# Quality of Life of Community-Residing Persons with Dementia Based on Self-Rated and Caregiver-Rated Measures

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## Abstract

**Purpose**—To identify correlates of self-rated and caregiver-rated quality of life (QOL) in community-residing persons with dementia (PWD) for intervention development.

**Methods**—Cross-sectional data of 254 PWD and their caregivers participating in a clinical trial were derived from in-home assessments. Self-rated QOL was measured with the Quality of Life-Alzheimer Disease (QOL-AD) scale, and caregiver-rated QOL was measured using the QOL-AD and Alzheimer Disease Related Quality of Life (ADRQL) scales. Multivariate modeling identified correlates of the PWD' QOL.

**Results**—Self-rated QOL was related significantly to participant race, unmet needs, depression, and total medications. Caregiver-rated QOL-AD scores were significantly associated with participant function, unmet needs, depression, and health problems and with caregiver burden and self-rated health. Significant correlates of ADRQL scores included neuropsychiatric symptom severity, functional and cognitive impairment, and caregiver burden and depression.

**Conclusions**—Correlates of QOL in community-residing PWD depend on who rates the PWD's QOL and which measure is used. Addressing health problems, medication use, and dementia-related unmet needs, reducing functional dependency, and treating neuropsychiatric symptoms in

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PWD, while reducing caregiver burden and depression, may maximize QOL in those with dementia.

## Introduction

A primary goal of care for persons with dementia (PWD) is to maximize their quality of life (QOL) [1], particularly because there are currently no preventive or curative therapies for most causes of dementia. However, interventions to improve cognitive function [2], address neuropsychiatric symptoms (NPS; e.g., behavioral disorders, depression) [3], and assist patients and caregivers in obtaining needed care and services [4], can potentially improve QOL [5-8]. Measuring QOL and determining its correlates will enable care providers to target effective interventions designed to improve the well-being of dementia patients.

Measuring QOL in dementia poses conceptual and practical challenges [9]. Health related QOL is a construct consisting of multiple domains, usually physical health, psychological well-being, function and social activity [10]. Dementia-specific measures of QOL vary in their domains, methods of assessment, and target population based on disease severity [11]. These differences in assessment tools likely influence correlates of QOL in a specific sample.

Perhaps the most challenging aspect of measuring QOL in dementia relates to the construct's subjective nature. Dementia impairs memory, insight, judgment and problem solving; affects attention, behavior, personality and communication skills; and can lead to NPS [12], all of which can influence QOL as well as one's ability to conceptualize and express an opinion on one's QOL. Consensus exists on the importance of obtaining self-assessed QOL from individuals who are capable of conceptualizing this construct and responding meaningfully to assessment items. There is clear evidence that it is feasible to assess QOL directly from those with mild to moderate dementia [13-15] and, in some cases, those with more severe impairments [16]. However, in cases where obtaining self-rated QOL is not feasible, either participants must be excluded from measurement or an alternative approach, such as relying on proxy-raters, must be used to assess the person's QOL.

Proxy-rated QOL has the disadvantage of filtering an inherently subjective measure through the perceptive lens of someone who may not share the same values. Dementia studies often show that proxy ratings of QOL are lower than self-ratings [17]. Agreement between self and proxy ratings are influenced by the nature of their relationship, the amount of time spent together, the objectivity of assessment items, patients' level of impairments, and proxy's well-being [14,18-22]. Nonetheless, if we are to assess and address QOL in advanced dementia, these limitations are unavoidable. Therefore, it is important to account for the impact that proxy-related factors may have on ratings. Furthermore, since informal caregivers provide care to most PWD in the community, understanding how caregiver characteristics impact proxy-rated QOL may suggest other potentially modifiable targets for interventions.

This study examined QOL in community-residing elders with dementia using three measures, one based on the PWD's perspectives and two based on the caregivers' perspectives. We expected that the three QOL measures would be significantly related to one another and that the correlates of each would differ based on whether the measure was self-rated or caregiver-rated and on the type of measure used. Based on prior research, we hypothesized that health and functional status [18], NPS [17], and unmet needs for dementia-related care and services [4] would be related significantly to the QOL of PWD. We also expected that caregivers' health and well-being [23] would influence their ratings of

the PWD's QOL. This study used data from Phase II of the Maximizing Independence at Home (MIND at Home) project.

## Methods

The MIND at Home – Phase II study is a randomized controlled trial of a care coordination program testing the effectiveness of a model that assists community-residing elders with cognitive disorders and their caregivers to obtain needed dementia-related care and services. The goals of MIND at Home are to address unmet needs of PWD related to cognitive disorders and thereby help them remain at home longer and improve their QOL and that of their caregivers. In this report, we examine cross-sectional baseline data collected prior to randomizing participants into intervention or augmented usual care arms.

