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STAGE OF CHANGE DISCREPANCIES AMONG
INDIVIDUALS WITH DEMENTIA AND CAREGIVERS

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ABSTRACT

The Transtheoretical Model (TTM) of behavior change outlines a five-step categorization of stages that delineate an individual's readiness to alter a behavior. This model has been used as a basis for understanding the behavioral change process and for tailoring interventions (e.g., smoking cessation and weight management). Little research exists, however, applying the TTM to behaviors among individuals with dementia (IWD) and their caregivers (CGs). Unlike many other behavior changes, the changes associated with adapting to and coping with dementia often rely on changes in both the CG and the IWD. Based on this cooperative aspect of the IWD/CG dyad, it was hypothesized that larger dyad discrepancies would predict poorer psychosocial well-being, as measured by depression, anxiety, quality of life, and relationship strain. This hypothesis, however, was not supported. This paper will discuss the literature to date, the psychometric testing of a novel Readiness to Change measure in this population, and future directions for this field.

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CHAPTER I

INTRODUCTION

The demands associated with the onset and advancement of dementia in older adulthood can be extremely taxing on both the individual with dementia (IWD) and the caregiver (CG). The number of individuals aged 65 and older with Alzheimer's disease and other related dementias in the United States alone is estimated at 5.2 million, and this number is projected to grow to 7.7 million in 2030 and 11 million in 2040 (Alzheimer's Association, 2012). This drastic increase is projected to come as a result of a growing number of adults aged 65 and over as the baby boom generation enters later life. Moreover, it is estimated that 65% to 75% of IWDs are cared for by a family member at home (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995).

These statistics reflect a growing disease epidemic as well as an enormous and growing body of caregivers to meet the associated demands. As the challenges associated with providing care for IWDs increase, the importance of the CG's role cannot be overstated. Typically, family CGs are spouses or children of the IWD (Nichols, Martindale-Adams, Burns, Graney, & Zuber, 2011). Many of these family CGs are informal CGs who do not have explicit training pertaining to providing care for IWDs.

Thus, high-quality and widely available caregiving resources have excellent potential to aid and equip caregivers and IWDs with tools and strategies needed to be successful. The dyadic (i.e., inclusive of both the CG and IWD) approach to non-pharmacological treatment for dementia emphasizes communication and a supportive environment for individuals within the dyad as a means of facilitating efficacious management of dementia through mutual understanding and collaboration.

Understanding this dyadic stage of change relationship can potentially lead to the use of the Transtheoretical Model (TTM) of behavior change as a guiding construct for dyadic non-pharmacological dementia treatment. In order to develop efficacious intervention protocols it is first necessary to understand how and why dyads differ in their readiness to change and how this is related to psychosocial outcomes for IWDs and CGs. The importance of communication and a positive relationship within the dyad makes the IWD/CG relationship unique from supportive relationship dynamics among other behavior change processes (e.g., smoking cessation). Potentially negative psychosocial effects on both the CG and the IWD may exist due to different stages of readiness to change between the IWD and the CG. Thus far, very little research exists applying the TTM to dementia care, and no research exists which examines stage of change discrepancies within the IWD/CG dyad. The following sections will outline the state of later life dementia in the United States, address concerns related to caregiving for an IWD, and discuss the TTM and its current applications.

1.1. *Dementia in Later Life*

Dementia constitutes a global decline in memory and cognitive ability as a product of a number of varying etiologies. The prevalence of Alzheimer's Disease and Related Dementias (ADRD) is significantly higher in populations over the age of 65 (Alzheimer's Association, 2012). The most common form of dementia is Alzheimer's Disease (AD), which accounts for between 60% and 80% of dementia cases, and is the sixth leading cause of death in the United States (Thies & Bleiler, 2012; Miniño, Murphy, Xu, & Kochanek, 2011). Although AD is not considered a part of normal aging, advancing age is the greatest risk factor for AD (Thies & Bleiler, 2012).

Coping with dementia involves more than learning to live with memory impairment and cognitive decline. The development and diagnosis of dementia, as well as the awareness of the degenerative trajectory of the disease, often leads to negative psychosocial reactions such as fear, anxiety and depression (Aminzadeh, Byszewski, Molnar, & Eisner, 2007). Non-disclosure of a dementia diagnosis is thought by some to be less emotionally taxing on an IWD. Alternatively, it has been suggested that the sense of relief in knowing, increased understanding of the disease and the opportunity to cope with the disease that are affiliated with disclosure provide a strong case against non-disclosure in terms of psychosocial well-being (Bamford et al., 2004). The negative social effects of having dementia are often very powerful and pose a significant obstacle for IWDs. As dementia progresses into the middle and later stages, communication becomes difficult. Remembering names and relationships begins to pose a significant challenge, and social activities that were once enjoyable can become cognitively demanding. Declines in activities of daily living, (from more complex activities such as

managing money to more basic and private activities such as dressing oneself or using the bathroom) might result in embarrassment when assistance is needed. If discrepancies in stage of change are significant predictors of negative psychosocial outcomes, it is feasible that dyad interventions which are sensitive to reducing this discrepancy can result in more positive psychosocial outcomes. It is hypothesized that reducing or eliminating these discrepancies can improve the quality of the CG/IWD relationship through communication and an increased understanding of the illness from the perspective of the dyad partner.

1.2. Caregiving for an Individual with Dementia

CGs of IWDs are susceptible to a number of different stressors associated with providing care. CGs tend to report higher levels of perceived stress, subjective well-being, depression and anxiety than non-caregivers (Pinquart & Sörensen, 2003a; Mahoney, Regan, Katona, & Livingston, 2005). Moreover, caregiving for an IWD usually requires an increasing level of care and involvement as a result of the degenerative trajectory of the disease (Aneshensel et al., 1995). Cognitive declines associated with dementia and increased dependencies with regard to activities of daily living (ADLs) are examples of more direct and pathological stressors associated with caregiving for this population. This stress may be potentially affiliated with the emotional responses to a loved one whose memory and cognitive ability is declining, or it may result from increased difficulties in caring for the individual (e.g., having to remind the IWD to take medications, dealing with an IWD who falsely believes that s/he has the ability to safely drive a vehicle, etc.). Disruptive behavioral and psychological symptoms

of dementia (BPSD) in the IWD can be a tremendous source of emotional and physical distress (Gauthier et al., 2010; Gaugler, Davey, Pearlin, & Zarit, 2000). These kinds of non-cognitive behaviors might include agitation, wandering, inappropriate sexual behaviors, depression and anxiety (Lawlor, 2002).

Dementia also can have a detrimental effect on the financial well-being of the CG. On average, the direct costs of dementia (e.g. medical appointments, medication, nursing care and residential care) total \$5,000.00 per IWD (Wimo, Jonsson, & Winblad, 2006). Indirect costs including wages lost from not working add to the economic disadvantage of the informal caregiver (Brodaty & Donkin, 2009). The collective negative effects of caregiving on psychological, social, physical and financial well-being have been termed “caregiver burden” (George & Gwyther, 1986). The increasing importance of understanding and addressing these care-related issues is reinforced by increases in life expectancy and potentially longer durations of disability and required care (Dinkel, 1994; Pinquart & Sörensen, 2003b). Following the hypothesized benefits of discrepancy reduction for psychosocial well-being in IWDs, reductions in psychosocial aspects of caregiver burden may also be possible through the use of stage of change targeted interventions.

1.3. Non-pharmacological Interventions for Dementia

The need for effective pharmacological and non-pharmacological approaches to the treatment of dementia is tremendous. Currently, there is no cure for dementia. The search for a disease-altering medication, specifically with regard to Alzheimer’s disease, has been a major focus of the pharmaceutical industry, but medications which have

undergone clinical trials in recent years have been, by-and-large, insufficient in treating the disease (Takeda, Tanaka, Okochi, & Kazui, 2012). Alternatively, a growing body of non-pharmacological interventions is developing to help slow the disease process of dementia and inform CGs of tools and strategies that can make caregiving more effective.

