

University of Nevada, Reno

**Quality of Life and the Eye of the Beholder: A Multidimensional Approach to
Assessing Quality of Life for Persons with Dementia**

A dissertation submitted in partial fulfillment of the requirement for the
degree of Doctor of Philosophy in Psychology

By

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Abstract

Formally assessing quality of life for persons with dementia presents a number of challenges due to the inherently subjective nature of the construct and the varying deficits observed in the progression of dementia. Caregiver judgments about affected individuals' functioning and quality of life can directly influence crucial care decisions for this vulnerable population. The current study employed a multi-trait multi-method paradigm to examine the discrepancies and congruencies between proxy, direct observation, and self-report measures of quality of life for persons with dementia. Results indicated that care recipients, professional caregivers, and family caregivers have distinctly different perspectives on the quality of life of persons with dementia with care recipients rating their quality of life significantly higher than family caregivers. Depressive symptoms, cognitive impairment, functional status and neuropsychiatric symptoms were variably associated with quality of life judgments across the three participant groups. Additionally, the validity of the QoL-AD, the dementia specific QoL measure was examined through assessment of the measure's convergent and divergent validity. The study results and directions for further research are discussed.

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Introduction

Overview of the Current Study

Dementia has emerged as a major form of disability for older adults worldwide. Currently an estimated 35.6 million people are affected with projections upwards of 115.4 million by 2050 (Alzheimer's Disease International, 2009). Worldwide, dementia is the most important independent contributor to disability in elderly people in countries with low and middle incomes (Sousa et al., 2009). In the United States close to 5.3 million Americans have Alzheimer's disease (AD), the most common form of dementia (Alzheimer's Association, 2009). To put this number in perspective, 1 in 8 people aged 65 or older in the United States are affected and the disease recently surpassed diabetes as the 6th leading cause of death in the US (Xu, Kochanek & Tejada-Vera, 2009). Within the 65 and plus age group it is the 5th leading cause of death (Xu et al., 2009).

Dementia exacts high costs to affected individuals, their families, and the healthcare system at large. The direct costs of dementia amount to more than \$112 billion dollars annually (Lewin Group, 2004) with indirect costs exceeding \$35 million (Koppel, 2002; Alzheimer's Association, 2009). Future projections reveal that the financial and emotional burdens of caring for individuals with dementia will continue to rise as the number of individuals aged 65 and older with AD is estimated to reach between 11 and 16 million by 2050, barring a breakthrough in prevention and treatment (Hebert, Beckett, Scherr & Evans, 2001).

Dementia is characterized by declines in new learning, verbal ability and motor functioning. There is, however, significant variability in the rate of decline and the

behavioral and affective manifestations of neurological changes across persons with dementia. Confusion, disorganized thinking, impaired judgment and disorientation to time, space and location typically increase as the disease progresses. In addition, behavioral and emotional changes often accompany the progressive cognitive declines observed in individuals with dementia including apathy, agitation, delusional speech, repetitive vocalizations, and wandering.

The decline in the verbal abilities of individuals with dementia results in an increased need for caregivers to step in and make judgments about the affected individual's well-being and quality of life. Due to the loss of cognitive abilities surrogate decision-making is the norm for individuals with dementia in the form of durable power of attorney for healthcare, guardianship and living wills (Maust et al. 2008; Givens, Kiely, Carey & Mitchell, 2009).

Caregiver judgments about affected individuals' functioning and quality of life can directly influence crucial care decisions involving the treatment of feeding problems, infections, pain, behavior problems, acute and long-term care admissions, and participation in research thereby greatly impacting affected individuals' lives. As persons with dementia become increasingly verbally impaired caregivers are faced with the critical and difficult task of interpreting the care recipient's wishes, current condition, and the pros and cons of different treatment options. Caregivers' perceptions of a care recipients' quality of life can directly influence choices that have life and death consequences.

Formally assessing quality of life (QoL) for individuals with dementia presents a number of challenges due to its inherently subjective nature, ambiguous definitions, and

the varying cognitive deficits observed in the progression of dementia. During the course of progressive dementia verbal deficits inevitably affect the person with dementia's ability to communicate his or her subjective state (Logsdon, Gibbons, McCurry & Teri, 2002; Sloane, Zimmerman, Williams, Reed, Gill & Preisser 2005). Researchers have attempted to overcome the challenges presented by verbal decline by developing a variety of measures. These measures have gained some empirical support over the last two decades (for a review see Ettema, Droes, Lange, Mellenbergh & Ribbe, 2005; and Sloane, et al., 2005). The measures are designed to address the challenges of assessing quality of life of verbally impaired individuals through the use of subjective, objective, and/or observational components.

As there is currently no cure for dementia, assessing quality of life has emerged as an important means to evaluate the experience of individuals with dementia and the effectiveness of care and services provided to them (Logsdon et al., 2002; Whitehouse, Patterson & Sami, 2003). The purpose of the current study is to compare self-reports, proxy reports and observational ratings of QoL and identify the clinical factors related to each reporter's ratings. Additionally, the relationship between family caregiver staff ratings of QoL and antipsychotic medication use will be examined.

The following sections will first provide an overview of dementia including a description of its causes, typical symptoms and characteristics, and the current treatments for behavioral symptoms and their side effects. Second, the construct of quality of life and how it is applied to individuals with dementia will be explored followed by a review of different methods of measuring quality of life for this population. Next, the research on different perceptions of quality of life and observed discrepancies will be reviewed.

Lastly, the implications of the extant research are discussed followed by the rationale and aims for the proposed study.

Overview of Dementia

The label “dementia” is a summary term for a group of symptoms that may accompany certain diseases and conditions. There are more than 50 known causes of cognitive impairment in older adults, some of which are reversible such as substance-induced, hormone or vitamin imbalances or depression, while others are currently irreversible including Alzheimer’s disease (AD), vascular dementia, and Parkinson’s disease (National Institute of Neurological Diseases and Stroke, 2010). AD, the most prevalent cause of dementia, accounts for approximately 70% of individuals with dementia while vascular dementia accounts for 17% and other diseases and conditions such as Lewy body disease, Parkinson’s disease, frontotemporal dementia and normal pressure hydrocephalus account for the remaining 13% (Plassman et al., 2007).

AD affects an individual’s ability to speak and understand language, recognize objects, execute motor activities, make sound judgments and complete complex tasks on a daily basis. As the disease progresses individuals with AD become increasingly dependent on others, often family members, for their care. As the symptoms increase family members often find themselves struggling to identify and manage their family member’s care needs. The transition from a private home to long-term care is common as up to 70% of individuals with dementia are living in a nursing home at the end of their life (Mitchell, Kiely & Hamel, 2005). Dementia, the most common health condition in long term care settings, currently affects over 50% of residents in nursing homes (Zimmerman et al., 2003; Kamble, Chen, Sherer & Aparasu, 2009).

Difficulty managing the behavioral challenges that develop over the course of dementia is a leading reason for placing a care recipient in a nursing home (Buhr, Kuchibhatla & Clipp, 2006). These behaviors, also called “neuropsychiatric symptoms” include social withdrawal, depressed affect, agitation, aggression, delusional speech, hallucinations, repetitive vocalizations, and wandering. Prevalence rates of clinically significant neuropsychiatric symptoms in individuals with dementia have been reported at over 60% (Lyketsos et al., 2002). While the dominant medical model of dementia views behavioral challenges as symptoms of neuropathology, the behaviors have also been conceptualized as the result of an individual’s diminished repertoire and the concomitant increasingly complex environment (Fisher, Drossel, Yury & Cherup, 2007). As dementia progresses and cognitive deficits increase individuals lose the ability to tact and report internal psychological or physiological states such as pain or discomfort. Cognitive deficits are also associated with a diminished ability to control and access support from the environment (Yury & Fisher 2007). As a result, persons with dementia may communicate distress or pain through behaviors that are then misattributed to the underlying neuropathology. When viewed within this alternative perspective, challenging behaviors are attributed to the affected individuals’ inability to report private events such as pain, fear, overstimulation, or boredom, and the diminished ability to access relief, rather than inevitable consequences of disease.

The misattribution of behavioral disturbances to the progression of dementia increases the risk of excess disability. Excess disability is defined as impairment in function beyond that which can be accounted for by the disease (Dawson, Wells & Kline, 1993). In excess disability the frequency of adaptive behavior is diminished prematurely

resulting in greater impairments than are due to the normal progression of dementia (Fisher et al., 2007). Lending support to this model are studies that have found that modification of the social and physical environment in which the problem behaviors occur results in a reduction of these problems and there in a reduction in excess disability (Yury & Fisher, 2007; Burgio & Stevens, 1999; Buchanan & Fisher, 2002; Cohen-Mansfield & Werner, 1998).

Historically, the biological or medical model of dementia has dominated the treatment of behavioral challenges. This model led to the practice of administering psychotropic medications as the first line of treatment to reduce or eliminate behavior problems (Fisher et al., 2007). While results from placebo-controlled trials of antipsychotics to treat behavioral problems in individuals with dementia, especially risperidone, have revealed modest improvement when compared with a placebo over 6-12 weeks of treatment (Schneider, Dagerman, & Insel, 2006; Carson, McDonagh, & Peterson, 2006; Sink, Holden & Yaffe, 2005), recent research indicates that the adverse effects of these medications offset the advantages (Schneider et al., 2006; Ballard et al., 2009). In an examination of adverse events associated with antipsychotic use for individuals with dementia, Schneider and colleagues (2006) found increased risk of parkinsonism (olanzapine, risperidone), extrapyramidal symptoms (olanzapine, risperidone), sedation (olanzapine, risperidone, quetiapine), confusion (olanzapine, risperidone), and cognitive disturbance and psychotic symptoms (olanzapine) than with placebo. Among the most startling adverse effects is an increased risk of mortality in patients taking antipsychotic medications, including thioridazine, chlorpromazine, haloperidol, trifluoperazine, and risperidone (Ballard et al., 2009).

These findings are particularly concerning as estimates of antipsychotic use in nursing home residents with dementia range from 32-58% (Ronchon et al., 2007; Margallo-Lana et al., 2001; Kamble et al., 2009). In a recent nationwide, cross-sectional study of antipsychotic prescribing patterns, Chen and colleagues (2010) assessed 16,586 newly admitted NH residents and found that more than 29% of the residents received at least one antipsychotic medication and 32% of the antipsychotic users had no identified clinical indication for the medication. Ballard and Margallo-Lana (2004) effectively sum up the current prescribing patterns as “prescriptions for antipsychotics are often issued uncritically and inappropriately, with little relationship existing between the types of symptoms patients experience and the drugs that are prescribed. In addition, subsequent monitoring and treatment reviews are often inadequate and prescriptions are rarely discontinued” (p. 23). The importance of reviewing antipsychotic prescriptions becomes clear when considering the lengthy list of severe adverse effects and the results of a recent study (Ruths, Straand, Nygaard, & Aarsland, 2008), which found that discontinuing long-term antipsychotic drug therapy of haloperidol, risperidone, or olanzapine, did not increase neuropsychiatric symptoms and even decreased symptoms in more than half the participants.

While it seems intuitive that a reduction in neuropsychiatric symptoms would increase an individual with dementia’s quality of life, research findings regarding the relationship between antipsychotic use and quality of life suggest otherwise (Ballard & Margallo-Lana, 2004). In one of the few studies on the subject, Ballard and colleagues (2001) examined the effect of psychotropic drugs on the quality of life for nursing home

residents with dementia and found that residents taking the drugs, which included neuroleptics, benzodiazepines and antidepressants, had significantly reduced well-being, a significant increase in time spent socially withdrawn, and a significantly reduced proportion of time actively or passively engaged in activities than the residents not taking the drugs. The investigators also found that neuropsychiatric symptoms were not significantly associated with the indices of QoL measured, indicating that individuals with these symptoms may not require specific interventions – particularly when considering what the side effects may be. In reviewing the medications prescribed to the residents in the study, they found that 31% of people without any neuropsychiatric symptoms were taking an antipsychotic medication, less than 60% of the people with depression were taking an antidepressant and “in general there was little evidence that individual psychotropic agents were being selectively prescribed for appropriate target symptoms” (p.101). Ultimately, the inappropriate use of psychotropic medications leads to excess disability through premature decreases in adaptive behavior and diminished quality of life.

Defining Quality of Life

A consensus regarding an acceptable definition of *quality of life* has been elusive with a variety of definitions proposed in the literature (Lawton; 1997; Sloane et al., 2005; Selai & Trimble, 1999). Some QoL definitions focus on disease-specific aspects (e.g. physical effects of stroke, cancer, arthritis) while others tend to be broad and multidimensional incorporating an individual’s physical, psychological and social well-being (Kane et al., 2003). The World Health Organization (1998) defined QoL as an “individual’s perceptions of their position in life in the context of the culture and value

system where they live, and in relation to their goals, expectations, standards and concerns”. The WHO goes on to describe QoL as “a broad ranging concept, incorporating in a complex way a person’s physical health, psychological state, level of independence, social relationships, personal beliefs and relationship to salient features of the environment” (p.17).

Lawton (1991) took a similar broad approach and defined quality of life as “the multidimensional evaluation, by both intrapersonal and social-normative criteria, of the person-environment system of an individual in time past, current and anticipated” (p.6). Lawton’s definition was derived from his conceptual framework of QoL in older adults, which was based on the four domains described below (1983; 1991):

1. Behavioral Competence: Refers to the objective measure or evaluation of the person’s health and cognitive functioning as well as their time-use and social behavior. All externally observable facets are included in this category.
2. Perceived Quality of Life: Refers to the subjective evaluation of function in any of the behavioral competence dimensions.
3. Objective Environment: The environment is viewed as being causally associated with some forms of behavioral competence. It constitutes a subset of important conditions of the dimensions of perceived quality of life.
4. Psychological Well-being: Refers to the ultimate outcome of the model and refers to the weighted and evaluated level of the person’s competence and perceived quality in all domains of life.