The Johns Hopkins Medicine Institutional Review Board approved this research. Oral consent was obtained during the study's telephone screening stage and written consent for both the primary participant (i.e., PWD) and study partner was obtained at the in-home assessment. For cognitively impaired individuals who lacked consent capacity, proxy consent was obtained from their legally authorized representatives using the Maryland Health Care Decisions act as a guide, and written or oral assent was obtained from the primary participants.

### Study Procedures and Measures

The inclusion criteria for primary participants in the MIND at Home study were that they be community-residing English-speaking individuals aged 70 or older who have a cognitive disorder (i.e., mild cognitive impairment (MCI) or dementia) and have a family member or friend to serve as their study partner. Individuals who did not meet one or more of these criteria or lived outside the recruitment catchment area were excluded from the study. The recruitment catchment area encompassed 28 postal codes in north/northwest Baltimore. Multiple approaches were used to identify potential participants, including referrals from 16 community service organizations whose staff were trained in dementia case-finding, letters from community service organizations to their clients informing them of the study, and promotions through news media and at community events for older adults.

A two-staged assessment process was used to identify eligible individuals referred to the study. First, trained research assistants conducted telephone screening to identify probable cases of cognitive disorder using the Telephone Interview for Cognitive Status (TICS) [24] and the Informant Questionnaire for Cognitive Disorders in the Elderly (IQCODE) [25]. The TICS is an 11-item measure of global cognitive function modeled after the Mini Mental State Examination (MMSE) [26], with scores of 0 to 41. The TICS has high test-retest reliability (r=0.95), sensitivity (94%) and specificity (100%) for cognitive impairment, and correlates with MMSE scores (r=0.94). The IQCODE is a 16-item informant-based questionnaire using a 5-point response scale of "much improved" to "much worse", with scores of 16 to 80. The IQCODE has high internal consistency (α=0.93-0.97) and test-retest reliability (r=0.96), with good sensitivity (75%-100%) and specificity (68%-86%) for dementia [25,27]. Using previously reported cut-off scores [24,28], a positive screen was defined as a TICS score of <31 and an IQCODE score of >52.

For the second stage, those who screened positive were invited to participate in an in-home assessment for the presence of a cognitive disorder. The assessment, conducted by either a geriatric physician or registered nurse with experience in geriatric mental health, included narrative reviews of medical and mental health histories, medications, physical health problems, mental status and neurological examinations, and structured cognitive, functional, and behavioral measures. Cognition was assessed using the 30-item MMSE [26], and

function was assessed using the 8-item Lawton and Brody [29] measure of instrumental activities of daily living (IADLs) and the 16-item Psychogeriatric Dependancy Rating Scale (PGDRS) for basic ADLs [30]. NPS were assessed using the 12-item Neuropsychiatric Inventory-Questionnaire (NPI-Q), an informant-based measure of symptom severity and caregiver distress [31], and the 19-item Cornell Scale for Depression in Dementia (CSDD) [32]. Table 1 provides a description of the study measures. Participant demographic data included gender, race, age, education, and living arrangement. Clinicians reviewed the assessment data to determine whether the individual met DSM-IV-TR [33] criteria for dementia or cognitive disorder NOS, referred to here as mild cognitive impairment (MCI).

A nosology of participants' current chronic health problems was used to classify each condition according to general (organ system) disease groups into the following categories: cardiovascular/hypertension, pulmonary, central nervous system/sensory, endocrine, rheumatology/orthopedics, gastrointestinal, hematology/oncology, renal/urological. An individual's total number of health problem categories was used as a health status indicator.

The Dementia Care Needs Assessment (DCNA) was used to identify dementia-related needs of those with cognitive disorders and their caregivers [34]. The DCNA includes 19 domains with multiple items in each domain (see Appendix) and documents whether needs are unmet, partially met, or fully met. Here, a need is defined as "unmet" if (1) it has not been addressed and potentially beneficial interventions are available, or (2) it has been or is being addressed but potential benefits of available interventions have not yet been achieved. A "fully met" need is one that is being addressed and potential benefits of available interventions have been achieved to the extent possible for the individual.

