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Correlates of Quality of Life for Individuals with Dementia Living at Home: The Role of Home Environment, Caregiver, and Patient-related Characteristics

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Abstract

Objectives—To examine prevalence of modifiable risk factors and their contribution to patient quality of life (QoL) as rated by dementia patients and family caregivers.

Design—Cross-sectional.

Setting—Home environment.

Participants—88 patients and their caregivers.

Measurements—Modifiable characteristics of home environments, patients, and caregivers were observed or obtained through interview. Demographics and ratings of patients' QoL were obtained from patients and caregivers.

Results—Patients had mean Mini-mental Status Examination (MMSE) score = 17.7 ± 4.6 , (range: 10–28) on an average 7.7 ± 2.4 neuropsychiatric behaviors, 6.0 ± 3.1 health conditions and moderate functional challenges; 70.7% (N = 58) had fall risk; 60.5% (N = 52) had sleep problems at least once weekly; and 42.5% (N = 37) had pain. An average of 8.1 ± 5.2 home hazards and 5.4 ± 4.1 adaptations were observed; 51.7% had unmet device/navigation needs. Patients' and caregivers' QoL ratings were unrelated to MMSE; and patients' self-rated QoL was higher than rated by caregivers. Number of health conditions and unmet device/navigation needs were inversely associated with patient self-rated QoL, and number of health conditions, frequency of behaviors, and level of negative communications were inversely associated with caregiver's assessment of patient QoL. Positive endorsement of caregiving was positively associated with caregiver's appraisal of patient QoL. Other factors were unrelated.

Conclusions—Most patients lived at home with high fall risk, unmanaged behavioral symptoms, pain, sleep disturbances, environmental challenges, and multiple hazards. Except for health, factors associated with lower QoL differed for patients and caregivers. Results suggest need to improve QoL by addressing modifiable risk factors and tailoring interventions to patient and caregiver perspectives.

Keywords

Dementia care; neuropsychiatric behaviors; caregiving; health-related quality of life

Over 5 million Americans have dementia, a progressive and irreversible neurodegenerative condition, with prevalence rates expected to reach over 16 million in the United States.^{1,2} A pandemic, dementia is the greatest single contributor to the burden of disability and poor life quality in older people, and also negatively affecting over 15 million family members responsible for ongoing dementia care at home.¹³

As a cure is not available, maintaining and maximizing quality of life (QoL) is an important treatment goal in caring for people with dementia, and there is still much room for improvement.^{4,5} Unclear is the best way to support QoL in patients at home where most will live throughout the disease course.⁶ Specific treatment strategies have not been systematically developed and tested for this purpose. As an initial step towards advancing practical care strategies to support QoL, this study examines the prevalence of conditions that may compromise daily life at home and relationships between patient QoL ratings and cognitive functioning, and then identifies modifiable correlates of patient QoL as rated by patients with mild to moderate dementia and their family caregivers. Identifying risk conditions and independent modifiable factors contributing to QoL can lead to developing better tailored care interventions to support daily life for patients with dementia living at home.

A substantive research literature on QoL has considered the scalability of this construct in dementia,⁷⁹ whether scales are valid across disease stages,¹⁰¹² and factors explaining patient proxy discordance.¹³ Studies consistently suggest that patient characteristics (higher cognitive status, functional capacity, pain management, and fewer behavioral problems) are associated with informal and formal caregivers' perceptions of higher patient QoL.^{14,15} A common finding is that caregivers rate patients' QoL lower than they believe patients would rate themselves¹⁶; similarly, patients report higher QoL than staff or family.^{17,18} Disparate proxy patient ratings have been attributed to elevated caregiver burden and perceptions of patient suffering.^{13,19} Of the few studies examining correlates of patient-rated QoL, most have been conducted outside of the United States.²⁰²³ Findings are inconsistent with some indicating lower QoL ratings with increased age and cognitive and functional declines and others not finding relationships. Limitations of QoL research include an almost exclusive focus on nursing home residents,^{14,24,25} or end-stage disease patients,²⁶ and inclusion of a restricted range of potential contributing factors, highlighting that more research in this area, particularly for persons living at home with dementia, is necessary.²⁷

A theoretical QoL framework relevant to dementia is Lawton's (1991) "good life" construct.²⁸ Consisting of four elements (psychological well-being, behavioral competence, objective environmental conditions, and perceived QoL), the framework emphasizes relationships between person-level (cognitive, functional competencies), and physical and social (caregiver) environmental attributes as QoL determinants. The framework suggests the need to consider intrapersonal, social-normative, and objective understandings of person environment factors that may be associated with perceived QoL.