Rejecting the idea of QoL as a single construct, Lawton argued that these four domains are independent of one another yet each is a member of a total interacting

model. Lawton stressed that both subjective and objective components are essential to fully encapsulate QoL. He argued that objective measures provide a baseline from which individual perceptions can deviate while the subjective component is essential because the person's subjective view of his or her competence may not be in line with the objective view. He describes the example of a person whose full adaptation to life in a wheelchair both physically and psychologically negates the observable objective disability.

Defining the most useful balance between subjective and objective components in measuring QoL has been debated for the past two decades. Adding to the debate is the use of proxy respondents when individuals are deemed unable to provide QoL information themselves. As QoL is inherently a subjective measure, the use of proxies adds another dimension to the construct. Novella and colleagues (2001) reviewed the literature on agreement between self reports and proxy reports and found that proxies tend to underestimate the individual's QoL and the accuracy of proxy ratings is higher for concrete and observable information (see also, Conde-Sala, Garre-Olmo, Turró-Garriga, López-Pousa, & Vilalta-Franch, 2009; Hoe, Katona, Orrell & Livingston, 2007; Thorgrimsen, et al., 2003; Logsdon, Gibbons, McCurry & Teri, 1999, 2002). Lawton (1991) articulately warned about relying too heavily on proxy ratings stating: "Determining a gold standard for valuing life under different health conditions by obtaining the judgments of those not suffering from the condition – a "public consensus" – carries with it the heavy risk of misrepresenting the judgments of those who actually are in the health state" (p. 21).

A comparison of care recipients' current functioning with pre-morbid levels may influence family caregivers evaluations of their care recipient's QoL. Caregivers' ratings of QoL may be based on the apparent discrepancy between levels of functioning instead of a more objective assessment of current QoL. For example, a caregiver's QoL rating may be influenced by the observation that the care recipient can no longer read the Wall Street Journal, once a daily practice, and now prefers to look at tabloid magazines. The psychological state of proxy raters' may also bias evaluations of care recipient QoL. For example, Logsdon and colleagues (2002) found that caregiver depression was significantly correlated with caregiver-reported QoL ($r = -0.48, p < .001$) for care recipients. It is important to evaluate the influence of these factors when making QoL judgments about individuals with dementia.

Assessing Quality of Life

While it is widely accepted in the QoL literature that the individual should be the primary judge regarding his/her QoL, the issue becomes more complex when measuring the QoL of an individual with a cognitive impairment (Novella et al., 2001). Measuring QoL for individuals with dementia comes with a specific set of challenges as deficits to memory, attention, judgment, insight and verbal abilities vary across individuals with dementia and complicates one's ability to communicate his or her subjective state (Logsdon et al., 2002; Sloane et al., 2005). For this reason research on QoL for individuals with dementia lags behind the well established literature on QoL for individuals with other chronic diseases (Logsdon et al., 2002). Fortunately, in recent years there has been a renewed interest in accurately assessing QoL for nursing home residents with cognitive impairments as the focus of long term care research has shifted

from emphasizing the quality of care provided by the facility to that of the quality of life achieved by its residents (Sloane et al., 2005). In this regard, efforts to accurately conceptualize and measure QoL in individuals with cognitive impairments have increased in recent years (Winzelberg et al., 2005).

The development of measures of QoL has been influenced by the belief that individuals with dementia cannot accurately report their subjective experiences (Whitehouse, Patterson & Sami, 2003; Schnelle, 2003). Research suggests that this view may be incorrect as patients with mild to moderate dementia are aware of and can report on their own quality of life (Novella et al., 2001; Logsdon et al., 1999; Kane et al., 2003). Individuals with Mini Mental Status scores as low as 3 (MMSE ranges from 0-30 with 0-10 indicating severe impairment), have been reported to competently complete the Quality of Life in Alzheimer's Disease (QoL-AD), a 13-item interview format measure where domains of QoL are rated on a 4 point scale (Hoe, Katona, Roch & Livingstom, 2005; Thorgrimsen et al., 2003). Hoe and colleagues (2005) found that more than half of participants with an MMSE<12 (n=79) were able to complete the QoL-AD. Of those who were not able to competently complete the measure, 65% were unable to answer any of the questions, indicating that the majority of those who could complete the initial question were able to go on to complete the entire assessment. While there is evidence that a majority of impaired individuals are able to complete self-reports, the "gold standard" for measuring QoL, observational measures can be of benefit for those who are unable to complete self report measure or for whom the validity of the self-report measure is in question (Kane et al., 2003; Brod, Stewart, Sands & Walton, 1999).

Measuring quality of life in institutionalized individuals with dementia. As research in the area of QoL for nursing home residents with dementia has developed, a number of measures assessing dementia-specific QoL have emerged (see Table 1; for a review see Ettema et al., 2005; Sloane et al., 2005). The measures cover a number of different domains and incorporate the four points of view available within the long term care environment: resident report, staff report, family report, and direct observation. Each point of view has its limitations and some measures have incorporated more than one.

Resident report. The self-report or resident-report directly assesses the individual's subjective experience emphasizing the personal experience of dementia. The progressive symptoms of dementia are frequently cited as a barrier to using a resident-report measure as the sole or primary component of quality of life measures. For the resident report to be valuable the measure must accommodate the effects of cognitive impairment and be appropriate to the individual's skill level (Logsdon et al., 2002).

Staff and family report. Staff and family reports, also called "proxy reports" are obtained from the professional or family caregiver of the individual with dementia. A review of the literature found that proxies consistently rate QoL lower than do the affected individuals themselves (Logsdon et al., 1999; Logsdon et al., 2002; Novella et al., 2001; Thorgrimsen et al., 2003; Hoe, Hancock & Orrell, 2006). A major concern with proxy ratings is the effect that the rater's biases, expectations, past relationship with the individual, and current levels of burden and depression may have on the QoL ratings (Logsdon et al., 2002).

Direct Observation. The strength of using direct observation to assess the domains of QoL lies in its objective nature. Observers free of a relationship with the observed are less likely to be influenced by factors like the individual's medical and social history and experience emotional ties to outcomes. Objectivity is increased through the use of predefined behaviors and categories. The main concern with observation-based QoL measures is that without a direct relationship with the individual being assessed it is unclear whether the behaviors being observed are what the individual finds relevant for determining his or her QoL.

Evaluating the adequacy of QoL measures. The lack of clarity around a definition of quality of life has created challenges in effectively and reliably measuring the construct (Lawton, 1997). The variety of domains assessed within dementia-specific QoL measures (see Table 1) reveals the wide scope of the construct and the variability in how it is operationalized. Empirical examinations of which domains are most important to persons with Alzheimer's disease have come up with varied and sometimes conflicting results (Sloane et al., 2005). The confusion in determining which domains to include when assessing QoL and how to measure them may be due in large part to the inherently subjective nature of the construct. In an ideal world, QoL measures would be custom designed to include only domains deemed relevant by the individual being assessed.

Validity. Without an agreed upon "gold standard" for assessing QoL in individuals with dementia there is a lack of consensus regarding an acceptable criteria against which to evaluate the validity of new measures. The dominant approach to establishing criterion validity in the literature has been through comparison of QoL measures to one another (see Edelman et al., 2005; Sloane et al., 2005). While the

comparison may provide some information on the usefulness of various methods across individuals and settings, this approach is relatively weak due to the lack of adequate evidence of concurrent and predictive validity for the measures used in the comparison.

Without a thoroughly validated “gold standard”, concurrent and predictive validity become difficult to establish. There are currently no studies evaluating whether QoL measures predict future important outcomes such as treatment decisions. Therefore an important way to establish validity for QoL measures is through examining each measure’s construct validity, in other words are the measures actually measuring QoL for persons with dementia or some other construct. The extent to which each measure is actually assessing QoL can be determined through an analysis of the measures convergent and discriminant validity. The relationship between QoL and constructs hypothesized to be related or unrelated to QoL should be evaluated such as mood, functional abilities, affect, and cognitive capabilities. For example, Thorgrimsen and colleagues (2003) provided some evidence for the convergent and divergent validity of the QoL-AD through comparing QoL ratings to cognition and depression ratings with the hypothesis that QoL would be more closely related to level of depression than cognitive abilities. The use of a multitrait-multimethod matrix (Campbell & Fiske, 1959) would increase and strengthen the evidence for the construct validity of QoL measures and for the uniqueness of the construct itself.

Reliability. Test-retest reliability is especially important for QoL measures as holding constant major life events QoL ratings from one time period to the next should be comparable. High test-retest reliability provides evidence that the measure was comprehensible and captured not just a specific moment’s assessment of QoL, but a more

pervasive and consistent report. The progressive nature of dementia makes the assessment of test-retest reliability over an extended amount of time difficult as the individual may no longer be able to complete the measure, but it remains feasible within shorter timeframes. The evaluation of internal consistency reliability is important for measures of QoL as many include a variety of domains hypothesized to be part of QoL. The relevance and necessity of each domain and the survey item created to assess it should be determined through an analysis of internal consistency reliability. Inter-rater reliability also needs to be established for all measures that rely on observation or clinical interpretation.

Treatment utility. Another important area to assess when reviewing the adequacy of QoL measures is each measure's treatment utility, defined as the degree to which assessment is shown to contribute to beneficial treatment outcome (Hayes, Nelson & Jarrett, 1987). Assessment of QoL in persons with dementia residing in long-term care facilities could have many benefits (Edelman, Fulton, Kuhn & Chang, 2005). Results could help inform intervention at the individual and facility level. Measuring QoL could increase family and professional caregivers understanding of the individual experience of dementia beyond physical and cognitive health indicators (Edelman et al., 2005). Caregivers can also use QoL measures to evaluate the effectiveness of interventions on residents.

Comparing Measures. Three recent studies evaluated several of the dementia-specific QoL measures to determine the adequacy of each measure within the long-term care setting (Edelman et al., 2005; Sloane et al., 2005; Schölzel-Dorenbos et al., 2007).

Psychometric criteria for the dementia-specific QoL measures evaluated in the studies are reviewed in Table 2.

Edelman and colleagues (2005) evaluated three measures, the Quality of Life in Alzheimer's Disease (QOL-AD; Logsdon et al., 1999), Dementia Quality of Life Instrument (D-QOL; Brod et al., 1999) and Dementia Care Mapping (DCM, Bradford Dementia Group, 1997) in both nursing facilities and assisted living facilities. No significant relationships between resident QoL measures and resident characteristics were found. The perspectives of staff and observers were more highly correlated across the three measures than either were with resident QoL ratings as evidenced by a significant correlation between observer well-being ratings from DCM and staff QOL-AD ratings (0.40) as well as a significant correlation between observer well-being scores and three subscales of the staff-reported ADRQL: social interaction (0.28), awareness of self (0.32) and feelings and mood (0.29). No significant correlations were found between resident ratings of QoL and staff/observer ratings. The authors conclude that evaluating QoL from different perspectives such as self-report, proxy report and observation creates three relatively unique perspectives. Taken together the three perspectives create a more complete picture of QoL in dementia, implying that a single measure or perspective does not fully capture QoL.

In the second study, Sloane and colleagues (2005) evaluated the QOL-AD (Logsdon et al., 1999), the D-QOL (Brod et al., 1999) and DCM (Bradford Dementia Group, 1997) as well as the Quality of Life in Dementia (QOL-D; Albert et al., 1996), Alzheimer's Disease Health-Related Quality of life (ADRQL; Rabins et al., 1999), the Resident and Staff Observation Checklist – Quality of Life Measure (RSOC-QOL;

Sloane et al., 1998) and the Philadelphia Geriatric Center Affect Rating Scale (PGC-ARS; Lawton et al., 1996) and found similar results. Proxy-rated measures correlated most highly with other proxy ratings (0.44-0.68), moderately with observational measures (0.21-0.35), and least well with resident-rated measures (0.02-0.30). A review of the data revealed that resident characteristics such as cognition, ADL functioning, depression, agitation and pain explained no more than 27% of the variance in any of the QoL measures with the QoL-AD capturing the most of any measure. The authors suggest that this is a result of the QoL measures encapsulating much more than can be inferred from resident characteristics alone implying that QoL has divergent validity from measures of resident characteristics assessed and that the QoL measures are assessing something unique. The authors concluded, “no ‘gold standard’ exists; so a combination of methods and sources is likely to provide the most complete picture of quality of life” (p.37).

In the third study, Schölzel-Dorenbos and colleagues evaluated dementia specific QoL measures based on their inclusion of domains important to patients and professional caregivers with the goal of determining which scales are best for evaluating the outcome of care at different stages of dementia and for specific settings. Domains important to patients and professional caregivers were determined by a review of the literature and included areas such as self-esteem, social contact, enjoyment of activities and being useful. For assessment of QoL in 24-hour care, the QoL-AD was recommended as they found it to contain most of the domains nursing assistants focus on and it remains applicable as the disease progresses. The authors suggest the addition of an observational instrument when assessing individuals with more severe dementia. Unfortunately the

review had serious limitations due to the lack of empirical support for their recommendations.

In an evaluation of the validity and reliability of the QoL-AD, Thorgrimsen and colleagues (2003) conclude that the measure has very good psychometric properties and can be completed with a wide range of dementia severity (MMSE > 2). In the absence of a gold standard for assessing QoL in dementia the authors used two dementia-specific QoL measures (D-QoL, DCM) and the EuroQol-5D, a generic measure of health-related QoL, to investigate concurrent validity. Total QoL-AD scores were significantly correlated with all other QoL indices measured (D-QoL =0.69; Euroqol-5D = 0.54) with the exception of the DCM well-being score (0.39). Construct validity was evaluated by factor analysis. Results showed that all 13 items of the QoL-AD loaded on component 1 indicating that the QoL-AD functioned as a scale and all items were needed. Convergent and discriminant validity were assessed through comparisons with the Cornell Scale for Depression in Dementia (Alexopoulos et al., 1988) and the Mini Mental Status Exam (MMSE; Folstein et al., 1975) with the hypothesis that QoL would be more closely related to the level of depression than cognitive abilities. Results revealed that depression was significantly negatively correlated with QoL-AD scores (-0.20, $p < 0.01$) while MMSE scores were not (-0.09, $p = 0.19$). The inclusion of more than one method of measuring depression and cognition is necessary in order to estimate the potential contribution of method variance and add evidence for convergent and discriminant validity. Inter-rater reliability was found to be very good (all Cohen's kappa values > 0.70), internal consistency was excellent ($\alpha=0.82$) and test-retest reliability good overall

(all intraclass correlation coefficients ≥ 0.60). Participants with a MMSE score as low as 3, indicating severe impairment, were able to complete the measure.