QOL in PWD was assessed using two instruments that can provide three QOL measures. The 13-item Quality of Life-Alzheimer's Disease (QOL-AD) scale is designed to be self-rated (i.e., QOL-AD_SR) by the cognitively impaired person and proxy-rated by a caregiver (i.e., QOL-AD_CR), resulting in two measures of QOL [18]. The QOL-AD_SR is suggested for individuals with MMSE scores >10, and each item is rated as poor, fair, good or excellent. The self-rated and caregiver-rated versions of the QOL-AD have good reliability ($\alpha$ = 0.83 to 0.90) and validity (i.e., are correlated with depression [r = −0.41 to −0.65], daily functioning [r = −0.10 to −0.45], and frequency of pleasant events [r = 0.18 to 0.51]) [15,18]. The 40-item Alzheimer Disease-Related Quality of Life (ADRQL) scale is a proxy-rated measure that can be used across all stages of dementia [35]. Each item describes an observable behavior that caregivers agree or disagree was present in the prior two weeks. The ADRQL has good reliability ($\alpha$ = 0.86) and validity (i.e., discriminates between individuals with and without severe cognitive impairment [p<.05], functional impairment [p<.05], and behavioral or psychological symptoms [p<.05]) [36].

Several measures were used to assess caregiver health and well-being. A single item was used to measure caregiver self-rated health as excellent, very good, good, fair or poor. Caregiver burden was assessed using the 12-item Zarit Burden Inventory (ZBI) [37], and symptoms of depression were identified using the 15-item Geriatric Depression Scale (GDS) [38]. The 6-item Caregiver Activity Survey (CAS) estimates the amount of time spent per day providing care to the primary participant [39]. Caregiver QOL was assessed using the SF-12 , which provides measures of both physical and mental well-being [40]. (See Table 1 for descriptions of caregiver measures.) Caregivers' demographics included gender, race, age, education, and relationship to the primary participant.

## Data Analyses

This study analyzed data on the PWD and their caregivers (excluding persons with MCI) in MIND at Home. Descriptive statistics (i.e., frequencies, means, standard deviations) were

calculated for all PWD and caregiver variables. Bivariate statistics (i.e., t-tests, Pearson correlations) identified relationships between the QOL measures and participants' characteristics as well as among the QOL measures. A series of multiple linear regression analyses were conducted to identify correlates of the three QOL measures. For the QOL-AD_SR analysis, the independent variables were the PWD's characteristics. Analyses of the two caregiver-rated measures (QOL-AD_CR, ADRQL) first included only characteristics of the PWD as independent variables; then a second set of analyses included variables related to both the PWD and their caregivers. For each QOL measure, the model building process began by including independent variables with p-values <.10 based on bivariate analyses. The process continued by manually eliminating from each subsequent analysis one independent variable at a time with the highest p-value >.05 to obtain the most parsimonious model that would explain the greatest amount of variance associated with the QOL measure. The variance inflation factor was used to test for multicollinearity, and the fit of each final model was assessed by plotting the error term against the dependent variable. SPSS, 17.0 was used for all analyses; p-values of <.05 were considered to be statistically significant.

## Results

A total of 1,275 individuals were referred to MIND at Home Phase II. Of those referred, 664 (52.1%) received a telephone screen, 255 (20.0%) were ineligible due to their demographic characteristics or had died before study contact, 188 (14.8%) were unreachable, 150 (11.8%) declined the screening, and 18 (1.4%) agreed to screening but could not be scheduled. Among those screened (n=664), 371 (55.9%) screened positive. Of those who screened positive (n=371), 57 (15.4%) received a home visit but did not meet eligibility criteria, 11 (3.0%) were eligible but did not complete the baseline assessment, and 303 (81.7%) completed the in-home assessment and were randomized into the trial. The randomized sample included 265 (87.5%) PWD and 38 (12.5%) participants with MCI. The total sample for the current analyses consists of 254 PWD whose study partners met the definition of an informal caregiver (i.e., a relative or friend who knows the person well, has contact with the person regularly and on whom the person relies for assistance).

A majority of the PWD were female (65%), white (68%), and lived with others (81%) (Table 2). Most (96%) of the non-white participants were African Americans. Participant mean age was 83.6. Participants were taking an average of 6.4 medications to address chronic health problems that fell into a mean of 3.0 disease group categories. With an average MMSE score of 17.8, the majority (59%) had scores >17, 26% had scores in the 10-17 range, and 15% scored <10 on the MMSE. The most prevalent dementia-related unmet needs related to safety (90%), general medical care (63%), and advance care planning (48%). The majority of caregivers were female (74.7%) and white (67.8%), with caregivers' average age being 66.2. Caregivers' relationships to PWD included spouses (40.2%), children (50.4%), other relatives (5.9%), and non-relatives (3.5%).