Interventions aimed at addressing the negative outcomes associated with dementia traditionally target CGs and IWDs separately. Approaches with a focus on the CG tend to utilize educational and skill-based interventions aimed at improving caregiving efficacy and psychosocial well-being (Coon, Thompson, Steffen, Sorocco, & Gallagher-Thompson, 2003; Whitebird et al., 2012). Non-pharmacological interventions for IWDs and individuals with mild cognitive impairment often focus on reducing cognitive and functional limitations (Bourgeois, 1990; Camp, 1989; Huckans, et al., 2013). Strategies such as Spaced Retrieval, which involves the practiced retrieval of information over successively longer periods of time, has been effective at improving implicit memory in older adults (Camp et al., 2006). This type of cognitive improvement can translate into improvement in many areas including ability to perform ADLs. Non-pharmacological interventions such as reality orientation, physical exercise, and music therapy, for example, may also benefit cognitive function and reduce BPSD (Takeda et al., 2012).

1.3.1. *The Dyadic Perspective*

Differences in the experience of dementia between the CG and IWD give merit to questions of congruences in perceptions of well-being, the CG's ability to understand accurately the IWD's needs, and the effects of a quality relationship on both members of the dyad. A 2004 study of congruences in dyad perceptions of pain suggested that

caregivers of IWDs in the community and in long-term care have a fairly accurate understanding of pain levels of the IWD (Shega, Hougham, Stocking, Cox-Hayley, & Sachs, 2004). Moreover, the quality of the relationship between the CG and the IWD may influence the well-being of the caregiver as well as the quality of the care that is provided (Quinn, Clare, & Woods, 2009). An emphasis on the CG/IWD relationship is the backbone of the dyadic intervention.

Skill-based interventions for CGs typically do not include cognitive rehabilitation for IWDs, and cognitive rehabilitation interventions for IWDs are often developed for professionals as opposed to informal CGs (Judge, Yarry, Looman, & Bass, 2012). Moreover, cognitive rehabilitation interventions often do not address the negative psychosocial impacts of dementia on the IWD (Judge, Menne, & Whitlatch, 2010). Instead of individually targeted interventions, a dyadic approach to intervention might provide a more holistic means of addressing cognitive rehabilitation as well as providing educational resources and skill-based training for the CG in a way that also strengthens the dyadic relationship.

Interventions that address the needs of both the IWD and the CG separately may miss opportunities for communication between members of the dyad. This opportunity for guided communication has the potential to produce “A-ha!” moments wherein the dyad partners gain insight into each other’s feelings and experiences in a way that can inspire more informed and effective caregiving. While dyadic approaches to intervention have been fairly successful thus far (Judge et al., 2012; Zarit, Femia, Watson, Rice-Oeschger, & Kakos, 2004; Teri, Logsdon, Uomoto, & McCurry, 1997; McCurry, Gibbons, Logsdon, Vitiello, & Teri, 2005; Teri et al., 2003), dyadic intervention research

is still developing. At this stage, honing intervention development using guiding models is necessary for this field of research to develop in a way that provides tangible results in the most effective and efficient way possible. Using the TTM as a guiding construct for tailoring intervention protocols may produce a more informed and effective intervention.

CHAPTER II

THE TRANSTHEORETICAL MODEL

The Transtheoretical Model (TTM) of behavior change was developed to address and identify the commonalities among the different theories of psychotherapy, and to organize these mechanism-based theories of change into a concise and integrative model of the behavior change process (Prochaska, DiClemente, & Norcross, 1992; Prochaska & DiClemente, 1982). The model consists of a stage-based categorization of change progression throughout the alteration of a behavior. Though the model was developed to address the behavior-related change process in substance dependent individuals, the stages of change may also apply to the process of coping with and managing dementia and dementia care among IWDs and their CGs. Thus far, the majority of research related to the TTM has had a focus on the original behavioral change paradigms (e.g., smoking cessation, drug addiction, problem eating behaviors, etc.) upon which the model was developed. A growing body of research has suggested that the TTM is not only an effective means of understanding behavior change, but is also an effective means of guiding changes related to psychotherapy (Norcross, Krebs, & Prochaska, 2011).

Interventions intended to guide an individual through the behavior change process utilize specific strategies tailored for each stage of change.

2.1. *Stages of Change*

The five stages of change, in progressive order, are: Precontemplation, Contemplation, Preparation, Action, and Maintenance (Prochaska & DiClemente, 1982; TTM; Prochaska, DiClemente, & Norcross, 1992; Velicer, Prochaska, Fava, Norman, & Redding, 1998). An individual is categorized by one of these stages based on his/her unique appraisal of the situation, desire to change, and actions taken toward changing. Although the stages will vary in duration based upon the individual, the tasks and accomplishments required to progress through each of the stages are universal (Prochaska & Norcross, 2001; Norcross et al., 2011).

Precontemplation. Precontemplation, the first stage of change, is understood by the TTM as a lack of recognition that a problem exists and the lack of awareness that a change needs to be made. Oftentimes, individuals who are close to a person categorized by this stage of change (e.g., family, friends, spouses, and co-workers) recognize that a problem exists and that the problems experienced by the individual needs to change. Typically, though, individuals in this stage do not foresee changing within the next six months, and an individual can be assessed as being within the Precontemplation stage by simply asking the individual if s/he is ready to make a change within this timeframe (Norcross et al, 2011). Precontemplation may be somewhat more complex when applied to dementia patient-caregiver dyads. When applied to a behavior change intervention for substance abuse, for instance, an individual is most likely aware that an alternative to

substance abuse exists. For IWD/CG dyads, however, the belief may persist among one or both individuals that there are no alternative methods or changes that can be made to alleviate the problems that result from having dementia and/or providing care for an IWD.

Contemplation. The key factor which distinguishes the Precontemplation stage and the Contemplation stage is the recognition that a problem exists. Individuals in the Contemplation stage of change have not yet committed to making a change, but they recognize that a change needs to be made. Individuals in this stage will report that they intend to make a change within the next 6 months. Norcross and colleagues (2011) report that the Contemplation stage is the stage in which individuals are most likely to get stuck during the change process.

Preparation. The Preparation stage is characterized by individuals who intend to take change-related actions within the next month. Individuals in the Preparation stage have typically been unsuccessful at taking action within the past year, but are now making plans for change. It is suggested that these individuals should be recruited for action-oriented behavior change interventions (Velicer et al., 1998).

Action. The Action stage of the TTM is the stage in which an individual is actually attempting to modify problematic behavior (Velicer et al., 1998). However, not every attempt at behavioral change constitutes a change in the Action stage of the TTM. Minor actions taken toward behavior change generally are not enough to merit a person as being in the Action stage. The specific qualifications regarding which types of behaviors merit this categorization are different depending on the behavior. For example, an individual who is trying to quit smoking is in the Action stage if s/he is completely

abstaining from the behavior. If this person has made changes such as switching to light cigarettes or cutting back on the number of cigarettes per day, s/he would not be categorized by the Action stage, but rather the Preparation stage (Velicer et al., 1998). Individuals in the Action stage must have modified their behavior for a period of one day to six months.

Maintenance. Once an individual's behavior has been modified for a period of six months, the TTM classifies this person as being in the Maintenance stage. The Maintenance stage of change is the final stage of change which extends indefinitely. An individual in the Maintenance stage works to remain free from the problem behavior that s/he has changed (Norcross, Krebs, & Prochaska, 2009).

Relapse. While not generally considered a stage in-and-of-itself, relapse plays a profound role in the process of behavior change. Relapse, or regression from a higher stage to a lower stage, can happen in any stage, but is most common in Action and Maintenance. Typically, however, an individual will not relapse all the way back to the Precontemplation stage from one of the higher stages (Velicer et al., 1998).

