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MEANINGFUL SELF-REPORTING OF QUALITY OF LIFE IN PEOPLE LIVING WITH
DEMENTIA

A project based upon an independent investigation, submitted
in partial fulfillment of the requirement for the degree of
Bachelor of Arts in Social Work.

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Abstract

The aim of this research study is to investigate the hypothesis that people living with dementia can comment meaningfully on their quality of life. A careful literature review revealed that “while it is generally agreed that any appraisal of quality of life should as far as possible rely on the individual’s own perspective, having people with dementia evaluate their own quality of life remains a much-debated issue” although the findings of many recent studies support the theory that people with dementia can evaluate their own quality of life (Cahill et al., 2004, p. 313). A 32-question questionnaire adapted from the Dementia Quality of Life scale (Brod, Stewart, Sands, & Walton, 1999) was administered to nine elder participants with dementia. A family caregiver and a professional caregiver also completed the Quality of Life Scale to reflect how they thought the elder with dementia experienced quality of life. Analysis indicated high inter-item consistency across all items and respondents on the Quality of Life Scale ($\alpha = 0.957$). Correlations between respondents (participants and informal and formal caregivers) on most subscales were high ($\tau = .040$ to $.717$) (although correlations often did not reach statistical significance with $N = 9$), further affirming that the ratings of Quality of Life by participants with dementia were as valid as the ratings of those who knew them and their lives best. The findings provide evidence that comments about quality of life made by people living with dementia can be regarded as meaningful, indicating that this population deserves greater respect regarding their ability to be included in decisions regarding their well-being and quality of life.

Introduction

Dr. Bob Moorehead, a former pastor of Seattle's Overlake Christian Church, wrote in his essay, *A Paradox of Our Age*, that, "We've added years to life, not life to years" (Moorehead, 1995, p.1). This is a problem particularly indicative of the American culture that views quality of life omnisciently. It appears one's quality of life is judged by society as a whole and based upon what that person can contribute to society, as opposed to being judged subjectively, based upon each person's individual determinations. Society dictates that children have a high quality of life because they hold a strong potential to contribute to society, but those that are deemed to have the highest quality of life are those that are actively contributing society in a manner that society appreciates. Society tends to appreciate those who are employed; thus, older adults are judged to have a low quality of life. American society sees them as contributing very little, since they are unable to or choose not to work. Subsequently, society ignores the wisdom and experience older adults have to offer. Because society is resigned to a low quality of life for older adults, little effort is spent investigating a manner of increasing the quality of life of elders.

Much time and energy has been spent on increasing someone's time living, yet very little time and energy has been spent on ensuring a high quality of life for these very same people. "The most current data shows that Americans, though living longer, are not necessarily living in better health during their senior years" (Merck Institute of Aging and Health and the National Academy on an Aging Society, 2003, p. i). American culture dismisses the typical and atypical changes that occur with age. Because of this naiveté, American culture appears unaware of the changes that occur regarding quality of life. It seems to be a common belief that nothing can be done to increase an older adult's quality of life.

This dismissal seems to stem from a lack of knowledge about atypical patterns of aging, such as dementia. Dementia is classified by "...the joint symptoms of memory disturbance and cognitive impairment;" these symptoms are progressive and beyond what is expected of typical aging (Fukushima, Nagahata, Ishibashi, Taskahashi, & Moriyama; 2005, p. 31). There are many different types of dementia, the most common of which is Alzheimer's disease. With constant developing knowledge, Alzheimer's disease can now be more specifically defined as "...a neurodegenerative disease that is characterized neuropathologically by the presence of β -amyloid plaques and neurofibrillary tangles in the cerebral cortex" (Fukushima et al., 2005, p. 30-31). Despite the increase in knowledge about the causes of certain types of dementia, "very little is known about changes in quality of life over time in people with dementia" (Selwood, Thorgrimsen, & Orrell, 2005, p. 232). Many people, both practitioners and caregivers alike, tend to hide behind the diagnosis of dementia as an excuse for a person living with dementia to maintain a low quality of life. However, these people are basing their opinions upon the societal view of quality of life and thus ignoring the specific factors that might determine the quality of life of a person living with dementia.

Cook clearly illustrates the subjectivity of quality of life; "...while the quality of life may seem low to a young person in, say, a wheelchair, it may seem much higher to an old person in a similar condition" (2005, p. 11). Practitioners and caregivers must put aside their mainstream opinions and truly empathize with a person living with dementia in order to gain a perspective that more closely aligns with that person. Practitioners must realize that just as each individual person has a subjective quality of life that is separate from another's, each individual person living with dementia is going to have different factors that contribute to their subjective quality of life.

“While it is generally agreed that any appraisal of quality of life should as far as possible rely on the individual’s own perspective, having people with dementia evaluate their own quality of life remains a much-debated issue” (Cahill et al., 2004, p. 313). Practitioners doubt the ability of a person who is living with dementia to determine their quality of life; while this is a daunting task, it is not impossible, particularly if careful consideration of quality of life is given when dementia is first diagnosed.

The lack of a focus on quality of life for older adults needs to change rapidly as this population is increasing sharply. “The United States population over age 65 is projected to grow from 35 million in 2000 to 70 million in 2030. At that time, one in five Americans will be age 65 or older” (Merck Institute of Aging and Health and the National Academy on an Aging Society, 2003, p. i). “Over the next forty years, the number of people aged 65 and older is expected to double, while the number of people aged 85 and older is expected to triple” (U.S. Department of Health and Human Services, 2006, p.1). The aging population is clearly growing; thus, interest in the field must also continue to grow. With the immense projected increase in the population of older adults in America, there must be a fund of knowledge to tap, that will help stimulate these generations and increase their subjective quality of life. Initial research has yielded that “people with dementia can competently participate in research on dementia and have more positive appraisals of their lives, roles and relationships than might be expected” (Cahill et al., 2004, 314). Unfortunately, the research is only just beginning, leaving little time to unravel the mysteries of a mind experiencing dementia prior to the rapid increase in the aging population.