The majority (87%) of participants could rate their own QOL based on the QOL-AD; although few (n=12) of those with MMSE scores <10 could do so. The mean QOL-AD_SR score (37.7, SD=6.8) was significantly higher than the mean QOL-AD_CR score (31.2, SD=6.0) (paired t-test=12.61, p<.001), and ADRQL scores averaged 83.1 (SD=13.2). As expected, the three QOL scores were significantly correlated with one another. While QOL-AD_SR scores were correlated moderately with both QOL-AD_CR (r=.36, p<.001) and ADRQL scores (r=.15, p<.05), the highest correlation was between QOL-AD_CR and ADRQL scores (r=.52, p<.001).

Significant bivariate relationships between the PWD's characteristics and the three QOL measures (see Table 2) reflect similarities and differences across these measures. Few

demographic characteristics were associated significantly with QOL in this sample. White participants had higher QOL-AD_SR and QOL-AD_CR scores; higher education was associated with higher QOL-AD_SR scores; and living alone was associated with higher ADRQL scores. Participants taking more medications had lower QOL-AD_SR scores, and those with more health problems had lower QOL-AD_SR and QOL-AD_CR scores. Lower QOL-AD_CR and ADRQL scores were associated with more functional impairments (IADLs, PGDRS) and lower cognitive function. Those with more severe and more distressing NPS and more severe depression had lower QOL on all three measures. Finally, having more dementia-related unmet needs was associated with lower QOL-AD_SR and QOL-AD_CR scores. The range of correlations among the independent variables for PWD was −.005 to .881.

Results of multiple regression models for the three QOL measures using only the PWD's characteristics as independent variables are in Table 3. QOL-AD_SR scores were significantly lower for non-whites, those with more unmet needs, more symptoms of depression (i.e., CSDD), and those taking more medications, with these variables accounting for 22% of the total variance. In contrast, those with more distressing NPS, more unmet needs, more functional impairments (i.e., IADLs, PGDRS scores), and more health problem categories had significantly lower QOL-AD_CR scores, with these variables accounting for 31% of the total variance. Lower ADRQL scores were significantly associated with more distressing NPS, greater IADL impairment, lower cognitive function, and more symptoms of depression, with these variables accounting for 45% of the total variance.

Bivariate relationships between caregiver characteristics and the two caregiver-rated QOL measures are shown in Table 4. Non-white race, the only significant demographic characteristic, was associated with lower QOL-AD_CR scores. Self-rated health, ZBI and GDS scores, CAS time, number of caregiver unmet needs, and SF-12 physical and mental health scores were significantly related to the QOL-AD_CR. Most of these same characteristics were significantly associated with ADRQL scores, with total caregiver unmet needs marginally (p=.067) related to the ADRQL. The range of correlations among the independent variables for the caregivers was .004 to .790.

The multiple regression analyses of the two caregiver-rated QOL measures that included characteristics of both PWD and caregivers are shown in Table 5. Caregiver burden and self-rated health along with the PWD's IADL impairments, unmet needs, depression, and total health problem categories were significantly related to QOL-AD_CR scores, accounting for 36% of the variance. Significant correlates of ADRQL scores included caregiver burden and symptoms of depression along with the PWD's neuropsychiatric symptom severity, IADL impairments and cognitive function, collectively accounting for half of the variance.

## Discussion

This study of community-residing PWD confirms that the correlates of their QOL depend on who rates the person's QOL and the content of the assessment instrument. When considering characteristics of only the PWD as independent variables, most correlates of self-rated QOL differed from those of the two caregiver-rated measures in the regression models. These findings suggest that PWD's perceptions of their own QOL are influenced by a different set of factors than those that influence caregiver perceptions of the PWD's QOL, even when both assessments are based on the same set of items (QOL-AD). These differences are likely due to multiple factors, including characteristics of the PWD (e.g., cognitive deficits, impaired insight) [41], caregiver factors (e.g., perceived distress, their own QOL) [42], aspects of their relationships [22,42], or differences in views on what constitutes QOL [43]. However, unmet dementia-related needs and depressive symptoms

correlated with both self-rated QOL and at least one of the caregiver-rated QOL measures, suggesting these may be especially salient factors and have particular relevance as intervention targets.

When comparing the correlates of the two caregiver-rated QOL measures (QOL-AD_CR and ADRQL) using only characteristics of the PWD, two factors—distressing NPS and IADL impairments—were associated with lower scores. While both of these QOL measures are dementia-specific instruments, they differ in the ranges of disease severity for which they were designed, the domains they assess, the number and types of items they include, and how scores are derived for each measure [15,35]. Given these differences, identifying NPS and functional impairment as correlates of both measures strengthens our confidence in the validity of these findings.