2.2. *Guiding Behavior Change*

The TTM is understood not only by the stages of change with which it categorizes the change process, but also by the influences which guide movement through the change stages. The two internal constructs that the TTM emphasizes as essential for progression through the stages of change are Decisional Balance and Self-efficacy (Prochaska & Velicer, 1997). Decisional Balance entails how the individual weighs the pros and cons of making a behavior change. An individual who believes that the pros of changing far

outweigh the cons is likely to be more successful at making an effective behavior change. Similarly, Self-efficacy is the confidence that an individual has in his/her ability to cope successfully with changes without relapsing on the problem behavior.

Prochaska and Velicer (1997) outline the core “Processes of Change” which serve as guides for intervention programs aimed at moving an individual through one stage to the next. Listed in Table 1 are some of the Processes of Change, which stage they are best implemented in, and how they may be related to IWD/CG dyad related changes.

2.3. Empirical Support

The TTM has come under some scrutiny in recent years. Some of the major critics of the TTM suggest that the stages of change posited by the model are artificial delineations (West, 2005; Sutton, 2002). Studies have suggested that stage-based interventions (specifically those focused on changing smoking behavior) are no more effective than non-stage-based interventions (Riemsma et al., 2003). A criticism from Sutton (2002) claimed that the different stages of change were not mutually exclusive and that the movement through the stages was not consistent and sequential.

Prochaska (2006) responded to the criticism that the model makes arbitrary distinctions between stages of change by saying that the categorization into stages is necessary. He defends the model by citing examples wherein continuous data is treated discretely as a means of making concrete clinical decisions. Cholesterol, for example, is a continuous measurement that is discretely categorized into high/normal for purposes of making practical decisions regarding treatment. Prochaska (2006) responded to criticisms of sequential stage change by citing large longitudinal studies which support progressive

movement through the stages (Abrams, Herzog, Emmons, & Linnan, 2000); Herzog, Abrams, Emmons, & Linnan, 2000).

2.4. Applications and Limitations

The vast majority of research and intervention development utilizing the TTM has been done in substance dependent populations such as smoking cessation (Prochaska, DiClemente, Velicer, & Rossi, 1993; Spencer, Pagell, Hallion, & Adams, 2002) and eating behaviors/weight management (Marshall, & Biddle, 2001; Hasler, Delsignore, Milos, Buddeberg, & Schnyder, 2004). Little research exists, however, applying the TTM to behaviors among older individuals with dementia and their caregivers. Gitlin and colleagues (2000) emphasized the importance of a theoretical framework for tailoring interventions for IWDs. This research suggested that behavioral change theories may prove to be effective for intervention development, and the TTM was presented as a potentially viable option. Yarry (2009) examined whether readiness to change stage had an effect on psychosocial outcomes for CGs after a dyadic intervention. This research did not find that CG stage of change was a good predictor of the psychosocial outcomes, but it did find that CGs tended to advance in stage as a result of the intervention. This research may not have been sensitive to relational aspects between CGs and IWDs, but rather only to CG readiness to change. Thus far, no research exists on TTM stage discrepancies in this population. Although very little research exists applying the TTM to this population, its use as a guiding construct for intervention development is promising.

CHAPTER III

CURRENT STUDY AIMS

Many approaches to intervention development for CG/IWD dyads use approaches that would be considered by the TTM to be action-based approaches to behavior change. If discrepancies in stage of change prove to be significant predictors of psychosocial outcomes, it may be efficacious to use the TTM to assess stage of change and, as a result, develop interventions that can provide guidance through the process of behavior change based on the dyad stages of change. The importance of understanding how and why dyads differ in their readiness to change and how this is related to outcomes for IWDs and CGs may result in more efficacious future intervention development for this population.

3.1. *Hypotheses*

H1: It was hypothesized that greater discrepancies in dyad's stage of change would significantly predict more symptoms of depression for CGs and IWDs.

H2: It was hypothesized that greater discrepancies in dyad's stage of change would significantly predict more symptoms of anxiety for CGs and IWDs.

H3: It was hypothesized that greater discrepancies in dyad's stage of change would significantly predict lower Quality of Life for CGs and IWDs.

H4: It was hypothesized that greater discrepancies in dyad's stage of change would significantly predict increased dyad relationship strain for CGs and IWDs.

CHAPTER IV

METHODS

The data used in the present research were secondary data collected at baseline of the Project ANSWERS intervention. These data were collected prior to random assignment to the control or experimental conditions of the ANSWERS intervention efficacy testing. Baseline interviews were conducted by a trained interviewer who traveled to meet with the dyad in the home or other preferred location.

4.1. *Measures*

4.1.1. *Preparatory Analyses*

The measures used in Project ANSWERS were administered such that each IWD participant had the option of answering yes/no for each item instead of using the full Likert scale. This option was implemented to help IWDs who had trouble using the full-scale of responses, and to facilitate more accurate and reliable responses in individuals with more severe memory impairments (for an overview and discussion of this process, see Krestar, Looman, Powers, Dawson & Judge, 2012).

Because of the dichotomous option for IWDs, each measure contained responses from participants who used the full-scale as well as some who used the yes/no response option. Thus, all measures for IWDs were re-coded into dichotomous responses (readiness to change, depression, anxiety, quality of life, and relationship strain). This was done so that all participants' responses were on the same scale. For CGs, only the readiness to change measure was re-coded into dichotomous responses. This was done in order to develop meaningful difference scores between the IWD and the CG's readiness to change responses. The Table 3 reliability tests reflect this recoding work.

Measures of Stage of Change, Relationship Strain, Quality of Life, Anxiety and Depression each underwent psychometric testing in order to affirm the reliability and validity for CGs as well as IWDs. Some of the measures used here, with the exception of the Mini-Mental Status Examination, have limited support in older adults with cognitive impairment. Due to this limited support, it was critical to examine the psychometric properties of these measures to assure that they are able to translate to a memory-impaired population. The psychometric work for each measure, as well as a description of the measure and its scoring, is discussed in the following sections.

4.1.2. The Mini-Mental Status Examination

The Mini-Mental Status Examination (MMSE; Folstein, Folstein, & McHugh, 1975) is a widely used screening tool for cognitive impairment. This measure uses 11-items which produce a score from 0-30, with lower score indicating greater cognitive impairment. The MMSE was administered to both CGs and IWDs.

4.1.3. *Stages of Change – Dementia and Memory Loss*

The Stages of Change – Dementia and Memory Loss (SC-DM) is a self-report questionnaire adapted from the URICA (McConaughy, Prochaska, Velicer, 1983). The URICA includes 32 items that assess stage of change using four TTM-based subscales: Precontemplation (PC), Contemplation (C), Action (A), and Maintenance (M). The SC-DM adaptation from the URICA includes all five stages of change (Preparation subscale was not included in the URICA). The SC-DM consists of 40 Likert-scale questions with 8 questions measuring each subscale (Appendix A). This measure was administered to both CGs and IWDs. For the purposes of the current study the 5-item Likert scale responses for this measure were dichotomized. “Strongly disagree” and “disagree” were recoded into “no,” “agree” and “strongly agree” were recoded into “yes” and the “undecided” response remained the same.

Previous research using the URICA has found that two separate factor structures exist such that Precontemplation is separate from the other stages (Yarry, 2009; Littell & Girvin, 2005; Edens & Willoughby, 2000). Due to the relatively new nature of the SC-DM, a series of factor analyses were conducted to explore whether each item in the SC-DM loaded on to its intended stage. The results of these factor analyses did not support the theoretical five-stage model; the 40 items did not load cleanly into five subscales representing the five stages of change, as intended. Moreover, factor structures were not consistent between CG and IWD measures. For IWDs, a factor analysis using a Principal Component Analysis extraction for the SC-DM was found to support the two factor structure found in psychometric work done on the URICA (all items loaded above .383 on their respective scales using a Varimax method of rotation). For CGs, the factor

analysis was more convoluted when limited to two extractions. The items for Precontemplation all loaded on the same factor (loadings over .322), but several of the non-Precontemplation items also loaded onto this factor (albeit negatively).