Regrettably, the bold achievement of increasing the human life span has had consequences, for as a person grows older, the chance of the onset of dementia greatly increases. As stated by the Alzheimer’s Association, “increasing age is the greatest risk factor for

Alzheimer's. One in 10 individuals over 65 and nearly half of those over 85 are affected" (*Statistics about Alzheimer's Disease*, 2006, p.1). With the expected increase in the older population, America must prepare and learn ways to positively increase the quality of life of a person living with dementia.

Unfortunately, the lack of attention directed towards an older person's quality of life has repercussions involving mental status. "Many primary care physicians are not trained to screen for mental illness, and, unfortunately, may attribute psychiatric symptoms to 'normal aging' or to chronic illness, As a result, close to 90 percent of depressed older patients in primary care get no treatment or inadequate treatment" (Merck Institute of Aging and Health and the National Academy on an Aging Society, 2003, p. ii). With more attention placed upon the quality of life of older Americans, physicians and other caregivers would be better aware of factors that contribute to an older person's quality of life and would be able to identify atypical behavior more readily.

Social workers, both by nature and job description, help those who cannot help themselves. They advocate for at-risk populations including the elderly. Gerontology, particularly working with those living with dementia, is a rapidly growing field. It is imperative that significant research is done in this field and that social workers reach out to this growing and increasingly vulnerable population.

Literature Review

Subjectivity and Aging

In the past 20 years, quality of life has become an increasingly popular tool for gauging the outcomes of different interventions. "[Quality of life] in the elderly appears to be particularly important in view of the increasing number of elderly persons, although the characteristics

particular to older adults make it difficult to define the concept of [quality of life]” (Bergland & Wyller, 2006, p. 479). Quality of life is an appraisal of an individual’s life, and should therefore rely on a person’s subjective perception (Cahill et al., 2004, p. 313). Appreciating and relying upon a person’s subjective experience becomes more difficult when the personal account is from an elder, as “generalized expectations about age and aging across all age groups are tainted by [negative] connotations” (Rothermund & Brandtstädter, 2003, p. 549). It is difficult to appreciate the validity of a personal account of quality of life from an elder, particularly because individual views of quality of life are based on personal subjective experiences; much of society fails to see this as they define quality of life as potential or current economic contributions to society.

Subjectivity and Dementia

While the subjective quality of life of elders is difficult to appreciate, respect concerning the subjective quality of life for an elder living with dementia is relatively non-existent. “Memory loss and confusion are not part of normal aging, even though the frequency of these problems increases with age” (Jones & Cox, 1999, p. 10). However, “in developed countries, the incidence of dementia in those over 85 years old is thought to be above 20%” (Fukushima et al., 2005, p. 31). The ability to measure quality of life in elders with dementia is important because it allows the opportunity for maintaining their sense of humanity; while “they have lost much of their ability to work and shoulder responsibilities...some new aspects of [their humanity] can be nurtured as they look to the future with thankful hearts and the desire for peace (Fukushima et al., 2005, p. 36).

Very little information is available on subjective quality of life in people living with dementia:

Quality of life assessment tools rely heavily on verbal skills and cognitive functioning and consequently a cognitively impaired person may have real difficulties self-reporting

due to word finding and language difficulties, along with limited comprehension. ... People with dementia lack insight and therefore are not well positioned to provide reliable accounts of their internal state of well-being. ... [Although it has been argued] that it is the person's own sense of reality which is critical in terms of measuring quality of life. (Cahill et al., 2004, p. 314)

Throughout history, society has often ignored that an individual's sense of reality must be included when evaluating quality of life. However, society is slowly beginning to realize the importance of an individual's sense of reality in measuring quality of life. Researchers are finally agreeing that the possibility exists for a person living with dementia to report accurately their quality of life, with the individual basing their report upon their perception of reality. "Baltes and Mayer (1999) looked at subjective wellbeing in older people with and without dementia and found that there was no difference between the two groups" (Selwood et al., 2005, p. 232). This discovery is now being received by other researchers and viewed as a valuable and significant contribution to the field.

A minute amount of research is being conducted regarding quality of life and dementia. "Albert et al. (1996) looked at the frequency of expressed emotion assessed by informants and found that increased severity of dementia was associated with a reduced frequency of positive affect and increased negative affect" (Selwood et al., 2005, p. 232). However, the study also concluded that "when participants were in the more severe stages of cognitive decline there was an upswing in contentment and pleasure, and a reduction in anxiety" (Selwood et al., 2005, p. 232).

Lyketsos et al. (2003) "looked at the change in quality of life over two years in people with dementia in long-term care" and found that there is a small statistical decline in quality of life as dementia severity increases (Selwood et al., 2005, p. 233). Lyketsos et al. was unable to

verify the clinical significance of the study because a substantial number of participants did not experience a change in quality of life over the two years (Selwood et al., 2005, p. 233).