The present study focuses on an understudied group in QoL research, community-living patients in the United States with mild to moderate dementia. We examine prevalence of risk conditions and whether they uniquely contribute to patient QoL as perceived by patients and

caregivers. Using objective assessments and caregiver and patient interviews, potential correlates of QoL were purposely selected from three domains (environment, patient, caregiver) consistent with Lawton's theoretical framework. Correlates selected also had to be amenable to intervention, clinically relevant, associated with well-being in other studies, or not previously considered. For example, no studies to our knowledge have examined home environmental factors in relationship to patient QoL although research with other clinical populations and Lawton's theoretical framework suggest a positive association.²⁹

As this study was exploratory and descriptive of modifiable risk conditions and whether they uniquely contribute to QoL, formal hypotheses were not posited. Based on previous studies, however, we expected patients to report their QoL as higher than caregiver ratings, that correlates significantly associated with QoL would differ for patients and caregivers, and that each domain (home environment, patient, and caregiver) would independently contribute to QoL ratings.

METHODS

Study Sample and Procedures

A total of 88 dyads (patients/caregivers) were enrolled in the study between June 2009 and October 2010 from an urban, East Coast region. We enrolled individuals with a Mini Mental Status Examination (MMSE) greater than or equal to 10, the cutoff for obtaining reliable patient QoL ratings.^{10,30,31} Also, patients were eligible if community-living and English-speaking. Patients who were bed-bound or unresponsive were excluded.

Eligible caregivers were 21 years or older; lived with/in close proximity to patients; English-speaking; provided care for 5 months or more; and self-identified as having primary care responsibilities. Both patients and caregivers needed to meet study criteria for enrollment.

Recruitment efforts targeted caregivers through media advertisements and mailings conducted by aging and faith-based organizations. Caregivers contacting the research office were administered a brief telephone screen to determine initial eligibility. If eligible and willing to participate, a 45-minute telephone interview was administered, and a follow-up home visit scheduled. At the home visit of approximately 90 minutes, after signing an institutional review board approved consent form, and obtaining assent from patients for participation, assessors (occupational therapists) administered the MMSE to confirm patient eligibility. If eligible, additional performance-based functional assessments and home observations were conducted. A second home visit to complete interviews occurred within 2 weeks.

Measures

Background characteristics for patients included age, race, sex, marital status; and for caregivers, age, race, sex, marital status, education, relationship (spouse/non-spouse), years caregiving, and financial difficulty (1 = not difficult at all to 4 = very difficult) paying for basics. We controlled for factors identified in previous research as possible contributors to QoL including patient age, cognitive (MMSE) and physical functioning (referred to as

observed functional capacity) derived from using the Allen batteries which are standardized performance-based assessments.^{32,33}

Measure of QoL—To assess patient QoL, the dementia-specific brief 13-item Quality of Life in Alzheimer Disease scale was used.³¹ Items reflect multiple dimensions (physical, social, emotional, and functional well-being) with each rated as 1 = poor, 2 = fair, 3 = good, or 4 = excellent. A total score representing the sum of items ranging from 13 to 52 was derived separately for patients and caregivers ($\alpha = 0.88$ and 0.84 , respectively, for sample). Also, a single item from this scale representing a global QoL assessment (“How would you describe your life/family member’s life as a whole?”) was examined to evaluate patient/caregiver congruence.

Potential correlates of QoL—Measures in three domains (home environment, patients, caregivers), were included.

Home Environment—For home environment, we examined home hazards, adaptations, and unmet assistive device/home navigation needs. Presence of home hazards (access to dangerous objects) and adaptations (grab bars) were identified using the Home Environmental Assessment Protocol, a reliable and valid tool consisting of 192 items directly observed (stove knobs disabled) or derived through caregiver interview (removal of dangerous objects).³⁴ Two indices were derived representing the total number of hazards and adaptations across all rooms used by patients.