Although some items cross-loaded onto two factors in the CG analysis, no items were rejected. The rationale for this decision was twofold. First, the items did not cross-load for both CG and IWD factor analyses. Because removing these items from the SC-DM would mean removing the item from both the IWD and the CG measures, several good items would be lost from the IWD measure. Second, the negative cross-loading that was discovered is not inconsistent with the theory behind the two-stage model. Since the Precontemplation stage is thought of as the lack of readiness to change, and the remaining five stages are thought to represent some degree of readiness to change (i.e., that these groups represent opposite ends of a readiness to change spectrum), it is reasonable to expect some degree of item cross-loading across these two factors. Above all, the two-factor model was far better supported by the factor analysis than the five-factor model.

Because there was much stronger evidence to support the two-stage model, the present analysis considered the items from the SC-DM as representative of two distinct stages rather than five; Precontemplation and non-Precontemplation (consisting of the stages Contemplation, Preparation, Action and Maintenance). In other words, the stages Contemplation, Preparation, Action and Maintenance were grouped as one stage (CPAM). Cronbach's Alphas indicated acceptable reliability on all scales (CGs: PC = .67, CPAM = .90; IWDs: PC = .76, CPAM = .93; see Table 3 for reliabilities for all subscales).

4.1.4. *Relationship Strain*

The tool used for assessing relationship strain was a 13 item self-report measure scored on a 0-3 Likert scale administered to both IWDs and CGs (Appendix B.; Bass, Tausig, & Noelker, 1989). Again, IWDs had the option to respond on a 0-1 Likert scale. Full scale IWD responses were re-coded into yes (“agree” and “strongly agree”) and no (“disagree” and “strongly disagree”). Higher scores on this measure represent higher levels of strain. A factor analysis indicated two distinct factor structures within the Relationship Strain measure. The two factors were representative of Dyad Strain (CG factor loadings between .53 - .75; IWD factor loadings between .56 – .84) and Role Captivity (CG factor loadings between .72 - .87; IWD factor loadings between .70 - .82). The Dyad Strain factor was marked by items which were characteristic of dyad-specific strain, such as “I felt that he/she tried to manipulate me” and “I felt resentful toward him/her.” Role Captivity, alternatively, was characterized by items which indicated feelings of being confined or trapped in the relationship. Such items included “I wished I could run away from this situation” and “I wished I were free to lead my own life.” Cronbach’s Alphas indicated acceptable reliabilities on the full scale measure (CGs = .82, IWDs = .72) as well as both the Role Captivity subscale (CGs = .82, IWDs = .64) and the Dyad Strain subscale (CGs = .83, IWDs = .81; see Table 3). Based on the psychometric work, the following analyses will consider this measure separately in terms of dyad strain and role captivity.

4.1.5. *Depression*

The depression measure, which was given to both CGs and IWDs, is an adaptation of the CES-D which includes 11 self-report Likert-scale items scaled from 0-2 (Appendix C.; Kohout, Berkman, Evans, & Cornoni-Huntley, 1993; Radloff, 1977). Higher scores on the depression measure represent higher levels of depression. Cronbach's Alphas for this measure indicated good reliability (IWDs = .74, CGs = .84; see Table 3). This measure was re-coded into yes/no scaling with the response "hardly ever/never" coded as "no," and the responses "sometimes" and "often" coded as "yes."

4.1.6. *Anxiety*

Anxiety was measured in both IWDs and CGs. The anxiety measure used is a 12-item self-report measure using a 0-3 Likert-scale (Appendix D.; Zung, 1980). Higher scores on this measure represent higher levels of anxiety. Cronbach's Alphas indicated acceptable reliability (CGs = .77, IWDs = .68; see Table 3).

4.1.7. *Quality of Life*

Quality of Life is also a 12-item self-report measure scored using 0-3 Likert scaling (Appendix E.; Logsdon, Gibbons, McCurry, & Teri, 1999). Higher scores on this assessment are indicative of a better quality of life. This assessment was given to both IWDs and CGs. Cronbach's Alphas indicated strong reliability (IWDs = .98, CGs = .83; see Table 3).

CHAPTER V

RESULTS

5.1. Participants

Participants were recruited over the course of 14 months through 16 social service agencies in Northeast Ohio. IWDs were considered eligible who had been given a diagnosis of dementia or memory loss, had an MMSE score of more than 7, were residing in the community, read and spoke English, and were being assisted by a friend or family member CG.

Participants were 69 dyads. The majority of IWDs were white (65 white, 4 black) and 35 were male. Caregivers were primarily female (17 male) and the majority were white (64 white, 1 Asian, 4 black). For a full account of demographic information, including marital status and education, see Table 2.

5.2 Analytic Strategy

Choosing an appropriate analytical strategy to address the hypothesized results was a matter of extensive discussion and exploration. This section is intended not only to

explicate the results of the analysis that was decided upon, but also to guide the reader to the decision to use that analysis.

A composite score for Precontemplation and CPAM was calculated for each individual. A discrepancy score was then created for each dyad by subtracting the CG's score from the IWD's score on each stage. An absolute value of the discrepancy score was created to address the pure magnitude of the difference (MOD) in IWD and CG scores (i.e., without respect to which person scored higher/lower). Higher discrepancies were more often seen in dyads when the CG was scoring high on readiness to change and the IWD was scoring low. For a full representation of the directionality and magnitude of the discrepancies among dyads, see Figure 1.

Separate regression analyses for IWDs and CGs were run for each of the five outcome measures (depression, anxiety, quality of life, role captivity and relationship strain). These analyses were run separately for the two different stages of readiness to change (PC and CPAM). A hierarchical linear regression model was created for each psychosocial outcome variable. The first step in the model for each stage included the IWD score, the CG score, the MOD score, the interaction term of the IWD score by the MOD score, and the interaction term of the CG score by the MOD score. The first step was designed to isolate the predictive ability of the MOD score while controlling for all other possible readiness to change variables that may have influenced the effect of the MOD score. The second step included the IWD's MMSE score and the relationship (spouse vs. non-spouse) of the CG and IWD as covariates. This step was included to determine if the MOD score was a useful predictor beyond the predictive capacity of these two variables. (see Table 4 and Table 5 for a full account of the PC and CPAM

models, respectively). Note that the regression models were run with all covariates in the first step (MMSE, relationship, CG score, IWD score, and both interaction terms) and the MOD score in the second step. The order of entry in the hierarchical regression analysis had no effect on the results. Since there were no differences in results based on the order of entry in the regression analyses, results from the first method discussed will be reported.

The hypotheses were that greater readiness to change discrepancies would predict higher levels of anxiety, depression, dyad strain and role captivity, and lower levels of quality of life. Results will be discussed separately in terms of each hypothesized outcome. All reported F values represent the second step of the regression analysis unless otherwise noted. See Table 6 for an account of correlations across psychosocial outcome measures for CGs and IWDs.

5.3. Anxiety

Discrepancies in Precontemplation scores were not predictive of IWD Anxiety levels, $R^2 = .06$, $F(7, 58) = .58$, $p > .05$. CG Anxiety, however, was significantly predicted in the first step of the model, $R^2 = .17$, $F(5, 60) = 2.4$, $p = .04$. The effect became non-significant when *MMSE score* and *Relationship* variables were included in the second step, $R^2 = .19$, $F(7, 58) = 1.90$, $p = .09$. Readiness to change discrepancy in this model was a significant individual predictor of CG Anxiety in both steps, $\beta = .86$, $t(65) = 2.14$, $p = .04$, and $\beta = 1.01$, $t(65) = 2.37$, $p = .02$.

Discrepancies in CPAM scores were not predictive of IWD anxiety levels, $R^2 = .14$, $F(7, 60) = 1.46$, $p > .05$, or CG anxiety levels, $R^2 = .11$, $F(7, 60) = 1.04$, $p > .05$.