Selwood et al. (2005) examined quality of life in people living with dementia in a one – year follow-up study. “The main finding of this study is that people with dementia do not perceive that their quality of life declined over a period of one-year” (Selwood et al., 2005, p. 232). The study found that “the only significant predictor of quality of life at follow-up was initial quality of life” (Selwood et al., 2005, p. 232). The study also found that “quality of life at follow-up correlated significantly with depression and anxiety, not with cognition” (Selwood et al., 2005, p. 232).

Cahill et al. (2004), using the Dementia Quality of Life Scale, looked at whether people with dementia could competently participate in dementia research (p. 314). The study surveyed 98 European older adults with dementia and found that a majority of participants reported feeling positive (happiness, cheerfulness, contentment, and hopefulness) very often, often or sometimes, while no participant reported never feeling positive (p. 320). “Findings demonstrated that contrary to popular belief, people with dementia can competently participate in quality of life research using a disease-specific scale. Only six out of 98 respondents (6%) had difficulty understanding the test questions posed in this scale and were unable to proceed to its completion” (Cahill et al., 2004, p. 326).

Assessment Tools

There are many assessment tools to measure quality of life in people living with dementia. “The PWB-CIP [Psychological Well-Being in Cognitively Impaired Persons scale] measures aspects of [quality of life] related to psychological well-being. It is an observer-rated, 11-item scale that measures positive and negative affective states and engagement behaviors”

(Ready & Ott, 2003, p. 4). The PWB-CIP has shown a relationship between caregiver factors and care recipient quality of life (Selwood et al., 2005, p. 233). However, “a drawback of the scale is that it is a relatively narrow measure of [quality of life], focusing only on affect and behavior” (Ready & Ott, 2003, p. 4).

The Alzheimer’s Disease Related Quality of Life (ADRQL) scale was developed “by focus groups and expert panels. The scale measures both positive and negative behaviors across five domains: Social Interaction, Awareness of Self, Feelings and Mood, Enjoyment of Activities, and Response to Surroundings” (Ready & Ott, 2003, p. 3). The ADRQL relies upon a proxy for particular information (Selwood et al., 2005, p. 233). “The majority of items measure observable behaviors and actions, although some rely on [caregiver] assessment of subjective and internal states (Ready & Ott, 2003, p. 3).

The Quality of Life - Alzheimer’s Disease (QOL-AD) scale, “is composed of 13-items that measure the domains of physical condition, mood, memory, functional abilities, interpersonal relationships, ability to participate in meaningful activities, financial situation, and global assessments of self as a whole and [quality of life] as a whole” (Ready & Ott, 2003, p. 5). The QOL-AD has tested well for reliability and validity (Selwood et al., 2005, p. 234). The scale is strong because “it relies on reports from patients, caregivers, or both,” however, “it relies on a conceptualization of [quality of life] that may be regarded by some investigators as somewhat broad because it includes items about memory and functional abilities” (Ready & Ott, 2003, p. 5).

The Dementia Quality of Life (DQoL) scale “is a 29-item scale, plus one-global item... that measures five domains of [quality of life]: Positive Affect, Negative Affect, Feelings of Belonging, Self-esteem, and Sense of Aesthetics” (Ready & Ott, 2003, p. 4). The scale was

created by “develop[ing] questions based on a literature review and focus groups” (Brod, Stewart, Sands, & Walton, 1999, p. 27). This scale has simply worded items and uses a 5-point visual scale to encourage patient responses (Ready & Ott, 2003, p. 4). “In order to assess comprehension of the response format, screening questions were added to the beginning of the instrument.... Screening questions used hypothetical situations that had a clear correct answer and were as concrete as possible” (Brod et al., 1999, p. 27). The DQoL is unique because it is the only scale developed exclusively to be administered to patients” (Ready & Ott, 2003, p. 4).

Quality of Life Themes

Family. Through analyzing previous studies and the tools used for measuring quality of life, an array of factors, indicators, and themes pertaining to subjective quality of life have been found. The theme that appeared the most is familial interaction. Most elderly prefer to be near their family (Berg-Warman & Brodsky, 2006, p. 79) because being near family increases the quality of their lives (Hsin & Macer, 2006, p. 202). Family members provide a quality of informal care and support that is difficult to find in formal caregiving. Many newly retired older adults prefer to move away from their families in search of independence and new experiences, however, “as need for care and support increases, the desire or necessity for kinship proximity represents a significant incentive to move closer to (or back to) areas where family, especially children, are located” (Silverstone & Horowitz, 1992, p. 28). Families provide much of the care and support older adults require; “three-fourths of community-dwelling frail elders receive all their support from family and friends” (Silverstone & Horowitz, 1992, p. 28).

Having family around also provides an emotional boost for older adults: “both Taiwan and NZ [New Zealand] senior citizens said their families gave them a purpose in life, and [thus they] viewed their lives as full” (Hsin & Macer, 2006, p. 202). “It is important for senior citizens

to incorporate previous experience into their current life view, giving them insight into the present and creating a more inspiring future;” family provides an opportunity to incorporate previous life experiences (Hsin & Macer, 2006, p. 203). A lack of family surrounding older adults has a negative affect on older adults. Rosel (2003) found in an interview-style study of ten older adults about aging in place, that “while [a particular older adult] enjoyed recounting raising three children and one grandchild in the house, he did make it clear that he is often lonely now” (p. 81). Surrounding oneself with family is a coping mechanism for older adults; it is a distraction from the current feelings of uselessness and reminds them of their lifetime achievements. For many older adults, “...nothing – not even full social welfare or generous medical pay - can replace the function of the family to fulfill an aged life” (Hsin & Macer, 2006, p. 205). Families give older adults “...a sense of security and well-being” (Berg-Warman & Brodsky, 2006, p. 79).

