (not just as a professor but also as a friend)</p> <p>She thinks the things that he used to do influence how successful the program was with him.</p> <p>She found out the family of other participants was much more involved than she was. She said that she was informed of the PAIRS program as a one-on-one activity (between the person with Alzheimer's and the medical student) because the medical student is going to end up talking to the spouse. Some of the families had closer ties and we've never done that. She thinks that this might be a function of what his professional</p>
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<p>program and to one-on-one with the medical student.</p> <p>One-on-one better because tendency to withdraw from a group</p> <p>Their doctors talk to the spouse only</p> <p>His joke (use humor) – coping strategy</p> <p>One-on-one was possible due to his background in medicine and his contact with younger people (as a professor)</p>	<p>because they had something of interest...um...that they could share even...you know even the reduced...um... memory of what he was teaching. Um...but nobody else of the whole program would've had. I thought it was very good. It's excellent. I was delighted that he was able to do that. And also delighted that he was able to do, you know, one-on-one with the medical student. And I think it is much better that way than having the whole family involved because...(hmm)[clearing her throat] as they progress the Alzheimer's, the Alzheimer's patient tends to withdraw from a group because things get more difficult, you know, words get more difficult... um... expressing what you feel and everything. Um...we go to the doctor's now and the doctors ask question look at me.</p> <p>I: Yeah. They don't talk to...</p> <p>S: Yeah. No. They talk to me and so...I think it's much better.</p> <p>P: You should talk to me. [Saying in a small voice] [Laugh]</p> <p>S: Ha ha. It's much better...the way... they did it. But then also as I said several times, I think it was a unique situation because of his background and...</p> <p>I: In...</p> <p>S: In medicine and being contact with people that age and...you know, just a whole thing. It was...it was so unique. You are not going to find out whole a lot of time. You find physicians...that have Alzheimer's, but...you are not going to find...you won't always find a professor... and he was a PhD, so he probably had even more contacts with students teaching. And they taught in different ways. They've gone now to the block system or they don't just teach straight</p>	<p>life was because they had shared interest and could share this. Nobody else of the whole program would've had. <u>Her belief: Other families would have difficulty to do one-on-one all the time because of no shared interest.</u></p> <p>It was very good, excellent. She was delighted that he was able to participate in the program and to one-on-one with the medical student. She thinks one-on-one is much better than having the whole family involved because people with Alzheimer's tend to withdraw from a group as words and expressing what the person feels become difficult.</p> <p>They go to the doctor's now and the doctors talk to the spouse only. So, she thinks doing one-on-one activity with the medical student is much better. His use of joke (use humor) <u>The doctor who talks to his wife only is rather depressing story that can weaken his self-esteem and affect his wife's feeling. He uses humor as a coping strategy to deal with the reality of living as a person with dementia.</u></p> <p>She mentions doing one-on-one was possible with him because of his background in medicine and his contact with younger people (as a professor) again.</p>
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<p>Very successful for him</p> <p>He was unique to the program which threw him in different categories</p> <p>She thinks having a two hour movie and then two hours conversation was a good format for him.</p> <p>The program met her expectations (giving him an opportunity to meet somebody who has mutual interest/socialize) We are new to KC and don't have a lot of contacts (different from others who have lived in KC for long times and have all kinds of friends) It gave him a social outlet that he could establish a new enjoyable relationship. It worked out very well.</p> <p>She thinks that the meetings (support groups) at AA give</p>	<p>a course. They teach the patients and they go through the every discipline with the patients, so it's a different sort of set up now than was he did most of the time. But I think it was very successful for him.</p> <p>I: So, you said that this program was unique to him because he... because of his background in medicine. So, do you...? S: Yes. Yes. Yes. Oh, he was unique to the program. The program wasn't unique to him. He was unique to the program which threw him in different categories. And um...I think the only time...that you didn't go to eat it the time when you went to the Nelson with Kyle unless you ate in Nelson. I don't really remember whether you did it or not. But I think that's what it was. Maybe four hours would be too long just talking. But having a two hour movie and then having...two hours conversation. I think that was a good format for him. um...more...back and forth...say walking through the museum or going to the zoo or something like that. But then again, this was a...different situation from most of them.</p> <p>I: What were your expectations before he participates in the PAIRS program? S: I think probably pretty much with what it turned out to be. It gave him an opportunity to meet somebody who has mutual interest. Um...It gave him...well. We also are different because we are new to Kansas City. And we don't have a lot of contacts. A lot of those people have lived here forever and have all kinds of friends and everything. It gave that sort of an outlet that...that was...new to us here.</p> <p>I: New relationship? S: Yeah. It...it provided us a social situation and um...enjoyable situation. And I thought it worked out very well.</p> <p>I: I heard from him that he goes to the meetings with... for people with Alzheimer's at the Alzheimer's Association. S: Yes. Yes.</p> <p>I: So, do you...you already talked about the unique thing...the one-on-one interaction was good for him. But, do you see any other</p>	<p>It was very successful for him.</p> <p>He was unique to the program which threw him in different categories.</p> <p>The only other activity other than going to the movies: Going to the Nelson-Atkins museum of Art She thinks having a two hour movie and then two hours conversation was a good format for him. She seems to think that activities such as walking through the museum or going to the zoo are better for the other participants with dementia (because others would not have shared interest in medicine and experience in contact with students)</p> <p>The program met her expectations (giving him an opportunity to meet somebody who has mutual interest/socialize) We are also different from others who have lived in KC for long times and have all kinds of friends. We are new to Kansa city and don't have a lot of contacts.</p> <p>It gave him a social outlet that he could establish a new enjoyable relationship. It worked out very well.</p>
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<p>him a group of peers because the people are going through the same situation (nothing related to his professional life)</p> <p>She thinks the people feel comfortable in the group because the person can be honest in the group</p> <p>She thinks the PAIRS program was like the bond between two people based on his prior profession</p> <p>The bond between him and the group of Alzheimer's is because what's going on right now (Alzheimer's)</p> <p>She regards the relationship between her husband and his pair as friends with the common interest (shared interests in medicine)</p>	<p>difference between the group meetings at the Alzheimer's Association for people with Alzheimer's and the PAIRS program?</p> <p>S: Oh, from what I feel, yes.</p> <p>I: Do you see any...?</p> <p>S: Oh, yes. Oh, yes. [Emphasizing and strongly agreeing]</p> <p>I: Can you tell me more about that?</p> <p>S: You mean the ones that he goes to the daytimes?</p> <p>I: Yeah.</p> <p>S: Okay. It gives him a group of peers. And they wouldn't have been a group of peers in his professional life at all. They are a group of peers now because they are people that are going through the same situation and he is going through. And they are...I think they are comfortable. Or, correct me if I am saying something is wrong because this is from somebody standing outside and...and looking at...but...it's a group...</p> <p>[Ringing of the telephone]</p> <p>P: Should I get it?</p> <p>S: Yeah. You get it. your turn.</p> <p>I: Ha ha.</p> <p>S: Um...if you miss it, it's not a big deal we will know who it is. Thank you caller ID. It's a group of people you can be honest with. And... you don't have to hide anything and they are not critical of you. And...you are not critical of them. Um...but it is a highly different situation than when it was with Kyle. (pause) That was...That was like...(pause) the bond between Kyle and Hank [the person with Alzheimer's] was based on his prior life...basically...his prior profession. The bond between him and the group of Alzheimer's is because what's going on right now.</p> <p>I: So, you feel like their relationship, his relationship with the medical student was more like student and professor relationship, something like that or was it more like friend?</p> <p>S: I think they were friends... at that point because he is not...didn't function as a professor. And he... isn't cable of functioning as a professor anymore. But I think...I think it was friend with the common</p>	<p>She thinks that the meetings (support groups) at AA give him a group of peers because the people are going through the same situation (nothing related to his professional life)</p> <p>She thinks the people feel comfortable in the group because the person can be honest in the group</p> <p>She thinks the PAIRS program was like the bond between two people based on his prior profession</p> <p>The bond between him and the group of Alzheimer's is because what's going on right now (Alzheimer's)</p> <p>Different from what he thinks (he thinks all are related to Alzheimer's)</p> <p>She regards the relationship between her husband and his pair as friends with the common interest (shared interests in medicine)</p> <p>He is so different from the other people with Alzheimer's who</p>
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<p>He is so different from the other people with Alzheimer's who participated in the PAIRS program.</p> <p>Having more social outlet was part of her expectation</p> <p>Another expectation was having intellectual stimulus too because of working with medical student who were picked over and bring young people.</p> <p>It wasn't just any social group. It was a specialized friend based on the common interest in Medicine.</p> <p>She used to teach a prep course for medical school.</p> <p>Medical students are the best of the best intellectually (very bright). She thinks he would get more intellectual stimulus from a really bright person (medical students) than his peers with Alzheimer's</p>	<p>interest.</p> <p>I: So, not related to...not necessarily related to having the same Alzheimer's...just based on the common interest between him and the medical student, right?</p> <p>S: Uh-huh.</p> <p>I: Okay.</p> <p>S: That's why he is so different.</p> <p>I: So you said that...your...maybe...from my understanding, your expectation for the program, for his involvement in the program was having more social outlet because you are new to Kansas City. So...</p> <p>S: That's part of it.</p> <p>I: Yeah. The social...more social gathering with new people. Was there any other expectation?</p> <p>S: Well. I...I think it was a certain amount of intellectual stimulus too...because you are working with...you are not working with Joe Bo off the street, you are working with medical students and they were picked over. They are bright young people, and... um...I think there was that too, so...but, it wasn't just any social group. It was a specialized...specialized friend. [Laugh]</p> <p>I: What do you mean by specialized friend?</p> <p>S: Well. Yeah, the common interest with him.</p> <p>I: In Medicine</p> <p>S: In Medicine. And... you had...um...(pause). This is really going to sound snobby, but people that are PhD students and...and...medical students. I taught...I taught a lab in college, and that was a prep course for medical school, vet school, or you know dental school that. And what's you are giving in the medical school and PhD programs, the medical school certainly, of the cream of the crop as far... intellectually. They may not be the most... socially adept, but...um...a lot of are...very very socially adept but they also are very bright. And so, that kinds of stimulus that you get from...a really bright person... as opposed to just a friend you are...chatting</p>	<p>participated in the PAIRS program. <u>His wife's belief: the other participants with Alzheimer's did not have the common interest with their paired students. His wife only considers the common interest in terms of profession (his previous profession as a professor in a medical school). His wife, thus, thinks that his participation in the program was so unique to the medical student / program compared to the other participants with Alzheimer's.</u></p> <p>Having more social outlet was part of her expectation</p> <p>Another expectation was having intellectual stimulus too because of working with medical student who were picked over and bring young people.</p> <p>It wasn't just any social group. It was a specialized friend based on the common interest in Medicine.</p> <p>She used to teach a prep course for medical school.</p> <p>Medical students are the best of the best intellectually (very bright)</p> <p>She thinks he would get more intellectual stimulus from a really bright person (medical students) than his peers with Alzheimer's <u>his wife's belief that bright people can give more (intellectual) stimulus to him as opposed to his group people with Alzheimer's at the association</u></p>
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<p>He avoids any argument. (He does not express whether he agrees with what she said or not).</p> <p>She thinks it was important that medical students are interested in learning, so they are willing to take their time although they are very busy.</p> <p>His pair was also doing research, so he was really busy. She appreciates that the medical students are willing to spend their time and have interests in the PAIRS program in their busy lives. She also value highly the medical students' attitude in academic (being curious and delved into)</p> <p>No issue in watching</p>	<p>with in the same boat. You are making a frowny face. [Looking at her husband with Alzheimer's] You don't agree with that?</p> <p>P: Oh. I have to... I don't know what you got. Ha ha. Yes. No. I don't care.</p> <p>I: So, from my understanding, relationship...having some relationship with the medical student was more understandable? Maybe...because the medical student knows about the disease, or maybe have some more knowledge in...</p> <p>S: I don't think they necessarily know more about the disease. I probably know more about the disease than most medical students. But they are interested in the...they are interested in learning. I think that's the biggie.</p> <p>I: So, they could be more engaged in...</p> <p>S: Oh, they are...I mean they are willing.</p> <p>P: Listen</p> <p>S: Yeah. They are willing to take their time, you know, when their medical students are very busy. In Kyle's situation, I think he was also doing research, so he was really busy. But, they are interested enough in the program to commit that time out of their lives...um...which is really different because...that's...you know they are very bright. They are working very hard. They have a lot of materials to take care on their own and they are still willing to spend this time they are interested in that. Some of the men end up being a neurologist or gerontologist. A lot of won't, but... anyway. It's a...it's something that they are interested in and their academic, their academic enough to, you know, really sort of be curious and delved into it, so...</p> <p>I: So... he said that the medical student always chose the activities, the things they are going to do...they are going to do. And how do you... Actually the program was supposed to...for the person with Alzheimer's to choose the things the person with Alzheimer's wants to do.</p> <p>S: Oh, really? I don't think it was any</p>	<p>His wife sees him with a frown face.</p> <p>He avoids any argument. (He does not express whether he agrees with what she said or not).</p> <p>She thinks medical students necessarily know more about the disease. She thinks it was important that medical students are interested in learning, so they are willing to take their time although they are very busy.</p> <p>His pair was also doing research, so he was really busy. She appreciates that the medical students are willing to spend their time and have interests in the PAISR program in their busy lives. She also value highly the medical students' attitude in academic (being curious and delved into) <u>Her past experiences in teaching medical students seem to affect her thinking. The couple might be more considerate of his pair's schedule when they make the appointment for meetings because the couple has some experience in working with medical students and may have more understanding about the medical student's busy life. Is she also having some hope for the med students to be better medical doctors than the medical doctors who the couple see currently (who just talk to the spouse not to the person with Alzheimer's)</u></p>
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<p>movie</p> <p>He was fine when the med student suggested going to the movie at the beginning, but he didn't like going to the movie all the time.</p> <p>Scheduling issue (in his pair)</p> <p>Better for communication</p>	<p>problem with it. You didn't have any problem with going to. He didn't like some of the movies just because he didn't like the subject matter than movies.</p> <p>I: But, watching movie is his one of the favorite hobbies? Or, did this activity have any special meaning to him? S: The movies? I: Yes, watching movies. S: We watch movies and media all the time, so he is interested in that. He might not be particularly, the student.</p> <p>P: In most of them, they were... curved and I had heard from the...you know...um...[He tapped on the table to help him remember the medical student's name?] Kyle did it. He knew what, he knew wants me... shown. And um...that was fine with me at the end. I mean it wasn't fine with me [he and his wife laugh] but... at the beginning it was fine with me.</p> <p>S: It was fine with him because of the movies. P: He wanted to.</p> <p>S: He [her husband] would not have picked some of the ones. Um...but we did not understand that was a person with Alzheimer's supposed to pick it. But I think the format as far as communication between him and Kyle probably was a better format. And I can't... see...I can't imagine what you would do for four hours just sitting and talking to somebody you need to do something. In fact, you have something first. And if you spend two hours at the zoo or two</p>	<p>She thinks choosing the activity by his pair didn't have any problem. She thinks he didn't like some of the movies because he didn't like the subject matter than movies</p> <p><u>This contrasts with what he said earlier (he said that he didn't like going to the movies all the time and he wanted to do different things</u></p> <p><u>Because the couple has nothing to do particularly other than watching movies and media? Doing all the time does not necessary mean that because that's what he likes to do. Also, because watching the movie and media is how the couple spends their time together, doing different activities with the medical student could be more enjoyable and interesting to him (e.g., Going to cultural places in Kansas City as a new comer to the KC)]</u></p> <p>He was fine when the med student suggested going to the movie at the beginning, but he didn't like going to the movie all the time.</p> <p><u>him -> the med student? Because if they went to the other places other than going to the movie, the med student would not be able to go or have difficulty in scheduling or too much burden because of his busy schedule?</u></p> <p><u>It seems that the med student picked the movies as well as the idea of going to the movie.</u></p> <p>They did not understand that was a person with Alzheimer's supposed to pick activities. She thinks the format (2 hour movie and 2 hour conversation while eating) as far as communication between him and</p>
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<p>Going to different places are much harder to set up</p> <p>She jumps in to talk about his past leisure/social activities</p> <p>His current leisure and social activities occur from the AA.</p>	<p>hours at the...at...Nelson or something like that, you are just basically not doing much of anything there. You are running around really fast and then you sit down and have two hour conversation which you probably wouldn't do if you went to the zoo, or you went to the Nelson, or you went to the baseball game. You might have... discussion of baseball game, but it's not...it's not baseball season. You are talking about professional football... and...you know, it's not that easy to get tickets from the Chief's game and...it's... a lot harder, it's much more difficult situation to set up than to go to the movie and...and...you know maybe...maybe is not what they envision in the program. But I think it worked out very well with him.</p> <p>I: What's your... what's your hobby? Or...what...what is your hobby...leisure or any social activities you'd like? P: Oh, well. I am old. I: You don't like to do anymore? S: When we had a house. I am gonna jump in here. When we had a house and yard, he's a lot of gardening involved and that sort of thing. In the past these down a lot with genealogy he doesn't golf. Um...play tennis, swim...um...but some of these things or thing you can't do that now when you moved to a place like this with basically no yard.</p> <p>P: I go to Alzheimer's (Alzheimer's Association) S: Hmm?</p>	<p>his pair was better than going out to different places. She thinks if they went to some places (like zoo or Nelson), they just run around really fast and do nothing much there. Not much conversation if they went to the zoo. Going to different places are much harder to set up than going to the movie. She thinks that maybe it is not what the program aimed, but she thinks it worked out very well with her husband.</p> <p><u>Was there her involvement in the decision? / she may say to her husband going to the movie is better than going to the other places when he said that "I don't like going to the movies anymore. Going to the movie would be easier for her too in terms of setup for the meeting (driving, buying tickets, and so on). Or is she rationalizing things that happened already? He may say like this when the med student asked about what he would like to do at the beginning, so the med student might think he does not have a particular interest in any cultural activities?</u></p> <p>She jumps in to talk about his past leisure/social activities (gardening when they had a yard, playing tennis, swimming) and explains that he cannot do some of these because they live a place with no yard.</p> <p>His current leisure and social activities occur from the AA.</p>
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<p>She talks about some of the activities of the AA which he used to do in his younger life: he was in plays and they have drama. He doesn't love the art part and they test the art part.</p> <p>She thinks he likes the group at AA.</p> <p>No friends in KC</p> <p>She thinks that they are different from everyone else in the group (odd ball)</p>	<p>P: I go to Alzheimer's. S: Yes. That's lots of things there. He...they have...and he did that in his younger life. He was in plays and they have drama. He is not...he doesn't... love the... art part, and... P: And they test the art part.</p> <p>S: Ha ha. But he likes the group. They do things, but it's hard...there again we're different probably from everyone else working in their group. Because we had just...this program we moved here in September of 2013. And this program picked up in the fall of 2013 until April of 2014. So... we were brand-new. So...that's not a situation everybody's in. Not only...are you...you don't have the...our son is here with his family but other than that we know a few people from Kansas City, but they are not particular friends. So, we were sort of the odd ball as far as the group with because everybody else, somebody lived here forever, you know, did this...knew what that was...and...so, we were just sort of... we are the one when you draw your curve, we are gonna be out of line with everybody else because it was...[laughing] we were so different.</p>	<p>She talks about some of the activities of the AA which he used to do in his younger life: he was in plays and they have drama. He doesn't love the art part and they test the art part. <u>The reason why he doesn't like the art part in AA is because they test the art part? Would he like the art part if they don't test the art part?</u></p> <p>She thinks he likes the group at AA. The couple knows a few people from KC, and she thinks they are not close enough to be friends. (just acquaintance) She thinks that they are different from everyone else in the group (odd ball) <u>Maybe he doesn't feel this way.</u></p> <p><u>Because they were really new to the Kansas City, they could be more passive in deciding activities (a possibility: when the med student asked the question about what he would like to do, because of unfamiliarity with the cultural activities on the list of activities, he might be reluctant to say and choose activities at the beginning. As the time passes, difficulty in scheduling the meeting time (busy schedule of the med student) and not knowing any cultural activities in Kansas City could influence that they end up going to the movie all the time except one time in Nelson; Even going to the Nelson seems to be the med student's decision because his wife said that he does not like the art part in his group (less interest in art): a possibility of the lack of communication about himself: the conversation can be more</u></p>
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<p>The couple: Not doing a whole a lot other than going to the meetings at AA (especially during the winter time)</p> <p>He drives very little She thinks he shouldn't drive at all.</p> <p>She drove him when he met with his pair.</p> <p>His pair was not familiar with Kansas City.</p>	<p>I: How do you spend your day other than going to the meeting at the Alzheimer's...?</p> <p>S: Not doing a whole a lot. not the winter time.</p> <p>P: Not the winter time.</p> <p>I: So, during the winter time, you...you...both of you just stay in the house together?</p> <p>S: A lot...a lot more than we normally would've done.</p> <p>I: I see.</p> <p>S: He doesn't...he drives...very little and probably shouldn't drive at all. Um...</p> <p>I: So, it's hard to go to some place or?</p> <p>S: Well. He shouldn't...He shouldn't drive. You shouldn't put somebody with Alzheimer's in the car left drive around Kansas City or any other place because it's not...just not a good idea.</p> <p>I: So, when he...when you meet with the medical student...</p> <p>S: I drive him. Oh, I drove him.</p> <p>I: So, you drove him to the theater?</p> <p>S: Oh, this is one of the...the medical student...he didn't know the ways around Kansas City. I...our son lived over here a couple of times. He lived over here before then he moved back over here, so I've driven around Kansas City. So, I am more familiar with that, but he has never driven around Kansas City. So, he just...his... place that he's gone and then very short... short drives down to... CVS or down to get his hair cut...corner of the Antioch.</p> <p>I: How do you think participation in the PAIRS program has affected your husband and his life?</p> <p>S: I think it enriched his life considerably...when it was going on.</p> <p>I: Enriched?</p> <p>S: Enriched. Uh-huh.</p> <p>I: Could you tell me more about that how</p>	<p><u>into their shared interest in medicine or daily life /effects after having the Alzheimer's</u></p> <p>Not doing a whole a lot other than going to the meetings at AA (especially during the winter time)</p> <p>He drives very little She thinks he shouldn't drive at all.</p> <p>She drove him when he met with his pair.</p> <p>His pair didn't know the ways around KC. She thinks she is more familiar with that because their son lived in KC several times and she has drive around KC.</p> <p>One of the reasons they just went to the movies all the time was because the med student was not familiar with Kansas City.</p> <p><u>Did the couple feel that they may give too much burden to the med student who usually does short driving and does not go around Kansas City for fun? If the spouse thinks that way, this is very different from another spouse who knew that the med student had never been to any places around the Kansas City and who thought going to those places would be good for the med student to give some opportunity for fun and experience.</u></p>
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<p>It enriched his life by having the opportunity to go out with somebody who isn't a family member as a "friend"</p> <p>She says that he considers his pair as a friend</p> <p>A chance to feel back in to Dr. while feeling as a friend.</p> <p>Increase his self-esteem</p> <p>A lot less bored than usual</p> <p>Elevated his mood</p>	<p>it...?</p> <p>S: How it enriched. Well. I mean the difference between being by yourself or so much of the time in and having the opportunity to go out and...and with somebody who isn't a family member [voice: emphasizing], you know, some other friends. And he considers Kyle as a friend. Um...that way enriched his life.</p> <p>I: Having a new friend...</p> <p>S: Yes. Of course</p> <p>I: and doing something fun with a friend</p> <p>S: Yes. Yes.</p> <p>I: from my...how about...what about... being...being more like himself.</p> <p>S: could be. Yeah.</p> <p>I: Because he... he can tell a lot about his interest in medicine with a medical student.</p> <p>S: That's right. That's right. Yes. Yes.</p> <p>I: Do you think...?</p> <p>S: He felt back into Dr. Riggs. You know. It's somebody who is...I don't he never calls him Dr. Riggs, but there's a difference between Hank Riggs and Dr. Riggs. And so he would have a chance to be...</p> <p>I: Dr.</p> <p>S: A friend but he would still Dr. Riggs.</p> <p>I: So, do you think it gave some opportunity to feel...for him to feel like...</p> <p>S: Self-esteem... self-esteem that certainly did.</p> <p>I: Yeah. I see. How do you think participation in the PAIRS program has affected his feeling or mood or any...feelings of belonging?</p> <p>S: He certainly was a lot less bored than...[laughing] um... I think it's elevating.</p> <p>I: His mood?</p> <p>S: Uh-huh.</p> <p>I: Did he talk about the things they did together after...?</p> <p>S: Yes, he did. He talked about...he didn't necessarily give me a blow by blow their conversation, but he certainly talked about the movies, which... is hard to find new movies nowadays that people in our ages like. There...and you know some of them are very good there. I mean they are really good production's going to get awards, but there</p>	<p>She thinks participation in the PAIRS program enriched his life by having the opportunity to go out with somebody who isn't a family member as a "friend"</p> <p>He considers his pair as a friend</p> <p>She thinks he could have a chance to feel back in to Dr. while feeling as a friend</p> <p>She thinks this could increase his self-esteem.</p> <p>She thinks he certainly was a lot less bored than usual. She thinks it elevated his mood.</p> <p>It seems that he talked about some of the movies he didn't like after watching the movie with his pair.</p>
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<p>She enjoyed knowing that he is happier and enjoyed the time with his pair</p> <p>Her wants to have more meetings for caregivers in the daytimes?</p> <p>Less burden? because she thinks the work she does for him is not necessarily related to his Alzheimer's; good part she does for him as a wife</p>	<p>are not ones that we will enjoy.</p> <p>I: How do you think participation in the PAIRS program has affected you? Is there any effect on you?</p> <p>S: Well, you know that he is happier you know he is happier because of things that were going on. Nothing else has frees up...you know...four hours you don't have free. And you know...um...I guess that's it because...I personally was not involved but...yes but I could enjoy... the benefits he got from it.</p> <p>I: Knowing that he enjoys the time with him [the med student]?</p> <p>S: Uh-huh.</p> <p>I: Do you go to the support groups for caregivers?</p> <p>S: Pardon me?</p> <p>I: Do you go to the support groups for caregivers at the Alzheimer's association?</p> <p>S: Yes. Yes. Yes, I do.</p> <p>I: So, both of you go to the group meetings...</p> <p>S: He...he goes to meeting day and night ones. Support groups meet twice a month at night and the Alzheimer's patients have a meeting at the time same time. But, I don't do anything...they don't have anything for caregivers in the day times when they have something over. They are nine to three.</p> <p>I: When you fill out the demographic information form, you said that you...usually the hours...the caregiving hours is Nine to...</p> <p>S: Nine to twenty. That's just a guess. That's a guess. Because I am...[cleared her throat] in this situation, I am certainly not unique among...it's...it's 100 percent responsibilities on the caregiver. So, how do you figure that out? You add it that... when you were...a wife and the age group that I am in, maybe not the younger age group. The...the amount of responsibility that they have for the house et cetera...other... you know the bills...you know, the whole thing. Everything is on you. So...how do I separate that? The amount that I spend probably is more than 20 hours a week, but... how do I separate what... the good part of I will be</p>	<p>She enjoyed knowing that he is happier and enjoyed the time with his pair</p> <p>He goes to the meeting day and night times (twice a week from nine to three and twice a month at night times) and she goes to the caregiver meeting twice a month at night.</p> <p>She says that they don't have anything for caregivers in the day times. <u>When considering their daily life in KC, she will want some more leisure and/or social activities. She may want the association has more time for caregivers in the day times.</u></p> <p>She checked the average caregiving hour a week as nine to twenty. Although she thinks the caregiver has 100 percent responsibilities for the house and everything, she doesn't feel some of the hours she spend for doing are not because he has Alzheimer's, just as a wife (the good part of I will be doing anyway as a wife).</p>
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<p>A son living close in KC and a daughter living in another state</p> <p>They travel during holidays to meet their families and friends living in another state.</p>	<p>doing anyway whether he has Alzheimer's or not.</p> <p>I: So, from my understanding, maybe the things you do is not just...because he has Alzheimer's.</p> <p>S: Oh, No.</p> <p>I: Just the normal things you used to do and you still do.</p> <p>S: uh-huh. There's a difference between a wife in my generation and a wife in our son's and daughter's generation.</p> <p>I: Right. You said that you have a son living close here.</p> <p>S: Uh-huh.</p> <p>I: Is there any other family?</p> <p>S: Not here. We have a daughter in North Carolina who is married. Um...her children are big though. They are both gone. The one that lives here...his children is little there twelve well getting ready to be thirteen and...eleven. They are twelve and ten right now.</p> <p>I: Because... when we met in last April, you talked... you told...you said that you have traveling plans a lot in July.</p> <p>S: Yeah. We did.</p> <p>I: When I talked with you last month, you also talked about your traveling plans. I thought you are so freaked about traveling.</p> <p>S: Oh, I will tell you. Traveling is not...was not fun when it's Christmas.</p> <p>I: Because now I understand why you had a lot of traveling plans. Because you are here...you are new here, so you have more familiar and friends in the other states. That's why you have many traveling plans. Yeah. I totally understand that why. Is there anything you want to add before we finish the interview?</p> <p>S: I think you covered things pretty well. I said when you draw your graph, we are gonna be outlined.</p> <p>I: No, no, no.</p> <p>S: No? Ha ha.</p> <p>I: Because I see each family just different in any way. Because I don't think every people can be the same and I don't think so. I see each person very differently, so I don't think you are out of the people...other people. Just each person is different and unique. So I</p>	<p>They have a son living close and their daughter lives in another state.</p> <p>They travel during holidays to meet their families and friends living in another state.</p>
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	<p>don't think that way. That's great. Is there anything you want to add before we finish the interview [looking at the person with Alzheimer's]?</p> <p>P: No, Thank you for coming by.</p> <p>I: No problem. I really appreciate for your help and time.</p> <p>S: How many people are you doing?</p> <p>I: Now you are fourth participants of my interview, but I will have two more people, two more families for this interview. I am also conducting the interviews with the participants who are currently in the program.</p> <p>S: Uh-huh. Do you do all of them or just ones that...?</p> <p>I: For the new group, I am going to interview six families or more than six. Now there are nine families fewer than past, last year.</p> <p>S: There are quite a few.</p>	
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Themes –Interview 4 (P4: person with dementia, C4: wife, I: interviewer)