When characteristics of both the PWD and their caregivers were considered in the regression models for the caregiver-rated QOL measures, the set of significant correlates changed somewhat. Notably, caregiver burden was significantly associated with both measures, while caregivers' self-rated health correlated with QOL-AD_CR scores and their symptoms of depression were associated with ADRQL scores. Other studies have also found lower caregiver-rated QOL for PWD when caregivers experienced greater burden [22,23] and depression [19]. With caregiver burden in the models, the NPI-Q distress variable was no longer significant in either model. This suggests that the two variables are related, with distressing NPS contributing to caregiver burden, as others have found [44]. With caregiver self-rated health in the QOL-AD_CR model, ADL impairments (i.e., PGDRS scores) were no longer significant. Likewise, with caregiver depression in the ADRQL model, the PWD's depression was no longer significant. These findings suggest that caregivers' well-being may have an impact on their perceptions of QOL for the PWD, a relationship that cannot be confirmed by our cross sectional data. Moreover, these results indicate that caution is warranted if only proxy-rated measures are used to assess QOL in PWD, and they highlight the importance of addressing the health and mental health care needs of both those with dementia and their caregivers.

NPS were significantly associated with lower QOL in PWD as rated by their caregivers. The relationship between behavioral and psychological symptoms of dementia and QOL has been widely reported [17,45], but studies vary in whether this relationship exists based only on proxy ratings [18,20] or based on both self-rated and proxy-rated QOL [46]. Non-pharmacologic [47] and pharmacologic [48] therapies can effectively treat these symptoms that occur in almost all PWD and may help to improve their QOL.

Symptoms of depression were significantly related to lower QOL in PWD based on both self-rated and caregiver-rated measures. The relationship between depression and lower QOL is a common finding for those with dementia [20,43]. As in our sample, others have found significant relationships between depression and QOL based on both self-rated and caregiver-rated measures [18,19]. While it could be speculated that measures of mood and QOL are indicators of the same concept, our data show that the depression (i.e., CSDD) accounts for 7%-10% of the variance in our three QOL measures. This suggests that a substantial portion of QOL is not accounted for by depression, albeit a significant correlate. When caregiver characteristics were included in our ADRQL model, the caregivers' depressive symptoms were associated with lower QOL in those with dementia. These findings emphasize the importance of diagnosing and treating depression in those with dementia and their caregivers.

Greater functional impairment was associated with lower QOL for the PWD. Investigators have often found significant relationships between greater physical dependency and

diminished QOL in PWD [18,22]. However, functional impairment in this study was not associated with self-rated QOL, a finding supported by the work of Edelman and colleagues [49]. While decline in functional status is a feature of progressive dementia, Gitlin and colleagues [8] have demonstrated that home-based non-pharmacological interventions can lessen functional dependency in PWD and improve caregivers' perceptions of the PWD's QOL.

Higher cognitive function was associated with higher ADRQL scores but was not related to either self-rated or caregiver-rated QOL-AD scores in the multivariate models. Based on a review of studies that used dementia-specific measures, Banerjee and colleagues [17] suggest that there is little relationship between cognitive impairment and QOL. However, investigators have found significant relationships between QOL and cognitive function [22,23,45,50]. Banerjee et al. [17] contend that the absolute level of correlation between these two factors is generally low, suggesting that QOL and cognition are independent constructs.

In this study, individuals with more unmet needs for dementia-related care and services had significantly lower QOL-AD_SR and QOL-AD_CR scores. In the few studies that have examined dementia patients' unmet needs and QOL the findings have been mixed. Vickrey et al. [4] demonstrated that a dementia care management program in primary care clinics could reduce unmet needs for caregiving assistance and improve patients' QOL. However, Orrell et al. [51] found that a 20-week personalized intervention package to address the unmet needs of PWD in residential care settings made no significant differences between groups in either unmet needs or QOL. The MIND at Home – Phase II study will determine whether an 18-month care coordination program can reduce unmet needs in this sample of community-dwelling PWD and improve their QOL.

The limitations of this study are worth noting. Since participants were community-residing PWD and were not selected randomly, these findings may not be generalizable to PWD who reside in other settings (e.g., assisted living, nursing homes). Less than half of caregivers in this study were spouses of those with dementia, a sample characteristic that may affect the external validity of our findings. For participants with severe dementia who could not respond to the QOL-AD items, only proxy-rated measures of their QOL were available. Thus, the correlates of QOL-AD_SR scores are primarily reflective of individuals with mild to moderate dementia. Since this study used cross-sectional data, we cannot assume that causal relationships exist between participant's QOL and the significant correlates.

## Conclusions

Our findings highlight differences in correlates of dementia-specific QOL measures based on perceptions of PWD and their caregivers. For individuals who can provide meaningful responses to questions about their own QOL, their opinions are of primary importance. Since many people with severe dementia cannot self-assess their QOL, caregiver-rated measures can provide complementary perspectives on QOL for PWD. However, this study demonstrates the importance of also accounting for the impact that caregiver characteristics have on proxy-rated QOL measures.