5.4. Depression.

The first step of the Precontemplation regression analysis predicting depression in IWDs was non-significant, $R^2 = .11$, $F(5, 60) = 1.60$, $p > .05$. The model became significant with the addition of *MMSE* and *Relationship* variables, $R^2 = .33$, $F(7, 58) = 4.03$, $p < .01$, but the individual effect of the discrepancy variable remained non-significant, $\beta = .44$, $t(65) = 1.13$, $p > .05$. Discrepancies in Precontemplation were not predictive of CG Depression levels, $R^2 = .14$, $F(7, 58) = 1.44$, $p > .05$.

Similar to the findings of for Precontemplation, the first step of the CPAM regression analysis predicting depression in IWDs was non-significant, $R^2 = .05$, $F(5, 62) = .74$, $p > .05$. The model became significant with the addition of *MMSE* and *Relationship* variables, $R^2 = .22$, $F(7, 60) = 2.47$, $p = .03$, but the individual effect of the discrepancy variable remained non-significant, $\beta = 1.28$, $t(67) = 1.03$, $p > .05$. Discrepancies in CPAM scores were not predictive of CG depression levels, $R^2 = .05$, $F(7, 60) = .45$, $p > .05$.

5.5. Quality of Life.

Discrepancies in Precontemplation were not predictive of IWD Quality of Life, $R^2 = .06$, $F(7, 58) = .54$, $p > .05$, or of CG Quality of Life, $R^2 = .17$, $F(7, 58) = 1.69$, $p > .05$. Similarly, discrepancies in CPAM were not predictive of IWD Quality of Life, $R^2 = .06$, $F(7, 60) = .59$, $p > .05$, or of CG Quality of Life, $R^2 = .07$, $F(7, 60) = .60$, $p > .05$.

5.6. Dyad Strain.

Discrepancies in Precontemplation were not predictive of IWD Dyad Strain, $R^2 = .11$, $F(7, 58) = .99$, $p > .05$, or of CG Dyad Strain, $R^2 = .04$, $F(7, 58) = .34$, $p > .05$. Similarly, discrepancies in CPAM were not predictive of IWD Dyad Strain, $R^2 = .10$, $F(7, 60) = 1.00$, $p > .05$, or of CG Dyad Strain, $R^2 = .14$, $F(7, 60) = 1.41$, $p > .05$.

5.7. Role Captivity.

Discrepancies in Precontemplation were not predictive of IWD Role Captivity, $R^2 = .12$, $F(7, 58) = 1.14$, $p > .05$, or of CG Role Captivity, $R^2 = .13$, $F(7, 58) = 1.30$, $p > .05$. Similarly, discrepancies in CPAM were not predictive of IWD Role Captivity, $R^2 = .12$, $F(7, 60) = 1.15$, $p > .05$, or of CG Role Captivity, $R^2 = .19$, $F(7, 60) = 2.04$, $p > .05$.

CHAPTER VI

DISCUSSION

In the present study, the effect of Readiness to Change discrepancies across the dyad were examined in terms of Anxiety, Depression, Quality of Life, and Relationship Strain. The original hypotheses that larger discrepancies would predict more negative psychosocial effects for both CGs and IWDs were largely not supported by the regression analyses using the MOD score. The MOD score was only found to be significant in predicting CG anxiety. While this result may indicate that larger discrepancies in readiness to change are responsible for higher levels of anxiety in CGs, this finding should be interpreted with caution. Of the regression analyses, this was the only one of twenty which produced a significant effect, and this significance disappeared in the second step of the regression model when the MMSE and relationship covariates were added.

The application of readiness to change in this population remains largely unknown. Due to the novel nature of the SC-DM, the research presented here was principally exploratory in nature. The psychometric work done with this new measure indicated that the readiness to change construct may be better measured in terms of two

factors: “ready to change” and “not ready to change.” The lack of five distinctly separate factors in the factor analysis underscores a major criticism of the TTM; that it posits rigid stages to conceptualize a process that may be very fluid. This finding may indicate that the development of a better measure may exist outside of the theoretical framework of the five-stage TTM. Moreover, the psychometric work done on the measures used in this study indicate that IWDs were able to reliably self-report.

Despite not having support for a five factor model, this measure still has potential to aid our understanding of intervention for this population. In order to fully explore its role in the creation of targeted interventions for IWDs and their CGs, alterations to this measure should be made in one of two ways. First, items for two subscales, *Ready to Change*, and *Not Ready to Change* could be developed and scored separately as part of the measure, similar to what was done in the present analysis. Alternatively, items indicating agreement with the *Not Ready to Change* stage could be reverse coded such that an individual score would represent readiness to change on a single spectrum from *Ready to Not Ready*.

The lack of significant findings in the present study is surprising. It seems logical that larger discrepancies in readiness to change would be distressing for both the CG and the IWD. This non-significant finding could be due to the measure itself, the sample that was used, or that readiness to change really does not play a role in psychosocial well-being (a finding that would be quite interesting in its own right). In order to further explore these possibilities in future work several limitations should be considered, as well as some recommendations for future research:

6.1. *Limitations*

There were several major unexpected limitations of the present research that should be noted for future work in the field. First, some sort of measure to assess the need to change should be adopted in order to qualify the administration of a measure of readiness to change. Unlike other populations in which the TTM is studied, the need to change behaviors related to dealing with dementia is not inherent in the population. For example, researchers examining readiness to change in a drug addicted population can reasonably presuppose that members of this population have a problem that needs changed. With IWDs and CGs, however, there may not be a need to change behaviors related to managing and coping with the dementing illness. To address this issue, future work should include some measure of the “need to change” among CGs and IWDs. Second, there may have been a sample bias based on the secondary nature of these data. The data used in the present study were from participants in a strength-based intervention study. The nature of their willingness to participate in the intervention study may be indicative of some existing level of readiness to change among these individuals. This limitation may serve as an obstacle for future work with this measure; individuals who need to change and are not ready to change (a critical demographic for intervention) may be less likely to volunteer for participation.

Further limitations include the newness of the SC-DM measure that was used here, as well as the small sample size. The number of participants in the present study was on the low end of what would generally be considered acceptable for the number of analyses conducted here and for the variables used in those analyses. However, based on the primarily exploratory nature of the study, it was thought to be beneficial to run

analyses for both the PC and CPAM stages. The generalizability of the findings from this study is also limited by the demographic nature of the sample (i.e., participants were well-educated and predominantly white).

6.2. Recommendations for Future Research

Future work in the field should include the re-evaluation of the items of the SC-DM measure. A modified version may also be considered based on the supported two factor model as opposed to the full five factor model.

After some consideration, it is speculated that the readiness to change construct may best be understood as a moderator of the effect of primary stressors (i.e., psychological stress, memory-related distress, distress associated with abilities to complete activities of daily living, etc.) and their impact on psychosocial well-being. Future work should examine the role of readiness to change in this context. The readiness to change construct may also serve as a “mediating variable” in the stress process model for IWDs and CGs (Pearlin, Mullan, Semple & Skaff, 1990; Judge, Menne & Whitlatch, 2010).

6.3 Conclusion

The relationship between readiness to change discrepancies across the IWD and CG dyad were examined. The results showed that discrepancies across the dyad were largely non-predictive of psychosocial outcomes in IWDs as well as CGs (depression, anxiety, quality of life, role captivity, and dyad strain). The significant lack of psychometrically validated measures in this field poses a challenge to addressing the

question of the influence of readiness to change in this population. The present research contributes evidence to support the future development of a two-factor model of readiness to change as opposed to the five factor model of change established by the TTM.