Themes	Quotes
<p>Being connected to his self-identity related to his past profession (shared profession in Medicine between him and his pair)</p>	<p><u>-It was good to hear and be with my past profession</u></p> <p>I: I think you enjoyed the time with him, but could you tell me why... the specific reasons...what was enjoyable to you?</p> <p>P4: What enjoyed to me?</p> <p>I: Yeah...of the participation in the PAIRS program.</p> <p>P4: The fact that he was...he [his pair] was a very honest young man. And he liked to talk ... the things. He was trying to talk very wazzy. He worked through his first year... the thing. And um...there were things that...I had worked for...but I had worked for those about... 15 years ago, so there were a lot of changes for me. And um...I learned a lot about what was going on... that I didn't know the things in...so much more than I had when I was there. So, it was good for me...um...get to...get to be with it.</p> <p>I: So, was it kind of information exchange?</p> <p>P4: Yeah.</p> <p>I: So, you learned from him, and he learned from you.</p> <p>P4: Yeah. We asked questions, asked questions or say "Oh, I wonder how they did that.", and maybe neither one of us knew, so we got together and found out what was happening. He...he is a very nice young man.</p> <p>P4: ...And he's talking about things that he wanted to hear and things I wanted to hear. And um...that was it. I had...I was a professor at the University of Missouri and um...he knew that I was that. And so, we talked about some of the things I worked with over there and... things like that.</p> <p><u>-He decided to participate in the PAIRS program because he wanted to help medical students who were doing things that he had done before (shared profession in Medicine).</u></p>

	<p>P4: Because I wanted to help the...you did...any of the students. They were doing it...from things I had done before. And I... there were things that I had done before that I could do.</p> <p>P4: Yeah. I like them [the medical student who participated in the PAIRS program] all. I mean...yeah. I...knew mine [his pair] the best. But um...yeah...it's nice to know them and try to help them if they had a question.</p> <p>P4: But I had to take care of my boy [his pair] first. I: Oh, your boy? P4: He [his pair] was very busy. Some of those guys who are working over there [other medical students] are really busy. And he was really trying to the...at the top of the...people. And um...so I...at least this is why I had thought about ...I wanted him let him do whatever he wanted to do and um...I would be very happy to help him and he wanted to know about Alzheimer's. And I tried to help him with Alzheimer's.</p> <p><u>-She thinks he could have a chance to feel back in to Dr. while feeling as a friend. She thinks this could improve his self-esteem.</u></p> <p>C4: He felt back into Dr.[his last name]. You know. It's somebody who is...I don't he never calls him Dr. [his last name], but there's a difference between [his full name] and Dr.[his last name]. And so he would have a chance to be... I: Dr. C4: A friend but he would still Dr. [his last name]. I: So, do you think it gave some opportunity to feel...for him to feel like... C4: Self-esteem... self-esteem that certainly did.</p>
<p>Having a nice new friend</p>	<p><u>-Glad that I have got a very nice new friend (Enjoyed being with him and talking to each other)</u></p> <p>I: Okay. And how do you think participation in the PAIRS program has affected you and your daily life? P4: Well. We [he and his wife] had moved up here...from...um...no...we moved up from some place else. And we've been here for about an hour...a year and a half. And um...I was...I wanted to get hold of some young man. I had never been to the Kansas...um...place. And...I got to hear him [his pair] and um...you know...picked up a lot of things out of that...that I may be heard a lot of the...um. And it was just...a plus for me, okay? <u>And I...I was very happy when he said that to...he wanted to be...a friend. And...I think we had a very good time.</u> Is that answering your question?</p> <p>I: I mean what was fun for you during the PAIRS program period? What was the best part? P4: Being with him [his pair]. Being with him. Talking with him about various things that were going on and what he was doing. He is really a sharp young man.</p> <p>P4: We...we were very kind each other and I enjoyed talking to him. And I think he enjoyed talking to him [It seems that he meant himself].</p>

P: Oh, I was certainly happy working with him [his pair]. Yes. Yes. He had never made me angry...never made me angry. Um...and he had lots of things he wanted to do, and... we tried to do. Well... I just enjoyed. And I hope he enjoyed me.

P4: ...And um... so I...we talked about things we were going on and I cannot tell you exactly what they are. But...the things we were interested in each other...and he is a really very interesting young man. [Emphasizing] He is going to be something I would say very very good. um...But we talked about...medicine, things, and that I've gone through and he's gone through. And um...That's all I can tell you. We...we were very kind each other and I enjoyed talking to him. And I think he enjoy talking to him.

P4: I don't know if there was more interesting. I think all of them are very interesting to me... a long time ago. But um...I was happy to take him...as a partner from the place....I don't remember... we were heading a meeting and put it and finding people to....work with each other.

P: ...They are doing another one, but thanks I was partnered up...at first time. And um...that was great and um...it's just been kind of entertaining. If I ever ran across my friend [his pair], um...I'd like to much see him and find out what he has been doing. And...I know he's very smart and getting high grades. I don't know that answered your question but...yeah...um...it helped me and as far as I know helped him.

<He regards/calls his pair as a friend>

P4: Because I think they do well. They really do. A lot of people from my...my Alzheimer's...has same thing I had with my friend [his pair]. And um...they really are enjoying it.

P4: ...And I didn't say this to...

I: Oh, so...

P4: my friend [the medical student]

<He thinks his pair is a very nice young man>

P4: He is really a nice young man.

P4: He is a really very interesting young man. [Emphasizing] He is going to be something I would say very very good.

P4: He is a very nice young man.

P4: He is really a sharp young man.

P4: What enjoyed to me?

I: Yeah...of the participation in the PAIRS program.

P4: The fact that he was...he [his pair] was a very honest young man. And he liked to talk ... the things. He was trying to talk very wazzy. He worked through his first year... the thing. And um...

-Enriched his life by having a new friend

I: How do you think participation in the PAIRS program has affected your husband

	<p>and his life? C4: I think it enriched his life considerably...when it was going on. I: Could you tell me more about how it enriched...? C4: How it enriched. Well. I mean the difference between being by yourself or so much of the time in and having the opportunity to go out and...and with somebody who isn't a family member [voice: emphasizing], you know, some other friends. And he considers his pair as a friend. Um...that way enriched his life. I: Having a new friend? C4: Yes. Of course I: and doing something fun with a friend? C4: Yes. Yes.</p> <p>C4: He certainly was a lot less bored than...[laughing] um... I think it's elevating. I: His mood? C4: Uh-huh.</p> <p>C4: It gave him an opportunity to meet somebody who has mutual interest. Um...It gave him...well. We also are different because we are new to Kansas City. And we don't have a lot of contacts. A lot of those people have lived here forever and have all kinds of friends and everything. It gave that sort of an outlet that...that was...new to us here. I: New relationship? C4: Yeah. It...it provided us a social situation and um...enjoyable situation. And I thought it worked out very well.</p>
<p>Knowing that he had some happy times</p>	<p><u>-She enjoyed knowing that he is happier and enjoyed the time with his pair</u></p> <p>I: How do you think participation in the PAIRS program has affected you? Is there any effect on you? C4: Well, you know that he is happier, you know, he is happier because of things that were going on. Nothing else has frees up...you know...four hours you don't have free. And you know...um...I guess that's it because...I personally was not involved but...yes but I could enjoy... the benefits he got from it. I: Knowing that he enjoys the time with him [his pair]? C4: Uh-huh.</p>
<p>Rather passive in deciding activities</p>	<p><u>-His pair suggested going to the movies and he accepted his pair's suggestion although he didn't like to go to the movie all the time.</u> He and his pair watched the movie (two hours) and talked while eating out after watching the movie (two hours) every time they met except one time (going to the Nelson-Atkins art gallery)</p> <p>I: And ...is there any reason you went to the theater? Did this activity have any special meaning to you? P4: Um...I don't think it's a...I think...he [his pair] chose them. I: Oh, the medical student chose watching the movie? P4: Yeah. And um...some I liked some I didn't. He liked them all...very well.</p> <p>I: Was there any reason why you wanted to watch the movie with him [his pair]? P4: I just told him that I would be very happy to do take that....to... I: Watch the movie? P4: Yes.</p>

I: Do you like watching movies?

P4: Some of them. [Laughing]

P4: And he [his pair] chose them [movies].

I: Oh, so he [his pair] suggested some movies?

P: He was the boss. I was just an old man standing at a...

I: Did you tell him [his pair] what you like?

P4: um... No. I don't think so. I take that I just went along with him listen to what he was saying. I would. You know. Even though something... you'd like to keep...you know. go out and say it "blah blah blah" you just...I don't know what thinking about what I am saying.

P4: He [his pair] was the one who decided the movies. Yes. If you want to do something for me, I don't have something to add something different [this seems what his pair said to him]. but um...he wanted to see the movies.

P4: I wanted him [his pair] to feel as free as he to feel.

I: That's why you let him choose the activities to do?

P4: I didn't let him do. He wanted to. Ha Ha. So...I...I mean...I did. But no. I didn't ask him to do it.

P4: And um...that [going to the movie] was fine with me at the end. I mean it [going to the movie] wasn't fine with me [he and his wife laugh] but... at the beginning it was fine with me.

C4: It was fine with him [his pair] because of the movies.

P4: He [his pair] wanted to.

I: Did he talk about the things they did together after...?

C4: Yes, he did. He talked about...he didn't necessarily give me a blow by blow their conversation, but he certainly talked about the movies, which... is hard to find new movies nowadays that people in our ages like. There...and you know some of them are very good there. I mean they are really good production's going to get awards, but there are not ones that we will enjoy.

-He wanted to have more to talk with (because they watched the movie for two hours when they met) and go to different places with his pair (because he was new to Kansas City)

P4: You know. We actually we didn't [talk much], no. We were interested in what we were talking about. We knew that we didn't have more than four hours...Ha ha... to talk...so we'd better to get it all done before...and fours with also eating...

I: I see. Do you...um...Was there any other activities you wanted to do with him [his pair] other than watching the movie?

P: I would like to have more time with him but he didn't have it to do.

I: Could you tell me the activities you wanted to do with him [his pair]?

P4: Well. If I can remember though. Um... you know, there are a lot of places here in Kansas that you can go and you can find out very interesting things. And I would

	<p>like have done that... I: More cultural activities? P4: Rather than going to movie all the time...to go out there and see the...the... the... [sigh] I don't know.</p> <p>P4: There are a lot of interesting animals. There are a lot of things you can do, but for me there was not that much time because he didn't have that much time. And I didn't want to say that "Well. if you are not going to do, I am not going to do these." Ha ha.</p> <p><u>-The couple thought medical students had to choose activities</u></p> <p>P4: And um...I didn't want to say "Well. You should do what I wanted to do." because that's not what I was told at the very beginning. I was not to...you know, force myself into their...people who were accepting us. They [medical students] were the ones who were supposed to tell me and tell you things about what they were doing as far as ...um...Alzheimer's does.</p> <p>P4: Well, that wasn't the way I understood. My person [his pair]...my person told me that...[he tapped on the table; to help him say/remember what he is trying to say] I: The medical students have to choose activities? P4: Yeah. Yeah. I: Really? P4: Yeah.</p> <p>C4: He [her husband] would not have picked some of the ones [movies]. Um...but we [she and her husband] did not understand that was a person with Alzheimer's supposed to pick it [activity]. ...</p>
<p>Impression that his pair was really busy</p>	<p>P4: He is really busy. [Emphasizing] And he...had to take..., you know, time...when he could... liked it and to listen to do things with it ...and if he didn't feel like he can do that he would call and tell me that we will have to go some other time. And I said "fine. We can do that." and um...because he was very very good at the university.</p> <p>P4: ...He was staying here at the...his first year... because he was working some place here at the university [research work based on what his wife said later]...and it was that he just got so busy that he....</p> <p>C4:...They [medical students] are willing to take their time, you know, when their medical students are very busy. In [his pair's name]'s situation, I think he was also doing research, so he was really busy.</p>
<p>Her thinking that he was unique to the program</p>	<p><u>-He was unique because he was a professor in a medical school (shared profession in Medicine between him and his pair and have had close relationships with medical students as a professor and a friend at the same time)</u></p> <p>C4: Oh, in...I thought it [his participation in the PAIRS program] was good. I think the thing that's...unique about him though is a fact that he was a professor in a</p>

medical school. He was very involved with students. He was on the Missions committee for years. He had a close relationship with these medical students and there quite a few of them are still...not only...when we lived in Columbia...not only whether they were his doctors but they were his friends. So...he is almost a...unique... person to be involved in something like that. I thought that was very positive, of course.

C4: I think the things that he used to do influence how successful it was with him. It would...but then I heard when we went to the final meeting and heard the other people talking about it. And it seems to me the family was much more involved than I. I was...I was informed at the beginning this is one-on-one. They don't want you to go to the movie with them. You know. They don't want you to go to the museum with them. You know. They don't want you to go to...out to eat with them because the medical student is going to end up talking to you. But, some of them had a closer tie...some of the families had closer ties and we've never done that. And this again might be a function of what is...his professional life was too because they had something of interest...um...that they could share even...you know even the reduced...um... memory of what he was teaching. Um...but nobody else of the whole program would've had. I thought it was very good. It's excellent. I was delighted that he was able to do that. And also delighted that he was able to do, you know, one-on-one with the medical student. And I think it is much better that way than having the whole family involved because...(hmm)[clearing her throat] as they progress the Alzheimer's, the Alzheimer's patient tends to withdraw from a group because things get more difficult, you know, words get more difficult...um...expressing what you feel and everything. Um...we go to the doctor's now and the doctors ask question look at me.

I: Yeah. They don't talk to...

C4: Yeah. No. They [medical doctors] talk to me and so...I think it's much better.

P4: You should talk to me. [Saying in a small voice]

[Laugh]

C4: Ha ha. It's much better...the way... they did it. But then also as I said several times, I think it was a unique situation because of his background and...

I: In...

C4: In medicine and being contact with people that age and...you know, just a whole thing. It was...it was so unique. You are not going to find out whole a lot of time. You find physicians...that have Alzheimer's, but...you are not going to find...you won't always find a professor... and he was a PhD, so he probably had even more contacts with students teaching. ...I think it was very successful for him.

C4: Yes. Yes. Yes. Oh, he was unique to the program. The program wasn't unique to him. He was unique to the program which threw him in different categories. And um...I think the only time...that you didn't go to eat it the time when you went to the Nelson with [his pair's name] unless you ate in Nelson. I don't really remember whether you did it or not. But I think that's what it was. Maybe four hours would be too long just talking. But having a two hour movie and then having...two hours conversation. I think that was a good format for him. um...more...back and forth...say walking through the museum or going to the zoo or something like that. But then again, this was a...different situation from most of them.

-He was unique because we were brand-new (we moved to Kansas City when the

	<p><u>PAIRS program started).</u></p> <p>S: Ha ha. But he likes the group. They do things, but it's hard...there again we're different probably from everyone else working in their group. Because we had just...this program we moved here in September of 2013. And this program picked up in the fall of 2013 until April of 2014. So... we were brand-new. So...that's not a situation everybody's in. Not only...are you...you don't have the...our son is here with his family but other than that we know a few people from Kansas City, but they are not particular friends. So, we were sort of the odd ball as far as the group with because everybody else, somebody lived here forever, you know, did this...knew what that was...and...so, we were just sort of... we are the one when you draw your curve, we are gonna be out of line with everybody else because it was...[laughing] we were so different.</p>
<p>A specialized friend that was based on his prior profession and gave more intellectual stimulus (it wasn't just any social group)</p>	<p><u>-More intellectual stimulus from a really bright person (medical student) as opposed to peers with Alzheimer's.</u> She thinks there is a difference between the PAIRS program (the bond based on his prior profession) and his group [the bond based on diagnosis of Alzheimer's] at the Alzheimer's Association.</p> <p>C4: Um...but it is a highly different situation than when it was with his pair. (pause) That was... That was like...(pause) the bond between his pair and him was based on his prior life... basically... his prior profession. The bond between him and the group of Alzheimer's is because what's going on right now.</p> <p>C4: Well. I... I think it was a certain amount of intellectual stimulus too... because you are working with... you are not working with Joe Bo off the street, you are working with medical students and they were picked over. They are bright young people, and... um... I think there was that too, so... but, it wasn't just any social group. It was a specialized... specialized friend. [Laugh]</p> <p>I: What do you mean by specialized friend?</p> <p>C4: Well. Yeah, the common interest with him.</p> <p>I: In Medicine?</p> <p>C4: In Medicine. And... you had... um...(pause). This is really going to sound snobby, but people that are PhD students and... and... medical students. I taught... I taught a lab in college, and that was a prep course for medical school, vet school, or you know dental school that. And what's you are giving in the medical school and PhD programs, the medical school certainly, of the cream of the crop as far... intellectually. They may not be the most... socially adept, but... um... a lot of are... very very socially adept but they also are very bright. And so, that kinds of stimulus that you get from... a really bright person... as opposed to just a friend you are... chatting with in the same boat. You are making a frowny face. [Looking at her husband with Alzheimer's] You don't agree with that?</p>
<p>No involvement of her in deciding activities and doing activities</p>	<p><u>-She was very aware of the requirement of the PAIRS program and she thought doing one-one-one activity was much better than having the whole family involved because people with Alzheimer's tend to withdraw from a group</u></p> <p>P4: She's [his wife] got to say here because I don't talk very...</p> <p>C4: Well. He wants me... She [the interviewer] doesn't want me to talk [during the first part of the interview]. This is like the PAIRS program. They want your</p>