In this study, issues of significance to QOL in community-residing PWD revolve around their health problems, medication use, neuropsychiatric symptoms, functional impairments and, to a lesser extent, cognitive impairments. Moreover, unmet dementia-related needs were associated with both self-rated and caregiver-rated QOL. These findings underscore the importance of identifying and addressing unmet needs for dementia-related care and services. Interventions are available to effectively address modifiable correlates of QOL for

those with dementia and by doing so may also improve the well-being of their informal caregivers.

## Acknowledgments

## Appendix

**Table 6**
**Dementia Care Needs Assessment (DCNA)**

| Need Domains | Number of Items in Domain |
|---|---|
| Care Recipient Needs | |
| a. Dementia Evaluation / Diagnosis | 6 |
| b. Treatment of Cognitive Symptoms | 2 |
| c. Treatment of Neuropsychiatric Symptoms | 5 |
| d. Behavior Management | 3 |
| e. Medication Management | |
| f. Medication Administration | 3 |
| g. General Medical / Health Care | 8 |
| h. Allied Health & Nursing Care | 5 |
| i. Safety | 9 |
| j. Assistance with Daily Activities | 10 |
| k. Meaningful Activities | 6 |
| l. Legal Issues / Advance Care Planning | 6 |
| m. Assistance with Health Insurance | 5 |
| n. Patient Education | 1 |
| o. Caregiver Availability | 3 |
| Caregiver Needs | |
| p. Caregiver Education | 3 |
| q. Resource Referrals | 5 |
| r. Caregiver Mental Health Care | 4 |
| s. Caregiver General Medical / Health Care | 3 |

## Abbreviations

| | |
|---|---|
| **ADLs** | Activities of daily living |
| **ADRQL** | Alzheimer Disease-Related Quality of Life |
| **CAS** | Caregiver Activity Survey |
| **CSDD** | Cornell Scale for Depression in Dementia |

| DCNA | Dementia Care Needs Assessment |
| DSM-IV-TR | Diagnostic and Statistical Manual Fourth Edition Text Revision |
| GDS | Geriatric Depression Scale |
| IADLs | Instrumental activities of daily living |
| IQCODE | Informant Questionnaire for Cognitive Disorders in the Elderly |
| MCI | Mild cognitive impairment |
| MIND at Home | Maximizing Independence at Home |
| MMSE | Mini Mental State Examination |
| NOS | Not otherwise specified |
| NPI-Q | Neuropsychiatric Inventory – Questionnaire |
| NPS | Neuropsychiatric symptoms |
| PGDRS | Psychogeriatric Dependency Rating Scale |
| PWD | Persons with dementia |
| QOL | Quality of life |
| QOL-AD | Quality of Life – Alzheimer Disease |
| QOL-AD_CR | Quality of Life – Alzheimer Disease _ Caregiver-Rated |
| QOL-AD_SR | Quality of Life – Alzheimer Disease _ Self-Rated |
| SF-12 | Short Form 12 Items |
| TICS | Telephone Interview for Cognitive Status |
| ZBI | Zarit Burden Inventory |

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**Table 1**

**Descriptions of Study Measurement Instruments**

| Measures | Items (Domains) | Score Range (Other) | Score Direction | Internal Reliability For This Study α |
|---|---|---|---|---|
| Measures for PWD | | | | |
| IADLs | 8 | 8 – 31 | Higher = Worse | .88 |
| PGDRS | 16 | 0 – 39 | Higher = Worse | .89 |
| MMSE | 30 | 0 – 30 | Higher = Better | NA |
| NPI-Q | | | | |
| Severity | 12 | 0 – 36 | Higher = Worse | .77 |
| Distress | 12 | 0 – 60 | Higher = Worse | .78 |
| CSDD | 19 | 0 – 38 | Higher = Worse | .76 |
| DCNA | (15) | (count) | -- | - |
| QOL-AD_SR [a] | 13 | 13 – 52 | Higher = Worse | .89 |
| QOL-AD_CR [a] | 13 | 13 – 52 | Higher = Worse | .82 |
| ADRQL [b] | 40 | 0 - 100 | Higher = Worse | .84 |
| Measures for Caregivers | | | | |
| ZBI | 12 | 0 – 48 | Higher = Worse | .87 |
| GDS | 15 | 0 – 15 | Higher = Worse | NA |
| CAS | 6 | (Time) | -- | - |
| DCNA | (4) | (Count) | -- | - |
| SF-12 | 12 | 0 - 100 | Higher = Worse | NA |

NA – not available.