Tables

Table 1. The Processes of Change are strategies for moving individuals through the TTM stages. The table provides a description of each Process of Change as well as the stages in which implementing each process is most critical

Processes of Change	Definition	Critical Stages
Consciousness Raising	Education and awareness. This might include providing information to the dyad about the dementia diagnosis and about tools and strategies that may be helpful for providing care.	Precontemplation, Contemplation
Social Liberation	Awareness, availability, and acceptance of an alternative to the problem behavior. Intervention should facilitate the realization that there <i>is</i> a way to deal with these problems.	Precontemplation, Contemplation
Dramatic Relief	Expressing feelings about the problematic behavior and discussing potential solutions. This might be addressed in a guided intervention session.	Precontemplation, Contemplation
Environmental Reevaluation	Reevaluation of how the behavior affects the physical and social environment. Discussion might include the social and financial impact of poor caregiving practices and inefficient/non-effective daily routines.	Precontemplation, Contemplation
Self-Reevaluation	Reassessment of values. An example may include the reassertion of the belief that these changes are making life easier for a loved one and improving the CG/IWD relationship.	Contemplation, Preparation
Self-Liberation	Making a commitment to alter the problem behavior. A New Year's resolution, for example. In the dyad relationship, a mutual commitment between partners might be effective.	Preparation, Action
Counter-conditioning	Substituting the problem behavior for a more positive alternative. This might include utilizing new and more effective caregiving technique, or implementing mechanisms for addressing BPSDs.	Preparation, Action, Maintenance
Helping Relationships	Relying on support from others to encourage and facilitate change. Communication within the dyad and development of relational role in the change process.	Preparation, Action, Maintenance
Stimulus Control	Avoiding situations and habits that lead back to the problem behavior. Avoiding relapse through positive encouragement through intervention as well as resources for maintaining good behavior over the course of the disease.	Action, Maintenance
Reinforcement Management	Rewards for positive behavior changes. Rewards may be implicit such as more positive psychosocial well-being, or explicit such as a piece of chocolate or relaxation time. Positive praise can also come from a professional guiding the intervention.	Action, Maintenance

Table 2. Demographics

N = 69 dyads	IWDs	CGs
Gender N (%)		
Female	34 (49.3)	52 (75.4)
Male	35 (50.7)	17 (24.6)
Age category N (%)		
Under 65	5 (7.2)	27 (39.1)
65 – 80	40 (58.0)	37 (53.6)
80 and over	23 (33.3)	5 (7.2)
Missing	1 (1.4)	0 (0)
Ethnicity N (%)		
White	65 (94.2)	64 (92.8)
Black	4 (5.8)	4 (5.8)
Asian	0 (0)	1 (1.4)
Education N (%)		
Did not graduate high school	10 (14.5)	1 (1.4)
Graduated high school	14 (20.3)	12 (17.4)
Vocational training/some college	23 (33.3)	20 (29.0)
College degree or higher	22 (31.9)	36 (52.2)
Relationship Status N (%)		
Single	6 (8.7)	8 (11.6)
Married	47 (68.1)	59 (85.5)
Widowed	14 (20.3)	1 (1.4)
Other	2 (2.8)	1 (1.4)

Table 3. Cronbach's Alpha values for each measure and subscale

Measure	Reliability	
	CG	IWD
Readiness To Change	.85	.89
- Precontemplation	.67	.76
- Contemplation	.70	.84
- Preparation	.70	.69
- Action	.85	.77
- Maintenance	.73	.77
- CPAM	.90	.93
Anxiety	.77	.68
Depression	.84	.74
Quality of Life	.83	.98
Relationship Strain	.82	.72
- Dyad Strain	.83	.81
- Role Captivity	.82	.64

Table 4. Hierarchical regression models for PC stage (unstandardized B-weights are reported)

Model	IWD_PC	CG_PC	PC_MOD	DISC×CG	DISC×IWD	MMSE	Relationship	Model total	
	<i>B</i>	<i>B</i>	<i>B</i>	<i>B</i>	<i>B</i>	<i>B</i>	<i>B</i>	<i>F</i>	<i>p</i>
1. IWD Depression	-0.50	-0.64	-0.57	1.25	1.36			1.60	0.18
	-0.22	0.18	2.32	1.33	-0.09	0.25	-0.86	4.02	0.00
2. IWD Anxiety	-0.01	-0.02	-0.02	0.01	0.04			0.18	0.97
	0.00	0.02	0.11	0.01	-0.02	0.01	-0.01	0.58	0.77
3. IWD Dyad Strain	0.27	-0.28	0.01	0.46	-0.22			1.11	0.37
	0.25	-0.26	0.05	0.44	-0.21	0.01	0.07	0.99	0.45
4. IWD Role Captivity	-0.13	0.44	0.61	-0.33	-0.19			1.14	0.35
	-0.10	0.47	0.76	-0.32	-0.28	0.01	-0.10	1.15	0.35
5. IWD Quality of Life	-0.09	0.12	0.09	-0.14	0.00			0.74	0.60
	-0.09	0.12	0.07	-0.14	0.01	0.00	0.00	0.54	0.80
6. CG Depression	4.14	2.35	1.18	-5.25	-2.67			1.77	0.13
	4.40	2.60	2.31	-5.11	-3.36	0.08	-0.83	1.44	0.21
7. CG Anxiety	0.43	0.34	0.82*	-1.05	-0.55			2.44	0.04
	0.45	0.38	0.96	-1.05	-0.62	0.01	-0.04	1.89	0.09
8. CG Dyad Strain	-0.02	0.48	0.52	-0.98	-0.17			0.43	0.83
	0.00	0.50	0.62	-0.97	-0.22	0.01	-0.06	0.34	0.93
9. CG Role Captivity	-0.37	0.85	1.27	-1.30	-0.38			0.91	0.48
	-0.24	0.79	1.30	-1.20	-0.50	-0.01	-0.43	1.29	0.27
10. CG Quality of Life	-0.31	-0.46	-0.36	1.03	0.16			2.31	0.05
	-0.32	-0.48	-0.44	1.04	0.20	-0.01	0.01	1.69	0.13

* $p < .05$

Table 5. Hierarchical regression models for CPAM stages (unstandardized B-weights are reported)

Model	IWD_CPAM	CG_CPAM	CPAM_MOD	MODxCG	MODxIWD	MMSE	Relationship	Model total	
	<i>B</i>	<i>B</i>	<i>B</i>	<i>B</i>	<i>B</i>	<i>B</i>	<i>B</i>	<i>F</i>	<i>p</i>
1. IWD Depression	0.17	1.19	8.32	-5.04	-0.63			0.74	0.60
	-0.12	1.09	9.19	-5.44	-1.66	0.19	-0.91	2.47	0.03
2. IWD Anxiety	0.07	0.21	0.91	-0.53	-0.08			1.40	0.24
	0.05	0.20	0.91	-0.54	-0.11	0.01	-0.01	1.46	0.20
3. IWD Dyad Strain	0.11	0.05	0.02	-0.05	-0.01			0.78	0.57
	0.07	0.03	-0.12	-0.01	0.04	0.00	0.13	1.00	0.44
4. IWD Role Captivity	0.15	-0.05	1.60	-0.81	-0.19			1.60	0.17
	0.14	-0.05	1.61	-0.82	-0.20	0.00	-0.01	1.15	0.34
5. IWD Quality of Life	0.08	-0.06	-0.16	0.14	0.00			0.59	0.71
	0.09	-0.05	-0.15	0.14	0.01	0.00	-0.01	0.59	0.76
6. CG Depression	3.11	-2.13	3.65	0.71	-2.71			0.56	0.73
	3.14	-2.09	4.24	0.50	-3.09	0.03	-0.57	0.45	0.86
7. CG Anxiety	0.30	0.32	1.51	-0.58	-0.62			1.46	0.22
	0.30	0.32	1.56	-0.60	-0.65	0.00	-0.05	1.04	0.41
8. CG Dyad Strain	0.27	0.77	2.54	-1.10	-0.34			1.97	0.10
	0.27	0.78	2.61	-1.13	-0.39	0.00	-0.07	1.41	0.22
9. CG Role Captivity	1.03	-0.10	1.41	0.02	-0.66			1.67	0.15
	1.16	-0.01	1.85	-0.11	-0.80	-0.02	-0.42	2.03	0.07
10. CG Quality of Life	0.24	0.15	-0.12	0.10	-0.06			0.87	0.51
	0.25	0.15	-0.13	0.10	-0.05	0.00	0.01	0.60	0.75