	<p>participation, not mine.</p> <p>C4: This was the major requirement. We [the PAIRS program] don't want you [the spouse] to go. We want one-on-one...which...you know...because you end up talking to the one person.</p> <p>C4: I think the things that he used to do influence how successful it was with him. It would...but then I heard when we went to the final meeting and heard the other people talking about it. And it seems to me the family was much more involved than I. I was...I was informed at the beginning this is one-on-one. They don't want you to go to the movie with them. You know. They don't want you to go to the museum with them. You know. They don't want you to go to...out to eat with them because the medical student is going to end up talking to you. But, some of them had a closer tie...some of the families had closer ties and we've never done that. And this again might be a function of what is...his professional life was too because they had something of interest...um...that they could share even...you know even the reduced...um... memory of what he was teaching. Um...but nobody else of the whole program would've had. I thought it was very good. It's excellent. I was delighted that he was able to do that. And also delighted that he was able to do, you know, one-on-one with the medical student. And I think it is much better that way than having the whole family involved because...(hmm)[clearing her throat] as they progress the Alzheimer's, the Alzheimer's patient tends to withdraw from a group because things get more difficult, you know, words get more difficult...um...expressing what you feel and everything. Um...we go to the doctor's now and the doctors ask question look at me.</p> <p>I: Yeah. They don't talk to...</p> <p>C4: Yeah. No. They [medical doctors] talk to me and so...I think it's much better.</p> <p>P4: You should talk to me. [Saying in a small voice] [Laugh]</p>
<p>Still feels close to his pair</p>	<p><u>-No contact after the program was ended, but he looks forward to meeting with his pair again. He still feels close to his pair.</u></p> <p>P4: I thought [relationship was] very good. um... it took a year I haven't seen him since.</p> <p>P4: I haven't talked to him [his pair] for a while.</p> <p>P4: Oh, I liked him a lot. Yes. I did. <u>I do.</u> Yes.</p> <p>P4: If I ever ran across my friend [his pair], um...I'd like to much see him and find out what he has been doing. ...</p> <p>P4: I go to... Alzheimer's [Alzheimer's Association] all the time. Um...and I guess they had started another one this year and I didn't know that. um...And a lot of them...Alzheimer's going trying to find places out in the Kansas...places. Um...if I had the opportunity and... and if um... my boy [his pair] would call me back... um...I would...go immediately.</p>
<p>His new identity</p>	

<p>as a person with Alzheimer's</p>	<p>P4: ...um...I just don't think there is any difference [between the PAIRS program and the meetings at Alzheimer's Association]. We are...all on the same track. I: So...um...what do you mean by you are on the... same track? P4: We all are interested in Alzheimer's. And... I mean...<u>I have go from Alzheimer's because that's I am so actively... now.</u></p> <p><His current leisure and social activities through the Alzheimer's Association> I: What's your... what's your hobby...or leisure or any social activities you'd like? P4: Oh, well. I am old. I: You don't like to do anymore? C4: When we had a house. I am gonna jump in here. When we had a house and yard, he's a lot of gardening involved and that sort of thing. In the past these down a lot with genealogy he doesn't golf. Um...play tennis, swim...um...but some of these things or thing you can't do that now when you moved to a place like this with basically no yard. P4: <u>I go to Alzheimer's</u> [Alzheimer's Association]. C4: Hmm? P4: I go to Alzheimer's.</p>
<p>Expression of his identity (not related to Alzheimer's)</p>	<p><u>-Identity related to his past profession</u></p> <p>P4: I was a professor at the University of Missouri</p> <p>C4: ...He was a professor in a medical school. He was very involved with students. ...He had a close relationship with these medical students and there quite a few of them are still...not only...when we lived in Columbia...not only whether they were his doctors but they were his friends.</p> <p><u>-Identity related to his past leisure and/or social activities</u></p> <p>C4: When we had a house. I am gonna jump in here. When we had a house and yard, he's a lot of gardening involved and that sort of thing. In the past these down a lot with genealogy he doesn't golf. Um...play tennis, swim...um...but some of these things or thing you can't do that now when you moved to a place like this with basically no yard.</p> <p>C4: ...He was on the Missions committee for years...</p> <p>C4: That's lots of things there [Alzheimer's Association]. He...they have...and he did that in his younger life. He was in plays and they have drama. He is not...he doesn't... love the... art part, and...</p>
<p>His strategy</p>	<p><u>-Use of humor</u></p> <p>C4: Yeah. No. They [doctors] talk to me and so...I think it's much better. P4: You should talk to me. [Saying in a small voice] [Laugh] C4: Ha ha.</p> <p>P4: I may be asked about from the start of the interview.</p>

	<p>I: So, I will start the second part of the interview. So, for this part, you can talk...both of you can talk. Feel please to talk. P4: I can't talk. [Pretending that his voice sounds hoarse]</p> <p><u>-Avoids any argument with his wife and just laugh.</u> (he does not express whether he agrees with what his wife said or not) C4: You are making a frowny face. [Looking at her husband with Alzheimer's] You don't agree with that? P4: Oh. I have to... I don't know what you got. Ha ha. Yes. No. I don't care.</p> <p><u>-Help himself understand a question better (and earn more time) by saying/repeating the question</u></p> <p>P4: I don't understand. Things doing with those students? I: Yeah. The medical student. P4: Okay. And what I was doing with him [his paired medical student]? I: Uh-huh. Your experience.</p>
<p>Her strategy</p>	<p><u>-Help him understand and answer the question</u> (rather than answering the question by herself), so he can still be an agent in talking, but his self-esteem is not hurt in front of another person (interviewer) before he can feel embarrassed (as soon as the interviewer asks about activities because she is very aware of his cognition).</p> <p>C4: What did you do with [his pair's name]?</p> <p><u>- She asks him if she can help (let him do by himself as much as he can and then help)</u> C4: May I assist? P4: You are going to have to. C4: Okay.</p> <p><u>-She doesn't feel some of the hours she spends for him are not because he has Alzheimer's, just as a wife (the good part of she will be doing anyway as his wife).</u></p> <p>C4: Nine to twenty [the caregiving hour a week]. That's just a guess. That's a guess. Because I am...[cleared her throat] in this situation, I am certainly not unique among...it's...it's 100 percent responsibilities on the caregiver. So, how do you figure that out? You add it that... when you were...a wife and the age group that I am in, maybe not the younger age group. The...the amount of responsibility that they have for the house et cetera...other... you know the bills...you know, the whole thing. Everything is on you. So...how do I separate that? The amount that I spend probably is more than 20 hours a week, but... how do I separate what... the good part of I will be doing anyway whether he has Alzheimer's or not. I: So, from my understanding, maybe the things you do is not just...because he has Alzheimer's. C4: Oh, No. I: Just the normal things you used to do and you still do. C4: uh-huh. There's a difference between a wife in my generation and a wife in our son's and daughter's generation.</p>

<p>Working as a team in talking (the couple's strategy)</p>	<p><u>-He tries to engage in the talk and she recognizes what he tries to say and organizes it in a clear way by adding what she knows too.</u></p> <p>I: Is there any other activities they did? C4: No. P4: No. C4: The first time he just... P4: Well. C4: He just...stayed with him [the medical student]. P4: We went to the thing in the end. C4: Oh. P4: And um... C4: Well the beginning too. P4: He got something. I don't want to..., so... C4: That parties at the Alzheimer's Association... at the beginning and at the end.</p> <p>I: How do you spend your day other than going to the meeting at the Alzheimer's Association? C4: Not doing a whole a lot. Not the winter time. P4: Not the winter time. I: So, during the winter time, you...you...both of you just stay in the house together? C4: A lot...a lot more than we normally would've done.</p>
<p>Impact of dementia</p>	<p><u>-Remembering that he went out t to see something but not remembering what he did with his pair exactly at the beginning</u></p> <p>P4: We went out and um...and look at...we went to the lawyer ...not to the lawyer. [Saying with hesitation because of difficulty in remembering activities] I: Take your time. Yeah. P4: We went to... to see something. [Saying with hesitation because of difficulty in remembering activities]</p> <p><u>-He remembers one activity he did with his pair other than going to the movie. He does not remember what the activity was or exact word.</u></p> <p>I: Was there any other thing you...? P4: He and I went to a...um...I can't remember...What was it... he and I watched? [Asking to his wife] [Coughing] Excuse me. um...It was at some animal we went out and saw. we went to the...you know... go out and see it and...see things going on and...all those things. I: Do you mean the museums? or any arts...? P4: Well. I...there are museums I guess you can call it. There are a lot of here in the... I: Kansas City. P4: Yeah. Kansas City. And we went to one of those. Just... just one. Then we went back to the...</p> <p><u>-Forgetting the exact word (Alzheimer's)</u></p>

	<p>P4: They call all of...a lot of people and...I think one of them are in the um...Al...zheim...but I am not sure.</p> <p>P4: Yeah. Yeah. He knew that I had.... He was coming in for the first year and he knew that I had...I was...um...with the school... that um...I knew a lot of the things he was interested in...the features of</p> <p><u>- Apologizes that he cannot remember the details</u></p> <p>P4: Well. We would go. We went many many times to the...theater and um...we...and I cannot tell you what date. I don't remember. I: That's okay. P4: I am sorry. I: That's okay.</p> <p><u>-Apologizes if what he is saying makes sense.</u></p> <p>P4: I don't know if that makes any sense to you. And I am sorry that if I am not making any sense to you. I: No. You are perfectly okay. Yeah.</p> <p><u>- Low confidence in his memory</u></p> <p>P4: She's [his wife] got to stay here because I don't talk very...</p> <p><u>-Feels very attached to Alzheimer's recently (after he moved to Kansas City one and a half years ago</u></p> <p>P4: I become... very attached to Alzheimer's...since I've been here. I started with it when I was in Columbia, but I...we were leaving and I really didn't. (pause) I don't know. um... it's much more effected here.</p> <p><u>-Driving</u></p> <p>C4: He doesn't...he drives...very little and probably shouldn't drive at all. Um...</p>
<p>His suggestion for the PAISR program</p>	<p><u>-His want for more people with Alzheimer's at Alzheimer's Association to be able to participate in the PAIRS program (at least giving them a little chance to meet with medical students)</u></p> <p>P4: Oh, I thought that was too bad too that that...you know. We had a bunch of people and we could've gone together...you know... maybe not... once a month maybe once every two months something like that. We can make ourselves...you know... aware...and we didn't do it. Some of them did...I found out later on...some of them did, but it was just a few people. P4: Well. I...I thought it would...I...I didn't... do a lot because I wasn't still there. I...I thought it would be nice to have a whole bunch of us together... not all the time but um...period of times. And I thought it would help them as well as it helped us.</p> <p><u>-His want that all PAIRS groups could get together and talk how and what they are doing and what they need to be helped with during the PAIRS program period (because he needed some help /explanation?)</u></p>

	<p>P4: Oh, I think it would be wonderful if the people who are... taking... charge of... what they... you know... that... I can say well... you know it just needs to be me and my boy or my girl, whatever it is. It would be good if we can say... I feel like once every month... I don't know how they do it now. um... my pair and I think we... I think we went twice a month... um... and I think that if... um... if other people I found out and a very few of them... would go for... once a month... once a... a week. And it's very helpful that way with them and if they would take... a bunch of them say once every... um... month... and all the groups would be together and see if that things have been... you know... passed about each other and what are they doing and what they need to be helped with... I think that would be wonderful, but it didn't happen that way.</p> <p>I: So, you think it would be... it would be better if you can get together and talk about each other's experience during that time... so you can get how the other people are doing...</p> <p>P4: I think... in my mind... that would be good... very good. Yeah. I don't know what the other people are thinking about that.</p> <p>P4: Don't wait until the end. It would help them if they meet each other. And that I mean they are not together all the time. They may think they are. But they are not. And it would help them have somebody to... to be there and explain different things.</p>
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Note

-Activities: Going to the movies and eating out after watching the movies (most of the time). The only other activity other than going to the movies: Going to the Nelson-Atkins museum of Art

-Because they [the couple] were really new to the Kansas City, they could be more passive in deciding activities (a possibility: when the med student asked the question about what he would like to do, because of unfamiliarly with the cultural activities on the list of activities, he might be reluctant to say and choose activities at the beginning. As the time passes, difficulty in scheduling the meeting time (busy schedule of the med student) and not knowing any cultural activities in Kansas City could influence that they end up going to the movie all the time except one time in Nelson; Even going to the Nelson seems to be the med student's decision because his wife said that he does not like the art part in his group (less interest in art): a possibility of the lack of communication about himself: the conversation can be more into their shared interest in medicine or daily life /effects after having the Alzheimer's

-Reduced opportunity for leisure/social activities after moving to KC: the couple does not do a whole a lot other than going to the meetings at AA (especially during the winter time). They often travel to other states during holidays to meet their families and friends.

-The couple has a son living close in KC and a daughter living in another state.

Interview 5.

I: Interviewer

P: Person with dementia

S: Spouse of the person with dementia

- Descriptive comments: focused on describing the content of what the participant has said, the subject of the talk within the transcript (normal text)
- Linguistic comments: focused on exploring the specific use of language by the participant (*italic*)
- Conceptual comments: focused on engaging at a more interrogative and conceptual level (underlined)

Emergent Theme	Original Transcript	Exploratory Comments
<p>Got along with her pair in the beginning</p> <p>Scheduling issue from the middle</p> <p>Impact of dementia</p> <p>Caregiver's strategy</p>	<p>I: I am a researcher of the PAIRS program that pairs people with Alzheimer's and medical students for social gatherings at the University of Kansas Medical Center. You participated in the PAIRS program from September, 2013 to April, 2014. I really appreciate that both of you agreed to do interviews. This interview is to know about your experience of the PAIRS program and your thoughts about its' impacts on you and your daily life. There are no right or wrong answers. I am just here to learn about your experience and learn about your thoughts, so no right or wrong answers. This interview will take about 1 hour. Before we start the interview, could you tell me activities you did with the medical student during the PAIRS program period? We will talk about the details later, so can you tell me just brief...?</p> <p>P: Well. um...one of, we had a... hit, hitch in the beginning, not coming in the middle of it we got it started and then she had to go... on a trip and it took, you know, she was gone for one two three months...</p> <p>S: Not... too much for that. We've got three weeks after she came back.</p> <p>P: And came back and just kind of like dis.. dissened...</p> <p>S: I think she is looking for what kinds or types of activities we did.</p> <p>P: Oh, types of activities.</p>	<p>She seems to mean that they got along with her pair in the beginning, but they had some issues in meetings in the middle.</p> <p>She remembers that her pair was gone for three months.</p> <p>He corrects that her pair was gone for three weeks.</p> <p><i>dissented-> dissented?</i></p> <p>He helps her in understanding the question correctly (the types of activities) and giving her a chance to talk by herself. He starts talking after</p>

<p>Working as a team in talking</p>	<p>S: We went to Nelson-Atkins museum. P: Uh-huh. S: We went to Harry Truman’s Library. P: Right. S: We went with her children as well to a...um... P: Farm... S: Pumpkin Patch P: Yeah, the Pumpkin Patch. S: Fall of the year. P: Uh-huh. S: Um...we went to...the Science City. P: Uh-huh. S: And um...Union Station. P: Uh-huh. S: And...we took her kids then we went to the Science City and we went over to...a Crown Center... P: Yeah. S: To have lunch. Um...That’s about it... that I can remember. I: So, you were...with her all the time, with them all the time? [Looking at the spouse] P & S: Yes. [Answering at the same time] I: So, you participated in the activities together? [The spouse coughs] When you went to the art gallery, you were with them, right? S: Yes. What this amounts to is that Marcia doesn’t drive outside the neighborhood anymore. She gets turn around and she gets lost. And so, I was concerned it would’ve worked out better many times if she could’ve driven some places to meet the PAIRS candidate, okay? But, I couldn’t have her drive by herself because...it’s okay baby. Just let it ring. [Talking to his wife] [The telephone starts ringing in the middle of his talk and continues] P: Okay. S: Darling, don’t pick it up. P: Okay. S: We will call later.</p>	<p>noticing she has difficulties in remembering activities.</p> <p>They work as a team in talking about the types of activities (she responds to what he says by agreeing mostly, but she remembers going to the farm: Pumpkin Patch)</p> <p>Activities: going to Nelson-Atkins museum of art, Harry Truman’s library, [pumpkin patch, Science City (union station), and Crown Center (for lunch)] with her pair’s children.</p>
<p>His participation in all the activities –driving issue</p>	<p>I: So, you participated in the activities together? [The spouse coughs] When you went to the art gallery, you were with them, right? S: Yes. What this amounts to is that Marcia doesn’t drive outside the neighborhood anymore. She gets turn around and she gets lost. And so, I was concerned it would’ve worked out better many times if she could’ve driven some places to meet the PAIRS candidate, okay? But, I couldn’t have her drive by herself because...it’s okay baby. Just let it ring. [Talking to his wife] [The telephone starts ringing in the middle of his talk and continues] P: Okay. S: Darling, don’t pick it up. P: Okay. S: We will call later.</p>	<p>He participated in all the activities together because she doesn’t drive outside the neighborhood anymore. He thinks she would’ve met her pair more times if she could’ve driven places to meet her pair by herself. He couldn’t have her drive by herself.</p>

<p>Impact of dementia or just different opinion?</p>	<p>P: Okay. S: I am sorry. I: That's okay. S: Would you rather I answer it? I: Yeah. Yeah. That would be better. [The spouse left to pick up the phone and the phone stopped ringing] S: Whoever it is, we'll call them back. P: Yeah. Nobody calls us. Nobody calls us. [Emphasizing] [Saying while coming back for the interview] I: Nobody? Why? P: Very few. S: We've got a number of calls all the time. P: Oh, yeah. Okay. I: So... for the first part of the interview, I would like to hear only from you [looking at the person with Alzheimer's], and then I will give both of you time to talk later [looking at the couple]. Because the interview has to be done in the same way for everyone, I'd like to hear from you without your help or involvement in her talks for the first part. But, it's up to you if you want to do something else and come back later, or you can stay also here. You are welcome to stay. S: I'll go see who it was that called. P: Okay. [Her husband left] I: So... do you have any questions before we start the interview? P: No, because I remember, you know, how it... last..., you know, last time when we did it, so... I: Are you ready for the interview? P: Yeah. I: Okay. Could you tell me about your experience of participation in the PAIRS program?</p>	<p>She thinks nobody/ very few people call them.</p> <p>He corrects that they've got a number of calls all the time. She agrees with it. <u>Maybe he answers the phone all the time and she doesn't remember it.</u></p>
<p>Confidence in remembering the PAIRS experience</p>	<p>S: I'll go see who it was that called. P: Okay. [Her husband left] I: So... do you have any questions before we start the interview? P: No, because I remember, you know, how it... last..., you know, last time when we did it, so... I: Are you ready for the interview? P: Yeah. I: Okay. Could you tell me about your experience of participation in the PAIRS program?</p>	<p>The spouse was not in the same room during the first part of the interview.</p> <p>Confidence in remembering the PAIRS experience</p>
<p>Use "we" (she and her husband) Impact of dementia She calls her pair as the other lady</p>	<p>P: Um... I... we [<i>she and her husband</i>] enjoyed it. It seemed like... um... we got... when they... the other lady [her pair] that was our... like you, you know.</p>	<p><i>Use of "we" (she and her husband) because they did activities together with her pair.</i> She doesn't remember her pair's name. <i>She calls her pair as the other lady; She might not feel very close to her</i></p>

<p>Relationship/connection had broken up</p> <p>It wasn't a smooth event because of scheduling issues and change in schedule</p> <p>Really enjoyed the program even with her[her pair]</p> <p>A great program</p> <p>Group meetings at AA as our place and social outlet</p> <p>Feeling uncomfortable beyond her group</p> <p>Group people as best buddies</p> <p>Not comfortable in a big group of people that she doesn't know</p> <p>Expression of self-identity: a very outgoing and active person</p>	<p>And...um...when she had leaved and gone for an extended time, it kind of had broken up. You know what I am saying? It's not... it wasn't a smooth...um...event. It was, you know, because there she was able to come and then she wasn't able to come. And... that sort of thing. But, we [<i>she and her husband</i>] really enjoyed...the...the program even with her. And um...so...</p> <p>I: Could you tell me about more...experience or your thoughts about your experience? P: The program? I: Yeah. P: I think it's a great program. Um...if...you know I go to the...what we call our place... with the...you know with our group that we...I go... two days a week... and um...almost all day. And um...that is a very good outlet for me [emphasizing a little bit] because I am with my peers...and um...you know I am not...[pause and sigh]. I feel comfortable, you know, with that, and um...but when I get...you know when I get out of my...area that I am comfortable with, then I get...it's, it's harder for me...so...</p> <p>I: So, you said that it was harder for you to...go out and to be with other people rather than the people in your group at the... P: The people in...in my group are...are my best buddies...so to speak. And if I am in a big group... of people that I don't know I am not... comfortable, you know. I...I've always been a very outgoing person and when I had my business, I had people coming in and out...all day long. When we...I ran Curves, so... a fitness center. And so...I was active the whole time. And um...then</p>	<p><u>pair because they just met three times.</u> She thinks their relationship/connection had broken up because they did not meet in the middle</p> <p>It wasn't a smooth event because she said that she was able to come and then she wasn't able to come (change in schedule) She use "we" for she and her husband (not for she and her pair) <u>"even with her"-> Does she feel uncomfortable when she is with other people?</u></p> <p>A great program She calls the group meetings at AA as our place She goes to the meetings at AA two days a week, almost all day (nine to three) The meeting at AA is a very good outlet for her because she is with her peers and she feels comfortable in the group.</p> <p>It's harder for her to feel comfortable when she is beyond her area/her group.</p> <p>She regards her group people as her best buddies. She is not comfortable when she is in a big group of people that she doesn't know.</p> <p>Expression of her self-identity: as a very outgoing and active person She's always been a very outgoing person and she had people coming in and out all day long when she ran a fitness center. So, she was active the whole time.</p>
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<p>Needed time to accept and cope with Alzheimer's</p> <p>Change in thinking about herself due to Alzheimer's?</p> <p>People in her group at AA has become her friends</p> <p>She still difficulty in talking to others about her Alzheimer's even if she knows the people.</p> <p>She doesn't like to talk with others because she fumbles</p> <p>Loved to drive</p> <p>She feels that she is still active. Less active?</p>	<p>when I... had to...well they told me I couldn't do it anymore...um...it was kind of like...it took me a long long time to...deal with it because I...I had some anger issues. I think we all do. And um...but...I think that's...what we call our places one of the best things that I... I have been...expand... experiencing with. And... [She stopped talking because of the sound of something dropping and her dog's move] What was that? What did you do? [Talking to her dog]</p> <p>I: Wow.</p> <p>P: Yeah. I don't know. Something fell somewhere. [A cough] So... um...that has become my... area of my friends, you know. And when I am out about with, even if I know them...real...you know I...I still... have difficult. I don't like to talk...with somebody that I haven't... um...just because I...get so... fumbled up in my brain. [A small laugh] So... but for the most part, I think it's...</p> <p>I: So...um...</p> <p>P: [A laugh] Yeah.</p> <p>I: So, you said that you was outgoing and...</p> <p>P: Uh-huh.</p> <p>I: You enjoyed going out and meeting people.</p> <p>P: Uh-huh.</p> <p>I: So...</p> <p>P: I loved...to drive. You know.</p> <p>I: You said that you were...you were a very active person.</p> <p>P: Uh-huh.</p> <p>I: So, do you think you are not very active or...?</p> <p>P: No, I think that...um...you know... like said with going to our place [the Alzheimer's Association]. And then Bill and I, we, take Sadie [her dog's name], you know, every day...for a walk and we have a park down at... English Landing [name of</p>	<p>She had some anger issues when she was told that she couldn't run her business anymore and it took her a long time to deal with it.</p> <p>She regards her places (her groups at AA) one of the best things that she has been experiencing with.</p> <p><i>Use of present tense (I've always been a very outgoing person and use of past tense (I was active the whole time:</i></p> <p><u>Does she feel that she is not that active now?</u></p> <p>People in her group at AA has become her friends</p> <p>She still difficulty in talking to others about her Alzheimer's even if she knows the people.</p> <p>She doesn't like to talk with others because she fumbles</p> <p><u>When she is with others beyond her group, as she does not feel comfortable, her stammer gets worse.</u></p> <p><u>Laugh: Does she think that I hesitate because I was shocked by what she said or because what she said is heavy?</u></p> <p>She loved to drive.</p> <p>I asked this question to know if she thinks she is not active anymore and to know about her daily life. She said that "I was active." when she talked about herself.</p> <p>She feels that she is active. She goes to her place (AA) and she and her husband takes their dog for a walk everyday and go to a park in the neighborhood. <u>But feel less active than before?</u></p>
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<p>Open about her diagnosis</p> <p>Stigma</p>	<p>the park]. And um...so we go down to... almost every day unless it's freezing or...and um...so, yeah that's pretty our...</p> <p>I: So, you said that you are...you are feeling, you are feeling more comfortable when...when you are in your place with your buddies there. So, do you...? And you said that you feel a little bit uncomfortable when you are not... when you are with other people who may not know about you well, so...</p> <p>P: Well. I've been very open about...you know... I've got Alzheimer's. And um...and you know... people can look at you and kind of funny...you know giggle over it, so...I...</p>	<p>She has been very open about her diagnosis but she felt that some people giggled over it (stigma)</p>
<p>Good</p>	<p>I: So, can you tell me more about the PAIRS program experience because the PAIRS program is a little bit...oh, how to say? It's not being with your buddies. It's one-on-one with a medical student, so...</p> <p>P: Yeah, we will meet about...just you and I, yeah. And um...I think that would be...a...good...good thing to...you know. Like I said, what happened was that she had to take....she went to...um... Africa. She had to go to Africa for some reason. And so...it, it took a big chunk of the... time that we had... for... our place and um... you know we had that problem.</p>	<p>She thought participation in the program would be good. Her pair had to visit her country and they had some time periods they didn't meet.</p>
<p>Time they didn't meet</p>	<p>I: So, you said that you had some difficulty in scheduling...</p>	<p>The problem-> scheduling meetings</p>
<p>Shcheduling issue</p>	<p>P: Yeah, scheduling things, yeah.</p> <p>I: Time together sometimes, but normally, mostly you enjoyed having time with your... with the medical student?</p>	<p>Her pair has two children and she thinks they were a lot of fun.</p>
<p>A lot of fun with student's kids</p>	<p>P: Yeah. Uh-huh. And um...she had two children of a boy and a girl and they were a lot of fun, you know. I really enjoy playing with kids. And um...we went to...the excellent Pumpkin Patch and all of that, so...</p>	<p>She really enjoys playing with kids.</p>
<p>She really enjoys playing with kids</p>	<p>Pumpkin Patch and all of that, so...</p>	<p>"excellent" Pumpkin Patch</p>