[a] Items – physical health, energy, mood, living situation, memory, family, friends, marriage, self as a whole, ability to do chores, ability to do things for fun, money, life as a whole.

[b] Domains – social interaction (12 items), awareness of self (8 items), feelings and mood (12 items), enjoyment of activities (4 items), response to surroundings (4 items).

**Table 2**

**Characteristics of Persons with Dementia and Their Relationships to Quality of Life (QOL)**

| Characteristics | Total Sample (n=254) % or Mean (SD) | Bivariate Relationships to QOL Measures Mean (SD) and/or Statistic | | |
|---|---|---|---|---|
| | | QOL-AD_SR [b] | QOL-AD_CR [c] | ADRQL [d] |
| **Demographics** | | | | |
| Sex | | | | |
| Female | 65.0 | 37.3 (6.8) | 31.3 (5.8) | 83.9 (12.7) |
| Male | 35.0 | 38.4 (6.7) t = 1.10 | 31.1 (6.4) t = − .25 | 81.7 (14.2) t = −1.28 |
| Race | | | | |
| White | 68.1 | 38.9 (6.4) | 31.8 (6.1) | 83.5 (13.6) |
| Non-white | 31.9 | 34.6 (6.9 t = −4.39 *** | 30.0 (5.6) t = −2.12 * | 82.4 (12.4) t = − .63 |
| Age, years | 83.6 (5.9) | r = .06 | r = .05 | r = − .01 |
| Education, years [a] | 13.0 (3.7) | r = .15 * | r = .08 | r = .02 |
| Living Arrangement | | | | |
| Lives alone | 18.9 | 37.8 (6.3) | 32.6 (6.3) | 89.2 (8.1) |
| Lives with others | 81.1 | 37.7 (6.9) t = − .02 | 30.9 (5.9) t = −1.77 | 81.7 (13.8) t = −4.96 *** |
| **Health & Function** | | | | |
| Total # Medications | 6.4 (3.1) | r = − .17 * | r = − .07 | r = .06 |
| Total # Health problems [a] | 3.0 (1.4) | r = − .21 ** | r = − .16 * | r = .04 |
| IADLs Score [a] | 23.0 (5.7) | r = − .04 | r = − .32 *** | r = − .47 *** |
| PGDRS Score [a] | 10.4 (8.2) | r = − .08 | r = − .34 *** | r = − .42 *** |
| MMSE Score [a] | 17.8 (7.6) | r = − .00 | r = .16 * | r = .38 *** |
| Neurpsychiatric Symptoms | | | | |
| NPI-Q Scores | 7.7 (6.1) | r = − .14 * | r = − .32 *** | r = − .54 *** |
| Severity [a] | 9.6 (8.5) | r = − .21 ** | r = − .36 *** | r = − .52 *** |
| Distress [a] | 6.1 (4.5) | r = − .32 *** | r = − .31 *** | r = − .26 *** |
| CSDD Score [a] | | | | |
| **Dementia-Related Needs** | | | | |
| Total # Unmet needs | 4.4 (2.3) | r = − .33 *** | r = − .21 ** | r = .02 |

[a] Missing data – Education=3, Health problems=2, IADLs=2, PGDRS=1, MMSE=3, NPI-Q Severity=3, NPI-Q Distress=5, CSDD=20, QOL-AD Self-rated=34, QOL-AD CG-rated=11.

[b] QOL-AD_SR – Skewness = −.26; Kurtosis = −.35

[c]QOL-AD_CR – Skewness = .10; Kurtosis = −.03

[d]ADRQL – Skewness = −1.05; Kurtosis = 1.20

[*]p < .05

[**]p < .01

[***]p < .001

**Table 3**

**Correlates of Quality of Life Using Characteristics of Persons with Dementia in Multiple Linear Regression Analyses**

| Variables in Final Models | $\beta$ [a] | t | p-value |
|---|---|---|---|
| **QOL-AD_SR Model** | | | |
| (Constant) | | 28.23 | <.001 |
| Total # Unmet needs | −.26 | −4.00 | <.001 |
| CSDD | −.22 | −3.49 | .001 |
| Race (white) | .19 | 3.02 | .003 |
| Total # Medications | −.15 | −2.44 | .016 |
| Adjusted $R^2$= .22 | | | |
| **QOL-AD_CR Model** | | | |
| (Constant) | | 22.93 | <.001 |
| NPI-Q Distress | −.28 | −5.04 | <.001 |
| Total # Unmet needs | −.25 | −4.43 | <.001 |
| IADLs | −.22 | −2.90 | .004 |
| PGDRS | −.20 | −2.66 | .008 |
| Total # Health Problems | −.16 | −2.97 | .003 |
| Adjusted $R^2$= .31 | | | |
| **ADRQL Model** | | | |
| (Constant) | | 23.13 | <.001 |
| NPI-Q Distress | − .43 | −7.42 | <.001 |
| IADLs | −.26 | −4.24 | <.001 |
| MMSE | .19 | 3.08 | .002 |
| CSDD | −.11 | −2.00 | .046 |
| Adjusted $R^2$= .45 | | | |

[a]Standardized coefficients.