Comparing perceptions of quality of life. A number of studies have evaluated the concurrent validity of QoL measures by comparing patient ratings and proxy ratings and investigating the discrepancies that arose.

Family caregivers as proxies. A review of the literature comparing the QoL perceptions of individuals with dementia and family caregivers found that care recipients report a significantly higher perception of QoL than their caregivers do (Conde-Sala et al., 2009; Hoe, Katona, Orrell & Livingston, 2007; Sands, Ferreira, Stewart, Brod & Yaffe, 2004; Thorgrimsen et al., 2003; Logsdon et al., 1999; Logsdon et al., 2002; Novella et al., 2001). Surprisingly, a lack of relationship between both caregiver and patient QoL ratings and the level of cognitive impairment has been reported (Conde-Sala et al., 2009; Thorgrimsen et al., 2003; Logsdon et al., 2002).

Higher levels of neuropsychiatric symptoms are associated with a lower perception of QoL by both patients and caregivers (Conde-Sala et al., 2009; Hoe et al., 2007) while greater functional autonomy is associated with higher ratings of the QoL by both patients and caregivers (Conde-Sala et al., 2009; Hoe et al., 2007; Logsdon et al., 2002). Patients' depressive symptoms are significantly correlated with QoL (Logsdon et al., 2002) and are the most important predictor for patients perceived QoL (Conde-Sala et al., 2009; Hoe et al., 2007). Residing in a facility versus home care is also a predictor of lower patient perceived QoL (Hoe et al., 2007). Important predictors for caregivers perceived QoL are patient autonomy in activities of daily living (Conde-Sala et al., 2009; Hoe et al., 2007), patient apathy (Conde-Sala et al., 2009; Hoe et al., 2007), caregiver

burden (Conde-Sala et al., 2009; Sands et al., 2004; Logsdon et al., 2002) and caregiver depression (Logsdon et al., 2002).

Conde-Sala and colleagues (2009) found that QoL scores for both patients and caregivers were higher when the patient is a man, married, living with a spouse and residing in his or her own home. A distinction regarding the type of relationship between the patient and family caregiver was observed in that caregivers who are sons or daughters perceive the patient's QoL to be lower than those who are spouses and the difference was also observed among patient's perceived QoL. The authors suggest the finding may be due to spouses being closer to the patient in several aspects of life such as age, having lived together for a long period of time and family and generational factors, resulting in greater empathy.

In an examination of the effect of medication used to slow the deterioration of cognitive abilities called acetyl cholinesterase inhibitors, on perceptions of QoL, Hoe and colleagues (2007) found that patients taking the medications had higher QoL ratings from both the caregiver and patient perspectives. As mentioned above, psychotropic drugs have been found to be negatively associated with the quality of life for nursing home residents with dementia as the residents taking the drugs had significantly reduced well-being, a significant increase in time spent socially withdrawn and a significantly reduced proportion of time actively or passively engaged in activities than the residents not taking the drugs (Ballard et al., 2001).

Professional caregivers as proxies. Staff of long-term care facilities, particularly direct care staff, play a vital role in promoting QoL because they deliver the majority of personal care to residents. Staff perceptions of residents are critical as they

may influence the manner in which they provide care and describe conditions to other medical providers (Winzelberg et al., 2005) and persons involved in health care decisions such as guardians and those with power of attorney for healthcare. Winzelberg describes biases in staff perceptions as “given their lack of dementia-care training, nursing assistants may rate resident quality of life on the basis of negative biases developed from daily interactions with severely impaired individuals rather than from more balanced observations of residents’ remaining capabilities” (p.107). The effect staff biases may have on perceptions of resident QoL is even more concerning in light of a recent study identifying the five more prevalent perceptions of residents with dementia as: they are anxious, have little control over their difficult behavior, are unpredictable, lonely and frightened/vulnerable (Brodaty, Draper & Low; 2003).

Winzelberg and colleagues (2005) examined the resident, nursing assistant, and facility factors associated with QoL ratings for residents with dementia. Results revealed that scores on the QoL scale were most strongly associated with resident clinical conditions, but there was a positive association between nursing assistants' attitudes towards dementia care and their level of training, and their evaluation of resident QoL. In contrast to studies using family caregivers as proxies, increased cognitive impairment was associated with lower QoL ratings while similar to family caregiver studies, increased resident functional impairment was associated with decreased QoL. Resident depression and behavioral symptoms were also associated with lower QoL ratings. Residents did not complete their own QoL ratings for this study so no comparisons between reporters can be made.

Hoe, Hancock and Orrell (2006) compared the QoL ratings of nursing home residents with dementia to the ratings of the nursing home staff caring for them and found that staff ratings were lower than patients ratings (see also Edelman et al., 2005), supporting earlier findings comparing patients and family caregivers ratings (see above). Residents' ratings of their own quality of life were highly associated with their mood, such as symptoms of depression and anxiety, while ratings of the residents' quality of life by staff were clearly associated with level of dependency (see also Edelman et al., 2005). The resident and the professional caregivers QoL ratings were not correlated at the level of clinical significance. The authors suggest that professional caregivers cannot be assumed to be a suitable proxy for quality of life from the viewpoint of a person with dementia (see also Novella et al., 2001). Adding to the literature in this area, Spector and Orrell (2006) found a correlation between increased hope in staff and better resident assessed QoL.

Novella and colleagues (2001) investigated QoL reports from the perspective of the resident, his or her professional caregiver and his or her family caregiver. Results revealed a poor to moderate agreement between patients QoL measures and their proxies. They found higher agreement for observable measures of function such as physical health or disability and lower for more subjective measures such as perceived health or social health. The study had a number of limitations including a failure to examine in depth which factors predicted each rater's perceptions of quality of life, they did not use a dementia-specific QoL measure, which makes comparisons to other studies difficult, and they lacked power for more informative statistical analyses.

Implications

A review of the literature on quality of life for individuals with dementia reveals that there is still much to be learned. As the number of individuals with dementia continues to increase at a rapid rate the need for a more thorough understanding of how to best assess quality of life for these individuals is vital. Assessing the factors that predict QoL for individuals with dementia can help pinpoint areas for treatment to enhance QoL.

The observed pattern of proxies rating patients QoL lower than the patients themselves deserves more attention, as the implications are profound. Although some individuals with mild dementia are capable of making medical decisions, the progression of the illness leads to impaired decision making and reliance on designated healthcare proxies to make medical decisions (Okonkwo et al. 2007). Nursing home staff play a pivotal role in healthcare decisions as well via the way they describe conditions to other medical providers (Winzelberg et al., 2005). In this sense the same proxies who are rating QoL lower are making or influencing vital healthcare decisions, such as the use of psychotropic medications.

Currently there is no “gold standard” measure of QoL in dementia and therefore no consensus in the field regarding an acceptable criterion for evaluating QoL measures. Lawton (1997) suggested that our understanding of QoL for persons with dementia can be broadened by examining the congruencies and incongruencies between sources and methods and attempting to explain them. A multidimensional approach to QoL assessment that takes into account subjective and objective data collected from multiple sources and methods is needed to strengthen the validity of dementia-specific QoL measures through assessment of convergent and divergent validity.

Rationale and Aims for the Proposed Study

The purpose of this study is to extend the current literature on quality of life for individuals with dementia by examining the discrepancies and congruencies between proxy and self reports of QoL and explicating which of several specific hypothesized factors described in the literature predict QoL. The four domains of QoL proposed by Lawton (1991) - behavioral competence, perceived quality of life, objective environment and psychological well-being - will guide the selection of measures. To date, no study has used a multi-construct multi-method paradigm that incorporates multiple perspectives to evaluate the construct of quality of life for persons with dementia. The current project will use multiple methods of measuring QoL and related constructs to evaluate the convergent, discriminant, and construct validity of QoL measures of individuals with dementia in nursing homes. The specific aims of this project are:

Specific aim 1: To compare the resident's rating of QoL with the ratings of his or her professional and family caregivers, and observational ratings and identify the concordances and discrepancies between ratings.

Hypothesis 1. Care recipients will rate their quality of life more favorably relative to their professional and family caregivers' ratings of the care recipients' quality of life.

Specific aim 2: To identify the clinical factors related to each reporter's ratings of QoL.

Hypothesis 2. Care recipients', professional caregivers', and family caregivers' ratings of QoL will be differentially related to clinical factors as specifically hypothesized below.

Hypothesis 2.1. QoL ratings will not be significantly correlated with cognitive impairment for care recipient and family caregiver ratings of QoL, but will be positively correlated for professional caregiver QoL ratings.

Hypothesis 2.2. Neuropsychiatric symptoms will be associated with care recipient, professional caregivers and family caregivers QoL ratings. Specifically, total scores on the Neuropsychiatric Inventory will be negatively correlated with all three QoL ratings.

Hypothesis 2.3. Care recipient ratings of QoL will be negatively correlated with care recipient depression ratings.

Hypothesis 2.4. Professional and family caregiver ratings of QoL will be positively correlated with functional status ratings.

Hypothesis 2.5. Professional and family caregiver depression and caregiver burden ratings will be negatively correlated with QoL ratings.

Hypothesis 2.6. Family caregivers' attitudes about dementia will be positively correlated with their QoL ratings.

Hypothesis 3. Clinical factors will independently predict QoL-AD care recipient ratings as well as family and professional caregivers' QoL-AD ratings.

Specific aim 3. To examine the relationship between family caregiver staff ratings of QoL and antipsychotic medication use.

Hypothesis 4. Care recipients taking psychotropic medications will have lower QoL ratings than care recipients not receiving psychotropic medications.

Method

Participant Recruitment

Three groups of individuals were recruited to participate in this study: (1) elderly persons with dementia (hereafter referred to as “care recipients”), (2) their family caregivers, and (3) their professional caregivers. Participants with dementia were recruited from 3 assisted living facilities, 2 skilled nursing facilities, and 2 adult day programs within the Reno/Sparks area. A total of 50 care recipients with dementia and their respective professional and family caregivers were recruited through flyers provided to care facilities.

Participant Characteristics

Care recipients. Inclusion criteria for care recipients consisted of the following: (1) a medically confirmed diagnosis of dementia, (2) speak English fluently, (3) have been a resident of a long term care facility or attended an adult daycare for at least 30 days, and (4) has a primary family caregiver or healthcare proxy who assists with medical decisions. The only exclusion criterion for care recipients was a recent abrupt decrease in functioning within the last two weeks due to medical co-morbidities.

Family and professional caregivers. The inclusion criteria for professional caregiver participants included (1) employment by the facility as nurses or nursing assistants for a minimum of 30 days, and (2) fluent in English. Inclusion criteria for family caregiver participants included (1) fluency in English and (2) being the primary family caregiver or healthcare proxy for a care recipient participant. There were no exclusion criteria for family and professional caregiver participants.

The primary investigator met with all eligible participants to obtain informed consent and discuss the study procedures. Family caregiver participants provided informed consent for themselves and the care recipient for whom they provide care when the care recipient was no longer able to consent due to the severity of his/her cognitive impairment. In the cases where care recipients' consent was obtained from their healthcare proxy, the care recipients were told about the nature and purpose of the study and assent was obtained. All participants were given the opportunity to refuse to complete selected measures as depicted in Table 3. All measures were collected within the same one-week time period.

Procedure

Assessment of care recipients. Demographic information was collected through review of care recipients' facility records. Care recipients' medical records were also reviewed for the presence of prescriptions for psychotropic medication and medications found to slow the disease process such as acetylcholinesterase (AChE) inhibitors and N-methyl-D-aspartate (NMDA) blockers. The type, dosage, start date and reason for prescription were recorded. Assessment of care recipients was completed in an interview format by the primary investigator in the facility where they reside. The following measures were administered:

- 1) Cognitive Status. Cognitive status was assessed using the Mini-Mental Status Exam (MMSE) (Folstein et al., 1975) and verbal fluency tasks. The MMSE is an 11-question measure that was developed to systematically and thoroughly assess mental status and is routinely used to select participants for dementia trials (Lezak, Howieson, & Loring, 2004). Estimates of internal consistency range

from .77 for a community sample to .96 for a sample of normal, delirium and dementia patients (Holzer et al., 1984; Foreman, 1987). Test-retest reliability estimates range from .80-.95 for intervals of less than two months (Strauss et al., 2006). Recommended cutoff levels are as follows: ≥ 27 = normal; 21–26 = mild; 11–20 = moderate; ≤ 10 = severe (Folstein et al, 2001). The MMSE has been found to be valid in distinguishing older adults with cognitive impairment from non-cognitively impaired older adults (Folstein et. al, 1975). The MMSE shows modest to high correlations with other brief cognitive screening tests and a variety of other cognitive measures (e.g. tests of intelligence and executive function) (Strauss et al., 2006). If the care recipient was unresponsive to the orientation questions the primary investigator moved on to the registration subtest. If the care recipient continued to be unresponsive to the assessment questions the testing was terminated and the care recipient received a score of zero on the measure and the assessment was concluded. Care recipients' ability to spontaneously produce words was assessed through a phonemic fluency task, where the examinee was asked to orally produce as many words as possible beginning with a specific letter during a one-minute time period, and a semantic fluency task, where the examinee was asked to produce as many animal names as possible within a one-minute interval. Test-retest correlations have been found to be high, typically above .70 for both phonemic and semantic fluency with short and long intervals (Basso, Bornstein & Lang, 1999; Dikmen, Heaton, Grant, & Temkin, 1999). Internal consistency estimates are high for phonemic fluency (.83; Ruff et al., 1996). Factor analytic findings have found that attentional control, working memory and

mental speed play an important role in tests of verbal fluency (Strauss et al., 2006).