Unmet home environmental needs was examined by asking caregivers two questions: Did patients have physical difficulty using or getting into/out of home/ rooms (yes/no); and did caregivers need assistive devices to help patients (yes/no) that they did not have. A sum representing the total number of unmet needs was derived; a score of “0” indicated no unmet needs; “1” indicated one unmet need; and “2” indicated two unmet needs reported.

Patient-related factors—Five measures were used (health conditions, behavioral frequency, fall risk, pain, and sleep quality). For patients’ health conditions, caregivers indicated presence (yes/no) of 26 common conditions (e.g., diabetes, high blood pressure, arthritis, vision impairments) used in various health-related surveys.³⁵ Total number of health conditions was derived.

Behaviors were assessed using the Neuropsychiatric Inventory, a well established and widely utilized brief 12-item tool (e.g., delusions, hallucinations, agitation, anxiety, apathy).³⁶ Caregivers reported whether behaviors occurred and if so, their frequency (1 = occasionally to 4 = very frequently/continuously). Two scores were derived: total number of behaviors occurring, and mean frequency of occurrences. Higher scores indicated greater number/ frequency.

Fall risk was assessed using the Timed Up and Go (TUG) Test,^{37,38} which measures, in seconds, the ability to stand from a chair, walk 10 feet, return to chair and sit down. Two trials are completed and averaged for a total timed score. A score of 14 seconds or more indicates high risk for falls.

Subjective pain intensity was assessed using the Visual Analog Scale³⁹ with the Faces Pain Scale, originally developed for children,⁴⁰ and validated with older adults.⁴¹ A horizontal row of faces (smiling to crying) with corresponding numbers (0 = no pain to 10 = worst possible pain), are presented to patients and a single numerical rating derived.

Sleep quality was assessed using the Pittsburgh Sleep Quality Index,⁴² in which caregivers report patients' frequency of sleep problems on five items using a four-point Likert scale (0 = not occurring past month to 3 = 3 times/week). Scores are calculated to produce a global score (0–21); a score greater than 5 suggests sleep disturbance. Also examined were number of patients experiencing 1 or more sleep disturbance more than once per week ($\alpha = 0.65$ for this sample).

Caregiver-based factors—Three factors were considered: mood, positive caregiving, and communication. For mood, the 20-item Center for Epidemiological Scale was used.⁴³ Participants rate frequency of symptoms during the past week (0 = 1 day to 3 = 5–7 days). Scores represent summed responses across 20 items with higher scores indicating greater depressive symptomatology ($\alpha = 0.86$ for this sample). We also examined the number of caregivers with scores greater than or equal to 16, the cutoff for clinical depression.

Positive endorsement of caregiving was assessed using 11 items.⁴⁴ Each item begins with “Providing help to (person with dementia) has.”, followed by specific beliefs (e.g., “made me feel more useful”, “made me feel strong and confident”). Each item is rated on a five-point Likert scale (0 = disagree a lot to 4 = agree a lot). An index representing mean response across 11 items was derived. Higher scores indicated greater endorsement of positive aspects of caregiving ($\alpha = 0.85$ for this sample).⁴⁵

Negative communication was assessed using items derived from two standardized scales; four items (criticizing, threatening, withdrawing, and yelling) from the Dementia Management Scale⁴⁶ and two items (harsh tone, screaming) from the Conflict Tactics Scales.^{47,48} Caregivers rated frequency using each item on a five-point Likert scale (1 = never to 5 = always). An index representing mean responses across six items was derived. Higher scores indicated greater negative communications ($\alpha = 0.83$ for this sample). We also examined the number of caregivers reporting use of each item “some” to always”.

Statistical Analysis

Descriptive data for patients/caregivers included sociodemographic characteristics and proposed correlates of QoL. Spearman correlation was used to examine relationships among patient and caregiver QoL ratings and MMSE. A paired t test was used to compare caregiver and patient ratings of total QoL scores. The Bhapkar test of marginal homogeneity was used to compare the proportion of responses in the four categories for the single global QoL question as assessed by patients and caregivers. Separate linear regression models with a two-block design were used to analyze patients/caregivers responses to total QoL scores.