<p>“<i>excellent</i>” Pumpkin Patch</p>	<p>I: Could you tell me about that story, playing the Pumpkin Patch? I don’t know about Pumpkin Patch.</p>	
<p>Familiar with Pumpkin Patch</p>	<p>P: We just go...um...it’s...South, okay? They have Pumpkin Patch. You just ...you go in and um...they have a little games you can play with the kids and that sort of thing. And then you can go pick up a pumpkin that you want. And then you can... take it... um...home...and, and...you know, when carved out if you want to...or you can just paint on it. And then the kids have something to go home... with.</p>	<p>She explains the Pumpkin Patch fairly well (because it is very familiar with her)</p>
<p>Really nice</p>	<p>I: Was it near to the Halloween...?</p>	<p>That (going to the Pumpkin Patch with her pair and her children) was really nice.</p>
<p>Nice weather</p>	<p>P: Yes. Yeah. Yeah. It kind of...you know...mashes up with the Halloween area. And um...we had some nice weather [talking slowly to emphasize “nice weather”], and so that was really nice. And um...so...if I... you know...I’ve done it several times...um...with the Pumpkin Patch...with our kids themselves and with the PAIRS group and because some...her having a little one that was a good... opportunity to play again. [Cough] But um...I am...I am pretty open to about anything that...um... I’ve been trying to think of one the one that we do... now. We might go to a...Royal’s game...then watch it. We’re at it Royal...play of...so...um...we will have that. We are going to...Saint Louis, no Saint Louis....Arizona for spring training.</p>	<p>“Nice weather”</p>
<p>Pumpkin Patch several time with her own kids</p>	<p>I: Arizona for spring training?</p>	<p>She’s gone to the Pumpkin Patch several time with her own kids</p>
<p>Leisure and social activities of her and her husband</p>	<p>P: Uh-huh.</p>	<p>She went to the Pumpkin Patch because she thought going to the Pumpkin Patch would be good for her pair’s little kid.</p>
<p>Likes sports</p>	<p>I: What is it?</p>	<p>She and her husband go to a Royal’s game to watch the game. <i>Use of might</i> -> <i>not sure</i>.</p>
<p>Use of humor</p>	<p>P: It is a...spring training is the boys from...the...um...tell you tomorrow. Um...[tapping on the table to help herself remember the word] baseball players. They go to Arizona. And that’s when they start getting ready to come back to Kansas City to...you know when they play their games. And so...we’ve done this for many many years. That we always... fly</p>	<p>She and her husband have been going to spring training in Arizona for many years. She likes sports.</p>
<p></p>	<p></p>	<p>She talks about the Spring training. <i>Use of humor</i></p>

<p>Going to Spring training is a kind of her family gathering.</p> <p>Her efforts to remember and speak correctly</p> <p>big hikers</p> <p>She talks about the story when they got lost during hiking.</p> <p>Participation in various outdoor activities with her husband</p> <p>She thinks Science City is fun and good for little kids. She thinks it's always fun to go and see other places and things</p>	<p>out to Saint Louis...I mean no...not to...[because she said Saint Louis instead of Arizona again].</p> <p>I: With your children?</p> <p>P: Um...Yeah, sometimes. My oldest daughter is going to come with us this year. Um...one time, we had...Okay. I will start this. My oldest daughter is going to come this time. My brother and his wife are coming. And then we have two people from Texas. They are going to drive up. And we rent a house, and so you can just...um...you know, just like when you were at, in your own home. And um...then you...you go out and watch the ball games or you hike. Bill and I are big hikers. And um...so...but last couple of times when we were hiking, we both got lost. Ha ha. And it's kind of funny when you call your daughter and just say...</p> <p>I: Oh, we are lost.</p> <p>P: We are lost and we are not sure where we are at, but we are in Arizona somewhere. Ha ha. [P and I laugh]</p> <p>I: Oh, that's great.</p> <p>P: Yeah. So...it's...it's a good thing that we can laugh about...um...</p> <p>I: That's funny.</p> <p>P: Yeah. I told her one of these days we're just going to walk on off the ocean.</p> <p>I: So, he said that you... went to some places...Nelson gallery and...</p> <p>P: Yeah. The...um...</p> <p>I: Library and...Scien...Scienfic City?</p> <p>P: Science City.</p> <p>I: Science City.</p> <p>P: It's a...kind of fun one.</p> <p>Um...it's...um...it's a good one for... little kids, little, smaller kids or even... teenagers. And um...but I mean it's always fun to go and see about...um...other places and that sort of things, so...maybe we can figure out something.</p>	<p>Going to Spring training is a kind of her family gathering.</p> <p>Her efforts to remember and speak correctly</p> <p>She and her husband are big hikers</p> <p>She talks about the story when they got lost during hiking.</p> <p>She thinks it (the story of being lose in Arizona during hiking) is a good thing that they can laugh about.</p> <p><u>She seems to like outdoor activities and she has been participating in various outdoor activities with her husband.</u></p> <p>She thinks Science City is fun and good for little kids. She thinks it's always fun to go and see other places and things</p>
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<p>These places are about themselves</p> <p>She and her husband tried to find places that somebody else would enjoy it with them</p> <p>A good opportunity for them to get out and do something else with another person</p>	<p>I: So, you went to Nelson gallery, Library, Science... City... P: The Science City. I: Pumpkin... P: The Pumpkin Patch. I: Union Station and Crown Center for eating out...so... P: Yeah. We had Crown Center. We had lunches there.</p> <p>I: How did you decide these activities? P: I think it's, it's about us because we are...um...this is where, you know, our area that we live and so we tried to find something that um...somebody else would enjoy it...with us. I: Somebody else, the medical...? P: You know, like you would be...with...um...this is a good opportunity for us to get out and do something else... with another person or people, so... I: So, you...when you chose the activities, oh, this will be good for you including the medical student? P: Yeah. I: All...all of them can enjoy? P: Yeah. I: Yeah. I see. P: Uh-huh.</p>	<p>She thinks these places (activities) are about themselves because these places are their area that they have lived. She and her husband tried to find places that somebody else would enjoy it with them.</p> <p><i>Like you</i> (her pair and the interviewer are from other countries)</p> <p>A good opportunity for them to get out and do something else with another person</p>
<p>Going to the Pumpkin Patch –meaningful: she has been there with her children many times</p>	<p>I: So, do these activities have any special meaning to you? Going to some gallery, or going for the...going to the Pumpkin Patch or...? P: You know. Like...I think the Pumpkin Patch, we, we connect that because...it's more...um...for the kids and to go buy a pumpkin. You can just go buy... you know. I: Because you were with... P: Yeah. I: You invited her children, right? P: Yeah. I: So, you wanted to... P: Yeah. Her children wanted to come and um...like I said, we had a lot of fun. They had a bouncy ball</p>	<p>She thinks going to the Pumpkin Patch has some meaning to her. <u>This seems that because she has been there with her children many times.</u></p> <p>They had a lot of fun in the Pumpkin Patch.</p>

<p>A lot of fun in the Pumpkin Patch</p> <p>Active but not that active in trying to find something else to do (same activities)</p> <p>The couple: pretty boring because they have lived in KC for so long and their life are limited to the same pattern</p> <p>Nice weather</p> <p>Activities at AA</p>	<p>and you know all kinds of things to do. And...um...Bill [her husband] and I are not...real...I mean we are active...but as far as...is trying to find something else to...to...We go to a lot of movies. And um...if there is any good ones... you know...there's kind of that...you know good movies and then...you have to wait until the next good one comes. So...we are avid...movie... um...and...golly gee, I don't know. um...we are pretty boring.</p> <p>I: Why? Why do you think you are...?</p> <p>P: Pretty boring?</p> <p>I: Yeah.</p> <p>P: Um...I think it's just because that we've lived here for... so long. Now, you know, we go to Saint Louis and visit our kids. And...that's a lot of fun. We have a daughter that lives in Arkansas, so we take a weekend. Nice weather, you know, we go up and um...go to... her house... and then she comes to...to us. And um...so, I mean, you know, we are... it, it seems like we are always...going somewhere or somebody is coming to our house. And um...but, um...um...</p> <p>I: So, do you think it's the same pattern...for...?</p> <p>P: It's pretty much a same pattern, yeah.</p> <p>I: Going, visiting your kids</p> <p>P: Kids.</p> <p>I: Or they visit you and...also you go to the Alzheimer's Association, right?</p> <p>P: Yeah.</p> <p>I: So, you do some activities there, but...</p> <p>P: Yeah. We do. We sing. We...um...dance a little...and um...we do lots of activities for the community. This last...yesterday, we...I was there all day. And um...we were getting ready to put...um...the little plastic eggs. And</p>	<p>She thinks that she and her husband are active but they are not that active in trying to find something else to do (same activities)</p> <p>She and her husband go to a lot of movies, but they have to wait until the next good movies come.</p> <p>She thinks that she and her husband are pretty boring because they have lived in KC for so long and their life are limited to the same pattern (going to other states to visit their kids and their kids visit them)</p> <p><u>Nice weather (she mentioned nice weather twice. One reason that she does and likes outdoor activities can be because she enjoys nice weather).</u></p> <p>She talks about activities she does in AA (singing, dancing and doing lots of activities for the community. She talks about what she did yesterday in AA (making something to give to kids)</p>
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<p>Difficulty in planning activities/things (EF)? (Difficulty in purposeful activities?)</p> <p>Leadership role in her group at AA/ helping others in her group</p> <p>Her group has a good relationship</p> <p>She likes playing the leadership role in her group because she feels she is being very active and helping. She regards this as a very</p>	<p>um...so...we were stuffing them...with the...um...to give the kids...for them. Jeanne [her group facilitator] will...take home to where...you know, supposed to go. So, that's...when I'm...I'm ...know what I am doing... and like...you know. I can get into that. I like to...okay, we want this and we can do this and that, you know, and...and I kind of...Jeanne...since she...I was... probably one of the first that came in with the PAIRS group... years ago. And I...so...she kind of...relies on me to...help...the other people who when they had problems. And I can always...you know, she look at me and go. Like this, I know. Okay, I need to go over here and help him, or I need to go over there and help him. So, we have a good...I feel like that we have a good...reformed... you know good relationship. Um...but...you know I try not to...be to...abrupt with people or you know say "Oh, no no no. You can't do like that." Ha ha.</p> <p>I: So, at the Alzheimer's asso, in your group, you are kind of... playing leadership roles?</p> <p>P: I...yeah, I think I do a little bit of leadership, you know.</p> <p>I: That's good.</p> <p>P: And I...so...and...Jeanne will...when there's time to become...and she will kind of pull me over and say "Someone's so...struggling with something, would you kind of... watch...for him?" "Not a problem." You know.</p> <p>I: Do you like...doing that way, or...?</p> <p>P: Yeah. Yeah, I do. Because I...I feel like that I am being very active plus I am helping. And...I am not always the one. I mean there's a lot of people that are going to do a lot of good...um...good things and um...Nobody sits...you know it's not like their cliquie groups. You know</p>	<p><u>That's because of her difficulty in organizing/planning things? She needs somebody who can organize / plan things.</u></p> <p>She plays a little bit of leadership role in her group by helping the other people when they have difficulties in doing things. She tried not to hurt other's feeling when helping them. (not to be bossy / critical)</p> <p>She thinks her group has a good relationship.</p> <p>The facilitator asks her if she could help the others when they have difficulties in doing things.</p> <p>She likes playing the leadership role in her group because she feels she is being very active and helping. She regards this as a very rewarding opportunity to help. She is not the only one who plays that role (others do a lot of good things)</p>
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<p>rewarding opportunity to help.</p>	<p>you just kind of walk in and kind of go. Oh, I don't want to sit...sit down and... maybe some of them come over and sit... by you or something else...or whatever. So...yeah...it's a...very rewarding opportunity to...to help.</p> <p>I: So, you mentioned that you have some kind of life style... in terms of activities. You go to...you visit your children or they visit you. You spend some time with your husband, so you go to some hiking, or watch some movies. And you also go to the meetings in your place. So, I feel like the PAIRS program experience will be...How do you feel about the PAIRS program when you think about your...? You said that you kind of feel like boring because you have some set of activities you usually do...</p>	
<p>Making herself busy</p> <p>She decided to participate because she thought it would be enjoying.</p> <p>She thinks it went well when considering the whole thing</p> <p>She enjoyed being out</p>	<p>P: Well. I don't ...you know when I am just home by myself...it...you know...it's...I get... I read...not a whole lot ...because I don't, can't focus that well, but I...I find myself busy. And um...so...you know I...I can always find something to...to do, so...</p> <p>I: Why did you decide to participate in the PAIRS program, the social gathering with a medical student?</p> <p>P: Um...because it was...um...enjoying. Um...last year that we had...um...like I said, there was a little, some...some bumps... in it, but um...as far as the whole thing, I found it, you know, it went well. We...um...I enjoyed...you know...being out and learn about...and um...you know... shopping. I am not a big shopper, but... you know.</p> <p>I: Was there any specific reason you think oh, this will be good or this will</p>	<p>She can always find something to do (making herself busy) She reads when she is home by herself (not a whole lot because of difficulty in concentration)</p> <p>She thinks it went well when considering the whole thing although they had some difficulties / issues in scheduling meetings</p> <p>She enjoyed being out and learning about</p>

<p>and learning about Impact of dementia</p> <p>Expression of self-identity: a people person</p> <p>She decided to participate because she likes being with people and this gives her social interaction.</p> <p>Her daily life: mostly indoor activities She and her husband prefer going out (being in the outside)</p> <p>Happy people, happy person.</p> <p>She wanted to do it.</p> <p>Opportunity cost because of his leave on work</p> <p>It's a good thing I really enjoyed it</p> <p>Her pair as PAIRS lady</p>	<p>be fun or something like that for...when you decide to participate in the PAIRS program? Was there any specific reason?</p> <p>P: Well. Probably not necessary a specific...um...I just like being...I am a people person. I like being with people. And...this gives me the opportunity to... interact with...you know... our...[tapping on the table to help her thinking] our friends...so to speak. And um...so and then, when I get home from at 3 O'clock when... and then Bill and I go out and walk Sadie and...you know...go to grocery store whatever what we need to do the end of that. Then, we come home and pretty much sit down from TV. Ha ha. [cough] So...but um...we do prefer to...as long as we can get out and in the air and um.. the... outside. We are happy people. I am a happy person. Ha ha. So... that's... I: So...meeting some new people and getting...having more opportunity to go out was... attracted you to for the PAIRS program? P: I don't know that it was an opportunity for me to the PAIRS group when they...we opted to do it. um...I wanted to do it. Bill's gonna like "do you know how much ...?" You know, this...because of...he has to leave work to pick me up and that sort of thing. And so I am gonna not like..."we don't really have to do it." you know... but I think it's a good thing. I really enjoy it, so...he's got a good... boss that...helps us, so... I: How was the relationship with the medical student? P: Um...the first PAIRS group, PAIRS lady? I: Yeah. Are you still participating in the PAIRS program or...? P: This...we, we participated it last year. Was it last year, Bill? [asking her husband in the other room]</p>	<p>Expression of herself: a people person She decided to participate in the PAIRS program because she likes being with people and this gives her social interaction.</p> <p>Her daily life: after coming back from the AA, she and her husband walk their dog and go to the grocery store and sit down from TV mostly. But, she and her husband prefer going out (being in the outside).</p> <p>She thinks that they are happy people and she is a happy person.</p> <p>She wanted to do it. Because her husband work full-time, there was some consideration about opportunity cost because of his leave on work</p> <p>She thinks it's a good thing and she really enjoyed it.</p> <p>She calls her pair as PAIRS lady</p>
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<p>Relationship with her pair was good even with scheduling issues</p> <p>A lot of fun when her pair brought pictures of her country</p> <p>Being with somebody that can identify her as a person with Alzheimer's makes her feel uncomfortable</p> <p>She talks slowly when she is not comfortable. She has tried to meet new people.</p> <p>She felt like that she is in a group when meeting with medical students.</p> <p>She is not an individual that is identified as a person with Alzheimer's</p> <p>PAIRS program is from</p>	<p>I: Yeah.</p> <p>P: Okay. And um...so...we...even though that we had some bumps along the way...um...yeah. You know, any opportunity that we can learn from you and you can learn from us is all good.</p> <p>I: What did you usually talk with the medical student when you went out together or...?</p> <p>P: We really didn't... talk that much. um...she...you know when she went to...to Africa, then she came back, she had lots of pictures and we all sat down and look. It was, it was a lot of fun. You know and um...but um...yeah, it's just...being with somebody that...can...identify...you know... that I have Alzheimer's and so on. I am a little slower when I have to...when I am talking... if I am not comfortable. You know that sort of thing. But other than...you know...I've...tried to...meet new people and um...I don't know what else to say. Ha ha.</p> <p>I: So...because you said sometimes you feel uncomfortable when you meet new people, but the medical student already...when you were meeting at the first time, um...she already knew that you have Alzheimer's. Do you think this made the relationship easier or made you feel more comfortable?</p> <p>P: Possibly. Yeah. Yeah. Because...I feel like that I'm...a group. You know, I'm not an...individual that I...I can...identify with.</p> <p>I: So...because the PAIRS program is...also a part of the program of your group. So, that's why you felt comfortable?</p> <p>P: Uh-huh. Yeah.</p> <p>I: Because this is set up for your group...so, not anywhere in outside or...</p> <p>P: Yeah. Uh-huh.</p> <p>I: So, you felt more comfortable because you are...even though this</p>	<p>Relationship with her pair was good although they had some scheduling issues.</p> <p>She thinks they really didn't talk that much.</p> <p>She recalls that her pair brought lots of picture after she came back from a trip to her home country. It was a lot of fun.</p> <p>Being with somebody that can identify her as a person with Alzheimer's makes her feel uncomfortable</p> <p>She talks slowly when she is not comfortable.</p> <p>She has tried to meet new people.</p> <p>She felt like that she is in a group when meeting with medical students</p> <p>She is not an individual that is identified as a person with Alzheimer's</p> <p>PAIRS program is from her group. This helped her to feel comfortable.</p>
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<p>her group. This helped her to feel comfortable.</p> <p>Talked about PAIRS experience with people in her group</p> <p>We are pretty tight like junior or high school friends (little clique of friends)</p> <p>Group people as her new friends</p> <p>The opportunity to get out and meet new friends (get out from her area?)</p> <p>Expression of her self-identify as a very direct person who says what</p>	<p>...the meeting with the medical student is one-on-one, but because it's from your group...</p> <p>P: Yeah.</p> <p>I: So...it's more comfortable.</p> <p>P: Yeah. And...we have...talked about our PAIRS group, you know, when they...during a...if we have a little law in the...this fourth group. Um...somebody will come over and say "Are you with...you know...the PAIRS group?", and you know, "What do you gonna do? What do you guys gonna do to... entertain her or him?" or whatever, you know. And um...so...it's a...you know...we're pretty tight... um...group, kind of like when you were in... junior or high school, you know, you got your little clique of friends and...so...that's kind of I...that's kind of how I...identify them. You know, they are my...my new friends.</p> <p>I: Very close friends.</p> <p>P: Very close friends.</p> <p>I: Right. Did you have any expectation before participating in the PAIRS program?</p> <p>P: I had no idea what it was gonna...entail to, but...for...for me, it's just the opportunity to... get out about and...meet new friends and... see old friends, so...yeah.</p> <p>I: How do you feel when you get out, go out from the house and meet new people or something like that? You already said that you are very... outgoing...</p> <p>P: I am a very outgoing person. Yeah. It doesn't take much for me to say...I am a very...what's such thing? [Saying because she cannot remember the exact word] I say what I think. Ha ha.</p> <p>I: You are very direct?</p> <p>P: I am a very direct person. You know, and um...</p> <p>I: Candid?</p> <p>P: You know. I am gonna like "No, you don't do that way. This is the</p>	<p>She talked about PAIRS group with people in her group at AA (what they are going to do to entertain their pairs).</p> <p>She thinks her group is pretty tight group like junior or high school friends (little clique of friends)</p> <p>She regards her group people as her new friends</p> <p>Her expectations before participating in the program" the opportunity to get out and meet new friends -> <u>get out from her area?</u></p> <p>Expression of her identify as a very direct person who says what she thinks</p>
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<p>she thinks</p> <p>She likes playing a leadership role in her group</p> <p>No difference due to feelings of belonging to her group</p>	<p>way you do. That's Marcia's way." Ha ha. Not really, that I mean pretty much I... um... and I... I like it that Jeanne will come to me and say, you know "He's struggling or she's struggling, would you sit with her today?" or something like that "Not a problem." You know... and ... as far as I know I am not everybody... you know... problem.</p> <p>I: So, you also participate in your group and you participated in the PAIRS program until... Do you see any difference between the two programs?</p> <p>P: The only difference that I see is that it's a... more... out... you know, being one-on-one versus being the group with twelve people or eighteen people, whatever is, so...</p> <p>I: Do you think that make any difference when you were with one-on-one or when you were with more...?</p> <p>P: I don't know. I don't know that's not a... um... (pause) I don't have a problem. I don't think that whatever... you know... We need to get done or we want to do or, you know... so... I don't...</p> <p>I: As I know, maybe the meetings at the Alzheimer's Association are more like indoor activities.</p> <p>P: Yes, much of them.</p> <p>I: And then the PAIRS program is you should go out, so... Is there any difference when you were... when you do some indoor activities in one place compared to doing more outside activities, variety of activities with...?</p> <p>P: Yeah. The outdoor activities are... that's an opportunity to go outside and or go somewhere else or you know even if you want to, we want to go out for lunch or something you know. It's... we can get my little circle... [laugh] so... anyway, no. I'm... I'm... I almost think that I'm more of pleased than I'm at a please</p>	<p>She mentions that she likes the facilitator asks her play a leadership role in her group again; <u>very similar role when she owned a fitness center and worked as a coach for members?</u></p> <p>Difference between the two programs is being one-on-one versus being in the group of people; <u>feels belonging to her group even in the PAIRS group?</u></p> <p>The outdoor activities -> an opportunity to go outside and go somewhere else</p> <p>She is a person who tries to keep people happier and pleased</p>
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<p>The outdoor activities: an opportunity to go outside and go somewhere else</p> <p>Expression of self-identity: a person who tries to keep people happier and pleased</p> <p>She has no secrets</p> <p>The best part is meeting other people</p> <p>Nice to talk about the program with people in her group at AA</p> <p>Contributes to learning of somebody who does not have Alzheimer's and who wants to learn about Alzheimer's</p>	<p>me, you know. I: What do you mean by...? P: That I will go out on my way to keep somebody happier, pleased, and um... I: rather than... P: if I am not...yeah...so...you know, I'm... Like I said, I'm an open book pretty much.</p> <p>I: What was the best part of the PAIRS program? What did you like the most?</p> <p>P: Um...just meeting...other people and um...then it is nice to...when...we go back to support group or whatever then, um...sometimes, somebody say "Are you with the...[tapping on the table because she cannot remember the word (PAIRS)] support group, you know, the PAIRS group?" and I...then I will say, "Yeah, I am with dadadadada." and then we kind of chit chat a little bit about what they are doing... that might help us be able to find out something that we can do to help you [students?] or something like that, so..."</p> <p>I: So...from my understanding, were you trying to help the medical student?</p> <p>P: No, I don't think I am trying to help them [medical students]. Um...I just...I think what...in my mind is that...you are trying to...I am trying ...you are getting in...education on somebody from who isn't an Alzheimer's person, somebody who knows Alzheimer's are of that is...is delved with Alzheimer's. And um...so...[sigh] I lost my train of thought.</p> <p>I: The questions are really deep...so...it's hard to...</p> <p>P: Yeah. Um...</p> <p>I: So...you are trying to...because the medical students have some wants to learn better about the people with</p>	<p>She has no secrets (same meaning as a direct person who says what she thinks)</p> <p>The best part of the program?</p> <p>Just meeting other people</p> <p>It is nice to talk about the PAIRS program with people in her group at AA (what they are doing) ; feelings of belonging?</p> <p>Contributes to learning of somebody who does not have Alzheimer's and who wants to learn about Alzheimer's (not necessarily helping med students)</p>
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<p>An outlet/opportunity to be in the community beyond her home and group at AA</p> <p>Going out to the community more often beyond her places she usually goes to</p> <p>They chose activities which everybody could be part of it /enjoy altogether even including her pair's kids</p> <p>She likes that everybody can be part of it (enjoying things together with people)</p> <p>They talked together</p>	<p>Alzheimer's.</p> <p>P: Yeah. That's what I gather. That...we can...um...I think it gives us an outlet... to... be just not in my home and just not in our place. There's an opportunity to get out about and...either be in the community or...um...just walk go down to the plaza, walk, you know, just...um...or whatever.</p> <p>I: So, do you mean that being in the community more often or...?</p> <p>P: I don't understand what you are saying.</p> <p>I: So, going out to the community more often, beyond your place you usually go to...</p> <p>P: Yeah. Uh-huh.</p> <p>I: So, that was the best part to be...to go out or...?</p> <p>P: Um...usually we would do and find an activity... and um...end of Oct...since she [her pair] had a dau...the kids then we tried to... circle under around with being with kids, so everybody could be part of it. And um... so that's what... I kind of like...I am not sure what, you know...what I can... help, you know, or...what we want to do. So...um...just figure out. I mean nothing else just...go for walks.</p> <p>I: So...before you decide to "what we are going to do next?" you had to...what did you...How did you decide at that time? So...did you talk with the medical student or did you talk with your husband to decide what...?</p> <p>P: We talked together.</p> <p>I: When you met in some place and you talked about what we are going to do next?</p> <p>P: Yeah. Usually we...um...we get contact with you [the medical student] or you know and or you contact us and say "Hey, this is a good day." Whatever, because you feel like a lot in your plate, too.</p> <p>So...um...you know, it's just how we</p>	<p>She thinks it gives them an outlet to be in the community (beyond home and their place /group at AA)</p> <p>An opportunity to be in the community</p> <p>Going out to the community more often beyond her places she usually goes to</p> <p>They chose activities which everybody could be part of it /enjoy altogether even including her pair's kids</p> <p>She likes that everybody can be part of it (enjoying things together with people)</p> <p>They talked together when deciding activities</p>
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<p>when deciding activities</p>	<p>get it to all...mushed together. I: So...is there...um...you went to some gallery, or library, or some Science City. P: Yeah. We went to Science City. We went to Pumpkin Patch. We went to...um...Bill, where did we go? [Asking her husband in the other room] I: Union station. P: Union station. And um...you know, they have all different...things going on at that the time. They had a...the... King Tut adventure, um...I don't...you know, as far as to...know exactly...something would be... I: Do you like watching, looking at the arts or do you like some...? P: Some of them I do, some of them I am gonna like "Really?", but I think that's just art. You know, there's a...you know, there's...people...artist is in the whole group of the person, so...yeah... I: But, do you enjoy going to the gallery? P: Yeah. We enjoy it and I enjoy it. Um...or...I mean as long as...I am not sure what the time frame...and um...that's gonna be...um...you know, I wasn't be all day, but you know... three or four hours...it will be okay. I: Did you find anything in common in your medical student? P: Um...the medical, medicine...the one that we had? I: Yeah, your pair. P: Oh, my pair. We...you know...we got along okay. I mean we had...um...but there were just...um...she had more on her plate that she can handle... that to be in the PAIRS group. And... you know, with her kids, having to go back to Africa and all of that, so...there was a big... spot there that kind of like...okay, but it's just...you know, it's not that big of deal. You know...we dealt</p>	
<p>Enjoys going to the art galleries</p>		<p>She enjoys going to the art galleries</p> <p>She thinks they got along well with her pair</p> <p>She thinks her pair had more responsibilities/ things to do that she can handle to be in the PAIRS group.</p>