Community. “Surveys of the elderly have found that the key determinants of quality of life include...being involved with the local community” (Kelshiker & Rehman, 2006, Features of Independence, para. 1). Contact with the community creates an opportunity for friendship, which “serves several important functions that contribute to [quality of life] in later life, such as providing social support during stressful events” (Bergland & Wyller, 2006, p. 493). Many older adults “...feel strongly that churches are a natural source of assistance to those in need” (Rosel, 2003, p. 86). “...[S]ocial support comes in the form of feeling protected and checked on by those living in relatively close proximity” (Rosel, 2003, p. 85). Many elderly often report feeling lonely and enjoy opportunities to meet new people (Berg-Warman & Brodsky, 2006, p. 76 -77) as “living together... and helping each other were considered by patients with dementia to be [some of] the important elements of their [quality of life]” (Fukushima et al., 2005, p. 30). In a

study conducted by Cahill et al. (2004), “contact with other people was identified by most as being a major source of well-being” (p. 320).

Aging in Place. Aging in place is another theme that was found frequently. “Implicit in the phrase ‘aging in place’ is the assumption that ‘inhabiting a place, over time, somehow results in development of a distinctive sense of attachment that may be adaptive -- particularly so for older people’” (Rosel, 2003, p. 78). It is “...estimated that approximately four times as many frail elderly live in residential settings as live in nursing homes” (Silverstone & Horowitz, 1992, p. 27). A small quality of life study by Fukushima et al. (2005) found that in their sample, half of the elders named their home as the most important place (p. 34). “Surveys by AARP in 1989, 1992, and 1996 all reflected a consistent desire on the part of seniors (more than 80% of them) to ‘stay in [their] own home and never move’” (Willging, 2006, p. 20). “Old people have been found to feel more in control of their lives living in familiar surroundings, even in situations that are objectively detrimental to the quality of their lives” (Silverstone & Horowitz, 1992, p. 28). Many elderly strongly desire to age independently in their own homes (Berg-Warman & Brodsky, 2006, p. 79; Kelshiker & Rehman, 2006, Introduction, para. 1).

One person’s desire to remain in place may, in fact, reflect a psychological attachment to the specific housing unit, that is, the home as the repository for family memories or as a familiar setting that confers an increasingly rare feeling of competence. For another person, the same articulated goal may more accurately reflect an attachment to specific furnishings or the status of homeowner, For still another elder, it is the attachment to neighborhood, community, and established friendships that primarily drives the desire to age in place. (Silverstone & Horowitz, 1992, p. 28)

In some cases, aging in place is a desire that can be fulfilled; “...in many cases, it takes little more than appropriate (and inexpensive) changes in the physical environment to forestall more expensive facility placement” (Willging, 2006, p. 22). However, as the conditions of many older adults worsen, “there are no alternatives to nursing home care when it is needed” (Willging,

2005, p. 14). “Two important, but seemingly contradictory goals of the elder- to remain in his or her home and to be in a safe environment --- can coexist at any one time and can shift in priority over time with changes in the health status of the elder, the residential environment, and the family resources available to support the elder” (Silverstone & Horowitz, 1992, p. 28). Older adults must realize that “aging in place should have nothing to do with physical location. It should have everything to do with self-fulfillment, [and] with personal empowerment” (Willging, 2005, p. 14). It is believed that in today’s society “the place elders should be aging is within themselves” (Willging, 2005, p. 17).

Subjective Well-being. A subjective sense of well-being is a theme in many quality of life studies and assessment tools.

‘The patients’ subjective perceptions and expectations translate that objective assessment into the actual quality of life experienced.’ Inferring subjective quality or well-being from external circumstances or from more objective domains (e.g. functioning) does not take fully into account the values, needs, and adaptabilities of individuals to various life circumstances. (Brod et al., 1999, p. 26)

The studies and tools that apply this theme use direct communication with the older adult being assessed, regardless if they are living with or without dementia. Brod et al. (1999) found that in people living with dementia “...sense of well-being is not defined solely in terms of mood states, but also in terms of embarrassment, self-consciousness, and feelings of being useful” (p. 32).

Laakkonen, Pitkala, Strandberg, Berglind, & Tilvis (2004) sought to determine the quality of life of the participants in terms of well-being.

The participants were asked the following six questions: (1) Are you satisfied with your life? (2) Do you have zest for life? (3) Do you feel needed? (4) Do you have plans for the future? (5) Do you suffer from loneliness? (6) Do you feel yourself depressed? (Laakkonen et al., 2004, p. 249)

Laakkonen et al. (2004) found that most participants rated the well-being questions positively (p. 250). The DQoL also asks questions regarding an individual’s subjective sense of well-being and

requires responses on a 5-point Likert scale (Cahill et al., 2004, p. 317-318). Using the DQoL, Brod et al. (1999) found that there were strong correlations between the different measures of well-being, concluding that people living with dementia are able to comment meaningfully on their well-being (p. 32). Elderly subjects' own experiences of health and functional ability are important aspects to take into consideration when planning therapy and obtaining the best possible well-being for them" (Bergland & Wyller, 2006, p. 493).