For each analysis, we included covariates identified in prior research as potentially associated with QoL (patient age, MMSE, functional capacity). Although findings have been inconsistent concerning these associations, we included these variables for two reasons: This

is a population not well studied; and it is plausible that age and function of patients influence perceived QoL. To further help ensure we were fully controlling for these three covariates, we also created three interaction products among covariates considered in this study (age, MMSE, functional capacity) to determine whether the effect of any of these variables on QoL might be moderated by a third variable. One interaction term (MMSE and observed functional capacity) approached significance and only for caregiver rating of patient QoL: Low cognitive and functional capacity was associated with perceived poorer patient QoL by caregivers. Thus, for patients, Block I included patient age, MMSE, and functional capacity for each separate analysis. For caregivers, Block I for each analysis included the same covariates for patients, but added an interaction term (MMSE by functional capacity). None of the covariates (including the interaction term) were significant in the final analyses, however, and are not shown.

For both patients and caregivers, Block II included each factor of each domain; physical environment domain included home hazards, adaptations, unmet environmental needs; patient domain included patient behavioral frequency, fall risk (TUG), sleep quality, health conditions, pain; caregiver domain included caregiver depressive symptoms, positive aspects of caring, and communication. Each variable was entered in separate analyses to evaluate its unique contribution after controlling for Block I factors.

Finally, for both patients and caregivers, we conducted a multivariate analysis such that we entered significant predictors (cutoff $p = 0.05$) identified from the above analyses in Block II to evaluate their relative contribution to QoL.

At a reviewer's request, we reran analyses using transformed values of predictors with skewed distributions (xx, yy, zz). When we transformed our count variables using square root transformation, our results were essentially unchanged. We therefore report the results based on the raw data.

SAS version 9.2 and SPSS version 18.0 were used. Statistical tests were two-sided when appropriate with significance level set at 0.05.

RESULTS

Of 113 dyads screened, 111 (98%) met initial study criteria and received the telephone interview. Of these, 101 (91%) received an initial home visit for which 91 were eligible with 10 (9%) dyads ineligible based on patient MMSE (<10). Of 91 eligible and enrolled dyads, 88 (97%) completed two home assessments and are included in the analyses.

Background Characteristics

Patients had mild to moderate cognitive impairment (Mean MMSE = 17.7; range: 10–28), were nearly evenly split by sex (52% female), were mostly white (76%), with an average age of 82 years (range: 56–97). Caregivers had an average age of 65.8 years (range: 38–89), were primarily female (89%), white (77%), and spouses (56%), with 100% having at least a high school education, and an average of 5.1 (range: 0.5–22) years of caregiving. Most reported little to no financial difficulty (65%) (Table 1).

Prevalence of Environmental Conditions

An average of 8.1 ± 5.2 hazards were observed with a maximum of 27 safety concerns. Most hazards, on average two per room, were found in kitchens, bathrooms, and bedrooms. In contrast, an average of 5 (range: 0–23) supportive adaptive features were found (de-cluttering, assistive devices). Whereas 48% reported no unmet environmental needs, half the sample (52%) indicated one or two unmet needs (Table 2). Of these, 30% ($N = 26$) indicated equipment needs (grab bars, tub benches); and 34% ($N = 30$) reported patient difficulty navigating through the home with stair-climbing being the most frequently cited.

Prevalence of Patient-related Risk Factors

Caregivers reported patients had on average six (range: 0–15) health conditions. Table 2 shows the most prevalent health conditions. Caregivers reported managing on average 7.7 ± 2.4 (range: 2–13) behaviors in the past month. Behaviors occurred “often” to “frequently” (Mean: 2.5 ± 0.6). On the TUG, of patients ambulating independently, 42% ($N = 34$) scored as able to ambulate but with fall risk (< 14 seconds); and 29% ($N = 24$) scored within poor mobility range. Thus, a total of 71% ($N = 58$) were at risk for falls. As to falls, 43% ($N = 36$ of 83) had 1 or more falls as reported by caregivers whereas 57% ($N = 47$ of 83) of patients had not fallen in the past year. Also, 43% ($N = 37$) of patients reported having some pain; 60% ($N = 52$ of 86) had sleep problems once a week or more according to caregivers. Finally, most patients had a moderate level of physical functioning requiring supervision in self-care and medication taking.

Prevalence of Caregiver-related Risk Factors

As to mood, 30% ($N = 26$) of caregivers scored 16 or higher, indicative of clinical depressive symptoms. On average, caregivers reported “a little” agreement with positive benefits from caregiving. Although on average, caregivers indicated using negative communications rarely, 53% ($N = 47$) reported screaming, 52% ($N = 46$) reported scolding, 40% ($N = 35$) indicated they used a harsh voice, 27% ($N = 24$) indicated they withdrew from the patient, 19% ($N = 17$) reported yelling, and 15% ($N = 13$) used threats either sometimes to always.