<p>Enjoyed being out with other people</p>	<p>student or...? P: I don't understand. I: So, you said that you learned from other people. So, the PAIRS program is the...pair thing, paired with the medical student for going out. So...do you think...did you feel that you learned from...the PAIRS program? Or, what do you mean by you learned from...?</p>	<p>An opportunity to do different things because she is running out of the things to keep her very active</p>
<p>An opportunity to do different things because she is running out of the things to keep her very active</p>	<p>P: I... enjoy... just about everything, you know, because there's an opportunity to do...um...different things. And um...and I, like I said, my opportunities, not my opportunities, but my...um... running out the things to... keep me...very active, so that's the goal that we set up that we want to make sure that we are active and...home and um... I: So, being active is kind of what you, what you think yourself? P: Yeah.</p>	<p>Being active as her goal because this is how she thinks herself</p>
<p>Being active as her goal</p>	<p>I: Do you think being out more was...do you feel that you feel more like yourself? P: Yeah. You know, I go to the Y and because this is the area, you know, where we live that I can drive...[a small laugh] to...um...you know go to water aerobics and...um...I have a friend that um...she's in Arizona right now, but she always comes in...we do yoga and that sort of thing, so...Yeah, I stay busy with...with that so... I: That's good. And...how do you think parti...you said that you enjoyed the experience of the PAIRS program, but how do you think participation in the PAIRS program has affected your feeling or mood or any...?</p>	<p>She can drive in the neighborhood. She goes to water aerobics and she does yoga with her friend who lives in Arizona now but her friend frequently visits her. She stays busy</p>
<p>She stays busy</p>	<p>P: I don't...I don't think so. I mean, you know, like I said, she had kids, so that was fun to play with kids. But um...you know...I'm...I adapt fairly easily. [a small laugh] You know, and</p>	<p>Her pair has kids, so that was fun to play with kids</p>

<p>Fun to play with her pair's kids</p>	<p>this is what...um...you know, I might find something that I'm gonna do 'Oh, that would be kind of nice', you know, and jot it down and say next time I see you [the medical student] "I thought about this, dadadadada" but, you know...it's...it's not a big deal.</p> <p>I: So, you are saying that you enjoyed the time with the medical student, and...but your basic mood didn't change because of the PAIRS program, or...?</p> <p>P: I think...the PAIRS program gave me more opportunities...</p> <p>I: for... socializing?</p> <p>P: For socializing with...</p> <p>I: with other people?</p> <p>P: Other people and other...ac...um...area, you know, different things...um...that's probably...</p> <p>I: How did that make you feel when you were more socializing with other people...then...other new people and going out more?</p> <p>P: Um...there were... times that I would, you know, I felt like that I was...you know...of here everybody else is over here having fun. But... it's, it's not... a big of deal for me. You know, it's not like...I'm mad because... I can't go do this. That's, that's not...not me. Okay, if I can't do it, well, okay, I will deal with it and eventually I will get it. You know, we will get it figured out so I can go or can do. And</p>	<p>There were times she felt like she was isolated (she is here and everybody else is over there and having fun)</p> <p>She accepted her situation/disease and she has coped with the disease</p> <p>Coping strategy: "If I can't do it, I will deal with it and eventually I will get it. We (she and her husband) will figure out (work as a team) so I can go or can do.</p>
<p>Times she felt like she was isolated</p> <p>Acceptance and coping</p> <p>Coping strategy</p>	<p>um...so...[cough] I'm sorry. That's because of cold. So, Anyway, that's...pretty much...everything in a nutshell so, anything else you need to...?</p> <p>(47:56)</p> <p>I: Um...can he come...?</p> <p>P: Bill, you want to come in?</p> <p>S: How's everybody doing, anyone</p>	<p>He joins the interview</p>

<p>I enjoyed it as an activity</p> <p>Feels guilty that they did not meet all the required hours</p> <p>We enjoyed</p> <p>Scheduling issue (due</p>	<p>need a glass of tea? I: I'm okay. I'm okay. S: Water or anything? P: I'm okay. S: You are alright? Croupie? P: Could be...[the spouse gives her a kiss] (48:23) I: So, I will start the second part of the interview. So, you can, both of you can talk now. S: Oh, good. I: So...how do you think about your...her participation in the PAIRS program? S: What do I think about it? I: Uh-huh. S: Okay. I enjoyed it as an activity. I feel...somewhat guilty and that we did not meet the...the total requirement that they laid out when they first started the program. We were supposed to meet for some many hours each month...because of the scheduling with juristic issue we didn't get the all of the hours, but we enjoyed the time we had together... P: Uh-huh. S: So... I: So, you are saying that sometimes you cannot meet. S: Sometimes...[because he does not understand what the interviewer has just said] I: Sometimes...there are four hours...minimum of four hours each month and sometimes... S: Sometimes we didn't meet four hours each month. Okay. That was just because of the scheduling issue. Okay? And part of that, it was just much my problem or my fault as anybody else. And that...the hours the student had available, okay? P: Uh-huh. S: Were hours that I was working and I couldn't get Marcia there. And I really felt bad. Marcia is quite capable of driving, but the problem is you never know when she is gonna</p>	<p>He first talks about his participation in the program because he participated together: <i>I</i> enjoyed it as an activity.</p> <p>He feels guilty because they did not meet the total requirement of the program due to scheduling issue / they did not meet all the hours required from the program</p> <p><i>We (he and his wife)</i> enjoyed the time we had together</p> <p>He thinks that part of the scheduling issue was just much his problem or his fault and the other part of the issue was due to her pair's available schedule. He works full time, so he is only available on the weekend.</p> <p>There were times that he couldn't get his wife to the meeting place because he was working. He thinks she is quite capable of driving, but he is concerned of her</p>
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<p>to him and her pair together)</p> <p>He couldn't get her to meeting places because he was working</p> <p>She is capable of driving, but he is concerned of her driving</p> <p>We enjoyed time together</p> <p>Her pair- a very interesting person (from Cameroon)</p> <p>Interesting: had an opportunity to visit about her pair's culture</p> <p>He didn't have a lot of expectations</p>	<p>get turn around and disoriented, and she's lost. And um...when we had daughters here in town, she can call. She used to, when she got lost, she called one of the daughters and then pulled up the Google map and say. "Okay. Start reading this screen side to take you as you go by." Then we figured out where she was from there and then talked a little bit on the phone how to get back. Oh...but that wouldn't work out so well while I was at work. So...anyway, I felt bad that we didn't do that. We enjoyed time together. We had...we had a very interesting PAIRS person.</p> <p>P: Uh-huh.</p> <p>S: She was...not from the States. She was from Cameroon.</p> <p>P: Yeah, Cameroon. Yeah.</p> <p>S: And um...so...we had an opportunity to visit about her culture where she came from and, who's interesting.</p> <p>I: What were your expectations before she participates in the PAIRS program?</p> <p>S: What were my expectations?</p> <p>I: Yes.</p> <p>S: I was pretty much blank slate.</p> <p>I: What do you mean by?</p> <p>S: I didn't have a lot of expectations. I wasn't real sure how a med student was going to help our lives. [<i>Talking slowly to emphasize</i>] Okay? Because she obviously couldn't give medical advice or recommend medical treatment or anything. And I wasn't real sure what we had to offer her [<i>tapping on the table to emphasize "her"</i>] in the way of training. We had no special knowledge we can... you know, we can be with her and met her...underst...observe...and see the Alzheimer's people. Sometimes they are perfectly normal. Sometimes they are not, you know. But, I don't think we can get that much to give.</p>	<p>driving.</p> <p>He felt bad that they didn't use strategy they used to do because he was at work (helping her find direction when she is lost)</p> <p>"We enjoyed time together and her pair was a very interesting person."</p> <p>Her pair was from Cameroon and they had an opportunity to visit about her pair's culture and that was interesting.</p> <p>She did not remember where her pair was from during the first part of the interview.</p> <p>He was pretty much blank slate</p> <p>He didn't have a lot of expectations because he was not sure how a med student was going to help their lives (no medical advice or recommendation of treatment) and what they had to offer her pair in the way of training (no special knowledge)</p> <p>They can be with her pair and may give her pair a chance to observe/see a person with Alzheimer's.</p> <p>He thinks that they did not show any moment she (a person with Alzheimer's) is not normal (signs or symptoms of Alzheimer's)</p>
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<p>Work as a team in making decision (couple)</p> <p>Decided to participate although they were not so sure and they may have some issues/problems</p> <p>Decided to participate because this is the way they can offer/ help research and people with Alzheimer's</p> <p>Their participation might help other people at AA</p> <p>Their wants to help</p>	<p>I: So...you were, at that ...</p> <p>S: I don't have a lot of expectations at all. No.</p> <p>I: So, at that time, she [the person with Alzheimer's] decided "Oh, I wanted to do this." and she told about this to you?</p> <p>P: I think she talked to Bill first.</p> <p>I: Yes.</p> <p>P: And she...and then we came home and talked together. And um...and we talked about "Oh, this is gonna be a problem, here." this, you know, "This is gonna be a problem here, but we will see what tell we can get it done." And um...so...</p> <p>S: We kind of made a decision together.</p> <p>I: But what was the reason why you think "Oh, we can try this." rather than "Oh, we cannot do this?"</p> <p>S: If there is something that we can offer, this is, this is not about ...helping Marcia and I. Okay? This is about helping research and Alzheimer's, period? Okay?</p> <p>I: So, did you think that this program will not help...?</p> <p>S: Our participation might help people down the road. If we help the students understand Alzheimer's better, so they can treat people better. That's a good thing. But, this is, this was much about...helping the Alzheimer's research as we understood, okay? More so than something that will be a direct benefit to us.</p> <p>I: So, you were more thinking about... this may help the medical students' learning and some future medical doctors, or some research...</p> <p>S: Right. Right. Anything that we can do to help Alzheimer's research, we are willing to try.</p> <p>I: That's good. How do you think</p>	<p>She seems to be a social worker of the support group for caregivers or her group's facilitator.</p> <p>She and her husband talked about what would be like if they participate in the PAIRS program (any problem). Work as a team in making decision They decided to participate in the program although they were not so sure and they may have some issues/problems ("we will see what tell we can get it done.")</p> <p>They decided to participate in the program because they thought this is the way they can offer/ help research and people with Alzheimer's</p> <p>Their participation might help other people at AA Their wants to help the medical student's learning, so they can treat people better when they become medical doctors.</p> <p>No direct benefit to themselves (the couple), but much more to help the Alzheimer's research</p> <p>They want to help Alzheimer's research as much as they can do.</p>
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<p>medical students' learning, so they can treat people better</p> <p>No direct benefit to themselves (the couple), but much more to help the Alzheimer's research as much as they can do</p> <p>Her relationship with her pair as friends at the beginning</p> <p>Became a mother and daughter relationship (maternal role)</p> <p>Her pair: similar age to their oldest daughter</p> <p>He felt the same way (paternal role)</p> <p>Multiple levels of relationship</p>	<p>about your... her relationship with the medical student?</p> <p>S: How do you...?</p> <p>I: How do you think about her relationship...?</p> <p>P: Hardest relationship.</p> <p>I: Yeah, with the medical student.</p> <p>P: With the medical stu...student.</p> <p>S: Your relationship with her?</p> <p>I: Yeah, how do you think about that?</p> <p>S: Well, I think...[P and I laugh because of his hesitation] it was a mixture of thing, okay?</p> <p>P: Yeah.</p> <p>S: Um...There was a very direct relationship of...these too getting to know each other and learning about each other, their past, where they came from...um...what they do. It happens that this, the medical student we had was about the age of our oldest daughter, okay? and had two children of her own. And therefore, there was some whatever mother-daughter relationship in...basis on that as well. Um...Marcia was very maternal... toward the student. Um...the student goes to school working full-time. Yep, I felt the same way. We...I mean we are parents, that's what we do. But, the relationship was on a couple, three different levels.</p> <p>I: Um...</p> <p>S: There was a level in which they were equals, okay? And they were both equal...</p> <p>I: Oh, I see.</p> <p>S: Do you understand what I am saying? And then it was some what this maternal relationship as well.</p> <p>I: I see. So, at the beginning, you felt like their relationship is more like a friend</p> <p>S: Yes.</p> <p>I: Or some...like some partner. But after you spend more time, she feels like oh, she is giving more maternal role because she ...</p> <p>S: Yes. That's natural. Anybody that</p>	<p><i>Your -> his spouse; her -> the medical student; He understands the question correctly.</i></p> <p>He thinks that her relationship with her pair was like friends at the beginning when they get to know each other and learn about each other</p> <p>The relationship became a mother and daughter relationship (her maternal role to her pair)</p> <p>Her pair was about the age of their oldest daughter</p> <p>He thinks his wife was very maternal toward her pair</p> <p>He felt the same way (paternal role)</p> <p>We are parents</p> <p>The relationship was on a two or three different levels</p>
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<p>Natural to play parental roles to anybody in similar age to their own children</p> <p>Her maternal role: Going to the Pumpkin Patch (not for adults at all) with her pair's kids</p>	<p>age. It wasn't unique to this student nor the fact that this student had two children. Okay? Anyone that was about to the age of our oldest daughter, okay? and has her trials and tribulations in her life. We are gonna take a very paternalistic or maternalistic approach to them as well. It's gonna happen.</p> <p>I: Can you tell me more about the...more about...can you tell me some stories about her maternal relationship with her, with the medical student?</p> <p>S: Did I? I am still only halfway in this as well. Ha ha.</p> <p>[Laugh all together]</p> <p>S: The thing of the Pumpkin Patch. The Pumpkin Patch is not necessarily about...adults at all. This isn't some place you will go to talk at the coffee shop sitting like adults, okay? This is much more case... at the Pumpkin Patch, they had a wagon ride out of the fields where the pumpkin tree grow for the kids to select pumpkins. Okay? They had...uh, you know what a maze is? ...um a maze, where you walk, it's like a uh, in England, they make them out of hedges, you walk in and you run into a dead end, you have to back up and you have to find a path to get through the maze. Okay? They do the same thing with hay bails during here, okay?...during October...um...</p> <p>I: Halloween</p> <p>S: Halloween type of activities. We took the kids over the kitchen, never had... any hot apple cider.</p> <p>P: Uh-huh.</p> <p>S: Okay? We bought them to drink...you know something that they had never tried before. And so...yeah.</p> <p>I: So, that activity wasn't for you.</p> <p>S: It was much more about...</p> <p>I: for the medical student's...</p> <p>S: Much more about parenting and, and...it...really...the kids weren't the</p>	<p>He thinks that's natural for them to play parental roles to anybody in that age (similar age to their own children)</p> <p>Example of her maternal role toward her pair: Going to the Pumpkin Patch (not for adults at all) with her pair's kids</p> <p>Halloween types of activities for her pair's kids</p> <p>They took her pair's kids over the kitchen because the kids have had any hot apple cider.</p> <p>The activity was more about parenting</p>
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<p>The activity was more about parenting</p> <p>Kids were not the basis but were much part too</p> <p>Scheduling issue</p> <p>Relationship as a friend or a person with authority when her pair was telling them more about African Art at Nelson-Atkins</p> <p>Multiple levels of relationship at the same time for the most part</p> <p>Good to have these multiple relationships</p>	<p>basis of it, but kids were much part too. You remember the scheduling issue that we had. Well, anytime...we had picked time for I was available. Okay? And we also had then to either take care of her kids or we had picked time for she had babysitting available. That was a big part of this logistics as well. Okay? So...</p> <p>P: So just being in the three of us... ha ha.</p> <p>S: We went to Nelson-Atkins and one of their major sections we toured was the African Art. Okay?</p> <p>P: Yeah. Uh-huh.</p> <p>S: And their relationship can kind of shift. Okay? It is no longer us being a parent. Okay? She was all about...telling us more...about African Art which we knew very little about. Okay? So, that was much more case of the equal or her taking the upper side...of the...the worthy authority.</p> <p>I: Right. So... you felt like there were some two or three relationships with...</p> <p>S: Get multiple levels and for the most of part, all same time.</p> <p>I: Do you think this was good...that... having that kind of relationship was good?</p> <p>S: Oh, yes.</p> <p>I: Being a...sometime being a more maternal role, playing the maternal role, sometime being an equal as a friend and...</p> <p>S: Well I think it was definitely a good for, thank for...us...not necessarily just now, not necessarily just for Alzheimer's patients. To be able to meet new people and establish new relationships is always good thing. Sometimes, even if they work on their doctorate whatever</p> <p>I: How do you think participation in the PAIRS program has affected her or her daily life?</p> <p>S: How do I think the...?</p>	<p>Her pair's kids were not the basis of it but kids were much part too.</p> <p>Scheduling issue: They had to consider his work schedule, her pair's kids' schedule, and available babysitting schedule</p> <p>That was a big of this logistics as well. (complicated in terms of schedule)</p> <p>They went to Nelson-Atkins and one of their major sections they toured was the African Art. The relationship changed when her pair was telling them more about African Art which they knew very little about : Her pair as a friend or as a person with authority</p> <p>Multiple levels of relationship and the relationship at the same time for the most part</p> <p>He thinks it was good to have these multiple relationships.</p> <p>He thinks being able to meet new people and establishing new relationship is always good thing, regardless of time and diagnosis of Alzheimer's</p>
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<p>He thinks being able to meet new people and establishing new relationship is always good thing, regardless of time and diagnosis of Alzheimer's</p> <p>No ongoing effect</p> <p>They meet new people anyway</p> <p>New people will come into the support group at AA</p> <p>Thinks they have a variety of ways to meet new people</p> <p>Participation was good Frustrating at that time (scheduling issue)</p> <p>This frustration due to schedules can occur in any relationship</p> <p>Similar to any other social activities/</p>	<p>I: How do you think participation in the PAIRS...?</p> <p>S: Oh, participation. Okay. Yes. um...I don't know that necessarily has affected us ongoing. Um...We still...I mean we...we whatever we meet new people anyway. Okay? Not necessarily just the PAIRS program. But, new people will come into...the support group, okay? or...um...we have a variety of ways to meet new people. um...and...we just...we just recently, my...my younger brother three of his daughters. He's got married within the last six months. So, we now have new, three new... nephews or nephews-in-law. Okay? And so, we are learning about them. We visit with them and find out about, you know, where they came from, and who they are and their lives now. It's still...it's same function. I think participation was good. Um...it was, it's frustrating at that time. But then...getting the opportunity to meet with three new nephews is frustrating at that time, too. Schedules don't always work out, so...</p> <p>I: So, it's very similar to any other social activities?</p> <p>S: I think so. The social interaction.</p> <p>I: Do you think her participation in the PAIRS program has affected her feeling or mood?</p> <p>S: Well. Okay. um...You have pluses and minuses, just like we have the relationship in multiple levels, you always have pluses and minuses. And during that program itself...um...whatever we would meet, and there was, there was obvious satisfaction and obvious joy about we had the chance to talk a little bit. After she came back from her trip to um...Cameroon, okay? and had...she had slide of program...</p>	<p>He doesn't think participation in the program has necessarily affected them ongoing.</p> <p>He thinks they meet new people anyway, not necessarily just through the PAIRS program, but new people will come into the support group at AA.</p> <p>He thinks they have a variety of ways to meet new people. He talks about the new nephews they got.</p> <p>It's still the same function. He thinks participation was good.</p> <p>It was frustrating at that time (when they had scheduling issues)</p> <p>He thinks this frustration due to schedules can occur in any relationship</p> <p>Similar to any other social activities/situations/interaction \</p> <p>Plus: Obvious satisfaction and joy by having the chance to talk with another person</p>
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<p>interaction</p> <p>Plus: Obvious satisfaction and joy by having the chance to talk with another person</p> <p>Really enjoyed seeing picture from her pair</p> <p>That was fantastic.</p> <p>Minus: frustrating when the schedules didn't work out, so they were meeting the obligation of the program</p> <p>Frustrating but willing to do it again. He thinks this happens all the time (everything else in life)</p> <p>They went to multiple places when they could meet (actively going to places)</p>	<p>P: Yeah.</p> <p>S: about...of...of the pictures she had taken of her home village, okay? and her family.</p> <p>P: Uh-huh.</p> <p>S: We really enjoyed seeing those. Okay? That was, that was fantastic.</p> <p>P: Uh-huh.</p> <p>S: But, at the same time too, when their time's, the schedules didn't work out, we weren't meeting the obligation of what we signed up for the program. That was frustrating as well. So, how you...how you balance out all and, all and all is a good thing, frustrating but willing to do it again. Okay? But, it happens both ways. It just...everything else in life.</p> <p>I: Do you remember how many...how many...? Um...so...you met every month but you didn't...</p> <p>S: We didn't meet every month.</p> <p>I: Oh, so...do you remember how many months you didn't meet...how long you didn't meet?</p> <p>P: I think she was...gone.</p> <p>S: We went to...we went to... Harry Truman's museum or Library, president Harry Truman's... library, and the Pumpkin Patch. That was both at the same time. Okay? We went to Nelson-Atkins. That was one trip. And we went to Science City and to take kids over to Crown Center for lunch.</p> <p>P: Yeah.</p> <p>S: So, we met three times...total.</p> <p>I: Really?</p> <p>S: Yep, total.</p> <p>I: Wow. Wow. Was it happened just in 2013 or was it spread out?</p> <p>S: Spread out. The...the one time that we met was in fall. That was obviously close to...Halloween. Okay? And, so that was in 2013. And then we tried to schedule...oh, there was a meeting close to Christmas because the one at Science City was at...it was at...I had asked for it specifically...because the Union</p>	<p>They really enjoyed seeing picture her pair had taken of her home village and her family after she came back from her trip on her country</p> <p>That was fantastic.</p> <p>Minus: frustrating when the schedules didn't work out, so they were meeting the obligation of the program</p> <p>Frustrating but willing to do it again. He thinks this happens all the time (everything else in life)</p> <p>They went to multiple places when they could meet (actively going to places)</p> <p>They met three times total. (one time close to Halloween, another time close to Christmas, and the other time in early March)</p>
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<p>They met three times total</p> <p>He suggested going to the Science City (Union Station) because of a big train exhibit in Christmas time</p> <p>Would be more enjoyable if they could meet more often</p> <p>Participation again after he retires</p> <p>He doesn't like the idea of depending on the student to come pick her up, take her some place and bring her back to home because</p>	<p>Station usually puts out a big train exhibit in Christmas time and its toy train is all set-up. And so, I asked her, you know, she was gonna hand kids and I said well. Why don't we go to the...um...?</p> <p>P: Train.</p> <p>S: Union station. Okay? They'll have this big train exhibit we go to Science City while we were there. So, that was about Christmas time. And then, we met, then...Nelson-Atkins. And that was on the spring. I think probably... early March, something like that. That was three times we met.</p> <p>I: Wow. So...do you think it would be enjoyable if you can meet the medical student more often?</p> <p>S: Yes. That's what I was talking about. I didn't think we would do this again until, after I retire.</p> <p>I: Because you...</p> <p>S: To where I'm no longer in impediment they want to meet in the afternoon some place then great. I can drive there. I don't have to participate. You know, I can go to something else. But I can't give you what you need to be... without having...I didn't really like the idea of ... by depending on the student...to come pick her up, take her some place, and bring her back then. I didn't...that didn't appeal to me either.</p> <p>I: Why?</p> <p>S: That's putting too much burden on the student...in my opinion.</p> <p>I: Even though the student is very willing to do that way?</p> <p>S: Even though the student is willing to do that, that's still...</p> <p>I: You don't feel comfortable?</p> <p>S: Yeah.</p> <p>I: I see.</p> <p>S: That's pushing too much of the responsibility off on them.</p> <p>P: But, it is also limiting.</p> <p>S: Yeah. Limits what we can do.</p>	<p>He suggested going to the Science City (Union Station) because of a big train exhibit in Christmas time</p> <p>He thinks it would be more enjoyable if they could meet her pair more often.</p> <p>He thinks they would not participate in the PAIRS program again until he retires.</p> <p>He thinks if he retires, he doesn't have to participate with them and he can go to something else.</p> <p>He doesn't like the idea of depending on the student to come pick her up, take her some place and bring her back to home because that puts too much burden on the student.</p> <p><u>If they would've done this way, she could be able to meet her pair more often, but he didn't want to do this way.</u></p> <p>Although the student is very willing to do that way, he doesn't want to do that way (too much responsibility to the student)</p>
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<p>that puts too much burden on the student.</p> <p>Although the student is very willing to do that way, he doesn't want to do that way (too much responsibility to the student)</p> <p>Going to the Pumpkin Patch had a special meaning because they always used to take their grandkids each year to the Pumpkin Patch. That reminds them of happy memories.</p> <p>Taking the kids to Union Station reminds him of the time when he used to take their own kids to Union Station to see the big train exhibit.</p> <p>He suggested going to the Union Station.</p>	<p>I: So, you mentioned several activities you did with the medical student. Do you think these activities have any special meaning to her...going to art gallery or...?</p> <p>S: I don't know the activities...some of them had special meaning.</p> <p>P: Uh-huh.</p> <p>S: Um...taking the kids to the Pumpkin Patch...had a special meaning in the, in our grandkids we knew. We always used to take them each year to Pumpkin Patch. Okay?</p> <p>I: So, this is real...this reminds you of some happy times...</p> <p>S: Right. Right.</p> <p>P: Yeah. Uh-huh.</p> <p>S: Taking the kids to... Union Station...reminds me of the time when I used to take our kids to Union Station to see the big train exhibit, you know. Um...the Nelson-Atkins is not some place. We normally go to...like art museums every so often when our daughter went down to...Vietnam film, we went to Chirstopher and just...art exhibit down there...um... museum. We go to museum, museum every so often. We hadn't been...to Nelson-Atkins really long time. So...I don't know if it had any particular, special significance. It was very enjoyable because that was one she had slideshow set up [cough] to tell us about better the trip back to Cameroon. So...</p> <p>I: So...she goes to the meetings at the Alzheimer's Association. And do you go to the caregivers, support group meeting for caregivers?</p> <p>S: Yes.</p> <p>I: Do you see any difference between the PAIRS program and the meetings at the Alzheimer's Association?</p> <p>S: I don't participate...on Marcia's side.</p> <p>I: So, you don't know about...</p>	<p>Going to the Pumpkin Patch had a special meaning because they always used to take their grandkids each year to the Pumpkin Patch. That reminds them of happy memories.</p> <p>Taking the kids to Union Station reminds him of the time when he used to take their own kids to Union Station to see the big train exhibit. He suggested going to the Union Station. Going to the Nelson-Atkins: no special meaning because they like and go to the art museums every so often</p> <p>They hadn't been to Nelson Atkins really long time.</p> <p>It (going to the Nelson Atkins with her pair) was very enjoyable because her pair had slideshow set up to tell them about better the trip back to her country.</p> <p>He does not make any guess because</p>
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<p>He does not make any guess because he does not participate in his wife's meetings at AA.</p> <p>support group meetings: very different from PAIPS</p> <p>PAIRS much more about exposure and giving more knowledgeable experience (to medical students)</p> <p>The best part is for students to have real life experiences and understand better each</p>	<p>S: I go to support group meetings and the support group meetings are very very different... than the PAIRS program at all. The support group meeting is...is much more about people... and they are having issues as caregiver... and they are either looking for emotional support...or they are looking for someone with similar experiences to see if there are better ways of handling issues that they have...in being a caregiver. Um...those two will be very different than what we address with the PAIRS program. PAIRS program is much more about exposure and giving more of...more knowledgeable...experience with seeing Alzheimer's and Alzheimer's behavior close.</p> <p>I: What do you think about...what do you think the best part, best part of the PAIRS program...what...?</p> <p>P: The best of the PAIRS program.</p> <p>S: I do think...for students to have real life experiences and understand the...the Alzheimer's, just not the textbook case. The people behave or react differently. People have...they have good things, have bad things. Okay. I...I think that's beneficial. I think...the satisfaction...that we enjoyed being able to participate in somehow... hopefully help future Alzheimer's patients. We...you know, that was good.</p> <p>P: Uh-huh.</p> <p>S: um...the interaction with somebody else is always good thing for us. Left to our own devices we get locked into and just seeing old people.</p> <p>P: Oh, come on.</p> <p>S: Well, that's my opinion. We're still gonna have nieces to get married again, so...</p> <p>I: So, do you mean that you are...mostly you spend with older</p>	<p>he does not participate in his wife's meetings at AA.</p> <p>He thinks the support group meetings are very different from the PAIPS program.</p> <p>PAIRS program is much more about exposure and giving more knowledgeable experience (to medical students) with seeing Alzheimer's and Alzheimer's behavior close.</p> <p>The best part of the PAISR program is for students to have real life experiences and understand better each individual with Alzheimer's (because they behave or react differently).</p> <p>That's good/ beneficial for them to have the satisfaction and enjoyable by being able to participate in somehow and help future Alzheimer's patients</p> <p>Also, social interaction is always good thing for them. <u>Limited social interaction and life?</u> "Left to our own devices we get locked into and just seeing old people."</p>
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<p>individual with Alzheimer's (because they behave or react differently).</p> <p>That's good/ beneficial for them to have the satisfaction and enjoyable by being able to participate in somehow and help future Alzheimer's patients</p> <p>social interaction is always good</p> <p>Social interaction with only older people</p> <p>A good opportunity to meet someone, very different than their normal everyday activities.</p> <p>An opportunity to establish multiple levels of relationships</p> <p>Good thing</p> <p>Having an exposure to younger people is a good thing</p>	<p>people or your peers, but...?</p> <p>S: A lot of the people we meet between...we will go...we have like season tickets to... dinner theater. Okay? We have...we go to the...our place. We go to the support group meetings. Most of the people who know at the organization, however, are about our age. Okay? So, we meet new people nine times out of the ten if it's from that event you... It's gonna be people in our age. This was a good opportunity to meet someone, you know, very different than our normal everyday activities.</p> <p>I: So, was it good for you? How was...?</p> <p>S: Oh, yeah. It was obviously good.</p> <p>I: In what ways? Just meeting the new...the younger...?</p> <p>S: It gives us, once again, to establish these multiple relationships or multiple level relationships. Okay? I think it is a good thing as well. um... It is part of...we really need somebody to mother or father anyway. Okay? But...um...but, having an exposure to younger people... is still a good thing.</p> <p>I: How do you think participation in the PAIRS program has affected you?</p> <p>S: Has affected me?</p> <p>I: Yeah.</p> <p>S: For the period of time, well, once again, pluses and minuses. I still...I have some feelings of a...failure...that we didn't meet the objectives. Okay? So, I have some...some bad feelings about that. But, in the meantime, we met somebody new and we got a good time...enjoyed what we were doing. That's a good thing. It's like good dates and bad dates, you know, you can have some...some disappointment.</p> <p>I: So...would you be willing to participate in the PAIRS program again if you are...if you are...if your</p>	<p>They have season tickets to dinner theater.</p> <p>Most of the people they know at AA are about their age (older adults)</p> <p>Participation in the PAIRS program was a good opportunity to meet someone, very different than their normal everyday activities.</p> <p>An opportunity to establish multiple levels of relationships</p> <p>Good thing</p> <p>Having an exposure to younger people is a good thing</p> <p>Pluses and minuses</p> <p>Minus: He still has some feelings of a failure that they didn't meet the objectives of the program (bad feelings about that)</p> <p>Plus: Meeting somebody new and having a good time was good. He enjoyed what they were doing.</p>
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<p>Minus: He still has some feelings of a failure that they didn't meet the objectives of the program (bad feelings about that)</p> <p>Plus: Meeting somebody new and having a good time was good. He enjoyed what they were doing.</p> <p>Willing to participate in the program again after he is retired and if there is no established criteria , in terms of hours of meeting (more flexibility /freedom in time)</p> <p>He just hated the idea that they didn't meet the criteria of the program</p>	<p>schedules are more available or...?</p> <p>S: Guess we get to the... Well. Okay. Let me put it this way. If we get to the point that I'm retired...and we can meet on the other person's schedule or frequently...then I will favor that. If we participate in the PAIRS program again and there were not...an established criteria that were supposed to meet like four hours a month. If we...the criteria was okay you meet whatever can be convenient. Okay? Good, I am good with that. I just hated the idea that we missed the objectives....at all. We didn't meet the criteria.</p> <p>I: Okay. I see. She said that she is very outgoing person and she likes meeting people, so did you feel any...any benefit on her... on being more like herself when she...after she started meeting, participating in the PAIRS program? Do you feel like she is more like...?</p> <p>S: Once again, consider we only met three times.</p> <p>I: Yeah. I understand that.</p> <p>S: How we were together was very good. um.. Marcia used to, she owned and operated a Curves, which is a ladies exercise center. And she was one who encourages each of the members then to do more, to do better, help them become physically fit. And...achieve their objectives. And she always liked that interaction with Marcia's every people...um...as we...as the curves...we had to get rid of the Curves as business. And so...that was a big whole in her life. And so for her to take this opportunity, then to be wanting to be equal but to...then the coach...as you...as you... That was a good thing for her. She enjoyed it very much. She would enjoy it again.</p> <p>I see. Is there anything you'd like to add or...?</p> <p>S: don't know.</p> <p>P: I think I told you my whole life</p>	<p>He is willing to participate in the program again after he is retired and if there is no established criteria , in terms of hours of meeting (more flexibility /freedom in time)</p> <p>He just hated the idea that they didn't meet the criteria of the program</p> <p>His wife owned and operated a ladies exercise center and she encourages each member to do more, do to better, help them become physically fit, and to achieve their objectives.</p> <p>She liked that interaction with every members in her exercise center. That was a big or whole part of her life (as a friend and coach)</p>
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<p>His wife owned and operated a ladies exercise center and she encourages each member to do more, do to better, help them become physically fit, and to achieve their objectives.</p> <p>She liked that interaction with every member in her exercise center. That was a big or whole part of her life (as a friend and coach)</p>	<p>story. Ha ha. [Laugh all together]</p>	
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Themes –Interview 5 (P5: person with dementia, C5: husband, I: interviewer)