Proxy Reports. Other factors that assess quality of life rely heavily upon proxy reports. These include bodily well-being, enjoyment of activities, physical functioning, mobility, and activities of daily living (Cahill et al., 2004, p. 317). Also included are feelings, moods, and response to surroundings (Selwood et al., 2005, p. 233). The problem with relying heavily upon proxy reports is illustrated in an article by Macready (1998) which examined the relationship between surrogate decision makers and hospitalized patients and found that "surrogate decision makers were not always aware of their chargers' preferences" (para. 3). The data from this study refute much of the research in the field. The data suggest that "older people just wanted to live as long as they could; quality of life was less important to them" (Macready, 1998, para. 4). "There are several caregiver factors such as depression and burden that may affect their reports of patient quality of life" (Ready & Ott, 2003, p. 7). However, "no systematic differences in quality of life reports were found between family and institutional caregivers" (Ready & Ott, 2003, p. 2). The scales that rely on proxy reports were developed with the belief that it is nearly impossible to obtain consistent information about quality of life from an older adult with cognitive impairment. However, it is now believed that "the most important requirement for obtaining reliable data from elderly individuals with cognitive impairment may not be overall level of

cognitive impairment but rather orientation, attention, and language skills” (Ready & Ott, 2003, p. 6).

Brod et al. argue that since loss of awareness is not a unitary phenomena in dementia, it is possible that awareness of cognitive impairment may be distinct from awareness of one’s own feeling states. Thus, patients may be able to report reliably on their [quality of life], even when they have poor insight into the severity of their dementia. (Ready & Ott, 2003, P. 6)

Researchers are beginning to agree that older adults living with dementia must be included in the assessment of their quality of life.

Health Related Quality of Life

One key distinction that must be made, but is often ignored in research, is the distinction between subjective quality of life in general and subjective health related quality of life. Health related quality of life “is defined as the extent to which health impacts an individual’s ability to function, and his/her perceived well-being in physical, mental, and social domains of life” (Bergland & Wyller, 2006, p. 480). Health related quality of life “does not decrease with age itself but with health constraints” (Bergland & Wyller, 2006, p. 492). This begs the question if health related quality of life is linked but not interconnected with quality of life. It would appear that a person on their deathbed might subjectively perceive their quality of life as good, while their health related quality of life might be perceived as failing.

Research Question

The hypothesis is that meaningful data about quality of life can be retrieved from the self-reporting of people living with dementia.

Methodology

Design

The study is designed as relational research involving a comparison of quality of life data gathered from older adults and their caregivers. Since the literature has identified that the veracity of self-reports of those with dementia is doubted, using the reports of family caregivers and professional caregivers as a valid standard is deemed necessary, as these people know the participants and their lives best.

Sampling Plan

The research was conducted with 26 respondents: a sample of nine participants selected from the population in attendance at the Cornerstone Adult Services, Inc., Alzheimer's Day Center, one professional staff member of the Cornerstone Adult Services, Inc., Alzheimer's Day Center, responding as the formal caregiver for each participant, and eight informal caregivers, one representing each of the participants. (One caregiver allowed their elder to participate, however withdrew himself or herself from the study prior to completing the survey.)

The nine elder participants ranged in age from 80 to 92 with a mean age of 85. Six elder participants were female and three elder participants were male. The nine elder participants' mini mental state exam (MMSE) scores ranged from 10 to 26 out of a possible maximum of 30. The MMSE is a widely accepted means of testing the cognitive impairment of an individual. MMSE scores ranging from 24-30 indicate an uncertain cognitive impairment. Scores ranging from 18-23 indicates mild to moderate cognitive impairment. Scores ranging from 0-17 indicate severe cognitive impairment. The mean MMSE score was 19.89; while the participants ranged from uncertain to severe cognitive impairment, the mean indicates a mild to moderate cognitive impairment.

The participants, the caregivers, and/or Power of Attorneys of the 21 participants at the Cornerstone Adult Services, Inc., Day Centers who met the criteria for the study received a

packet from Cornerstone Adult Services, Inc. These 21 participants each had a doctor's diagnosis of dementia, attended the Cornerstone Adult Services, Inc. day program, and has a MMSE score ranging from 10 to 26. The participants were not allowed to have a diagnosis of aphasia or catatonia. This packet contained a letter from the Director of Day Services of Cornerstone Adult Services Inc., which invited the families to participate in the study and reassured the families that the services they are receiving would not be affected if they declined participation. The packet also contained a letter from the researcher explaining the purpose, methodology, and significance of the study; two releases, one for the caregiver and one for the elder; and a return envelope addressed to Cornerstone Adult Services, INC. Nine of those caregivers/Power of Attorneys chose to participate in the research study and allow their loved one to participate.

The sampling procedure allows for minimal ethical concerns, as it is formulated using the NASW Code of Ethics, and obtains "voluntary and written informed consent from participants, when appropriate" (NASW Code of Ethics). When not appropriate, the sampling procedure "provide[s] an appropriate explanation to the participants, obtain[s] the participants' assent to the extent they are able, and obtain[s] written consent from an appropriate proxy" (NASW Code of Ethics).

Data Collection

A questionnaire measuring self-reported quality of life was administered interview-style to each of the elder participants by the same interviewer (see Appendix I). The questionnaire was short in length, allowing the interviews to be conducted within twenty minutes. The questionnaire was formulated from a literature review on quality of life and is adapted from the Dementia Quality of Life Scale (Brod et al., 1999, p. 31). The questionnaire had 32 questions organized in five categories: self-esteem, positive affect, negative affect, feelings of belonging,

and sense of aesthetics. It also contained two open-ended questions addressing perceived happiness and quality of life. The design required participants to rate statements orally using the corresponding visual scales provided by the interviewer. Two five-point response scales were used, the first scale ranging from never (1) to very often (5) and the second scale ranging from not at all (1) to very much (5). The interviewer marked the participant's answers on the questionnaire. The same questionnaire was given to all participants.