**Table 4**

**Characteristics of Caregivers and Their Relationships to Caregiver-rated Quality of Life (QOL) of Persons with Dementia**

| Caregiver Characteristics | Total Sample (n=245) [a] % or Mean (SD) | Bivariate Relationships to Caregiver-rated QOL Measures Mean (SD) and/or Statistic | |
| --- | --- | --- | --- |
| | | QOL-AD_CR | ADRQL |
| **Demographics** | | | |
| Sex | | | |
|   Female | 74.7 | 31.1 (6.0) | 82.6 (13.7) |
|   Male | 25.3 | 31.8 (6.0) t = .78 | 84.9 (12.2) t = 1.18 |
| Race [b] | | | |
|   White | 67.8 | 31.8 (6.1) | 83.3 (13.8) |
|   Non-white | 31.0 | 29.9 (5.6) t = −2.22 [*] | 82.6 (12.4) t = −.37 |
| Age, years [b] | 66.2 (13.2) | r = .03 | r = −.05 |
| Education, years [b] | 15.4 (3.0) | r = .00 | r = .09 |
| Relationship to Care Recipient | | | |
|   Spouse | 40.2 | 31.5 (6.3) | 81.7 (14.3) |
|   Other | 59.8 | 31.0 (5.8) t = −.63 | 84.2 (12.5) t = 1.47 |
| **Health & Well-Being** | | | |
| Self-Rated Health [b] | | | |
|   Excellent/Very Good/Good | 78.2 | 32.2 (5.9) | 84.3 (12.9) |
|   Fair/Poor | 21.8 | 28.1 (5.2) t = −4.45 [***] | 79.4 (14.2) t = −2.37 [*] |
| Zarit Burden Inventory [b] | 15.0 (8.6) | r = −.45 [***] | r = −.45 [***] |
| Geriatric Depression Scale [b] | 2.8 (3.0) | r = −.41 [***] | r = −.44 [***] |
| Caregiving | | | |
| Caregiver Activity Survey, Hours/Day [b] | 12.9 (13.6) | r = −.16 [*] | r = −.34 [***] |
| Total # Unmet Needs [b] | 2.5 (1.0) | r = −.16 [*] | r = −.12 [†] |
| **Quality of Life** | | | |
| SF-12 Physical Health [b] | 48.2 (11.0) | r = .22 [**] | r = .17 [**] |
| SF-12 Mental Health [b] | 48.2 (10.1) | r = .37 [***] | r = .30 [***] |

[a] Nine caregivers provided care to each of two care recipients who had dementia.

[b] Missing Data – Race=3, Age=5, Education=5, Self-rated Health=2, Zarit Burden Inventory=1, Geriatric Depression Scale=2, Caregiver Activity Survey=4, # Unmet Needs=3, SF-12=1

[†] $p < .10$

[*] $p < .05$

[**] $p < .01$

*** p < .001

**Table 5**

**Correlates of Caregiver-Rated Quality of Life Measures Using Characteristics of the Caregivers and Persons with Dementia in Multiple Linear Regression Analyses**

| Variables in Final Models | β [a] | t | p-value |
|---|---|---|---|
| **QOL-AD_CR Model** | | | |
| (Constant) | | 21.99 | <.001 |
| Caregivers' Characteristics | | | |
| ZBI | −.32 | −5.66 | <.001 |
| Self-Rated Health | .15 | 2.65 | .009 |
| PWDs' Characteristics | | | |
| IADLs | −.27 | −4.67 | <.001 |
| Total # Unmet Needs | −.18 | −3.14 | .002 |
| CSDD | −.16 | −2.70 | .008 |
| Total # Health Problems | −.15 | −2.70 | .008 |
| Adjusted $R^2$= .36 | | | |
| **ADRQL Model** | | | |
| (Constant) | | 23.37 | <.001 |
| Caregivers' Characteristics | | | |
| ZBI | −.17 | −3.05 | .003 |
| GDS | −.15 | −2.73 | .007 |
| PWDs' Characteristics | | | |
| NPI-Q Severity | −.39 | −7.76 | <.001 |
| IADLs | −.18 | −3.09 | .002 |
| MMSE | .18 | 3.13 | .002 |
| Adjusted $R^2$= .50 | | | |

[a]Standardized coefficients.