Themes	Quotes
<p>An enjoyable opportunity to go out, socialize with people, and do different things, that are aligned with her identity (as a people person, likes going out, being active)</p>	<p><u>-An enjoyable opportunity to go out and meet new friends</u></p> <p>I: Did you have any expectation before participating in the PAIRS program? P5: I had no idea what it was gonna...entail to, but...for...for me, it's just the opportunity to... get out about and...meet new friends and... see old friends, so...yeah.</p> <p>I: Why did you decide to participate in the PAIRS program, the social gathering with a medical student? P5: Um...because it was...um...enjoying. Um...last year that we had...um...like I said, there was a little, some...some bumps [because of scheduling issues]... in it, but um...as far as the whole thing, I found it, you know, it went well. <u>We...um...I enjoyed...you know...being out</u> ...</p> <p><u>-She likes being with people and going out (being in the outside)</u></p> <p>P5: Well. Probably not necessary a specific...um...<u>I just like being...I am a people person. I like being with people. And...this gives me the opportunity to... interact with...you know... our...[tapping on the table to help her thinking] our friends...so</u></p>

to speak. And um...so and then, when I get home from at 3 O'clock when... and then my husband and I go out and walk our dog and...you know...go to grocery store whatever what we need to do the end of that. Then, we come home and pretty much sit down from TV. Ha ha. [cough] So...but um...we do prefer to...as long as we can get out and in the air and um.. the... outside. We are happy people. I am a happy person. Ha ha. So... that's...

P5: ...I...I've always been a very outgoing person and when I had my business, I had people coming in and out...all day long. When we...I ran Curves, so... a fitness center. And so...I was active the whole time. And um...then when I... had to...well they told me I couldn't do it anymore...um...it was kind of like...it took me a long long time to...deal with it because I...I had some anger issues. I think we all do.

-An opportunity to do different things that might help her feel more active (her identity and goal)

P5: Yeah. Her children wanted to come and um...like I said, we had a lot of fun. They had a bouncy ball and you know all kinds of things to do. And...um...[her husband's name] and I are not...real...I mean we [she and her husband]are active...but as far as...is trying to find something else to...to... We go to a lot of movies. And um...if there is any good ones... you know...there's kind of that...you know good movies and then...you have to wait until the next good one comes. So...we are avid...movie... um...and...golly gee, I don't know. um...we are pretty boring.

I: Why? Why do you think you are...?

P5: Pretty boring?

I: Yeah.

P5: Um...I think it's just because that we've lived here for... so long. Now, you know, we go to Saint Louis and visit our kids. And...that's a lot of fun. We have a daughter that lives in Arkansas, so we take a weekend. Nice weather, you know, we go up and um...go to... her house... and then she comes to...to us. And um...so, I mean, you know, we are... it, it seems like we are always...going somewhere or somebody is coming to our house. And um...but, um...um...

I: So, do you think it's the same pattern...for...?

P5: It's pretty much a same pattern, yeah.

P5: I... enjoy... just about everything, you know, because there's an opportunity to do...um...different things. And um...and I, like I said, my opportunities, not my opportunities, but my...um... running out the things to... keep me...very active, so that's the goal that we set up that we want to make sure that we are active and...home and um...

I: So, being active is kind of what you, what you think yourself?

P5: Yeah.

P5: I think...the PAIRS program gave me more opportunities...

I: For... socializing?

P5: For socializing with...other people and other...ac...um...area, you know, different things...um...that's probably...

P5: It's [Science City] a...kind of fun one. Um...it's...um...it's a good one for...

	<p>little kids, little, smaller kids or even... teenagers. And um...<u>but I mean it's always fun to go and see about...um...other places and that sort of things</u>, so...maybe we can figure out something.</p>
<p>Being connected to the community (feeling included in the community; beyond her area)</p>	<p><u>-A good opportunity/outlet to do something else with another person beyond her area in the community (just not in her home or in her group at Alzheimer's Association): Medical students who want to/are willing to learn about Alzheimer's were good medium that link her to the community.</u></p> <p>P5: um...this is a good opportunity for us [she and her husband] to get out and do something else... with another person or people, so...</p> <p>I: What was the best part of the PAIRS program? What did you like the most? P5: <u>Um...just meeting...other people and um...then it is nice to...when...we go back to support group or whatever then</u>, um...sometimes, somebody say "Are you with the...[tapping on the table because she cannot remember the word (PAIRS)] support group, you know, the PAIRS group?" and I...then I will say, "Yeah, I am with dadadadada." <u>and then we kind of chit chat a little bit about what they are doing...</u> that might help us be able to find out something that we can do to help you [students] or something like that, so..."</p> <p>I: So...from my understanding, were you trying to help the medical students? P5: No, I don't think I am trying to help them [medical students]. Um...I just...I think what...in my mind is that...you are trying to...I am trying ...you are getting in...education on somebody from who isn't an Alzheimer's person, somebody who knows Alzheimer's are of that is...is delved with Alzheimer's. And um...so...[sigh] I lost my train of thought.</p> <p>I: The questions are really deep...so...it's hard to... P5: Yeah. Um...</p> <p>I: So...you are trying to...because the medical students have some wants to learn better about the people with Alzheimer's? P5: Yeah. That's what I gather. That...we can...um...<u>I think it gives us an outlet...to... be just not in my home and just not in our place. There's an opportunity to get out about and...either be in the community or...um...just walk go down to the plaza, walk, you know, just...um...or whatever.</u></p> <p>I: So, do you mean that being in the community more often or...? P5: I don't understand what you are saying. I: So, going out to the community more often, beyond your place you usually go to... P5: Yeah. Uh-huh. I: So, that was the best part to be...to go out or...? P5: Um...usually we would do and find an activity... and um...end of Oct...since she [her pair] had a dau...the kids then <u>we tried to... circle under around with being with kids, so everybody could be part of it. And um... so that's what... I kind of like...I am not sure what, you know...what I can... help, you know, or...what we want to do. So...um...just figure out. I mean nothing else just...go for walks.</u></p> <p>P5: Um...there were... times that I would, you know, I felt like that I was...you know...of here everybody else is over here having fun.</p>
<p>Felt comfortable</p>	<p><u>- She feels comfortable with her group at Alzheimer's Association and feels</u></p>

<p>because she was with her group (she feels comfortable with) and she was not an individual that was identified as a person with Alzheimer's</p>	<p><u>uncomfortable beyond her area</u></p> <p>P5: I think it's a great program. Um...if...you know I go to the...what we call our place... with the...you know with <u>our group</u> that we...I go... two days a week... and um...almost all day. And um...that is a very good outlet for me [emphasizing a little bit] because I am with my peers...and um...you know I am not...[pause and sigh]. <u>I feel comfortable, you know, with that, and um...but when I get...you know when I get out of my...area that I am comfortable with, then I get...it's, it's harder for me...so...</u></p> <p><u>-She felt like that she was in a group when meeting with medical students. She was not an individual who was identified as a person with Alzheimer's. This helped her to feel comfortable.</u></p> <p>P5: ...You know and um...but um...yeah, it's just...<u>being with somebody that...can...identify...you know... that I have Alzheimer's</u> and so on. I am a little slower when I have to...when I am talking... if I am not comfortable. You know that sort of thing. But other than...you know...I've...tried to...meet new people and um...I don't know what else to say. Ha ha.</p> <p>I: So...because you said sometimes you feel uncomfortable when you meet new people, but the medical student already...when you were meeting at the first time, um...she already knew that you have Alzheimer's. Do you think this made the relationship easier or made you feel more comfortable?</p> <p>P5: Possibly. Yeah. Yeah. <u>Because...I feel like that I'm...a group. You know, I'm not an...individual that I...I can...identify with.</u></p> <p>I: So...because the PAIRS program is...also a part of the program of your group. So, that's why you felt comfortable?</p> <p>P5: Uh-huh. Yeah.</p> <p>I: So, you felt more comfortable because you are...even though this ...the meeting with the medical student is one-on-one, but because it's from your group...</p> <p>P5: Yeah.</p> <p>I: So...it's more comfortable.</p> <p>P5: <u>Yeah. And...we [her group at Alzheimer's Association] have...talked about our PAIRS group, you know, when they...during a...if we have a little law in the...this fourth group. Um...somebody will come over and say "Are you with...you know...the PAIRS group?", and you know, "What do you gonna do? What do you guys gonna do to... entertain her or him?" or whatever, you know. And um...so...it's a...you know...we're pretty tight... um...group, kind of like when you were in... junior or high school, you know, you got your little clique of friends and...so...that's kind of I...that's kind of how I...identify them. You know, they are my...my new friends.</u></p>
<p>Having multiple relationships was good</p>	<p><u>-Her relationship with her pair as friends and a mother-daughter; He felt the same way (very natural to play parental roles to anybody in similar age to their own children).</u></p> <p>C5: Um...There was a very direct relationship of...these too getting to know each other and learning about each other, their past, where they came from...um...what they do. It happens that this, the medical student we had was about the age of our oldest daughter, okay? and had two children of her own. And therefore, there was</p>

some whatever mother-daughter relationship in...basis on that as well. Um...my wife was very maternal... toward the student. Um...the student goes to school working full-time. Yep, I felt the same way. We...I mean we are parents, that's what we do. But, the relationship was on a couple, three different levels. There was a level in which they were equals, okay? And they were both equal...

I: Oh, I see.

C5: And then it was some what this maternal relationship as well.

I: I see. So, at the beginning, you felt like their relationship is more like a friend

C5: Yes.

I: Or some...like some partner. But after you spend more time, she feels like oh, she is giving more maternal role because she ...