- 2) Quality of Life (QoL). QoL was assessed using the Quality of Life-Alzheimer Disease (QOL-AD) (Logsdon et al., 1999). The QOL-AD is a self- and caregiver-report measure of quality of life for individuals with Alzheimer's disease. The measure was used to assess several domains of QoL including: physical health, mood, living situation, memory, interpersonal relationships, functional abilities, , and life and self as a whole. A version adapted for use in long-term care was used for the current study (Edelman et al., 2005). High internal reliability has been reported for both patient and caregiver with alpha ranges from 0.75-0.90 as well as high test-retest reliability (patients = 0.76; caregivers = 0.92) (Logsdon et al., 2002; Logsdon et al., 1999; Thorgrimsen et al., 2003). While the QoL-AD was originally designed for individuals with MMSE scores > 10, limited research has shown that more impaired individuals (MMSE = 3-11) are able to complete the measure (Hoe et al., 2005). Hoe and colleagues (2005) found that 71.2% of participants with MMSE scores ranging from 3-11 could complete the measure and found high internal consistency reliability ($\alpha = 0.78$) and a high 6 month test-retest reliability ($\alpha = 0.89$) for the 17 original participants (54.8%) that were able to complete the measure at retest (Hoe et al., 2005). The author's explicit instructions will be followed to avoid influencing the care recipient's responses (Logsdon, 1996). It will be noted if the care recipient is unable to respond to more than two items and he or she will be considered a "non-completer" as described by Logsdon and colleagues (2002) and omitted from the study.

- 3) Depression. Care recipient self-report of depressive symptoms was assessed using the Geriatric Depression Scale (GDS) (Yesavage et al., 1983). The GDS is a widely used 30-item measure developed to assess for depressive symptoms specifically in older adults. The simple yes/no response set and the brevity of the GDS are advantages for administration with this population. Convergent validity for the GDS has been established through statistically significant correlations with other measures of depression such as the BDI (Hyer & Blount, 1984) the Zung scale (Brink et al., 1982; Yesavage et al., 1983) and the Hamilton scale (Brink et al., 1982; Yesavage et al., 1983). Significant but moderate correlations have been found between self-reports on the GDS and direct-care staff ratings of depression (Parmelee et al., 1989). Parmelee and colleagues (1989) found GDS-based cutoffs for possible depression to be fairly consistent with those based on a symptom checklist (presence vs. absence of depression 79.9%) and with clinical diagnoses (presence vs. absence of depression 78%). Support for the divergent validity of the GDS comes from low correlations with cognitive screening tests (Parmelee et al., 1989). Internal consistency for the GDS ranges from 0.82 to 0.94 (Strauss et al., 2006). Good internal consistency ($\alpha = .92$) and test-retest reliability ($r = .86$, $p < .001$) have been found with cognitively impaired individuals in a long-term care setting (Parmelee et al., 1989). Logsdon and colleagues (2002) administered the GDS in interview format and found high internal consistency ($\alpha=0.83$), which was not adversely affected by patients' cognitive status.

The assessments described below were completed by a professional caregiver regarding his or her care recipient. Twenty-five percent of care recipients will have the measures completed by two professional caregivers to assess inter-rater reliability.

- 1) Quality of Life (QoL). See #1 above for a description of the QoL-AD.

Professional caregivers completed the QoL-AD for their care recipients as a questionnaire with assistance from the principal investigator as needed.

- 2) Neuropsychiatric Symptoms. The presence and severity of care recipients' neuropsychiatric symptoms and psychopathology was assessed using the Neuropsychiatric Inventory : Nursing Home Version (NPI-NH; Cummings et al., 1994 ; Wood et al., 2000). The NPI-NH was derived from the Neuropsychiatric Inventory (Cummings et al., 1994) to assess for neuropsychiatric symptoms in individuals with Alzheimer's disease and other dementias residing in extended care facilities. Between-rater reliability for the NPI ranges from 93.6 – 100% and has 3-week test-retest reliability correlations of 0.79 for frequency and 0.86 for severity (Cummings, 1997). Acceptable content and concurrent validity for the NPI has been established (Cummings, 1997). The following behavioral areas are covered by the NPI-NH: delusions, hallucinations, agitation/aggression, depression/dysphoria, anxiety, elation/euphoria, apathy/indifference, disinhibition, irritability/lability, aberrant motor behavior, sleep and nighttime behavior, and appetite and eating. Woods and colleagues (2000) assessed the validity of the NPI-NH version through comparison of ratings on the measure from day shift charge nurses and certified nursing assistants (CNA) and measures of psychiatric symptom disturbance determined by trained observers. Validity of

the nurses' ratings was established for 9 of the 11 behavioral domains with significant yet moderate correlations with the clinical observations, while only 3 of the 11 behavioral domains were significantly correlated for the CNA's ratings. In addition concurrent validity was established for the NPI-NH agitation scale through a significant correlation ($r=0.449$, $p < 0.01$) with the Cohen-Mansfield Agitation Inventory (Cohen-Mansfield et al., 1989). Based on these findings, the NPI-NH was completed by the appropriate charge nurse when available for each care recipient. The NPI-NH was administered in an interview format by the principal investigator.

- 3) Activities of Daily Living. Care recipients' functional abilities were assessed using the Barthel Index (BI, Mahoney & Barthel, 1965; Collin & Wade, 1988). The BI is a 10-item measure developed to assess functioning in the following domains: bowels, bladder, grooming, toilet use, feeding, transfer, mobility, dressing, stairs and bathing. Concurrent and predictive validity have been established for the BI as well as construct validity (Wade & Collin, 1988). Estimates of test-retest reliability ($r = 0.89$) are inter-rater reliability ($r = .089$) are high (Granger et al., 1979; Wade & Collin, 1988). The BI has shown to be reliable across several different conditions (Wade & Collin, 1998).

The assessments described below were completed by a family caregiver regarding his or her care recipient:

- 1) Quality of Life (QoL). See above description of the QoL-AD. Family caregivers completed the QoL-AD about their care recipient as a questionnaire with assistance from the principal investigator as needed.

- 2) Depression. Care recipients' depressive symptoms were assessed using the Geriatric Depression Scale (GDS) (Yesavage et al., 1983). Family caregivers completed the measure as a questionnaire. Logsdon and colleagues (2002) found high internal consistency reliability (0.87) for the GDS when completed as a proxy measure by caregivers. See #3 under care recipient assessment for further detail.
- 3) Activities of Daily Living. Care recipients' functional abilities were assessed by family caregivers using the Barthel Index (BI, Mahoney & Barthel, 1965; Collin & Wade, 1988). See #3 under assessment completed by a professional caregiver regarding his or her care recipient for further detail.

The assessment described below was completed by trained observers:

- 1) Care Recipient Affect. Care recipients' affect was observed and assessed through the use of the Observed Emotion Rating Scale (OERS; Lawton, Van Haitsma, Klapper, 1996; Lawton, Van Haitsma, Perkinson & Ruckdeschel, 1999). The OERS was developed to measure the frequency and duration of the following six emotions in nursing home residents with Alzheimer's disease: pleasure, interest, contentment, sadness, anxiety, and anger – by direct observation of facial expression, body movement, and other cues that do not depend on self-report. Each affect scale has been found to have high inter-rater reliability (kappas = 0.76-0.89; Lawton et al., 1996). Discriminant and convergent validity has been established through correlation between the negative states and other measures of depression, anger, anxiety and withdrawal; and between the positive states and various measures of social and engaged behavior (Lawton et al., 1996). While the

OERS lacks support with other populations, it has been used as a measure of QoL for individuals with dementia (see Sloane et al., 2005) and was used to establish concurrent validity for the QoL-AD in the current study.

For feasibility purposes a subset of the care recipient sample were observed for the two weeks prior to the above described assessments. Trained undergraduate research assistants, blind to the purpose of the study, collected observational data on care recipient affect. Observations were conducted at fixed intervals over the two-week period. At least thirty percent (30%) of all observation periods were coded independently by two trained observers to assess inter-rater reliability.

Professional caregiver measures. Information such as age, gender, education level, socioeconomic status, and duration of caregiving relationship was collected through completion of a demographic form. Professional caregivers will complete the following self-report measures at the facility where they are employed:

- 1) Staff Burnout. Professional caregiver burnout was assessed through the use of the Maslach Burnout Inventory (MBI; Maslach & Jackson, 1981). The 22-item MBI was designed to assess three components of burnout: emotional exhaustion ($\alpha = 0.90$), depersonalization ($\alpha = 0.79$), and reduced personal accomplishment ($\alpha = 0.71$). Test-retest reliability for the MBI ranges from .50 to .82 for time spans of three months to one year (Maslach, Jackson & Leiter, 1997). Convergent validity has been established for the MBI through correlation with behavioral ratings made independently by a person who knows the individual well, the presence of certain job characteristics expected to contribute to burnout and with measures of

various outcomes hypothesized to be related to burnout (Maslach et al., 1997). Discriminant validity has been established through comparison of MBI scores with social desirability (uncorrelated), job dissatisfaction (moderate negative correlation with emotional exhaustion and depersonalization and slight positive correlation with personal accomplishment) and depression where each component of burnout is more closely tied to one another than to any aspect of depression (Maslach et al., 1997).

Family caregiver measures. Information such as age, gender, education level, socioeconomic status, and type and duration of caregiving relationship were collected through completion of a demographic form. Family caregivers completed the following self-report measures at the facility where their care recipient resides:

- 1) Attitudes Towards Dementia. Family caregivers' attitudes towards dementia care were assessed through the use of the Approaches to Dementia Care Questionnaire (ADQ, Lintern, Woods, & Phair, 2000). The 19-item ADQ consists of a total score as well as a hope sub-score and a person-centered sub-score. Acceptable test-retest reliability (0.76) and internal consistency have been established (total score, $\alpha = 0.83$; hope subscale, $\alpha = 0.76$; person centered subscale, $\alpha = 0.85$) (Lintern & Woods, 2000). ADQ scores correlate with scores on the 'Dementia Care Styles Questionnaire', responses to video vignettes and observed staff behavior (Lintern & Woods, 2000).
- 2) Depression and Anxiety. Family caregivers' depressive symptoms and anxiety were assessed using the Depression Anxiety Stress Scales (DASS-21; Lovibond & Lovibond, 1995). The widely used DASS-21 is a self-report questionnaire

designed to measure the severity of a range of symptoms common to both depression and anxiety. High internal consistency has been established for each of the three subscales: depression ($\alpha = .94$), anxiety ($\alpha = .87$) and stress ($\alpha = .91$) (Antony et al., 1998). Test–retest reliability of the DASS-21 is high, with .71 for depression, .79 for anxiety, and .81 for stress (Brown et al., 1997) Acceptable convergent validity and discriminant validity has been established (Antony et al., 1998; Gloster et al., 2008).

- 3) Caregiver Burden. Family caregivers' burden was assessed using the Burden Interview (Zarit et al., 1980; Zarit & Zarit, 1987). The 22-item self-report inventory measures common areas of concern: health, finances, social life, and interpersonal relations. The measure items have content validity as they were derived from clinical and research experience of caregivers of individuals with dementia. Construct validity has been established (Zarit & Zarit, 1987; Pratt, Schmall & Wright, 1986). The Burden Interview has high internal consistency ($\alpha = 0.91$) and test-retest reliability ($\alpha = 0.71$).
- 4) Family Caregiver Grief. The Marwit-Meuser Caregiver Grief Inventory-Short Form (MM-CGI; Marwit & Meuser, 2002) was used to measure family caregivers' grief. The 18-item MM-CGI was developed to specifically assess grief responses in individuals caring for a person with Alzheimer's disease. The items were derived from caregiver statements under controlled conditions and the following three factors emerged: personal sacrifice and burden, heartfelt sadness and longing, and worry and felt isolation. Estimates of internal consistency reliability range from .90-.96 for each factor as well as the total grief score.

Construct validity was established through convergent and discriminant correlations with related measures from the field of caregiver research (e.g. Anticipatory Grief Scale, Geriatric Depression Scale, Caregiver Strain Index).

Assessment of Construct Validity

Construct validity for QoL was assessed through the use of a Multitrait-Multimethod Matrix (Campbell & Fiske, 1959). Convergent and discriminant validity for QoL were analyzed through comparison of measures of QoL with depression ratings and functional impairment ratings as both of these latter functions have been found to be strong predictors of QoL ratings (Conde-Sala et al., 2009; Hoe et al., 2007). All three constructs (quality of life, functional impairment, depression) were assessed across a combination of methods including resident self-report, professional caregiver report, family caregiver report, and observation by objective observers blind to the purpose of this study.

Results

Data Screening

All data were entered twice by trained undergraduate research assistants and the student investigator in the student investigator's laboratory. Any discrepancies that appeared were checked with the original source and the correct data were entered. Descriptive statistics were computed for all variables included in the data analysis to ensure that entries were in the range of expected means and standard deviations. A review of the data found that two care recipients did not have the QoL-AD measure completed by all 3 perspectives so they were eliminated from the study, resulting in 48 complete triads (care recipient with dementia, professional caregiver and family caregiver).

Missing data were screened to evaluate whether missing values appeared to be random or systematic. Assessment questions that systematically had missing values were removed from the data set. In cases where only one item was missing on a particular measure and the item was not systematically missing across participants, the mean score on the measure for the particular participant was substituted.

Sample Characteristics

Descriptive statistics including means and standard deviations were computed for socio-demographic data (Tables 4-6). A total of 48 family caregivers and 26 professional caregivers rated 48 care recipients' quality of life. On average each professional caregiver rated the quality of life of 1.85 care recipients with a range of 1-12.

The majority of participants across the three populations were women, including approximately 75% of family caregivers, 73% of care recipients and 96% of professional

caregivers and white accounting for all of care recipients and their family caregivers and 73% of the professional caregivers. Participant age varied across the three populations. Daughters comprised the largest subset of family caregivers accounting for 50% of the family caregivers. The majority of family caregivers (62.5%) spent at least 11 hours a month with the care recipient while 29% reported spending over 30 hours a month. Approximately half (52%) of the care recipients were residents of a memory care unit while the remainder consisted of skilled nursing facility residents (35%) and adult day program attendees (13%). A review of the care recipients' medical chart found that two-thirds (67%) of care recipients had a prescription for at least one psychotropic medication and close to a third (31%) had a prescription for an acetylcholinesterase (AChE) inhibitor or a N-methyl-D-aspartate (NMDA) blockers. More than 70% of the professional caregivers had an associates or bachelors degree and the majority (65%) had been working in a long-term care setting for more than four years.