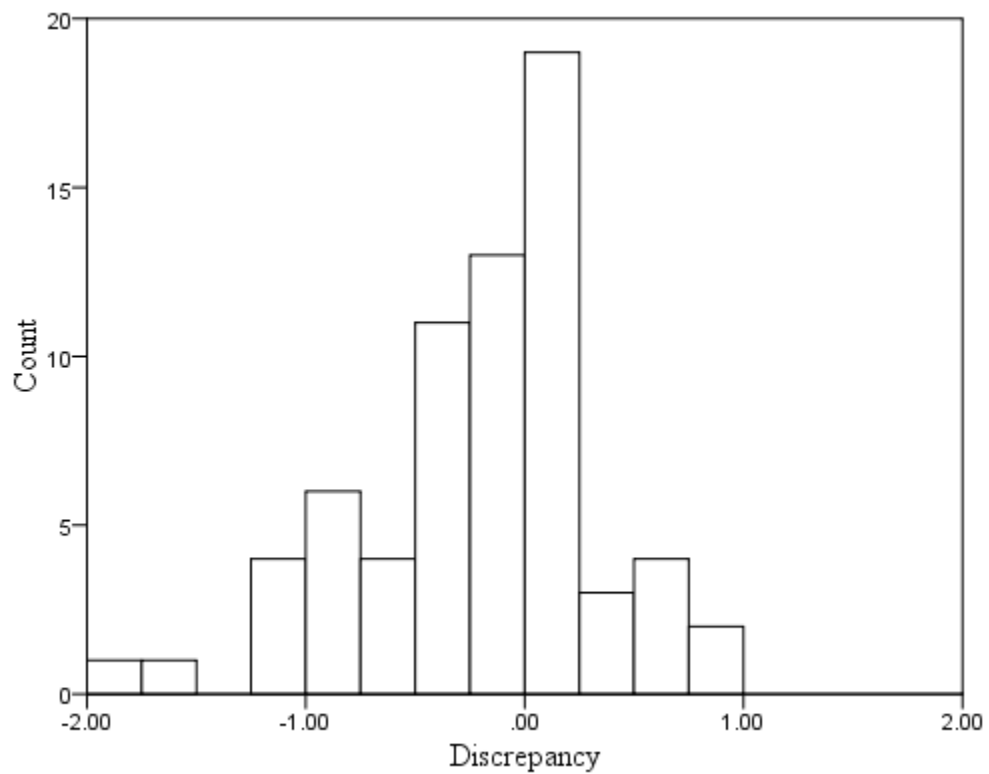
Table 6. Correlations Among Psychosocial Outcome Measures

	1	2	3	4	5	6	7	8	9
1 IWD Depression	—								
2 CG Depression	.37**	—							
3 IWD SAS	.64**	.31**	—						
4 CG SAS	.29*	.61**	.25*	—					
5 IWD Dyad Strain	.32**	.32**	.49**	.22	—				
6 CG Dyad Strain	.14	.31**	.29*	.28*	.34**	—			
7 IWD Role Captivity	.50**	.29*	.44**	.17	.51**	.17	—		
8 CG Role Captivity	.15	.31*	.15	.32**	.07	.52**	.14	—	
9 IWD QOL	-.28*	-.09	-.38**	-.06	-.17	-.10	-.07	-.11	—
10 CG QOL	-.26*	-.72**	-.26*	-.49**	-.18	-.32**	-.13	-.28*	.19

** p < 0.01 (2-tailed).

*p < 0.05 (2-tailed).

Figure 1. CPAM discrepancy score distribution. Negative values represent high discrepancy dyads in which the CG is more ready to change and the IWD is less ready to change. Positive values represent high discrepancy dyads in which the IWD is more ready to change and the CG is less ready to change. A zero value represents no discrepancy.



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APPENDICES

Appendix A: SC-DM

The next set of questions I will ask you will help us to improve services. I will read you statements that describe how a person might feel when approaching a problem such as dementia or memory loss. Please indicate the extent to which you agree or disagree with each statement. Please make your choice according to how you are feeling right now, not how you have felt in the past or how you would like to feel. There are five possible choices to each statement I will read. The five choices are **strongly disagree, disagree, undecided, agree, and strongly agree.**(PLEASE HAND RESPONSE CARD TO RESPONDENT.)

	STRONGLY DISAGREE	DISAGREE	UNDECIDED	AGREE	STRONGLY AGREE
a) As far as I'm concerned, I don't need to change the way I deal with dementia or memory loss.	1	2	3	4	5
b) I think I might be ready to improve the way I'm dealing with dementia or memory loss.	1	2	3	4	5
c) I am changing the way I deal with dementia or memory loss.	1	2	3	4	5
d) It might be worthwhile to work on how I deal with dementia or memory loss.	1	2	3	4	5
e) I am currently preparing to change the way I deal with dementia or memory loss.	1	2	3	4	5
f) I do not have a problem in dealing with dementia or memory loss so it does not make much sense for me to change.	1	2	3	4	5
g) It worries me that my care situation may change, so I am seeking help.	1	2	3	4	5
h) I am finally doing something to change the way I deal with dementia or memory loss.	1	2	3	4	5
i) I've been thinking that I might want to change the way I deal with dementia or memory loss.	1	2	3	4	5
j) I have plans to change the way I deal with dementia or memory loss in the next month.	1	2	3	4	5

The next set of questions I will ask you will help us to improve services. I will read you statements that describe how a person might feel when approaching a problem such as dementia or memory loss. Please indicate the extent to which you agree or disagree with each statement. Please make your choice according to how you are feeling right now, not how you have felt in the past or how you would like to feel. There are five possible choices to each statement I will read. The five choices are **strongly disagree, disagree, undecided, agree, and strongly agree.**(PLEASE HAND RESPONSE CARD TO RESPONDENT.)

	STRONGLY DISAGREE	DISAGREE	UNDECIDED	AGREE	STRONGLY AGREE
k) I have been successful so far in dealing with dementia or memory loss but I'm not sure I can keep up the effort on my own.	1	2	3	4	5
l) At times, dealing with dementia or memory loss is difficult, but I'm working on it.	1	2	3	4	5
m) Changing how I deal with dementia or memory loss is pretty much a waste of time for me because the problem doesn't have to do with me.	1	2	3	4	5
n) I'm hoping I will learn things that will help me to better deal with dementia or memory loss.	1	2	3	4	5
o) I have already made changes in the way I deal with dementia or memory loss in the last year.	1	2	3	4	5
p) I guess I have faults, but there's nothing I really need to change in the way I deal with dementia or memory loss.	1	2	3	4	5
q) I am really working hard to change the way I deal with dementia or memory loss.	1	2	3	4	5
r) The way I deal with dementia or memory loss is problematic and I really think I should work on it.	1	2	3	4	5
s) I have made changes in how I deal with dementia or memory loss but I'm not doing as well as I had hoped so I am seeking help.	1	2	3	4	5
t) I have a plan of action for how I would like to change the way I deal with dementia or	1	2	3	4	5

The next set of questions I will ask you will help us to improve services. I will read you statements that describe how a person might feel when approaching a problem such as dementia or memory loss. Please indicate the extent to which you agree or disagree with each statement. Please make your choice according to how you are feeling right now, not how you have felt in the past or how you would like to feel. There are five possible choices to each statement I will read. The five choices are **strongly disagree, disagree, undecided, agree, and strongly agree.**(PLEASE HAND RESPONSE CARD TO RESPONDENT.)