C5: Yes. That's natural. Anybody that age. It wasn't unique to this student nor the fact that this student had two children. Okay? Anyone that was about to the age of our oldest daughter, okay? and has her trials and tribulations in her life. We are gonna take a very paternalistic or maternalistic approach to them as well. It's gonna happen.

I: Can you tell me some stories about her maternal relationship with her, with the medical student?

C5: The thing of the Pumpkin Patch. The Pumpkin Patch is not necessarily about...adults at all. This isn't some place you will go to talk at the coffee shop sitting like adults, okay? This is much more case... at the Pumpkin Patch, they had a wagon ride out of the fields where the pumpkin tree grow for the kids to select pumpkins. Okay? They had...uh, you know what a maze is? ...um a maze, where you walk, it's like a uh, in England, they make them out of hedges, you walk in and you run into a dead end, you have to back up and you have to find a path to get through the maze. Okay? They do the same thing with hay bails during here, okay?...during October...um...

I: Halloween

C5: Halloween type of activities. We took the kids over the kitchen, never had... any hot apple cider.

P5: Uh-huh.

C5: Okay? We bought them to drink...you know something that they had never tried before. And so...yeah.

I: So, that activity wasn't for you.

C5: It was much more about...

I: for the medical student's...

C5: Much more about parenting and, and...it...really...the kids weren't the basis of it, but kids were much part too. You remember the scheduling issue that we had. Well, anytime...we had picked time for I was available. Okay? And we also had then to either take care of her kids or we had picked time for she had babysitting available. That was a big part of this logistics as well. Okay? So...

P5: So just being in the three of us... ha ha.

C5: We went to Nelson-Atkins and one of their major sections we toured was the African Art. Okay?

P: Yeah. Uh-huh.

C5: And their relationship can kind of shift. Okay? It is no longer us being a parent. Okay? She was all about...telling us more...about African Art which we knew very little about. Okay? So, that was much more case of the equal or her taking the upper side...of the...the worthy authority.

I: Right. So... you felt like there were some two or three relationships with...

	<p>C5: Get multiple levels and for the most of part, all same time. I: Do you think this was good...that... having that kind of relationship was good? C5: Oh, yes. I: Being a...sometime being a more maternal role, playing the maternal role, sometime being an equal as a friend and... C5: Well I think it was definitely a good for, thank for...us...not necessarily just now, not necessarily just for Alzheimer’s patients. To be able to meet new people and establish new relationships is always good thing. Sometimes, even if they work on their doctorate whatever.</p> <p><u>-Meeting with a younger person [the medical student] allowed them to have multiple relationships (Most of the people they meet and interact are older adults and most of the new people are through the support groups at Alzheimer’s Association.)</u></p> <p>C5: um...the interaction with somebody else is always good thing for us. Left to our own devices we get locked into and just seeing old people. P5: Oh, come on. C5: Well, that’s my opinion. We’re still gonna have nieces to get married again, so... I: So, do you mean that you are...mostly you spend with older people or your peers, but...? C5: A lot of the people we meet between...we will go...we have like season tickets to... dinner theater. Okay? We have...we go to the...our place. We go to the support group meetings. <u>Most of the people who know at the organization, however, are about our age. Okay? So, we meet new people nine times out of the ten if it’s from that event you... It’s gonna be people in our age. This was a good opportunity to meet someone, you know, very different than our normal everyday activities.</u> I: So, was it good for you? How was...? S: Oh, yeah. <u>It was obviously good.</u> I: In what ways? Just meeting the new...the younger...? S: <u>It gives us, once again, to establish these multiple relationships or multiple level relationships. Okay? I think it is a good thing as well. um... It is part of...we really need somebody to mother or father anyway. Okay? But...um...but, <u>having an exposure to younger people... is still a good thing.</u></u></p>
<p>Engaging in the activities again they used to do with their own children and grandkids</p>	<p><u>- A lot of fun and a good opportunity to play again and reminds the couple of their happy memories with their own children and grandkids</u></p> <p>P5: She had two children of a boy and a girl and they were a lot of fun, you know. I really enjoy playing with kids. And um...we went to...the excellent Pumpkin Patch and all of that, so... I: Was it near to the Halloween...? P5: Yes. Yeah. Yeah. It kind of...you know...mashes up with the Halloween area. And um...we had some nice weather [talking slowly to emphasize “nice weather”], and so that was really nice. And um...so...if I... you know...I’ve done it several times...um...with the Pumpkin Patch...with our kids themselves and with the PAIRS group and because some...her having a little one that was a good... opportunity to play again.</p>

	<p>I: So, do these activities have any special meaning to you? Going to some gallery, or going to the Pumpkin Patch or...?</p> <p>P5: You know. Like...I think the Pumpkin Patch, we [she and her husband], we connect that because...it's more...um...for the kids...</p> <p>I: So you wanted to...</p> <p>P5: Yeah. Her children wanted to come and um...like I said, we had a lot of fun. They had a bouncy ball and you know all kinds of things to do. And...um...my husband and I are not...real...I mean we are active...but as far as...is trying to find something else to...to...We go to a lot of movies. And um...if there is any good ones... you know...there's kind of that...you know good movies and then...you have to wait until the next good one comes. So...we are avid...movie...um...and...golly gee, I don't know. um...we are pretty boring.</p> <p>C5: Um...taking the kids to the Pumpkin Patch...had a special meaning in the, in our grandkids we knew. We always used to take them each year to Pumpkin Patch. Okay?</p> <p>I: So, this is real...this reminds you of some happy times...</p> <p>C5: Right. Right.</p> <p>P5: Yeah. Uh-huh.</p> <p>C5: Taking the kids to... Union Station...reminds me of the time when I used to take our kids to Union Station to see the big train exhibit, you know.</p>
<p>It wasn't a smooth event because of scheduling issue</p>	<p><u>-We got along in the beginning, but, from the middle, it wasn't a smooth event because of scheduling issue</u></p> <p>P5: Well. um...one of, we had a... hit, hitch in the beginning, not coming in the middle of it we got it started and then she had to go... on a trip and it took, you know, she was gone for one two three months...</p> <p>C5: Not... too much for that. We've got three weeks after she came back.</p> <p>P5: And came back and just kind of like dis.. dissened...</p> <p>P5: ...Like I said, what happened was that she had to take....she went to...um... Africa. She had to go to Africa for some reason. And so...it, it took a big chunk of the... time that we had... for... our place and um... you know we had that problem.</p> <p>P5: Um...I...we [she and her husband] enjoyed it. It seemed like...um...we got...when they... the other lady [her pair] that was our... like you, you know. And...um...when she had leaved and gone for an extended time, it kind of had broken up. You know what I am saying? <u>It's not... it wasn't a smooth...um...event. It was, you know, because there she was able to come and then she wasn't able to come.</u> And... that sort of thing. But, we [she and her husband] really enjoyed...the...the program even with her. And um...so...</p> <p>P5: ...We...you know...<u>we got along okay. I mean we had...um...but there were just...um...she had more on her plate that she can handle... that to be in the PAIRS group. And... you know, with her kids, having to go back to Africa and all of that,</u> so...there was a big... spot there that kind of like...okay, but it's just...you know, it's not that big of deal. You know...we dealt with that.</p> <p><u>-Hard to schedule because he works full time, she doesn't drive outside the</u></p>

	<p><u>neighborhood, and her pair was busy with her school and her pair's own kids.</u></p> <p>I: So, you participated in the activities together? [The spouse coughs] When you went to the art gallery, you were with them, right?</p> <p>C5: Yes. What this amounts to is that my wife doesn't drive outside the neighborhood anymore. She gets turn around and she gets lost. And so, I was concerned it would've worked out better many times if she could've driven some places to meet the PAIRS candidate, okay? But, I couldn't have her drive by herself.</p> <p>C5: Sometimes we didn't meet four hours each month. Okay. That was just because of the scheduling issue. Okay? And part of that, it was just much my problem or my fault as anybody else. And that...the hours the student had available, okay?</p> <p>P5: Uh-huh.</p> <p>C5: Were hours that I was working and I couldn't get my wife there. And I really felt bad. My wife is quite capable of driving, but the problem is you never know when she is gonna get turn around and disoriented, and she's lost. And um...when we had daughters here in town, she can call. She used to, when she got lost, she called one of the daughters and then pulled up the Google map and say. "Okay. Start reading this screen side to take you as you go by." Then we figured out where she was from there and then talked a little bit on the phone how to get back. Oh...but that wouldn't work out so well while I was at work. So...anyway, I felt bad that we didn't do that. We enjoyed time together. We had...we had a very interesting PAIRS person.</p> <p>I: Wow. So...do you think it would be enjoyable if you can meet the medical student more often?</p> <p>C5: Yes. That's what I was talking about. I didn't think we would do this again until, after I retire.</p> <p>I: Because you...</p> <p>C5: To where I'm no longer in impediment they want to meet in the afternoon some place then great. I can drive there. I don't have to participate. You know, I can go to something else. But I can't give you what you need to be... without having...I didn't really like the idea of ... by depending on the student...to come pick her up, take her some place, and bring her back then. I didn't...that didn't appeal to me either.</p> <p>I: Why?</p> <p>C5: That's putting too much burden on the student...in my opinion.</p> <p>I: Even though the student is very willing to do that way?</p> <p>C5: Even though the student is willing to do that, that's still...</p> <p>I: You don't feel comfortable?</p> <p>C5: Yeah.</p> <p>I: I see.</p> <p>C5: That's pushing too much of the responsibility off on them.</p> <p>P: But, it is also limiting.</p> <p>C5 Yeah. Limits what we can do.</p>
<p>Pluses and minuses on the couple's feelings</p>	<p><u>-Effects on her feelings:</u> Plus (Obvious satisfaction and joy by having the chance to talk with another person) & Minus (frustrating when the schedules didn't work out)</p> <p>I: Do you think her participation in the PAIRS program has affected her feeling or</p>

	<p>mood?</p> <p>C5: Well. Okay. um... You have pluses and minuses, just like we have the relationship in multiple levels, you always have pluses and minuses. And during that program itself...um...whatever we would meet, and there was, there was obvious satisfaction and obvious joy about we had the chance to talk a little bit. After she came back from her trip to um...Cameroon, okay? and had...she had slide of program...</p> <p>P5: Yeah.</p> <p>C5: about...of...of the pictures she had taken of her home village, okay? and her family.</p> <p>P5: Uh-huh.</p> <p>C5: We really enjoyed seeing those. Okay? That was, that was fantastic.</p> <p>P5: Uh-huh.</p> <p>C5: But, at the same time too, when their time's, the schedules didn't work out, we weren't meeting the obligation of what we signed up for the program. That was frustrating as well. So, how you...how you balance out all and, all and all is a good thing, frustrating but willing to do it again. Okay? But, it happens both ways. It just...everything else in life.</p> <p><u>-Effects on his feelings:</u> Plus (Enjoyed meeting somebody new) & Minus (feelings of a failure that they didn't meet the objectives of the program)</p> <p>I: How do you think participation in the PAIRS program has affected you?</p> <p>C5: For the period of time, well, once again, pluses and minuses. I still...I have some feelings of a...failure...that we didn't meet the objectives. Okay? So, I have some...some bad feelings about that. But, in the meantime, we met somebody new and we got a good time...enjoyed what we were doing. That's a good thing. It's like good dates and bad dates, you know, you can have some...some disappointment.</p>
<p>Hope to help the future people with Alzheimer's and Alzheimer's research</p>	<p>I: What do you think to be the best part of the PAIRS program?</p> <p>C5: I do think...for students to have real life experiences and understand the...the Alzheimer's, just not the textbook case. The people behave or react differently. People have...they have good things, have bad things. Okay. I...I think that's beneficial. I think...the satisfaction...that we enjoyed being able to participate in somehow... hopefully help future Alzheimer's patients. We...you know, that was good.</p> <p>P5: Uh-huh.</p> <p>C5: If there is something that we can offer, this is, this is not about ...helping my wife and I. Okay? This is about helping research and Alzheimer's, period? Okay?</p> <p>C5: Our participation might help people down the road. If we help the students understand Alzheimer's better, so they can treat people better. That's a good thing. But, this is, this was much about...helping the Alzheimer's research as we understood, okay? More so than something that will be a direct benefit to us.</p> <p>C5: Right. Right. Anything that we can do to help Alzheimer's research, we are willing to try.</p>

	<p>C5: ...PAIRS program is much more about exposure and giving more of...more knowledgeable...experience with seeing Alzheimer's and Alzheimer's behavior close.</p>
<p>Her new role in her group that is aligned with her self-identity</p>	<p><u>-She likes her role (helping and encouraging people) in her group at Alzheimer's Association because she feels that she is being very active and she is helping. She regards this as a very rewarding opportunity to help.</u></p> <p>P5: ... And I...so...she [Her group facilitator] kind of...relies on me to...help...the other people who when they had problems. And I can always...you know, she look at me and go. Like this, I know. Okay, I need to go over here and help him, or I need to go over there and help him. So, we have a good...I feel like that we have a good...reformed... you know good relationship. Um...but...you know I try not to...be to...abrupt with people or you know say "Oh, no no no. You can't do like that." Ha ha.</p> <p>I: So, at the Alzheimer's asso, in your group, you are kind of... playing leadership roles?</p> <p>P5: I...yeah, I think I do a little bit of leadership, you know.</p> <p>I: That's good.</p> <p>P5: And I...so...and... [Name of her group facilitator] will...when there's time to become...and she will kind of pull me over and say "Someone's so...struggling with something, would you kind of... watch...for him?" "Not a problem." You know.</p> <p>I: Do you like...doing that way, or...?</p> <p>P: Yeah. Yeah, I do. Because I...I feel like that I am being very active plus I am helping. And...I am not always the one. I mean there's a lot people that are going to do a lot of good...um...good things and um...Nobody sits...you know it's not like their cliquie groups. You know you just kind of walk in and kind of go. Oh, I don't want to sit...sit down and... maybe some of them come over and sit... by you or something else...or whatever. So...yeah...it's a...very rewarding opportunity to...to help.</p> <p>P5: ...I...I like it that [Name of her group facilitator] will come to me and say, you know "He's struggling or she's struggling, would you sit with her today?" or something like that "Not a problem." You know...and ...as far as I know I am not everybody...you know...problem.</p> <p>C5: How we were together was very good. um.. My wife used to, she owned and operated a [name], which is a ladies exercise center. And she was one who encourages each of the members then to do more, to do better, help them become physically fit. And...achieve their objectives. And she always liked that interaction with my wife's every people...um...as we...as the curves...we had to get rid of the [name] as business. And so...that was a big whole in her life. And so for her to take this opportunity, then to be wanting to be equal but to...then the coach...as you...as you... That was a good thing for her. She enjoyed it very much. She would enjoy it again.</p>
<p>Her strategy</p>	<p><u>-Use of humor when having difficulty in finding the word</u></p> <p>P5: It is a...spring training is the boys from...the...um...tell you tomorrow. Um...[tapping on the table to help herself remember the word] baseball players.</p>

-Her efforts to speak correctly (organizing thinking by starting talking again)

P5: Um... Yeah, sometimes. My oldest daughter is going to come with us this year. Um...one time, we had...Okay. I will start this. My oldest daughter is going to come this time. My brother and his wife are coming. And then we have two people from Texas. ...

-Working as team with her husband in talking (she tries to engage in the talk by responding to/agreeing what he says mostly and by adding content if she can remember)

C5: I think she is looking for what kinds or types of activities we did.

P5: Oh, types of activities.

C5: We went to Nelson-Atkins museum.

P5: Uh-huh.

C5: We went to Harry Truman's Library.

P5: Right.

C5: We went with her children as well to a...um...

P5: Farm...

C5: Pumpkin Patch

P5: Yeah, the Pumpkin Patch.

C5: Fall of the year.

P5: Uh-huh.

C5: Um...we went to...the Science City.

P5: Uh-huh.

C5: And um...Union Station.

P5: Uh-huh.

C5: And...we took her kids then we went to the Science City and we went over to...a Crown Center...

P5: Yeah.

C5: To have lunch. Um...That's about it... that I can remember.

I: So, you were...with her all the time, with them all the time? [Looking at the spouse]

P5 & C5: Yes. [Answering at the same time]

C5: ...

P5: Uh-huh.

C5:...

P5: Uh-huh.

C5: She was...not from the States. She was from Cameroon.

P5: Yeah, Cameroon. Yeah.

-Relying on her husband in recalling/remembering something

P5: Yeah. We went to Science City. We went to Pumpkin Patch. We went to...um...Y [name of her husband], where did we go? [Asking her husband in the other room]

-Reminiscing happy memories that she and her husband can laugh about

P5: ...And um...then you...you go out and watch the ball games or you hike. Bill and I are big hikers. And um...so...but last couple of times when we were hiking,

	<p>we both got lost. Ha ha. And it's kind of funny when you call your daughter and just say...</p> <p>I: Oh, we are lost.</p> <p>P: We are lost and we are not sure where we are at, but we are in Arizona somewhere. Ha ha. [P and I laugh]</p> <p>I: Oh, that's great.</p> <p>P: Yeah. So...it's...it's a good thing that we can laugh about...um...</p> <p>I: That's funny.</p> <p>P: Yeah. I told her one of these days we're just going to walk on off the ocean.</p> <p><u>-She makes herself busy within her ability</u></p> <p>P5: Well. I don't ...you know when I am just home by myself...it...you know...it's...I get... I read...not a whole lot ...because I don't, can't focus that well, but I...I find myself busy. And um...so...you know I...I can always find something to...to do, so...</p> <p>P5: Yeah. You know, I go to the Y and because this is the area, you know, where we live that I can drive...[a small laugh] to...um...you know go to water aerobics and...um...I have a friend that um...she's in Arizona right now, but she always comes in...we do yoga and that sort of thing, so... Yeah, I stay busy with...with that so...</p> <p><u>-She has tried to meet new people although she feels uncomfortable when being with somebody that can identify her as a person with Alzheimer's.</u></p> <p>P5: ...You know and um...but um...yeah, it's just...being with somebody that...can...identify...you know... that I have Alzheimer's and so on. I am a little slower when I have to...when I am talking... if I am not comfortable. You know that sort of thing. But other than...you know...I've...tried to...meet new people and um...I don't know what else to say. Ha ha.</p> <p><u>-Dealing with challenges during the PAIRS program</u></p> <p>P5: Um...the medical, medicine...the one that we had?</p> <p>I: Yeah, your pair.</p> <p>P5: Oh, my pair. We...you know...we got along okay. I mean we had...um...but there were just...um...she had more on her plate that she can handle... that to be in the PAIRS group. And... you know, with her kids, having to go back to Africa and all of that, so...there was a big... spot there that kind of like...okay, but it's just...you know, it's not that big of deal. You know...we dealt with that.</p> <p><u>-Dealing with challenges in accepting and coping with impacts due to Alzheimer's</u></p> <p>P5: Um...there were... times that I would, you know, I felt like that I was...you know...of here everybody else is over here having fun. But... it's, it's not... a big of deal for me. You know, it's not like...I'm mad because... I can't go do this. That's, that's not...not me. Okay, if I can't do it, well, okay, I will deal with it and eventually I will get it. You know, we will get it figured out so I can go or can do. And um...so...[cough] I'm sorry. That's because of cold. So, Anyway, that's...pretty much...everything in a nutshell so, anything else you need to...?</p>
His strategy	<u>-He helps her understand the question correctly and gives her a chance to talk by herself and starts talking after noticing she has difficulties in remembering activities</u>

	<p>P5: Well. um...one of, we had a... hit, hitch in the beginning, not coming in the middle of it we got it started and then she had to go... on a trip and it took, you know, she was gone for one two three months...</p> <p>C5: Not... too much for that. We've got three weeks after she came back.</p> <p>P5: And came back and just kind of like dis.. dissened...</p> <p>C5: I think she is looking for what kinds or types of activities we did.</p> <p>P5: Oh, types of activities.</p> <p><u>-He understands what she tries to say and says it in a clear/understandable way</u></p> <p>C5: That's pushing too much of the responsibility off on them.</p> <p>P: But, it is also limiting.</p> <p>C5 Yeah. Limits what we can do.</p> <p><u>-He jumps in talking to correct what his wife says.</u> (She remembers that her pair was gone for three months. He corrects that her pair was gone for three weeks.)</p> <p>P5: Well. um...one of, we had a... hit, hitch in the beginning, not coming in the middle of it we got it started and then she had to go... on a trip and it took, you know, she was gone for one two three months...</p> <p>C5: Not... too much for that. We've got three weeks after she came back.</p>
<p>The couple's strategy</p>	<p><u>-Trying (making efforts) as much as they can</u></p> <p>P5: And she...and then we came home and talked together. And um...and we talked about "Oh, this is gonna be a problem, here." this, you know, "This is gonna be a problem here, but we will see what tell we can get it done." And um...so...</p> <p>C5: Right. Right. Anything that we can do to help Alzheimer's research, we are willing to try.</p> <p><u>-Working as a team in making decisions</u> (whether they will participate in the program or not)</p> <p>I: So, at that time, she [the person with Alzheimer's] decided "Oh, I wanted to do this." and she told about this to you?</p> <p>P5: I think she [social worker at AA] talked to my husband first.</p> <p>I: Yes.</p> <p>P5: And she...and then we came home and talked together. And um...and we talked about "Oh, this is gonna be a problem, here." this, you know, "This is gonna be a problem here, but we will see what tell we can get it done." And um...so...</p> <p>C5: We kind of made a decision together.</p>
<p>Impact of dementia</p>	<p><u>-She doesn't remember her pair's name.</u></p> <p><u>-She does not feel comfortable when she is in a big group of people beyond her group at AA. She doesn't like to talk with somebody beyond her group because she fumbles.</u></p> <p>P5: ...Um...if...you know I go to the...what we call our place... with the...you know with our group that we...I go... two days a week... and um...almost all day. And um...that is a very good outlet for me [emphasizing a little bit] because I am</p>

with my peers...and um...you know I am not...[pause and sigh]. I feel comfortable, you know, with that, and um...but when I get...you know when I get out of my...area that I am comfortable with, then I get...it's, it's harder for me...so...

P5: The people in...in my group are...are my best buddies...so to speak. And if I am in a big group... of people that I don't know I am not... comfortable, you know. I...I've always been a very outgoing person and when I had my business, I had people coming in and out...all day long. When we...I ran Curves, so... a fitness center. And so...I was active the whole time. And um...then when I... had to... well they told me I couldn't do it anymore...um...it was kind of like...it took me a long long time to...deal with it because I...I had some anger issues. I think we all do. And um...but...I think that's...what we call our places one of the best things that I... I have been...expand... experiencing with.

P5: ...So... um...that has become my... area of my friends, you know. And when I am out about with, even if I know them...real...you know I...I still... have difficult. I don't like to talk...with somebody that I haven't... um...just because I...get so... fumbled up in my brain. [A small laugh] So... but for the most part, I think it's...

P5: ...You know and um...but um...yeah, it's just...being with somebody that...can...identify...you know... that I have Alzheimer's and so on. I am a little slower when I have to...when I am talking... if I am not comfortable. You know that sort of thing. But other than...you know...I've...tried to...meet new people and um...I don't know what else to say. Ha ha.

-Experienced stigmatizing response of others when she was open about her diagnosis

P5: Well. I've been very open about...you know... I've got Alzheimer's. And um...and you know... people can look at you and kind of funny...you know giggle over it, so...I...

-Anger and long time to accept/deal with Alzheimer's: Anger issues when she was told that she couldn't run her business anymore and it took her a long time to deal with/accept it.

P5: ...I...I've always been a very outgoing person and when I had my business, I had people coming in and out...all day long. When we...I ran Curves, so... a fitness center. And so...I was active the whole time. And um...then when I... had to... well they told me I couldn't do it anymore...um...it was kind of like...it took me a long long time to...deal with it because I...I had some anger issues. I think we all do.

-There were times when she felt isolated

P5: Um...there were... times that I would, you know, I felt like that I was...you know...of here everybody else is over here having fun.

-Difficulty in finding the word

P5: It is a...spring training is the boys from...the...um...tell you tomorrow. Um...[tapping on the table to help herself remember the word] baseball players.