The interview was conducted in a quiet, enclosed room during the participant's time at a Cornerstone Adult Services, INC., Day Center. The researcher read all the questions to the elder participants and marked the responses. To ensure they understood the visual scales provided, prior to the questionnaire, each of the elder respondents was given the following three test questions:

1. If you just received some very good news, which choice would describe how you felt?
2. If you just finished a task or completed a goal, which choice would describe how you felt?
3. If you just received some very bad news, which choice would describe how you felt?

Each of the elder participants responded with socially appropriate feelings to the test questions. Once an interview was conducted with each participant, the researcher mailed the questionnaires to the informal caregivers and handed the questionnaires to the formal caregiver, asking the caregivers to complete the questionnaire, responding as they believed the elder would respond.

Internal Validity

The interviewer was also the researcher, and thus a possible threat to internal validity is researcher bias. The interviewer knew the purpose of the study, thus it is possible the interviewer unintentionally led the participants' responses. The interviewer's awareness of this possibility

prior to each interview allowed the interviewer the opportunity to control biases and thus lessen the threat to internal validity.

Data Analysis

Each participant and corresponding informal and formal caregiver questionnaires were given a number, separating the data into nine sets. Graphs were created comparing the three respondents in each set for each of the 5 subscales and the overall Quality of Life scale, which varied from a possible 160 (high quality of life) to 32 (low quality of life). Each of the six scales were tested for reliability revealing a high inter-item reliability for each scale (Chronbach's Alpha: Self-Esteem: 0.864; Positive Affect: 0.862; Negative Affect: 0.948; Feelings of Belonging: 0.792; Sense of Aesthetics: 0.935; Quality of Life: 0.957). A bivariate Kendall's tau-b correlation was used to analyze the correlation between the three respondent scores on each of the five sub-scales and the overall quality of life scale. The correlation coefficient yielded from the Kendall's tau-b correlation test was used to determine the coefficient of determination, which in turn was used to interpret the conceptual significance of the results. The seven common quality of life themes identified through the literature review: socialization, aging in place, subjective well-being, bodily well-being, activities of daily living, physical functioning/mobility, and enjoyment of activities, were used to analyze the two open response questions. The responses were classified using the frequency each theme appeared in the 26 responses.

Key Concepts

In order to obtain a concrete understanding of the issues being investigated, there must be a concrete understanding of the concepts, as they are understood in this study. A person who has a diagnosis of catatonia often remains in a rigid position and does not respond to external stimuli. People with this diagnosis tend not to make eye contact and often are mute. A person who has a

diagnosis of aphasia is unable, or has a limited ability, to understand and use language. A person who has a diagnosis of dementia has a decline in cognitive function not in accordance with normal aging. Quality of life is defined as a subjective judgment regarding well-being.

Participant is defined as an attendee of the Cornerstone Adult Services, Inc. Day program.

Informal caregiver is defined as a person who cares for another person and does not receive payment; usually this is a family member. Formal caregiver is defined as a professional staff member of Cornerstone Adult Services, Inc.

Results

Analysis indicated high inter-item consistency across all items and respondents on the Quality of Life Scale ($\alpha = 0.957$). (See Table 1.) Correlations between respondents (participants

Table 1

Chronbach's Alpha (Inter-item Reliability)	
Scale	Chronbach's Alpha
Quality of Life	0.957
Self-Esteem	0.864
Positive Affect	0.862
Negative Affect	0.948
Feelings of Belonging	0.792
Sense of Aesthetics	0.935

and informal and formal caregivers) on most subscales were high for relationships between complex, multi-determined human variables ($\tau = .040$ to $.717$) (although often did not reach statistical significance with $N = 9$). (See Table 2.)

The bivariate Kendall's tau-b correlation yielded coefficients of determination that indicate a strong conceptually significant relationship between participant scores and informal caregiver scores; there is a co-variation of 40.6% on the Self-Esteem sub-scale, 35.2% on the Negative Affect sub-scale, and 51.4% on the Sense of Aesthetics sub-scale. There is a strong conceptually significant relationship between participant scores and formal caregiver scores on the Sense of Aesthetics sub-scale; the variables co-vary by 28.1%.

Of the five subscales, the Sense of Aesthetics sub-scale and the Negative Affect sub-scale, show a positive statistically significant relationship between the informal caregiver

responses and the participant responses (Sense of Aesthetics sub-scale: $p=0.016$; Negative Affect sub-scale: $p=0.044$). The scores on the overall Quality of Life scale were not significant; however, the significance can be considered high for a sample size of 8 or 9 (Informal/Formal: $p=0.216$; Informal/Participant: $p=0.262$; Formal/Participant: $p=0.673$).