Clinical data

The mean score of care recipients on the MMSE was 7.94 (SD = 7.79) out of a possible 30 points. The majority of care recipients (67%) scored in the severe impairment range, while 25% scored within the moderate impairment range and 8% were in the mild impairment range (Table 4). It is important to note that 16 of the participants scored a 0 on the MMSE, effectively lowering the average score for all participants. Verbal fluency, which was a combination of scores on the semantic and phonemic fluency measures, had a mean score of 16.63 (SD = 9.67) (Table 7). The mean Barthel Index (BI) score, which measures functional status in care recipients, was 8.98 (SD=5.87). The mean total score on the Neuropsychiatric Inventory – Nursing Home

(NPI-NH) was 12.97 (SD = 13.02). The Geriatric Depression Scale (GDS) was completed by both the family caregiver and the care recipient, when able, and had mean scores of 7.52 (SD = 3.29) and 3.51 (SD = 3.55) respectively.

The clinical measures administered to family caregivers revealed a mean score of 46.62 (SD = 12.61) on the Marwit-Meuser Caregiver Grief Inventory- Short Form (MM-CGI) and 12.01 (SD = 8.79) on the Zarit Burden Inventory (ZBI). The mean score on the Depression Anxiety Stress Scales (DASS-21) was 11.57 (SD = 13.25), while the mean score on the Approaches to Dementia Care Questionnaire (ADQ) was 63.38 (6.94).

The Maslach Burnout Inventory (MBI), completed by the professional caregivers, resulted in mean scores of 18.59 (SD = 10.36) on the emotional exhaustion component, 42.32 (SD = 5.00) on personal accomplishment and 2.26 (SD = 2.60) on the depersonalization component.

Hypothesis Testing

Hypothesis 1: Care recipients will rate their quality of life more favorably relative to their professional and family caregivers' ratings of the care recipients' quality of life. Out of 48 residents participating in the study, 27 were able to fully complete the QoL-AD while 21 were not able to understand the questions sufficiently to provide meaningful answers. Logsdon and colleagues (2002) non-completion guidelines were followed where care recipients unable to respond to more than two items were considered “non-completers”. Significant differences between the care recipients able to complete the QoL-AD and those who were unable were observed on the MMSE; the BI, which measures functional impairment; and the NPI-NH which assesses for neuropsychiatric symptoms (Table 8).

The total mean scores of the QoL-AD ratings showed that care recipients ($n = 27$, mean=36.76, SD=6.53), professional caregivers ($n = 48$, mean=32.85, SD=6.41) and family caregivers ($n = 48$, mean=29.95, SD=5.97) had different perspectives on the care recipients' quality of life. Three *a priori* paired sample t-tests were used to evaluate the difference in means for the QoL-AD scores across the three participant groups: care recipients, professional caregivers and family caregivers.

Care recipients rated their quality of life significantly more favorably than their family caregivers, $t(26) = 4.13$; $p < 0.001$. The difference between care recipients' ratings of quality of life and those completed by professional caregivers was not significant, $t(26) = 0.74$; $p = 0.46$, while professional caregivers rated the care recipients' quality of life significantly more positively than their family caregivers, $t(47) = 3.30$; $p < 0.01$. The finding that care recipients rated their QoL significantly more favorably than their family caregivers, but not significantly higher than their professional caregivers partially supports the study hypothesis (hypothesis 1) that care recipients will rate their quality of life more favorably relative to their professional and family caregivers' ratings.

Observational data of care recipient affect were collected from 11 of the 48 (23%) care recipient participants. Data were collected by trained undergraduate research assistants using the Observed Emotion Rating Scale (OERS). Observations were conducted in 10-minute intervals over a two-week period resulting in a total of 115 observations with 7-11 observations per participant (mean = 10.5). 39% ($n=45$) of the observations were conducted by two trained observers to assess for inter-rater reliability (Table 9). Kappas ranged from .60-.86 across the five affect states while percent agreement ranged from 88.9-97.8%.

Pearson correlation coefficients were used to analyze the relationship between observed affect and QoL ratings (see Table 10). A review of the results found that none of the observed affect states were associated with the care recipients' QoL ratings. Pleasure was significantly correlated with family caregiver and professional caregiver ratings of QoL ($r = 0.65, p < 0.05$; $r = 0.62, p < 0.05$) while general alertness was also significantly correlated with professional caregiver QoL ratings ($r = 0.61, p < 0.05$).

Hypothesis 2: Care recipients', professional caregivers' and family caregivers' ratings of QoL will be differentially related to clinical factors.

Specifically, we examined the relationship between QoL ratings and residents' levels of cognitive impairment, neuropsychiatric symptoms, depressive symptoms, functional impairment, family and professional caregivers' depression and burden as well as their attitudes towards dementia. The relationship between the three ratings of QoL and the clinical factors were analyzed using Pearson correlation coefficients (see Table 11).

Cognitive impairment, as measured by the MMSE, was not significantly correlated with care recipient or family caregiver QoL ratings, but was significantly positively correlated with professional caregiver QoL ratings ($r = 0.55, p < 0.01$) as hypothesized (hypothesis 2.1). Care recipient verbal fluency, a combination of scores on the semantic and phonemic fluency tasks, was significantly correlated with professional caregiver ratings of QoL ($r = .54, p < 0.05$).

Neuropsychiatric symptoms, as assessed by the professional caregiver, were negatively correlated with the care recipient and the professional caregivers' ratings of quality of life ($r = -.38, p < 0.05$; $r = -.45, p < 0.01$), but were not significantly correlated with family caregivers' ratings of quality of life. Results partially support the study

hypothesis (2.2) that ratings from all three perspectives would be negatively correlated with scores on the NPI-NH.

Care recipient reported depression scores on the Geriatric Depression Scale were significantly negatively correlated with both care recipient and family caregiver ratings of QoL ($r = -.79, p < 0.01$; $r = -.50, p < 0.01$) as hypothesized (hypothesis 2.3). A significant relationship was not found between family caregiver reported depression scores on the GDS and care recipient and family caregiver ratings of QoL.

Professional and family caregiver ratings of QoL were found to be significantly positively correlated with functional impairment ($r = .47, p < 0.01$; $r = .42, p < .01$) as hypothesized (hypothesis 2.4).

Scores on the questionnaires completed by the family and professional caregivers to assess for emotional functioning (MM-CGI, ZBI, DASS-21) were not found to be significant with the QoL ratings. Therefore, hypothesis 2.5, that professional and family caregiver depression and burden ratings would be negatively correlated with QoL ratings was not supported.

Family caregivers' scores on the Hope subscale of the Attitudes Towards Dementia Questionnaire were significantly positively correlated with family caregiver ratings of QoL as partially hypothesized (hypothesis 2.6).

Hypothesis 3: Clinical factors will independently predict care recipients', family caregivers' and professional caregivers' QoL-AD ratings. Multiple regression was used to examine the extent to which clinical factors predicted QoL ratings as well as discrepancies in the QoL ratings. Skew and kurtosis were checked for each variable included in the regression analyses. All values fell within the +2 to -2 range therefore no

data transformations were necessary. Multicollinearity was assessed for each regression, including an examination of the following: the correlation matrix, tolerance values, the Variance Inflation Factor and the Condition Index. The data were also screened for outliers through an examination of the standardized residuals, leverage, Mahalanobis distances and Cook's D. Preliminary analyses were conducted to ensure no violation of the assumptions of normality, linearity, multicollinearity and homoscedasticity.

To examine the extent to which clinical factors predicted QoL ratings, three regressions were run with the care recipients', professional caregivers' and family caregivers' ratings of QoL as the dependent variables respectively (Table 12).

Care recipient quality of life ratings. To examine the predictors of care recipients' QoL-AD scores, scores on the Geriatric Depression Scale (GDS), Neuropsychiatric Inventory-NH (NPI-NH), Barthel Index (BI) and the Mini-Mental State Exam (MMSE) and a composite score of measures used to assess the emotional functioning of the family caregivers (DASS-21, MM-CGI, ZBI) were entered into the model. The omnibus test was significant, $F(5,20) = 10.56, p < .001$, explaining 72.5% of the variance of care recipients' QoL-AD scores. Only depressive symptoms as measured with the GDS significantly predicted care recipients' QoL-AD scores ($p < .001$) although functional status approached significance ($p = .07$).

Family caregiver quality of life ratings. The same variables were entered into the regression model to examine the predictors of family caregivers QoL-AD ratings, with the exception of using the GDS scores submitted by the family caregivers for their care recipient, instead of those completed directly by the care recipient. The omnibus test was significant, $F(5,35) = 3.28, p < .05$, explaining 31.9% of the variance of family

caregivers' QoL-AD scores. Care recipients' functional impairment and family caregivers' emotional functioning, as measured by a composite of the DASS-21, MM-CGI, ZBI, were found to be significant predictors of family caregivers' QoL-AD scores ($p < .001$; $p < .05$). Cognitive impairment also approached significance ($p = .07$).

Professional caregiver quality of life ratings. To examine the predictors of the professional caregivers' QoL-AD ratings, scores on the MMSE, the NPI-NH, the BI and the family caregiver emotional functioning composite score were entered into the model. The omnibus test was significant, $F(4,40) = 6.67$, $p < .001$, explaining 40.0% of the variance in QoL-AD scores. No significant predictors were identified in the model although cognitive impairment approached significance ($p = .07$).

Another set of regression analyses were completed to examine the extent to which clinical factors predicted the observed differences between the three groups' QoL ratings. The difference of means between the three groups' z-scores were used as the dependant variables (Table 13).

Difference between care recipient and family caregiver quality of life ratings. To examine the predictors of the observed difference between care recipient and family caregiver QoL-AD scores, scores on the MMSE, the NPI, the BI, the GDS (family report and care recipient report) and family caregiver emotional functioning composite score were entered into the model. The omnibus test was significant, $F(6,19) = 5.83$, $p \leq .001$, explaining 64.8% of the variance of the difference between care recipient and family caregiver QoL-AD scores. Functional status ($p \leq .001$), depressive symptoms as reported by both the care recipient ($p \leq .05$) and family caregiver ($p \leq .01$), and family caregiver

emotional functioning ($p \leq .01$) significantly predicted the observed difference between care recipient and family caregiver QoL-AD scores.

Difference between care recipient and professional caregiver quality of life ratings. The same variables as in the above analysis were entered into the regression model to examine the predictors of the observed difference between care recipient and professional caregiver QoL-AD scores. The omnibus test was significant, $F(6,19) = 10.24, p < .001$, explaining 76.4% of the variance of the difference between care recipient and professional caregiver QoL-AD scores. Neuropsychiatric symptoms ($p < .05$) and depressive symptoms ($p < .05$) were found to be significant predictors of the observed difference between care recipient and professional caregiver QoL-AD scores.

Difference between professional caregiver and family caregiver quality of life ratings. The same variables, with the exception of care recipient reported depressive symptoms, were entered into the regression model to examine the predictors of the observed difference between professional caregiver and family caregiver QoL-AD scores. The omnibus test was significant, $F(5,35) = 4.47, p < .01$, explaining 39.0% of the variance of the difference between professional caregiver and family caregiver QoL-AD scores. Cognitive impairment ($p < .01$), functional status ($p < .05$) and caregiver emotional functioning ($p < .05$) were found to be significant predictors of the observed difference between the two groups' ratings.

Results supported study hypothesis 3 that clinical factors would independently predict QoL-AD scores across the three participant groups.

Hypothesis 4: Care recipients taking psychotropic medications will have lower QoL ratings than care recipients not receiving psychotropic medications.

Independent sample t-tests were used to assess if QoL-AD scores are associated with psychotropic medication use. Supporting study hypothesis 4, care recipients without a prescription for a psychotropic medication rated their quality of life significantly more favorably than those care recipients with a prescription, $t(25) = 2.30$; $p < .05$.

Professional caregivers rated the QoL of care recipients with a PRN prescription for psychotropic medications significantly lower than care recipients without a PRN prescription, $t(46) = 3.13$ $p < .01$. An examination of the QoL ratings completed by family caregivers found no significant differences between QoL ratings of care recipients with a psychotropic medication prescription (daily or PRN) and those without.

Independent sample t-tests were also used to evaluate the difference in mean QoL-AD scores for care recipients taking acetylcholinesterase (AChE) inhibitor or a N-methyl-D-aspartate (NMDA) blockers and care recipients not taking the specific medications. Family caregivers of care recipients taking an AChE inhibitor or a NMDA blocker rated their care recipients' QoL significantly higher than family caregivers whose care recipients were not taking the medications.

Construct Validity

A Multitrait-Multimethod Matrix (Campbell & Fiske, 1959) approach was used to assess the construct validity of the QoL-AD (Table 14). The matrix was an incomplete design due to the following three factors: 1) a measure of functional impairment was not completed by the care recipients, 2) cognitive functioning was only assessed by one method, and 3) the professional caregivers completed a different measure of depression (NPI-depression subscale) than the care recipients and family caregivers (GDS).

The convergent validity and divergent validity of the QoL measure were investigated by comparing the QoL-AD scores with measures assessing functional impairment, cognitive impairment and depression symptoms from several perspectives. Depression (care recipient report) was significantly negatively correlated with care recipient QoL-AD scores ($r = -.79, p < 0.001$) while cognition and functional status (professional report) were not significantly correlated ($r = -.23, p = .25; r = .01, p = .97$). Professional caregiver QoL-AD scores were significantly positively correlated with cognitive status ($r = .55, p < .001$) and functional status ($r = .47, p < .001$), but were not correlated with resident or family caregiver reports of depression ($r = .10, p = .62; r = -.12, p = .47$). Family caregiver QoL-AD scores were significantly negatively correlated with depression (care recipient report; $r = -.50, p < .01$) and positively correlated with functional status (professional report; $r = .42, p < 0.01$), but were not correlated with cognitive status ($r = .11, p = .46$).