P5: And so...we've done this for many many years. That we always... fly out to Saint Louis...I mean no...not to...[because she said Saint Louis instead of Arizona

	<p>again].</p> <p><u>-Difficulty in planning activities/things in daily lives?</u> P5: Yeah. We [her group at Alzheimer’s Association] do. We sing. We...um...dance a little...and um...we do lots of activities for the community. This last...yesterday, we...I was there all day. And um...we were getting ready to put...um...the little plastic eggs. And um...so...we were stuffing them...with the...um...to give the kids...for them. [Name of her group facilitator] will...take home to where...you know, supposed to go. So, that’s...when I’m...I’m ...know what I am doing... and like...you know. I can get into that. I like to...okay, we want this and we can do this and that, you know, and...and...</p> <p><u>-Difficulty in concentration (reading)</u> P5: Well. I don’t ...you know when I am just home by myself...it...you know...it’s...I get... I read...not a whole lot ...because I don’t, can’t focus that well, but I...I find myself busy. And um...so...you know I...I can always find something to...to do, so...</p> <p><u>-Losing her train of thought</u> P5: ...And um...so...[sigh] I lost my train of thought.</p>
<p>Her expression of her self-identity and shared identity with her husband</p>	<p><u>-A very outgoing, active, direct person</u> P5: I’ve always been a very outgoing person and when I had my business, I had people coming in and out...all day long. When we...I ran Curves, so... a fitness center. And so...I was active the whole time.</p> <p>P5: I am a very outgoing person. Yeah. It doesn’t take much for me to say...I am a very...what’s such thing? [Saying because she cannot remember the exact word] I say what I think. Ha ha. I: You are very direct? P5: I am a very direct person. You know, and um...</p> <p>I: You said that you were...you were a very active person. P5: Uh-huh. I: So, do you think you are not very active or...? P5: No, I think that...um...you know... like said with going to our place [the Alzheimer’s Association]. And then my husband and I, we, take our dog, you know, every day...for a walk and we have a park down at... English Landing [name of the park]. And um...so we go down to... almost every day unless it’s freezing or...and um...so, yeah that’s pretty our...</p> <p><u>-She loved to drive.</u> P5: I loved...to drive. You know.</p> <p><u>-She enjoys playing with kids</u> P5: I really enjoy playing with kids.</p> <p>I: You also said that you like playing with kids before, so... P5: I...I...yeah...I enjoy playing with kids. We have two girls at the...Cameron and play every once in a while. And we still have the playroom...when our...[her</p>

grandchild name] is...how old she is? She is nine. I think now she is getting old. We have a playroom in there in a...so she always goes in there.

I: Your grandchildren or?

P5: Uh-huh. But they don't...you know...they don't see as anymore, we're almost pretty ready to put the bunk beds away [cough] but anyway. Yeah. It's a...

-She and her husband like sports (outdoor activities) and being in the outside.

P5: My husband and I are big hikers.

P5: We [she and her husband] might go to a...Royal's game...then watch it. We're at it Royal...play of...so...um...we will have that. We are going to...Saint Louis, no Saint Louis....Arizona for spring training. ... And so...we've done this for many many years.

P5: And um...so and then, when I get home from at 3 O'clock when... and then my husband and I go out and walk our dog and...you know...go to grocery store whatever what we need to do the end of that. Then, we come home and pretty much sit down from TV. Ha ha. [cough] So...but um...we do prefer to...as long as we can get out and in the air and um.. the... outside.

-Being out in the nice weather may be one of the reasons she likes outdoor activities.

P5: Yes. Yeah. Yeah. It kind of...you know...mashes up with the Halloween area. And um...we had some nice weather [talking slowly to emphasize "nice weather"], and so that was really nice. ...

P5: Um...I think it's just because that we've lived here for... so long. Now, you know, we go to Saint Louis and visit our kids. And...that's a lot of fun. We have a daughter that lives in Arkansas, so we take a weekend. Nice weather, you know, we go up and um...go to... her house... and then she comes to...to us. ...

-She and her husband go to the movies a lot.

P5: ...We go to a lot of movies. And um...if there is any good ones... you know...there's kind of that...you know good movies and then...you have to wait until the next good one comes. So...we are avid...movie... um...and...golly gee. ...

-A people person (she likes being with people)

P5: I just like being...I am a people person. I like being with people.

-Happy people, happy person

P5: We [she and her husband] are happy people. I am a happy person. Ha ha.

-A person who tries to keep people happier and pleased & An open book (no secrets; same meaning as a direct person who says what one thinks?)

P5: ...I'm...I'm...I almost think that I'm more of pleased than I'm at a please me, you know.

I: What do you mean by...?

P5: That I will go out on my way to keep somebody happier, pleased, and um...

I: rather than...

P5: if I am not...yeah...so...you know, I'm... Like I said, I'm an open book pretty

	much.
His expression of her identity	<p><u>-She liked interaction with each of the members and encouraged the people to help them do better when she owned and operated a ladies exercise center. That was a big part of her life.</u></p> <p>C5: How we were together was very good. um.. My wife used to, she owned and operated a [name], which is a ladies exercise center. And she was one who encourages each of the members then to do more, to do better, help them become physically fit. And...achieve their objectives. And she always liked that interaction with my wife's every people...um...as we...as the curves...we had to get rid of the [name] as business. And so...that was a big whole in her life. And so for her to take this opportunity, then to be wanting to be equal but to...then the coach...as you...as you... That was a good thing for her. She enjoyed it very much. She would enjoy it again.</p>

Note

-Her husband participated/ did the activities together, so use “we” to indicate she and her husband rather than use “we” to indicate she and her pair.

-Activities: Going to Nelson-Atkins museum of art, Harry Truman’s library, [pumpkin patch, Science City (union station), and Crown Center (for lunch)] with her pair’s children.

-She feels uncomfortable when she is with people beyond her area of people (families, her close friends, or people in her group at AA). Being with somebody that can identify her as a person with Alzheimer’s makes her feel uncomfortable. She felt like that she is in a group when meeting with medical students. She is not an individual that is identified as a person with Alzheimer’s PAIRS program is from her group. This helped her to feel comfortable.

-Her leadership role in her group may be similar when she owned a fitness center and served as a coach for members.

-They only met three times total but they went to multiple places when they could meet (actively going to places); one time close to Halloween, another time close to Christmas, and the other time in early March

Appendix 5: Data Collection Forms

Demographic information (for a participant with Alzheimer's)

You can skip some questions if you are not comfortable with answering them.

Name	
What is your age?	
What is your sex?	<input type="checkbox"/> Male <input type="checkbox"/> Female
How do you describe yourself? (Please check the one option that best describes you)	<input type="checkbox"/> Non-Hispanic White <input type="checkbox"/> Black or African American <input type="checkbox"/> Hispanic or Latino <input type="checkbox"/> Asian or Asian American <input type="checkbox"/> American Indian or Alaska Native <input type="checkbox"/> Hawaiian or Other Pacific Islander
What is your marital status?	<input type="checkbox"/> Married/ Living with a partner <input type="checkbox"/> Divorced / Separated <input type="checkbox"/> Widowed <input type="checkbox"/> Single
Living situation	<input type="checkbox"/> Living alone <input type="checkbox"/> Living with others (specify: _____)
What was your job before retirement?	
What is the highest grade or year of school you completed?	
What is your religious affiliation (e.g., Christian, Atheist)?	

Demographic information (for the relative/ friend of a person with Alzheimer’s disease)

You can skip some questions if you are not comfortable with answering them.

Name	
What is your age?	
What is your sex?	<input type="checkbox"/> Male <input type="checkbox"/> Female
How do you describe yourself? (Please check the one option that best describes you)	<input type="checkbox"/> Non-Hispanic White <input type="checkbox"/> Black or African American <input type="checkbox"/> Hispanic or Latino <input type="checkbox"/> Asian or Asian American <input type="checkbox"/> American Indian or Alaska Native <input type="checkbox"/> Hawaiian or Other Pacific Islander
What is your marital status?	<input type="checkbox"/> Married/ Living with a partner <input type="checkbox"/> Divorced / Separated <input type="checkbox"/> Widowed <input type="checkbox"/> Single
What is the highest grade or year of school you completed?	
What is your religious preference?	
Caregiver relationship	<input type="checkbox"/> Spouse/partner <input type="checkbox"/> Daughter <input type="checkbox"/> Son <input type="checkbox"/> Other relative (specify: _____) <input type="checkbox"/> Friend
Current employment	<input type="checkbox"/> Employed full time <input type="checkbox"/> Employed part time <input type="checkbox"/> Not employed
Co-resident caregiver	<input type="checkbox"/> Yes (living together) <input type="checkbox"/> No
When was your family member/friend diagnosed with dementia?	
Thinking now of all the kinds of help you provide for your relative/friend, about how many hours do you spend <u>in an average week</u> , doing these things?	<input type="checkbox"/> 8 hours or less <input type="checkbox"/> 9-20 hours <input type="checkbox"/> 21-39 hours <input type="checkbox"/> More than 40 hours

Appendix 6: Forms used for Informed Consent of Human Subjects

RESEARCH CONSENT FORM for PERSONS with ALZHEIMER'S DISEASE

Pairs to promote social participation of older adults with Alzheimer's disease Protocol # 00000561

You are being asked to join a research study. You are being asked to take part in this study because you are a person with Alzheimer's disease who currently or previously enrolled in the PAIRS Program at the University of Kansas Medical Center. The PAIRS program pairs first year medical students with people with early stage Alzheimer's disease for monthly social gatherings. You do not have to participate in this research study. The main purpose of research is to create new knowledge for the benefit of future patients and society in general. Research studies may or may not benefit the people who participate.

Research is voluntary, and you may change your mind at any time. There will be no penalty to you if you decide not to participate, or if you start the study and decide to stop early. Either way, you can still get medical care and services at the University of Kansas Medical Center.

This consent form explains what you have to do if you are in the study. It also describes the possible risks and benefits. Please read the form carefully and ask as many questions as you need to, before deciding about this research.

You can ask questions now or anytime during the study. The researchers will tell you if they receive any new information that might cause you to change your mind about participating.

This research study will take place at the University of Kansas Medical Center with Dr. Dory Sabata and members of her research team. Approximately 40 people will be in the study.

BACKGROUND

Engagement in pleasant, social, or personally meaningful activities has positive health benefits to aging adults with chronic disease including Alzheimer's disease. Community-based recreational activities involving social engagement and hobbies are recommended strongly for people with Alzheimer's disease. Person-centered, individualized practices are regarded as the gold standard, and emphasize individuals' preferences, choices, values, and interests by providing individualized meaningful activities in positive social environment.

PAIRS program promotes older adults having early stage Alzheimer's disease to engage in individually chosen activities one-on-one with younger generation outside of their typical immediate social contacts. A new friendship may be established based on shared interests and leisure-based social activities. The program has been replicated at several universities and has focused only on student outcomes. Nothing has been reported about potential impact of the program upon the aging participants with Alzheimer's disease and their caregivers (e.g., family member or friend).

PURPOSE

By doing this study, researchers hope to learn benefits to the people with Alzheimer's disease who participate in the PAIRS program and their care partners, such as a family member or friend.

PROCEDURES

If you are eligible and decide to participate in this study, you will complete questionnaires of quality of life, perceived social support, depression, loneliness, perceived inner strength in self and decision making, and perceived consequences of living with Alzheimer's disease. It will take about from 30 minutes to 45 minutes for you to complete these questionnaires. You will be asked to complete the questionnaires at the beginning and at the end of the PAIRS program participation. You may be asked to complete the same questionnaires aging later, several months after the PAIRS program is ended.

You and your caregiver will be contacted by a member of our research team to schedule an interview to understand your experience with the PAIRS program and your thoughts on impact of the PAIRS program. You will be asked to complete a demographic form while completing questionnaires or before doing the interview. Demographic information is only collected for study purposes and will allow researchers to make comparisons to similar studies. The interviewer will ask questions about your experiences and any benefits of the PAIRS program on you and your caregiver. Interviews will take between 30 minutes to 1 hour. The interview will be audio recorded and the recordings will be used for study purposes only. You may decline to be audio recorded and still remain in the study. Researchers may schedule a second interview if the initial interview does not seem to cover the whole story and if you agree to do the second interview.

RISKS

You may feel tired while completing questionnaires. You can ask for a break at any time when you feel tired. You might find some of the questions the researchers ask you to be personal, or to be difficult to answer. You do not have to answer any questions that make you feel uncomfortable. There may be other risks of the study that are not yet known.

NEW FINDINGS STATEMENT

You will be told about anything new that might change your decision to be in this study. You may be asked to sign a new consent form if this occurs.

BENEFITS

You may or may not benefit directly from this study. You may feel useful or proud of yourself in contributing to the development of a better program for others with Alzheimer's disease.

The researchers hope that the information from this research study may be useful in improving social service programs to better meet needs of an aging population with Alzheimer's disease and to provide more benefit to the caregivers for those individuals.

ALTERNATIVES

Participation in this study is voluntary. Deciding not to participate will have no effect on the care or services you or your family member/friend receives at the University of Kansas Medical Center.

COSTS

There is no cost for being in the study.

PAYMENT TO SUBJECTS

There is no payment for this study.

IN THE EVENT OF INJURY

No side effects are expected from your participation in this study. However if you experience a problem related to this study, you should contact Dory Sabata at (913)-945-7338. If it is after 5:00 p.m., a holiday

or a weekend, you should call (913)-284-6583. A member of the research team will decide what type of treatment, if any, is best for you at that time.

INSTITUTIONAL DISCLAIMER STATEMENT

If you think you have been harmed as a result of participating in research at the University of Kansas Medical Center, you should contact the Director, Human Research Protection Program, Mail Stop #1032, University of Kansas Medical Center, 3901 Rainbow Blvd., Kansas City, KS 66160. Under certain conditions, Kansas state law or the Kansas Tort Claims Act may allow for payment to persons who are injured in research at the University of Kansas Medical Center.

CONFIDENTIALITY AND PRIVACY AUTHORIZATION

The researchers will protect your information, as required by law. Absolute confidentiality cannot be guaranteed because persons outside the study team may need to look at your study records. The researchers may publish the results of the study. If they do, your name will not be used in any publication or presentation about the study.

Your health information is protected by a federal privacy law called HIPAA. By signing this consent form, you are giving permission for the University of Kansas Medical Center to use and share your health information. If you decide not to sign the form, you cannot be in the study.

The researchers will only use and share information that is needed for the study. To do the study, they will collect health information from the study activities *and* from your medical record. You may be identified by information such as name, address, phone, date of birth, social security number, or other identifiers. Your health information will be used at the University of Kansas Medical Center by Dr. Dory Sabata, members of the research team, the University of Kansas Medical Center's Research Institute, the Human Subjects Committee and other committees and offices that review and monitor research studies. Study records might be reviewed by government officials who oversee research, if a regulatory review takes place.

All study information that is sent outside KU Medical Center will have your name and other identifying characteristics removed, so that your identity will not be known. Because identifiers will be removed, your health information will not be re-disclosed by outside persons or groups and will not lose its federal privacy protection.

Your permission to use and share your health information remains in effect until the study is complete and the results are analyzed. After that time, researchers will remove personal information from study records.

All research data will be maintained confidentially by numerical code in password-protected databases. All paper records and all recorded audio files will be filed by subject number in accordance with professional standards of privileged information and stored in a locked, secure storage facility at the University of Kansas Medical Center. All research data, including audio files, will be kept for 15 years after the study has ended.

QUESTIONS

Before you sign this form, Dr. Dory Sabata or other members of the study team should answer all your questions. You can talk to the researchers if you have any more questions, suggestions, concerns or complaints after signing this form. If you have any questions about your rights as a research subject, or if you want to talk with someone who is not involved in the study, you may call the Human Subjects

Committee at (913) 588-1240. You may also write the Human Subjects Committee at Mail Stop #1032, University of Kansas Medical Center, 3901 Rainbow Blvd., Kansas City, KS 66160.

SUBJECT RIGHTS AND WITHDRAWAL FROM THE STUDY

You may stop being in the study at any time. Your decision to stop will not prevent you from getting treatment or services at the University of Kansas Medical Center. The entire study may be discontinued for any reason without your consent by the investigator conducting the study.

You have the right to cancel your permission for researchers to use your health information. If you want to cancel your permission, please write to Dr. Dory Sabata. The mailing address is Dory Sabata, Occupational Therapy Education, University of Kansas Medical Center, 3901 Rainbow Boulevard/MS 2003, Kansas City, KS 66160. If you cancel permission to use your health information, you will be withdrawn from the study. The research team will stop collecting any additional information about you. The research team may use and share information that was gathered before they received your cancellation.

CONSENT

Dr. Dory Sabata or a member of her research team has given you information about this research study. They have explained what will be done and how long it will take. They explained any inconvenience, discomfort or risks that may be experienced during this study.

By signing this form, you say that you freely and voluntarily consent to participate in this research study. You have read the information and had your questions answered.

You will be given a signed copy of the consent form to keep for your records.

Print Participant's Name

Signature of Participant

Time

Date

Print Name of Person Obtaining Consent

Signature of Person Obtaining Consent

Date

RESEARCH CONSENT FORM
for Caregivers

Pairs to promote social participation of older adults with Alzheimer's disease
Protocol # 00000561

You are being asked to join a research study. You are being asked to take part in this study because you are a family member or a friend of a person with Alzheimer's disease who currently or previously enrolled in the PAIRS program at the University of Kansas Medical Center. The PAIRS program pairs first year medical students with people with early stage Alzheimer's disease for monthly social gatherings. You do not have to participate in this research study. The main purpose of research is to create new knowledge for the benefit of future patients and society in general. Research studies may or may not benefit the people who participate.

Research is voluntary, and you may change your mind at any time. There will be no penalty to you if you decide not to participate, or if you start the study and decide to stop early. Either way, you can still get medical care and services at the University of Kansas Medical Center.

This consent form explains what you have to do if you are in the study. It also describes the possible risks and benefits. Please read the form carefully and ask as many questions as you need to, before deciding about this research.

You can ask questions now or anytime during the study. The researchers will tell you if they receive any new information that might cause you to change your mind about participating.

This research study will take place at the University of Kansas Medical Center with Dr. Dory Sabata and members of her research team. Approximately 40 people will be in the study.

BACKGROUND

Engagement in pleasant, social, or personally meaningful activities has positive health benefits to aging adults with chronic disease including Alzheimer's disease. Community-based recreational activities involving social engagement and hobbies are recommended strongly for people with Alzheimer's disease. Person-centered, individualized practices are regarded as the gold standard, and emphasize individuals' preferences, choices, values, and interests by providing individualized meaningful activities in positive social environment.

PAIRS program promotes older adults having early stage Alzheimer's disease to engage in individually chosen activities one-on-one with younger generation outside of their typical immediate social contacts. A new friendship may be established based on shared interests and leisure-based social activities. The program has been replicated at several universities and has focused only on student outcomes. Nothing has been reported about potential impact of the program upon the aging participants with Alzheimer's disease.

PURPOSE

By doing this study, researchers hope to learn benefits to the people with Alzheimer's disease who participate in the PAIRS program and their caregiver, such as a family member or friend.

PROCEDURES

If you are eligible and decide to participate in this study, you will complete questionnaires about your family member's or friend's quality of life, and a questionnaire about your feelings of your role as a caregiver. It will take about 15 minutes for you to complete these questionnaires. You will be asked to complete the questionnaires at the beginning and at the end of the PAIRS program participation. You may be asked to complete the same questionnaires again later, several months after the PAIRS program is ended.

You and the person for whom you provide care will be contacted by a member of the research team to schedule an interview to understand your experience with the PAIRS program and your thoughts on impact of the PAIRS program. You will be asked to complete a demographic form while completing questionnaires or before doing the interview. Demographic information is only collected for study purposes and will allow researchers to make comparisons to similar studies. The interviewer will ask questions about your experiences and any benefits of the PAIRS program on you and the person for whom you provide care. Interviews will take between 30 minutes to 1 hour. The interview will be audio recorded and the recordings will be used for study purposes only. You may decline to be audio recorded and still remain in the study. Researchers may schedule a second interview if the initial interview does not seem to cover the whole story and if you agree to do the second interview.

RISKS

You may feel tired while completing questionnaires. You can ask for a break at any time when you feel tired. You might find some of the questions the researchers ask you to be personal, or to be difficult to answer. You do not have to answer any questions that make you feel uncomfortable. There may be other risks of the study that are not yet known.

NEW FINDINGS STATEMENT

You will be told about anything new that might change your decision to be in this study. You may be asked to sign a new consent form if this occurs.

BENEFITS

You may or may not benefit directly from this study. The researchers hope that the information from this research study may be useful in improving social service programs to better meet needs of an aging population with Alzheimer's disease and to provide more benefit to the caregivers for those individuals.

ALTERNATIVES

Participation in this study is voluntary. Deciding not to participate will have no effect on the care or services your or your family member or friend receives at the University of Kansas Medical Center.

COSTS

There is no cost for being in the study.

PAYMENT TO SUBJECTS

There is no payment for this study.

IN THE EVENT OF INJURY

It is not expected that you will have any serious side effects from participating in this study. However if you experience any problem related to this study, you should contact Dory Sabata at (913)-945-7338. If it is after 5:00 p.m., a holiday or a weekend, you should call (913)-284-6583. A member of the research team will be made available to discuss your problem.

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The researchers will protect your information, as required by law. Absolute confidentiality cannot be guaranteed because persons outside the study team may need to look at your study records. The researchers may publish the results of the study. If they do, your name will not be used in any publication or presentation about the study.

All research data will be maintained confidentially by numerical code in password-protected databases. All paper records and all recorded audio files will be filed by subject number in accordance with professional standards of privileged information and stored in a locked, secure storage facility at the University of Kansas Medical Center. All research data, including audio files, will be kept for 15 years after the study has ended.

QUESTIONS

Before you sign this form, Dr. Dory Sabata or other members of the study team should answer all your questions. You can talk to the researchers if you have any more questions, suggestions, concerns or complaints after signing this form. If you have any questions about your rights as a research subject, or if you want to talk with someone who is not involved in the study, you may call the Human Subjects Committee at (913) 588-1240. You may also write the Human Subjects Committee at Mail Stop #1032, University of Kansas Medical Center, 3901 Rainbow Blvd., Kansas City, KS 66160.

SUBJECT RIGHTS AND WITHDRAWAL FROM THE STUDY

You may stop being in the study at any time. Your decision to stop will not prevent you from getting treatment or services at the University of Kansas Medical Center. The entire study may be discontinued for any reason without your consent by the investigator conducting the study.

CONSENT

Dr. Dory Sabata or a member of her research team has given you information about this research study. They have explained what will be done and how long it will take. They explained any inconvenience, discomfort, or risks that may be experienced during this study.

By signing this form, you say that you freely and voluntarily consent to participate in this research study. You have read the information and had your questions answered.

You will be given a signed copy of the consent form to keep for your records.

Print Participant's Name

Signature of Participant

Time

Date

Print Name of Person Obtaining Consent

Signature of Person Obtaining Consent

Date

Appendix 7: Semi-structured Interview Guide

Date: _____ Study Number: _____

Start Time: _____ End Time: _____

I am a researcher of the PAIRS program that pairs people with Alzheimer's and medical students for social gatherings at the University of Kansas Medical Center. You participated in the PAIRS program from September, year to April, year. I really appreciate that both of you agreed to be interviewed. This interview is to know about your experience of participation in the PAIRS program and your thoughts about its' impacts on you and your daily life. I would like to hear your experience and thoughts first (*looking at the person with dementia*), and then I will give both of you time to talk (*looking at the couple*). The interview will take about 1 hour. Your responses are confidential and will not be shared with other participants in the program, including students, persons with dementia, and their family members. Your name is not used for this audio recorded interview by assigning you a study number. This interview is not recorded until you are ready. Do you have any questions before we start the interview? (*pause*) Are you ready for the interview? (*pause*) Then, the interview will be recorded.

General opening question: "Could you tell me about your experience of participating in the PAIRS program?"

Possible sub-questions

1. What do you think to be the important features of the PAIRS program?
2. How do you feel/think about participating in the PAIRS program?
3. What did you do with your paired student?
4. How did you decide what to do with your paired student?
5. How was the relationship with the student?
6. How did you feel when you socialized with your pair?
7. What were your expectations before participating in the PAIRS program?
 - Why did you decide to participate in the program?
 - How does the program meet your expectations?

How do you think participation in the PAIRS program affected you (and/or your relative/friend) and your daily life? (e.g., mood, feelings, participation in activities, strategies)

General probes: "Can you tell me more about that?" or "How did you feel about that?"

Closing: Is there anything else you would like to add before we end this interview? Or Do you have anything further to add?