Table 2

Correlations (Kendall's tau-b)		Participant/Informal	Participant/Formal	Informal/Formal
Quality of Life	Correlation Coefficient	0.327	0.114	0.357
	Coefficient of Determination	0.107	0.013	0.127
	Sig. (2-tailed)	0.262	0.673	0.216
	N	8	9	8
Self-Esteem	Correlation Coefficient	0.637	0.393	0.228
	Coefficient of Determination	0.406	0.154	0.052
	Sig. (2-tailed)	0.054	0.198	0.485
	N	8	9	8
Positive Affect	Correlation Coefficient	0.34	-0.149	0.308
	Coefficient of Determination	0.116	0.022	0.095
	Sig. (2-tailed)	0.255	0.591	0.308
	N	8	9	8
Negative Affect	Correlation Coefficient	0.593	0.056	0.296
	Coefficient of Determination	0.352	0.003	0.088
	Sig. (2-tailed)	0.044	0.835	0.315
	N	8	9	8
Feelings of Belonging	Correlation Coefficient	0.04	0.125	-0.044
	Coefficient of Determination	0.002	0.016	0.002
	Sig. (2-tailed)	0.896	0.658	0.891
	N	8	9	8
Sense of Aesthetics	Correlation Coefficient	0.717	0.53	0.314
	Coefficient of Determination	0.514	0.281	0.301
	Sig. (2-tailed)	0.016	0.054	0.099
	N	8	9	8

In cases of presumed incompetence in the part of a client, the most involved family members and professionals are often looked toward to make judgments in the best interest of the client. It can be seen here, that there is a high degree of correlation between the judgments of these nine identified participants with dementia and the judgments of their caregivers, suggesting

that these participants can meaningfully and accurately contribute to the assessment of their own quality of life.

The 26 respondents were asked two open-response questions at the end of the Quality of Life Scale (What makes you happy? How would you describe your quality of life?). The responses to these questions were organized using the seven themes identified in the literature as factors in determining quality of life: socialization, aging in place, subjective sense of well-being, bodily well-being, activities of daily living, physical functioning/mobility, and enjoyment of activities. In response to the questions, 26 respondents made comments that can be classified as socialization; these comments stressed the importance of family, community, people, and pets. Comments made by one respondent can be classified as aging in place; this respondent stressed the importance of being with her current surroundings. Comments from all 26 respondents can be classified as subjective well-being, as each respondent identified the individual perspective of quality of life as important. Five respondents made comments regarding bodily well-being, highlighting good health as an important characteristic of quality of life. Six respondents made comments regarding activities of daily living, stating the importance of accomplishing tasks and chores in determining quality of life. Seven respondents made comments that can be classified as physical functioning/mobility, conveying the importance of being able to mobilize independently as a factor determining quality of life. Twelve respondents made comments that can be classified as enjoyment of activities, signifying the importance of fun and pleasurable activities in determining quality of life.

Discussion

Discussion of Results

The aim of this research was to confirm the ability of an elder living with dementia to comment meaningfully on their quality of life. The results conceptually support the research question. There was a strong conceptual significance between participant scores and informal caregiver scores on three of the subscales: Self-Esteem, Negative Affect, and Sense of Aesthetics. There was a weaker, but nevertheless existent, conceptual significance between participant scores and informal caregiver scores on the Positive Affect sub-scale and the overall Quality of Life scale. There was also a weak correlation between participant scores and formal caregiver scores on the Self-Esteem sub-scale. The conceptually significant relationship between participant scores and caregiver scores indicates that elder participants living with dementia can meaningfully comment on their quality of life; the participant responses correlate with the caregiver responses and it is socially accepted that caregivers can meaningfully comment on the quality of life of those they care for.

The results failed to fully support the research question statistically, as few statistically significant correlations could be identified between participant and caregiver responses. However, the significance of this study should not be abandoned, as the lack of statistical significance correlates with the limitations of this study.

The open-response questions were included in the questionnaire to confirm common quality of life themes identified in the literature. The results support the literature in identifying socialization and a subjective sense of well-being as frequently mentioned quality of life themes.

The high inter-item reliability tests, used to confirm the validity of the sub-scales and overall quality of life scale, provide support to the claim that people living with dementia can comment meaningfully on their quality of life. The high inter-item reliability indicates a correlation among all three respondents answers; a low inter-item reliability would indicate that

the responses were significantly different, thus indicating a lack of significant consistency among respondent's answers.

Strengths and Limitations

Strengths. A strength of this study is the wide range of MMSE scores. This range allowed the opportunity to analyze the ability of people living with different levels of cognitive impairment to comment meaningfully on their quality of life. Another strength of the study is the triangulation used to confirm the ability of the elders with dementia to comment meaningfully on their quality of life. It is socially accepted that caregivers can make decisions and judgments about the internal states of those they care for; this study compared the elder participant responses with both formal and informal caregiver responses, allowing the opportunity to identify the variable relationship between all three respondents in each set. The informal caregivers and elder participants living in the same home was another strength of the study. Two respondents living together tends to yield a higher correlation as the caregiver tends to have a stronger relationship with the care recipient.

Limitations. While the costs are small, there is the financial cost of paper, stamps, and envelopes as well as the cost of research and respondent time. The sample size is small, with only nine sets of respondents and one of those sets is incomplete. The participants are all attendees of Cornerstone Adult Services, INC., Day Centers. Thus, the ability of this study to be applied to the general population is limited. Another limitation of the study is the lack of a control group; sets of respondents including participants living without dementia could have confirmed the significance of the correlations between caregiver and participant responses and thus the ability of people with dementia to comment meaningfully on their quality of life.

The lack of a consistent statistically significant correlation between the three respondents on the six scales could be dependent on an array of factors. People with dementia might be unable to comment meaningfully on their own quality of life, however, there was no positive statistically significant relationship between the informal and formal caregiver responses, indicating that the ratings of quality of life were not consistent between the two types of caregivers. A person might be unable to rate another person's quality of life, thus the caregiver responses, both informal and formal, are nothing more than educated guesses at the internal feelings and processes in the mind of another individual. The caregivers might have responded to quality of life over time, while the individual living with dementia might have commented on their quality of life at the exact moment they are responding to the question. Another possibility is that an individual dealing with difficulty might view their situation more positively than those who care about this individual and must watch the individual survive the difficulty.