The correlation matrix (Table 14) highlights the finding that the care recipients' QoL scores were not significantly correlated with the family caregiver scores ($r = .37, p = .06$) nor the professional caregiver scores ($r = .01, p = .95$). The family caregiver QoL scores and the professional caregivers scores were significantly correlated ($r = .52, p < .01$).

Exploratory Analyses

To explore the thought process behind selecting specific ratings on the QoL-AD a subset of participants were asked to explain the rationale behind their ratings of particular domains of quality of life (e.g. "Please explain why you rated your mother's life overall as fair"). The following domains were selected for examination because they were found

to be highly correlated with total scores on the QoL-AD for care recipient and family caregiver reporters (Logsdon et al., 1996): Mood, living situation, relationship with family, and self and life overall. Across the three participant groups, 25-30% of participants completed the interview (family caregivers, n = 13; professional caregivers, n = 13; care recipients, n = 8).

The interviews were audio recorded with participant approval and transcribed verbatim. Transcriptions were checked for accuracy and all potentially identifying information was removed. All interviews were analyzed by the primary investigator using conventional content analysis, where themes are derived directly from the text as a means of describing interview content (Hsieh & Shannon, 2005). Table 15 describes the themes that arose for each domain across the three participant groups.

Mood. Family and professional caregiver participants frequently used observed affect (e.g., smiling, laughter, anger, lack of affect) and direct verbal reports from care recipients as evidence for their ratings of care recipient mood. The level of engagement with family, other residents and staff was also used by caregivers as an indicator of care recipient mood. Caregivers also described the effect of declining physical and cognitive health on their care recipient's mood. When the care recipients were asked directly, they described the effect of decreased independence on their mood and the role of attention from caregivers. A few also mentioned the stable nature of their mood throughout their lives.

Living Situation. The balance between care recipient safety and independence was a reoccurring theme in the discussions about living situation. Family and professional caregivers repeatedly mentioned the facility's ability to meet care recipient

needs (e.g. physical care, activities, social interaction) and maintain safety. Family caregivers frequently mentioned the effectiveness of the professional caregivers in meeting the care recipients' needs. Care recipients focused on more specific environmental factors such as roommate relationships and friendliness of staff.

Relationship with Family. Across the three participant groups the quantity of family visits and the level of involvement in resident care arose as the most common rationales for family relationship ratings. Family and professional caregivers reported using observations of care recipient engagement and affect while visiting with family members as an indicator of the quality of the family relationship. Family caregivers described a continuation of the quality of the family relationship across time whether positive or negative.

Self/Life Overall. The ability to engage in preferred activities emerged as dominant themes in discussions of self and life overall ratings for both family caregivers and care recipients. All three groups frequently referenced the care recipient's level of independence as a factor in rating life overall. Family and professional caregivers frequently mentioned mood, physical health and direct care recipient verbal reports as key factors in determining ratings. The declining ability of care recipients to communicate wants and needs due to cognitive impairment and the discrepancy between the care recipient's current living situation and their true preferences were also reoccurring themes for family and professional caregivers.

Discussion

The current study employed a multi-trait multi-method paradigm to examine the discrepancies and congruencies between proxy, direct observation, and self-report measures of quality of life for persons with dementia. This is the first study to compare judgments of quality of life from care recipients', family caregivers' and professional caregivers' perspectives using a dementia specific measure. Findings from this study shed light on the complex nature of assessing quality of life (QoL) for individuals with dementia. The results have important implications for understanding the factors that influence quality of life judgments, which can directly affect crucial care decisions for this vulnerable population. Our thorough examination of the factors that predict QoL highlights specific areas to target with interventions to improve QoL for institutionalized persons with dementia.

The results indicate that care recipients, professional caregivers, and family caregivers have distinctly different perspectives on the QoL of persons with dementia. An examination of the clinical factors associated with the QoL ratings revealed specific congruencies and discrepancies between the three groups' ratings. Depressive symptoms, cognitive impairment, functional status and neuropsychiatric symptoms were variably associated with QoL judgments across the three participant groups. Additionally, the validity of the QoL-AD, the dementia specific QoL measure was examined through assessment of the measure's convergent and divergent validity.

The following sections provide a summary and interpretation of results pertaining to each of the study hypotheses.

Construct Validity

Before reviewing the three groups' discrepant perceptions of QoL it is important to discuss the construct validity of the dementia-specific QoL-AD. The convergent and divergent validity of the measure varied across the three participant groups. Consistent with findings from Thorgrimsen and colleagues' (2003) analysis of the QoL-AD's construct validity, family caregivers and care recipients QoL-AD scores were found to be significantly negatively correlated with depression scores and uncorrelated with cognitive impairment. The associations between family caregiver QoL-AD scores and related measures were consistent with previous studies on the validity of the QoL-AD by Logsdon and colleagues (1996, 2002). Care recipient QoL ratings were significantly negatively correlated with depression scores indicating that depressive symptoms are associated with QoL ratings as expected (Logsdon et al., 1996, 2002). In contrast with previous studies, an association between care recipient QoL ratings and functional impairment was not found in the current study, although this may have been due to the small sample size (Logsdon et al., 1996, 2002). Professional caregiver QoL-AD ratings were significantly associated with cognitive impairment and uncorrelated with depression scores, which is a variation from the expected pattern. The current study is the first to examine QoL-AD ratings by professional caregivers. Further research is needed to more fully determine the measure's validity when completed from the perspective of a professional caregiver.

Discrepant Perceptions of Quality of Life

Consistent with findings from earlier studies (e.g., Conde-Sala et al., 2009; Hoe et al., 2007; Sands et al., 2004; Thorgrimsen et al., 2003; Logsdon et al., 2002), care

recipient ratings of QoL were significantly higher than family caregiver ratings. On average, care recipients rated their QoL more favorably than professional caregivers, but the difference was not found to be significant as it has previously (Hoe et al., 2006). A related finding of interest was that professional caregivers rated care recipient QoL significantly more positively than family caregivers. A possible cause of the observed discrepancy may be the point of comparison used by the two groups of caregivers. Professional caregivers may be comparing the care recipient to other medically frail facility residents, while the family caregiver, who has a much longer history with the care recipient, may use premorbid functioning as the comparison point. For example, a nurse may reflect on the cognitive, emotional and physical functioning of the other residents in her care when rating a specific resident's QoL while the family member may be reflecting on how much their family member has declined in the past several years. Preliminary evidence for this hypothesis was found in the exploratory analysis of the rationale behind selecting specific ratings where family caregivers frequently mentioned the care recipients' ability to engage in activities they enjoyed earlier in their lives. Winzelberg and colleagues (2005) raised a similar question about points of comparison in their analysis of nursing assistant QoL ratings. Further research is needed in this area to explicate the discrepancies in QoL ratings between family and professional caregivers.

The observational data of care recipient affect collected from a subset of the participants helps to elucidate the discrepancies in QoL ratings across the three groups. Results indicated that professional caregiver ratings of QoL were significantly correlated with observed pleasure and general alertness, while family caregiver ratings were significantly correlated with pleasure. This finding suggests that professional caregivers

and family caregivers' QoL judgments were influenced by specific care recipient emotions or states. Of note, professional caregivers ratings were positively associated with general alertness indicating that just being awake and oriented was associated with QoL ratings. In keeping with earlier studies comparing different QoL measures, a significant association was not found between care recipients' self-report ratings of QoL and their observed affect (Edelman et al., 2005).

Clinical Factors & Quality of Life Ratings

Consistent with earlier studies and the study hypothesis, no association was found between family caregiver and care recipient ratings of QoL and cognitive functioning (Conde-Sala et al., 2009; Hoe et al., 2007). Professional caregivers' QoL ratings were positively associated with cognitive functioning in accordance with findings by Winzelberg and colleagues (2005).

In support of previous findings, both care recipient and family caregiver ratings of QoL were associated with care recipient-reports of depressive symptoms (Logsdon et al., 2002). Interestingly, proxy reports of depression completed by the family caregivers were not significantly associated with care recipient or family caregiver QoL ratings nor were they associated with the care recipient-reports of depressive symptoms. This finding suggests that the family caregivers did not perceive depressive symptoms in their care recipients, which may be due in part to difficulty differentiating between symptoms of depression and dementia. The relationship between the two disorders is complex as there are several symptoms that overlap, such as irritability, psychomotor retardation and weight loss (Purandone, Burns, Craig, Faragher & Scott, 2011). The implications of failing to recognize treatable depressive symptoms are large for this vulnerable

population, who often rely on family caregivers to advocate for their needs.

Misattributing depressive symptoms to dementia or missing them all together can lead to excess disability, which as previously mentioned is impairment in function beyond that which can be accounted for by the disease (Dawson et al., 1993). Appropriate evaluations of depressive symptoms that lead to effective treatment are vital to reduce excess disability and improve quality of life.

Evaluation of the association between QoL ratings and neuropsychiatric symptoms raised similar concerns about family caregivers' ability to recognize treatable care recipient symptoms. In accordance with the study hypothesis and findings from previous research, neuropsychiatric symptoms were associated with lower QoL ratings in both the care recipient (Conde-Sala et al., 2009; Hoe et al., 2007) and professional caregiver groups (Winzelberg et al., 2005). Surprisingly, family caregiver ratings of QoL were not significantly associated with neuropsychiatric symptoms. This finding may be due to family members' more limited sample of current care recipient behaviors relative to the professional caregivers, who completed the assessment of neuropsychiatric symptoms. Additionally, family members usually have a very limited sample of the behavior of persons with dementia from which to make judgments about what may be the typical progression of specific types of dementia versus what may be excess disability (e.g., increased confusion due to an untreated urinary tract infection). As family caregivers did not complete their own measure of neuropsychiatric symptoms it is difficult to determine whether family caregivers are unable to recognize neuropsychiatric symptoms or only failed to take them into consideration when completing their QoL ratings. Further research on this topic that includes independent expert observations of

care recipient psychiatric symptomatology is needed to clarify the cause of these observations. Family caregivers' ability to recognize psychiatric symptoms has critical implications for persons with dementia who are relying on family members to make important health care decisions.

Care recipient functional status was also associated with professional and caregiver ratings of QoL, as hypothesized, and as found in previous studies (Conde-Sala et al., 2009; Logsdon et al., 2002; Winzelberg et al., 2005). Family caregiver depression, burden and grief were not associated with QoL ratings across the three participant groups. In contrast to previous studies that found an association between caregiver emotional functioning and QoL ratings, the caregivers in the current study were for the most part no longer living with the care recipient. A possible explanation for the lack of relationship is that research has found a significant decrease in caregiver burden and depression after long-term care placement (Gaugler, Mittelman, Hepburn & Newcomer, 2009). While family caregivers' attitudes about dementia were not directly associated with QoL ratings, the degree of hope as measured by the ADQ was associated with QoL ratings as hypothesized. Specifically, family caregivers who indicated that care recipients are still able to enjoy things and make some decisions on their own rated QoL higher.

Predictors of Quality of Life Ratings

The regression analysis revealed that depression was the most important predictor of care recipient QoL ratings with fewer depressive symptoms predictive of higher QoL. While care recipient depression has been found to be an important predictor of QoL ratings in previous studies (Conde-Sala et al., 2009; Hoe et al., 2007), the current study used a self-report measure instead of relying on a proxy report (Logsdon et al., 1996).

Functional status and family caregiver emotional functioning arose as the most important predictors for family caregiver QoL ratings. Independent functioning in activities of daily living has been found to be an important predictor in family caregiver QoL ratings in previous studies focused on community-dwelling individuals (Conde-Sala et al., 2009; Hoe et al., 2007; Logsdon et al., 1996).

The regression model accounted for the majority of the difference between care recipient and family caregiver QoL ratings and the difference between care recipient and professional caregiver QoL ratings. Of note, the regression model explained less than half of the difference between professional and family caregiver QoL ratings suggesting that the unexplained variability may be due to the exclusion of a relevant variable(s). This finding provides further evidence for the need for additional research on the validity of the QoL-AD measure when completed by a professional caregiver.

Quality of Life & Psychotropic Medications

A notable finding arose from the examination of the relationship between quality of life and psychotropic medications, including antidepressants, antipsychotics and anti-anxiety medications. Care recipients taking one or more psychotropic medications (daily and/or PRN) rated their QoL significantly lower than those not taking a psychotropic medication. Professional caregivers evaluated QoL lower for care recipients with a PRN prescription for psychotropic medications as well. This is the first study we are aware of that uses a dementia specific QoL measure to assess the impact of psychotropic medications on perceptions of QoL across three different perspectives.

The results are consistent with earlier findings that residents on psychotropic medications, experienced reduced well-being, increased time spent withdrawn and a

significant reduction of time spent actively and passively engaged in activities (Ballard et al., 2001). The findings are particularly concerning in light of the recent research on the adverse effects of antipsychotic medications, which include increased risk of cerebrovascular adverse events (for a review see Mittal et al., 2011), and increased mortality (Ballard et al., 2009) as discussed in the introduction.

Although causality cannot be shown in a cross-sectional study the results raise questions about whether: a) the symptoms that the medications were intended to reduce or b) the medications themselves are associated with lower QoL. The relationship between QoL in individuals with dementia and psychotropic medications warrants further examination to understand the residents' perspective, which may be overlooked when the individual has dementia and a proxy is making health care decisions.

Implications for Improving the Care of Persons with Dementia

The results of the present study exemplify the complex nature of measuring quality of life for long-term care residents with dementia. The significant difference between the three groups' QoL assessments highlights the finding that proxy ratings, and even objective observation, do not adequately capture the care recipients' experience. It is imperative that family caregivers, who often make crucial healthcare decisions for their family members, understand the perspective of the care recipient at their current level of functioning. An approach that includes multiple perspectives is necessary to gain the clearest picture of QoL in persons with dementia.