	STRONGLY DISAGREE	DISAGREE	UNDECIDED	AGREE	STRONGLY AGREE
memory loss.					
u) Even though I'm not always successful in changing, I am at least working on the way I deal with dementia or memory loss.	1	2	3	4	5
v) I thought once I had learned ways of dealing with dementia or memory loss that the problem would be resolved, but I still sometimes find myself struggling with it.	1	2	3	4	5
w) I wish I had more ideas on how to deal with dementia or memory loss.	1	2	3	4	5
x) I have started working on how I deal with dementia or memory loss but I would like help.	1	2	3	4	5
y) I am willing to listen to information about dealing with dementia or memory loss.	1	2	3	4	5
z) Maybe learning new information will be able to help me in the way I deal with dementia or memory loss.	1	2	3	4	5
aa) I may need help right now in dealing with dementia or memory loss to maintain the changes I've already made.	1	2	3	4	5
bb) I may have a problem in dealing with dementia or memory loss, but I don't really think I do.	1	2	3	4	5
cc) I hope I can learn new skills to manage dementia or memory loss.	1	2	3	4	5
dd) I am willing to ask questions regarding how	1	2	3	4	5

The next set of questions I will ask you will help us to improve services. I will read you statements that describe how a person might feel when approaching a problem such as dementia or memory loss. Please indicate the extent to which you agree or disagree with each statement. Please make your choice according to how you are feeling right now, not how you have felt in the past or how you would like to feel. There are five possible choices to each statement I will read. The five choices are **strongly disagree, disagree, undecided, agree, and strongly agree.**(PLEASE HAND RESPONSE CARD TO RESPONDENT.)

	STRONGLY DISAGREE	DISAGREE	UNDECIDED	AGREE	STRONGLY AGREE
I can better deal with dementia or memory loss.					
ee) Anyone can talk about changing the way they deal with dementia or memory loss but I'm actually doing something about it.	1	2	3	4	5
ff) All this talk about dementia or memory loss is not for me. Why can't people just stop dwelling on their problems?	1	2	3	4	5
gg) I'm learning new skills to prevent myself from going backwards in dealing with dementia or memory loss.	1	2	3	4	5
hh) It's frustrating to think that my care situation may change one day.	1	2	3	4	5
ii) I think I have learned skills that will help me to better deal with dementia or memory loss in the future.	1	2	3	4	5
jj) I worry about dementia or memory loss but so do a lot of people. Why spend time thinking about it?	1	2	3	4	5
kk) I am actively working on how I deal with dementia or memory loss.	1	2	3	4	5
ll) Rather than change, I would prefer to deal with dementia or memory loss in the same way I have been.	1	2	3	4	5
mm) After all I have done to deal with dementia or memory loss, it is still difficult to manage.	1	2	3	4	5

The next set of questions I will ask you will help us to improve services. I will read you statements that describe how a person might feel when approaching a problem such as dementia or memory loss. Please indicate the extent to which you agree or disagree with each statement. Please make your choice according to how you are feeling right now, not how you have felt in the past or how you would like to feel. There are five possible choices to each statement I will read. The five choices are **strongly disagree, disagree, undecided, agree, and strongly agree.**(PLEASE HAND RESPONSE CARD TO RESPONDENT.)

	STRONGLY DISAGREE	DISAGREE	UNDECIDED	AGREE	STRONGLY AGREE
nn) I am confident that I will change the way I deal with dementia or memory loss in the coming weeks.	1	2	3	4	5

Appendix B: Relationship Strain

Because of my (RELATIONSHIP)'s memory problems:	STRONGLY AGREE	AGREE	DISAGREE	STRONGLY DISAGREE
a) I felt that he/she tried to manipulate me.	3	2	1	0
b) I felt my relationship with him/her was strained.	3	2	1	0
c) I felt resentful toward him/her.	3	2	1	0
d) I felt angry toward him/her.	3	2	1	0
e) I did not feel appreciated for what I do.	3	2	1	0
f) I wished I were free to lead my own life.	3	2	1	0
g) I did not feel close to him/her.	3	2	1	0
h) I felt that he/she made requests over and above what he/she needed.	3	2	1	0
i) I learned some good things about him/her.	0	1	2	3
j) I felt depressed because of my relationship with him/her.	3	2	1	0
k) I had more patience than I have had in the past.	0	1	2	3
l) I felt trapped having to care for him/her.	3	2	1	0
m) I learned some good things about myself.	0	1	2	3
n) I felt communication with my (RELATIONSHIP) improved.	0	1	2	3
o) I wished I could run away from this situation.	3	2	1	0

Appendix C: Depression

During the past week , how often did you:	HARDLY EVER OR NEVER (LESS THAN 1 DAY)	SOMETIMES (1-3 DAYS)	OFTEN (4-7 DAYS)
a) not feel like eating or you had a poor appetite?	0	1	2
b) feel depressed?	0	1	2
c) feel that everything you did was an effort?	0	1	2
d) sleep restlessly?	0	1	2
e) feel happy?	2	1	0
f) feel lonely?	0	1	2
g) feel people were unfriendly?	0	1	2
h) enjoy life?	2	1	0
i) feel sad?	0	1	2
j) feel people disliked you?	0	1	2
k) not seem to be able to "get going?"	0	1	2

Appendix D: Anxiety

After I read each statement, please tell me if during the past **week** you felt this way **none or little of the time, some of the time, a good part of the time, or most or all of the time.**

	NONE OR A LITTLE OF THE TIME	SOME OF THE TIME	GOOD PART OF THE TIME	MOST OR ALL OF THE TIME
a) I felt more nervous and anxious than usual.	0	1	2	3
b) I felt afraid for no reason at all.	0	1	2	3
c) I got upset easily or felt panicky.	0	1	2	3
d) I felt like I was falling apart and going to pieces.	0	1	2	3
e) I felt that everything was all right and nothing bad would happen.	3	2	1	0
f) I felt calm and could sit still easily.	3	2	1	0
g) I felt that, because of the time I spend with my (RELATIONSHIP), I didn't have enough time for myself.	0	1	2	3
h) I felt stressed between caring for my (RELATIONSHIP) and trying to meet other responsibilities such as work or family.	0	1	2	3
i) I felt that my (RELATIONSHIP) affected my relationship with family members or friends in a negative way.	0	1	2	3
j) I felt that I didn't have as much privacy as I would like because of my (RELATIONSHIP).	0	1	2	3
k) I felt that my social life has suffered since my (RELATIONSHIP)'s illness.	0	1	2	3
l) I felt that I should be doing more for my (RELATIONSHIP).	0	1	2	3

Appendix E: Quality of Life

[INTERVIEWER: PLEASE READ THE RESPONSE CATEGORIES AFTER EACH QUESTION.] How do you rate:	POOR	FAIR	GOOD	EXCELLENT
a) Your physical health?	0	1	2	3
b) Your energy level?	0	1	2	3
c) Your mood?	0	1	2	3
d) Your living situation?	0	1	2	3
e) Your memory?	0	1	2	3
f) Yourself?	0	1	2	3
g) Your marriage? FOR UNMARRIED RESPONDENTS ASK: “Is there one person who you feel the closest to? Who is this?” RELATIONSHIP TO RESPONDENT: _____ How do you feel about this person? Do you feel your relationship is poor, fair, good, or excellent?”	0	1	2	3
h) Your current relationship with your friends? If RESPONDENT SAYS S/HE HAS NO FRIENDS, ASK: “Do you have anyone you enjoy being with besides family? Would you call that person a friend?”	0	1	2	3
i) Your ability to do things like chores?	0	1	2	3
j) Your ability to do things for fun?	0	1	2	3
k) Your financial situation? IF RESPONDENT IS HESITANT, EXPLAIN THAT YOU DON’T WANT TO KNOW WHAT THEIR SITUATION IS (AS IN AMOUNT OF MONEY), JUST HOW THEY FEEL ABOUT IT.	0	1	2	3
l) Your life as a whole?	0	1	2	3