Future research should be completed with a larger sample and a control group containing elders living without a diagnosis of dementia and their caregivers. This would allow the research to be completed at a more statistically significant level. This would also offer the opportunity to compare the correlation of the elder participants living without dementia and their caregiver responses to the responses of the elder participants living with dementia and their caregivers. Similar correlations would provide further evidence to support the claim the elders living with dementia can comment meaningfully on their quality of life.

Implications

Micro. The findings provide evidence that comments about quality of life made by people living with dementia can be regarded as meaningful, indicating that this population deserves

greater respect regarding their ability to be included in decisions regarding their well-being and quality of life.

Mezzo. At the community level, the findings provide a means for community programs to investigate and include programming that embraces factors deemed significant by people with dementia for increasing and maintaining the quality of life. Many community programs seek to maintain the quality of life for elders; these findings offer an opportunity to identify the factors significant to an individual living with dementia and thus develop programming to address these factors.

Macro. The findings also provide the government and policy makers a means of obtaining concrete evidence regarding the quality and quantity of programs and funding necessary in maintaining the quality of life of this population. This population tends to be underrepresented in government and policy; the findings offer an opportunity to increase the power of their voice.

Education. The findings support a key value found in social work education; social work education encourages individuals to learn more about those they do not understand before judging. The findings offer an opportunity to learn about individuals living with dementia and their individual subjective perception of their quality of life. When examined over time in a particular individual, the findings offer an opportunity to examine the subjective perceptions of individuals as their mind changes overtime and their cognitive impairment becomes more significant (Selwood et al., 2005, p. 232).

Conclusion

The study sought to support the claim that people living with dementia have the ability to comment meaningfully on their quality of life. The findings were able to conceptually support

the aim of the study, confirming the results found by Cahill et al. (2004) that people with dementia “can competently participate in research” (p. 314). The findings also offer valid conceptual support to the highly debated issue regarding the ability of people with dementia to evaluate their quality of life (Cahill et al., 2004, p. 313).

The study also offers an opportunity to maintain an individual living with dementia’s sense of humanity; the ability to comment and judge one’s internal feelings and emotions as a human characteristic. (Fukushima et al. 2005, p. 31). This study provides power to people living with dementia, displaying that they contain the humane ability to judge their own feeling states.

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Appendix I
Quality of Life Scale
(adapted from the DQoL scale by Brod et al.)

Self-Esteem

1. I feel confident.

Never	Seldom	Sometimes	Often	Very Often

2. I feel satisfied with myself.

Never	Seldom	Sometimes	Often	Very Often

3. I feel I have accomplished something.

Never	Seldom	Sometimes	Often	Very Often

4. I make my own decisions.

Never	Seldom	Sometimes	Often	Very Often

Positive Affect

5. I feel happy.

Never	Seldom	Sometimes	Often	Very Often

6. I feel cheerful

Never	Seldom	Sometimes	Often	Very Often

7. I feel content.

Never	Seldom	Sometimes	Often	Very Often

8. I feel hopeful.

Never	Seldom	Sometimes	Often	Very Often

9. I find something that makes me laugh.

Never	Seldom	Sometimes	Often	Very Often

10. I laugh and joke with others.

Never	Seldom	Sometimes	Often	Very Often

Negative Affect

11. I feel afraid.

Never	Seldom	Sometimes	Often	Very Often

12. I feel alone.

Never	Seldom	Sometimes	Often	Very Often

13. I feel lonely.

Never	Seldom	Sometimes	Often	Very Often

14. I feel frustrated.

Never	Seldom	Sometimes	Often	Very Often

15. I feel embarrassed.

_____	_____	_____	_____	_____
Never	Seldom	Sometimes	Often	Very Often

16. I feel angry.

_____	_____	_____	_____	_____
Never	Seldom	Sometimes	Often	Very Often

17. I feel worried.

_____	_____	_____	_____	_____
Never	Seldom	Sometimes	Often	Very Often

18. I feel depressed.

_____	_____	_____	_____	_____
Never	Seldom	Sometimes	Often	Very Often

19. I feel nervous.

_____	_____	_____	_____	_____
Never	Seldom	Sometimes	Often	Very Often

20. I feel sad.

_____	_____	_____	_____	_____
Never	Seldom	Sometimes	Often	Very Often

21. I feel irritated.

_____	_____	_____	_____	_____
Never	Seldom	Sometimes	Often	Very Often

22. I feel anxious.

_____	_____	_____	_____	_____
Never	Seldom	Sometimes	Often	Very Often

Feelings of Belonging

23. I feel useful.

Never	Seldom	Sometimes	Often	Very Often

24. I feel people like me.

Never	Seldom	Sometimes	Often	Very Often

25. I feel lovable.

Never	Seldom	Sometimes	Often	Very Often

26. I interact with people.

Never	Seldom	Sometimes	Often	Very Often

27. I enjoy participating in activities.

Never	Seldom	Sometimes	Often	Very Often

Sense of Aesthetics

28. I enjoy listening to music.

Not at All	A Little	Somewhat	Mostly	Very

29. I enjoy listening to the sounds of nature.

Not at All	A Little	Somewhat	Mostly	Very

30. I enjoying watching animals and birds.

Not at All A Little Somewhat Mostly Very

31. I enjoy looking at colorful things.

Not at All A Little Somewhat Mostly Very

32. I enjoy watching the clouds and the sky.

Not at All A Little Somewhat Mostly Very

Quality of Life

33. What makes you happy?

34. How would you describe your quality of life?