The finding that depressive symptoms are strongly associated with and a predictor of care recipient QoL emphasizes the need to actively assess for and treat depression in persons with dementia. Depression in older adults with dementia is associated with a

number of adverse medical, psychiatric and cognitive outcomes (Steffens & Potter, 2008; Lyketsos & Olin, 2002). Appropriate evaluations of depressive symptoms are vital to reduce excess disability and improve QoL as studies report that 30-50% of individuals with AD experience symptoms of depression (Zubenko et al., 2003). Rates are particularly high within LTC settings where the prevalence of major depression ranges from 6-25%, while rates for minor depression and depressive symptoms are reported as much higher, ranging from 30-50% (Teresi, Abrams, Holmes, Ramirez & Eimicke, 2001; Katz & Parmelee, 1997; Jones, Marcantonio & Rabinowitz, 2003; Payne et al. 2002). Qualities within the nursing home environment, such as a lack of privacy due to sharing a room and confinement to the facility schedule of meals and care time, often result in feelings of dependence and confinement (Hyer et al., 2005). Overall the environment can be depressogenic as residents inevitably experience a loss of ability to control the environmental reinforcements of their behavior (Chen, Zimmerman, Sloane & Barrick, 2007).

There is evidence for both pharmacological and psychotherapeutic treatments of depression in nursing home residents with Alzheimer's disease (Lyketsos & Olin, 2002). Lyketsos and colleagues (2002) recommend that specific nonpharmacologic therapies, such as developing a daily routine that includes access to pleasant activities, be instituted as the first line of treatment for depression in persons with dementia. There are several factors to consider when opting for a pharmacological treatment approach. The first is the effectiveness of specific antidepressants with this population. Banjeree and colleagues (2011) recently assessed the effectiveness of two popular antidepressants. Results indicated that the use of sertraline and mirtazapine should be reconsidered as a

first line of treatment for individuals with Alzheimer's Disease and depression due to a lack of benefit when compared with a placebo and increased risk of adverse events. The second factor to consider is the potential impact of verbal impairment on the placebo effect. Persons with dementia may lack the ability to comprehend the purpose of taking the antidepressant medication, which may in turn reduce or completely eliminate a placebo effect. Lastly, prescribing an anti-depressant for residents, who on average are already taking 7-8 prescription medications simultaneously (Doshi, Shaffer & Briesacher, 2005), increases the risks of adverse effects from polypharmacy, including increased risk of hospitalization, drug-drug interactions, medication errors, and mortality (Rollason & Vogt, 2003; Espino et al., 2006).

Results of the current study also point to the importance of maintaining functional independence as long as possible and effectively managing neuropsychiatric symptoms. Within the contextual model of dementia presented in the introduction, an idiographic approach to assessment and intervention should be taken due to the significant variability in the topography and etiology of behavioral changes across persons with dementia. An idiographic approach to treatment would reduce the risk of excess disability which can occur when behavioral disturbances are misattributed to the progression of dementia (Fisher et al., 2007).

While this study demonstrates significant associations between QoL ratings and clinical factors, a relevant finding is that a substantial portion of the variance of each group's QoL ratings were not explained by the clinical factors included in the multiple regression model. The unexplained variability may be due measurement error among the variables included or exclusion of a relevant variable. Future research should examine

other variables relevant to QoL, such as pain status, which could have a large effect on QoL judgments and has been found to be undertreated in the dementia population (Nygaard & Jarland, 2005; Reynolds et al., 2008).

Limitations of the Study & Future Directions

Despite several interesting findings, there are a few noteworthy limitations of the current study. First, the small sample size may have limited our ability to detect associations between variables. The sample of care recipients able to complete the self-report quality of life measure was particularly small ($n=27$), which limits the generalizability of the results. This is in part due to the large number of participants that fell into the severe cognitive impairment range ($MMSE \leq 10$; $n = 32$). Results regarding care recipient's QoL ratings cannot be generalized to persons with severe cognitive impairment. Second, the homogeneity of the sample may have potentially biased the results. The care recipient and family caregiver participants were all white and half consisted of mother – daughter dyads. Third, observational data of care recipient affect were limited to a subset of the sample ($n = 11$) thereby restricting the number of analyses we were able to run. Results indicating that observed affect was associated with caregiver QoL ratings, but was not associated with care recipient ratings raise interesting questions about affect in persons with dementia and needs further investigation.

The cross-sectional nature of the study is also a limitation as it provides only a snap shot of a complex set of variables. There is a strong need for longitudinal research on quality of life that measures relevant variables throughout the progression of the disease. A study that addresses the dynamic nature of the functioning of persons with dementia and the evolving care recipient/caregiver relationship would greatly increase

our understanding of this complex construct and the relationship between perceptions of quality of life, healthcare decisions by proxy, and long-term outcomes of older adults with dementia.

Summary & Conclusion

In sum, care recipients, family caregivers and professional caregivers have distinctly different perspectives on QoL. Results from the current study indicate that proxy ratings of QoL for persons with dementia cannot replace care recipient ratings. Instead, multiple perspectives should be used to gain a fuller understanding of the individual with dementia's experience, especially when critical health care decisions need to be made. Several studies have now shown that care recipients with dementia are able to rate their own QoL well into the progression of the disease (Logsdon et al., 2002; Conde-Sala et al. 2009; Hoe et al., 2007) so including the care recipient perspective for as long as possible is critical. Furthermore, the study results highlight the importance of actively assessing and treating depression and other sources of excess disability in older adults with dementia.

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Table 1
Dementia-specific QoL Measures

| Measure | Authors | Data Source | Dementia Severity | Domains of Quality of Life |
|---------------------------------------------------------------|-------------------------------------------------|------------------------------|-------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------|
| Dementia Care Mapping (DCM) | Bradford Dementia Group, 1997 | Observation | Mild-severe | Observed activity, well- and ill-being |
| Alzheimer's Disease Related Quality of Life (ADRQL) | Rabins, Kasper, Kleinman, Black & Patrick, 1999 | Care provider | Mild-severe | Social interaction, awareness of self, enjoyment of activities, feelings and mood, and response to surroundings |
| Quality of Life for Dementia (QOL-D) | Albert et al., 1996 | Care provider and/or patient | Mild-severe | Activity participation, positive and negative affect (care provider version only) |
| Quality of Life in Alzheimer's Disease (QOL-AD) | Logsdon, Gibbons, McCurry & Teri, 1999 | Care provider and/or patient | Mild-severe | Physical health, mood, living situation, memory, interpersonal relationships, functional abilities, concerns about finances, and life and self as a whole |
| Dementia Quality of Life Instrument (D-QOL) | Brod, Stewart, Sands & Walton, 1999 | Patient | Mild-moderate | Self-esteem, positive and negative affect, feelings of belonging, sense of aesthetics |
| The Cornell-Brown Scale for Quality of Life in Dementia (CBS) | Ready, Ott, Grace & Fernandez, 2002 | Care provider and patient | Mild-moderate | Positive and negative affect, physical complaints, satisfaction |

Table 2
Psychometric Properties of QoL Measures

| Measure | Inter-rater reliability | Internal Consistency | Test-retest reliability | Validity* |
|---------------------------------------------|--------------------------------|---------------------------------------------------------|---------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| DCM <i>Bradford Dementia Group, 1997</i> | 0.70 -0.95 ^c | n.a. | Well-being score = 0.55, activity score = 0.40 ^b | Correlates with measure of engagement ($r = 0.81$) ^e , well-being scale correlated with observed affect ($r = 0.52$) ^a |
| ADRQL <i>Rabins, et al., 1999</i> | n.a. | 0.80 | n.a. | Significant correlations with cognition ($r = 0.51$), physical dependence ($r = -0.54$), orientation ($r = -0.52$), behavioral disturbances ($r = -0.38$) and depression ($r = -0.43$) ^d |
| QOL-D <i>Albert et al., 1996</i> | 0.63-0.93 | 0.79- 0.91 | Caregiver rating of affect = 0.53-0.92 and above 0.40 for 13 of the 15 activity items | Correlates with cognitive functioning and ADL scores. |
| QOL-AD <i>Logsdon, et al., 1999</i> | >0.70 ^c | Care provider = .87 Patient = .88, 0.82 ^c | Care provider = 0.92 Patient = 0.76, >.60 ^c | <i>Patient report:</i> Correlations with cognitive functioning ($r = .24$), activities of daily living ($r = -0.33$), patient reported depression ($r = -0.56$), caregiver report of patient depression ($r = -0.40$) and pleasant events ($r = 0.30$). <i>Caregiver report:</i> Correlations with patient cognitive functioning ($r = 0.02$), activities of daily living ($r = -0.32$), patient report of depression ($r = -0.14$), caregiver report of patient depression ($r = -0.57$), pleasant events ($r = 0.41$) and caregiver depression ($r = -0.23$) |
| D-QOL <i>Brod et al., 1999</i> | Patient is reporter n.a. | 0.67-0.89 | 0.64-0.90 | Well-being subtests correlated with the GDS; Self-esteem ($r = -0.48$), Positive Affect/Sense of humor ($r = -0.61$), Absence of negative affect ($r = -0.64$), Feelings of belonging ($r = -0.42$) |
| CBS <i>Ready et al., 2002</i> | 0.90 Intraclass correlation | 0.81 Cronbach alpha | n.a. | Positive correlation with visual analogue positive mood ratings from the VADS ($r = 0.63$) ; negative correlation with dementia severity as measured by the Clinical Dementia Ratings ($r = -0.35$) |

Unless otherwise stated, data on reliability and validity derived from reference in the first column.

*There is no gold standard from which to determine concurrent validity as QoL is by definition subjective

n.a. = not available

^a Sloane et al., 2005

^b Fossey et al., 2002

^c Thorgrimsen et al., 2003

^d Gonzalez-Salvador et al., 2000

^e Beavis et al., 2002

Table 3

Assessment Across Participant Groups

| Measure | Care Recipient | Completed by Staff CG on Care Recipient | Completed by Family CG on Care Recipient | Completed by Observers on Care Recipients | Staff CG | Family CG |
|----------------------------------------------|----------------|-----------------------------------------|------------------------------------------|-------------------------------------------|----------|-----------|
| Quality of Life-AD | X | X | X | | | |
| Mini Mental State Exam | X | | | | | |
| Geriatric Depression Scale | X | | X | | | |
| Verbal Fluency | X | | | | | |
| Neuropsychiatric Inventory-NH | | X | | | | |
| Barthel Activities of Daily Living Index | | X | X | | | |
| Observed Emotion Rating Scale | | | | X | | |
| Maslach Burnout Inventory | | | | | X | |
| Approaches to Dementia Care Questionnaire | | | | | | X |
| Depression Anxiety and Stress Scale-21 | | | | | | X |
| Zarit Burden Interview | | | | | | X |
| Marwit-Meuser Caregiver Grief Inventory – SF | | | | | | X |

Table 4

Socio-demographic Factors of Family Caregiver Participants

| Family Caregiver (<i>n</i> =48) | |
|---------------------------------------|--------------|
| Characteristic | <i>n</i> (%) |
| Sex | |
| Male | 12 (25.0) |
| Female | 36 (75.0) |
| Age | |
| 31-50 | 6 (12.5) |
| 51-60 | 11 (22.9) |
| 61-70 | 16 (33.3) |
| 71-80 | 11 (22.9) |
| 80+ | 4 (8.3) |
| Race | |
| White | 48 (100) |
| Relationship to Resident | |
| Husband | 7 (14.6) |
| Wife | 9 (18.8) |
| Son | 5 (10.4) |
| Daughter | 24 (50.0) |
| Other | 3 (6.3) |
| Time Spent with Resident per Month | |
| < 1 hour | 3 (6.3) |
| 1-5 hours | 6 (12.5) |
| 6-10 hours | 9 (18.8) |
| 11-20 hours | 12 (25.0) |
| 21-30 hours | 4 (8.3) |
| 30+ hours | 14 (29.2) |

Table 5

Socio-demographic Factors of Care Recipient Participants

| Care Recipients (<i>n</i> =48) | |
|------------------------------------|--------------|
| Characteristic | <i>n</i> (%) |
| Sex | |
| Male | 13 (27.1) |
| Female | 35 (72.9) |
| Age | |
| 60-69 | 1 (2.1) |
| 70-79 | 13 (27.1) |
| 80-89 | 23 (47.9) |
| 90-99 | 11 (22.9) |
| Race | |
| White | 48 (100) |
| Type of Facility | |
| Memory Care | 25 (52.1) |
| Skilled Nursing Facility | 17 (35.4) |
| Adult Day Program | 6 (12.5) |
| Cognitive Impairment | |
| Mild | 4 (8.3) |
| Moderate | 12 (25.0) |
| Severe | 32 (66.7) |
| Medications | |
| Psychotropic Prescription | 32 (66.7) |
| Daily | 26 (54.2) |
| PRN | 18 (37.5) |
| Cognitive Med | 15 (31.3) |

Note. Mild = MMSE 21-26; Moderate = MMSE 11-20;
Severe = MMSE ≤ 10

Table 6
Socio-demographic Factors of Professional Caregiver Participants

| Professional Caregiver (<i>n</i> =26) | |
|-------------------------------------------|--------------|
| Characteristic | <i>n</i> (%) |
| Sex | |
| Male | 1 (3.) |
| Female | 26 (96.2) |
| Age | |
| 18-25 | 2 (7.7) |
| 26-30 | 3 (11.5) |
| 31-40 | 7 (26.9) |
| 41-50 | 7 (26.9) |
| 51-60 | 7 (26.9) |
| Race | |
| White | 19 (73.1) |
| Asian | 3 (11.5) |
| N Hawaii/ Pacific Islander | 2 (7.7) |
| Hispanic / Latino | 1 (3.8) |
| Black | 1 (3.8) |
| Education | |
| High School | 7 (26.9) |
| Associates Degree | 10 (38.5) |
| Bachelor Degree | 9 (34.6) |
| Long Term Care Work Experience | |
| < 1 year | 2 (7.7) |
| 1-3 years | 6 (23.1) |
| 4-6 years | 6 (23.1) |
| 7+ years | 11 (42.3) |

Table 7

Clinical Characteristics of Participants

| Care Recipients | | | | Family Caregivers | | | |
|-------------------------|----------|-------------|-------------|--------------------------------|----------|-------------|-------------|
| | n | Mean | (SD) | | n | Mean | (SD) |
| MMSE | 48 | 7.94 | (7.49) | MM-CGI | 45 | 46.42 | (12.61) |
| BI | 48 | 8.98 | (5.87) | ZBI | 48 | 12.01 | (8.79) |
| NPI-NH | 48 | | | DASS-21 | | | |
| Delusions | | 1.71 | (3.19) | Anxiety | 48 | 2.42 | (3.54) |
| Hallucinations | | 0.75 | (1.77) | Depression | 48 | 4.04 | (5.36) |
| Agitation | | 2.13 | (2.89) | Stress | 48 | 5.11 | (5.13) |
| Depression | | 0.56 | (1.22) | Total | 48 | 11.57 | (13.25) |
| Anxiety | | 1.88 | (2.57) | ADQ | | | |
| Elation | | 0.38 | (1.36) | Hope | 46 | 18.87 | (4.48) |
| Apathy | | 1.75 | (3.24) | Person-centered | 47 | 44.39 | (4.78) |
| Disinhibition | | 0.50 | (1.84) | Total | 46 | 63.38 | (6.94) |
| Irritability | | 1.78 | (2.96) | | | | |
| Abberant motor behavior | | 1.56 | (3.11) | Professional Caregivers | | | |
| Total NPI | | 12.97 | (13.02) | MBI | | | |
| GDS | | | | EE | 23 | 18.59 | (10.36) |
| Family report | 42 | 7.52 | (2.39) | PA | 22 | 42.32 | (5.00) |
| Resident report | 28 | 3.51 | (3.55) | D | 23 | 2.26 | (2.60) |
| Verbal Fluency | 19 | 16.63 | (9.67) | | | | |

Table 8
Clinical Characteristics of Care Recipients Able vs Unable to Complete the QoL-AD

| | Able | | | Unable | | |
|-----------------------------|------|-------|---------|--------|-------|------------|
| | N | Mean | (SD) | N | Mean | (SD) |
| Age | 27 | 83.89 | (6.78) | 21 | 82.86 | (8.35) |
| MMSE | 27 | 13.59 | (5.67) | 21 | 0.67 | (1.49)*** |
| GDS – Family report | 26 | 7.25 | (2.27) | 16 | 7.97 | (2.59) |
| BI | 27 | 11.04 | (5.78) | 21 | 6.33 | (4.93)** |
| NPI-NH | 27 | 7.39 | (9.46) | 21 | 20.14 | (13.63)*** |
| CG Grief | 26 | 45.81 | (13.81) | 19 | 47.25 | (11.06) |
| ZBI | 27 | 11.69 | (8.85) | 21 | 12.43 | (8.91) |
| DASS, Family Caregiver | 27 | | | 21 | | |
| Anxiety | | 2.85 | (3.86) | | 1.86 | (3.09) |
| Depression | | 4.78 | (5.51) | | 3.10 | (5.14) |
| Stress | | 5.72 | (5.43) | | 4.33 | (4.72) |
| Total | | 13.35 | (13.95) | | 9.29 | (12.24) |
| ADQ, Family Caregiver | 26 | | | 21 | | |
| Hope | | 19.00 | (3.37) | | 18.70 | (5.69) |
| Person Centered | | 43.83 | (5.08) | | 45.10 | (4.39) |
| Total | | 62.83 | (5.91) | | 64.10 | (8.19) |
| MBI, Professional caregiver | 23 | | | 19 | | |
| Emotional Exhaustion | | 19.52 | (7.61) | | 21.21 | (10.15) |
| Personal Accomplishment | | 41.50 | (4.88) | | 43.87 | (2.70) |
| Depersonalization | | 3.52 | (2.48) | | 2.26 | (2.35) |
| QoL-AD | 27 | | | 21 | | |
| Family Report | | 30.81 | (6.75) | | 28.85 | (4.72) |
| Professional Report | | 35.57 | (5.28) | | 29.35 | (6.12)** |

* $p \leq .05$; ** $p < .01$; *** $p < .001$.

Table 9

Agreement on Ratings by Research Assistants for Five Affects

| | Kappa | %Agree |
|-------------------|-------|--------|
| Pleasure | .855 | 95.6 |
| Anger | .656 | 97.8 |
| Anxiety/Fear | .799 | 93.3 |
| Sadness | .601 | 88.9 |
| General Alertness | .843 | 91.1 |

Table 10

Correlations Between Observed Affect and QoL-AD Scores Across Participants

| | Resident QoL-AD (N=8) | Family Caregiver QoL-AD (N=11) | Professional Caregiver QoL-AD (N=11) |
|-------------------|-----------------------------|--------------------------------------|--------------------------------------------|
| Pleasure | .038 | .653* | .624* |
| Anger | .036 | .155 | .032 |
| Anxiety/Fear | .073 | .270 | -.183 |
| Sadness | .287 | -.068 | -.364 |
| General Alertness | .124 | .155 | .614* |

*Correlation is significant at the 0.05 level (2-tailed)

Table 11

Correlations of QoL-AD Scores with Care Recipient Clinical Factors

| Clinical Factors | Measure | Care Recipient QoL Scores | Family Caregiver QoL Scores | Professional Caregiver QoL Scores |
|---------------------------------------------------|------------------------|------------------------------|--------------------------------|-----------------------------------------|
| Cognitive Impairment | MMSE | -.229 | .110 | .546** |
| | <i>n</i> | 27 | 48 | 48 |
| | hypothesized direction | | | positive |
| Depression | GDS ^a | -.794** | -.497** | .099 |
| | <i>n</i> | 27 | 28 | 28 |
| | hypothesized direction | negative | | |
| Functional Status | GDS ^b | .048 | -.235 | -.116 |
| | <i>n</i> | 26 | 42 | 42 |
| Verbal Fluency | BI ^c | .009 | .424** | .465** |
| | <i>n</i> | 27 | 48 | 48 |
| | hypothesized direction | | positive | positive |
| Neuropsychiatric Symptoms | Semantic + Phonemic | .157 | .179 | .538* |
| | <i>n</i> | 19 | 19 | 19 |
| Family Caregiver Emotional Functioning | NPI-NH ^c | -.381* | -.154 | -.454** |
| | <i>n</i> | 27 | 48 | 48 |
| | hypothesized direction | negative | negative | negative |
| Family Caregiver Emotional Functioning | MM-CGI | .194 | -.182 | -.048 |
| | <i>n</i> | 26 | 45 | 45 |
| Family Caregiver Attitudes Towards Dementia | ZBI | -.136 | -.089 | .078 |
| | <i>n</i> | 27 | 48 | 48 |
| | hypothesized direction | | negative | |
| Family Caregiver Attitudes Towards Dementia | DASS – Depression | -.120 | -.086 | .195 |
| | DASS – Anxiety | .080 | .044 | .279 |
| Family Caregiver Attitudes Towards Dementia | DASS- Stress | -.141 | -.173 | .153 |
| | <i>n</i> | 27 | 48 | 48 |
| | hypothesized direction | | negative | |
| Family Caregiver Attitudes Towards Dementia | ADQ | -.318 | .092 | -.028 |
| | <i>n</i> | 26 | 47 | 47 |
| Family Caregiver Attitudes Towards Dementia | ADQ- Hope | -.004 | .290* | .111 |
| | <i>n</i> | 26 | 47 | 47 |
| Family Caregiver Attitudes Towards Dementia | ADQ- Person-Centered | -.368 | -.172 | -.169 |
| | <i>n</i> | 26 | 47 | 47 |
| | hypothesized direction | | positive | |
| Staff Burnout | MBI – EE | -.140 | .172 | -.085 |
| | <i>n</i> | 23 | 42 | 42 |
| Staff Burnout | MBI-PA | .155 | .262 | -.009 |
| | <i>n</i> | 23 | 42 | 42 |
| Staff Burnout | MBI- D | .376 | .061 | -.173 |
| | <i>n</i> | 23 | 42 | 42 |

^aCompleted by resident ^b Completed by family caregiver ^c Completed by professional caregiver*, $p \leq .05$;
** $p < .01$

Table 12
 Identified Predictors of Resident, Family Caregiver and Professional Caregiver Rated
 QoL Using Regression Analysis

| Variables | Care Recipient QoL Scores (<i>n</i> = 26) | | Family-CG QoL Scores (<i>n</i> = 41) | | Professional-CG QoL Scores (<i>n</i> = 45) | |
|----------------------------------------|---------------------------------------------------|----------|------------------------------------------|----------|---------------------------------------------------|----------|
| | <i>Beta</i> | <i>p</i> | <i>Beta</i> | <i>p</i> | <i>Beta</i> | <i>p</i> |
| | Cognitive Impairment | .07 | .67 | -.33 | .07 | .30 |
| Neuropsychiatric Symptoms | -.03 | .84 | -.14 | .40 | -.28 | .06 |
| Functional Status | -.29 | .07 | .56 | .00 | .23 | .14 |
| Depression symptoms ^a | -.90 | .00 | -.12 | .45 | - | - |
| Family Caregiver Emotional Functioning | .16 | .22 | -.33 | .04 | .06 | .65 |
| <i>F</i> = | 10.56 | | 3.28 | | 6.67 | |
| <i>p</i> ≤ | .001 | | .05 | | .001 | |
| <i>R</i> ² | .73 | | .32 | | .40 | |
| Adjusted <i>R</i> ² | .66 | | .22 | | .34 | |

^a GDS scores completed by care recipients was used in the care recipient model. GDS scores completed by family caregivers about their care recipient was used in the family caregiver model.

Table 13

Identified Predictors of the Difference of Means Between the Three Groups' QoL-AD Scores

| Variables | Difference between CR and Family-CG QoL Scores (<i>n</i> = 26) | | Difference between CR and Pro-CG QoL Scores (<i>n</i> = 26) | | Difference between Pro-CG and Family-CG QoL Scores (<i>n</i> = 41) | |
|----------------------------------------|--------------------------------------------------------------------|----------|-----------------------------------------------------------------|----------|------------------------------------------------------------------------|----------|
| | <i>Beta</i> | <i>p</i> | <i>Beta</i> | <i>p</i> | <i>Beta</i> | <i>p</i> |
| Cognitive Impairment | .35 | .07 | .00 | .99 | .57 | .00 |
| Neuropsychiatric Symptoms | .17 | .33 | .33 | .03 | -.12 | .45 |
| Functional Status | -.68 | .00 | -.28 | .07 | -.35 | .04 |
| Depression Symptoms – FC report | .31 | .05 | .26 | .05 | .08 | .57 |
| Depression Symptoms- CR report | -.64 | .00 | -.97 | .00 | – | – |
| Family Caregiver Emotional Functioning | 0.51 | .00 | .18 | .14 | .36 | .02 |
| <i>F</i> = | 5.83 | | 10.24 | | 4.47 | |
| <i>p</i> ≤ | .001 | | .00 | | .00 | |
| <i>R</i> ² | .65 | | .76 | | .39 | |
| Adjusted <i>R</i> ² | .54 | | .69 | | .30 | |

Table 14
Multitrait-Multimethod Matrix

| | | Care Recipient | | | Professional Caregiver | | | Family Caregiver | | |
|---------------------------------------|-----------------------------------|--------------------|------------|--------------------|------------------------|-------------|---------------------------------|--------------------|-------------|---------------------------------|
| | | GDS: Depression | QoL | MMSE: Cognition | NPI – D: Depression | QoL | BI: Functional Impairment | GDS: Depression | QoL | BI: Functional Impairment |
| Care Recipient Measures | GDS: Depression N | 1.00 28 | - | - | - | - | - | - | - | - |
| | QoL-AD N | -.79** 27 | 1.00 27 | - | - | - | - | - | - | - |
| | MMSE: Cognition N | .25 28 | -.23 27 | 1.00 48 | - | - | - | - | - | - |
| Professional Caregiver Measures | NPI – D: Depression N | .21 28 | -.21 27 | -.07 48 | 1.00 48 | - | - | - | - | - |
| | QoL-AD N | .10 28 | .01 27 | .55** 48 | -.27 48 | 1.00 48 | - | - | - | - |
| | BI: Functional Impairment N | -.22 28 | .01 27 | .50** 48 | -.15 48 | .47** 48 | 1.00 48 | - | - | - |
| Family Caregiver Measures | GDS: Depression N | .16 27 | .05 26 | -.20 42 | .06 42 | -.12 42 | -.36 42 | 1.00 | - | - |
| | QoL-AD N | -.50** 28 | .37 27 | .11 48 | -.16 48 | .52** 48 | .42** 48 | -.24 42 | 1.00 48 | . - |
| | BI: Functional Impairment N | -.28 28 | .03 27 | .43** 46 | -.14 46 | .30* 46 | .90** 46 | -.27 40 | .39** 46 | 1.00 46 |

* $p < 0.05$ level ; ** $p < 0.01$, GDS = Geriatric Depression Scale; QoL-AD = Quality of Life – Alzheimer’s Disease; MMSE = Mini-Mental State Exam; B = Barthel Index

Table 15

Themes from Exploratory Analysis of Qol-AD Rating Rationales

| Domain | Family and Professional Caregiver | Care Recipient |
|--------------------------|------------------------------------------------------|------------------------------|
| Mood | Observed affect | Level of freedom |
| | Verbal reports from resident or collateral | Personal attention |
| | Physical/cognitive health effect on mood | Stable mood across life |
| | Level of engagement with staff/residents/family | |
| Living Situation | Capacity to meet care recipient needs | Environmental factors |
| | Safety vs independence | |
| | Quality of staff (F) | |
| Relationship with Family | Quantity of family visits | Quantity of visits |
| | Affect and engagement when with family | Level of involvement in care |
| | Relationship history (F) | |
| | Level of involvement in care and support (P) | Level of support |
| Self/Life Overall | Level of independence vs safety | (In)ability to do things |
| | (In)ability to engage in activities once enjoyed (F) | once enjoyed |
| | Discrepancies with care recipient preferences | Reflection on past |
| | Physical health & mood status | |
| | Needs met | |
| | Ability to communicate wants and needs/ | |
| | Direct verbal reports | |
| | | |

F = family caregiver; P = professional caregiver