QoL Scores

Patients’ self-rated QoL was higher than caregivers’ ratings (Mean: 36.6 ± 6.7 ; 31.5 ± 6.4 , respectively). This difference in means (5.1, 95% confidence interval [CI] 3.6, 6.6) was statistically significant ($df = 86$; $t = 6.88$; $p < 0.001$). For the single global QoL item, proportions of patients in four categories (1 = poor, 2 = fair, 3 = good, 4 = excellent) differed for patient and caregiver ratings ($\chi^2 = 21.3$, $df = 3$, $p < 0.001$). Also, 45% ($N = 39$) of patients rated their QoL higher than caregivers rated it, 37% ($N = 32$) rated it similarly, and only 18% ($N = 16$) rated it lower than caregivers (Table 3).

Patient self-rated QoL was moderately associated with caregiver ratings of patient QoL (Spearman $r = 0.47$, $df = 85$, $t = 4.94$, $p < 0.001$). Neither patient nor caregiver ratings of patient QoL were associated with cognitive impairment (MMSE, $p = 0.69$, $df = 85$, $t = 0.403$; $p = 0.32$, $df = 85$, $t = 0.991$, respectively).

Correlates of Patient-rated QOL

For patients' ratings of their QoL, having more unmet assistive device/navigation needs and health conditions were associated with patient-perceived lower QoL in separate regressions; pain approached statistical significance. Other environmental (hazards, adaptations), patient (sleep, behaviors), and caregiver (depression, positive caregiving appraisals, negative communications) factors were not associated with QoL (Table 4).

A final regression with health conditions and unmet needs entered together resulted in health conditions ($B = -0.59$, 95% CI, $-1.09, -0.09$, $t = -2.35$, $df = 78$; $p = 0.022$) as the only independent contributor to patient QoL that reached statistical significance.

Correlates of Caregiver-rated Patient QOL

For caregivers, greater frequency of behaviors, more patient health conditions, lower endorsement of positive aspects of caregiving, and greater use of negative communications were each associated with caregivers' lower rating of patients' QoL in separate regressions. Environmental-related factors, patient pain and sleep, and caregiver depression were not independently associated with caregivers' QoL appraisals (Table 4).

A final regression including all statistically significant factors from the previous analyses resulted in patient health conditions ($B = -0.46$; 95% CI, $-0.86, -0.07$; $t = -2.34$; $df = 72$; $p = 0.022$) and behavioral frequency ($B = -2.76$; 95% CI, $-4.88, -0.65$; $t = -2.60$; $df = 72$; $p = 0.011$) as the two independent contributors to patient QoL that reached statistical significance.

DISCUSSION

This exploratory, cross-sectional study describes the presence of modifiable risk factors of individuals with dementia living at home and, of these factors, their separate and joint contributions to patient and caregiver subjective appraisals of patient QoL.

We found that most patients lived at home with conditions that placed them at increased risk for adverse outcomes. These conditions included unmet environmental needs, fall risk, home hazards, poor sleep, pain, behavioral symptoms, and negative caregiver communications. These factors are modifiable, however. For example, a brief home safety assessment yielding recommendations for adaptive equipment could help caregivers create a safer environment, address unmet environmental needs, and ease caregiving.⁴⁹ The TUG, a brief clinical screen, can easily be administered in clinical or home settings to quickly identify patients at fall risk and who may benefit from referrals to occupational therapy or physical therapy, although evidence-based dementia specific rehabilitation and fall prevention programs need to be developed and tested. Previous trials show that caregiver skills-training can reduce caregiver burden and negative or ineffective communications, and minimize home hazards.^{48,50} As pain and sleep disturbances may contribute to behavioral symptoms and caregiver distress, ongoing assessment and treatment of these areas may also improve home life for patients. Specifically, teaching caregivers to recognize atypical presentations of pain (e.g., grimacing, holding a body part) and implement good sleep hygiene (e.g.,

minimizing caffeine, establishing nighttime routines) can effectively address these common negative conditions that patients live with.⁴⁸

We also found that caregivers implemented environmental adaptations to support daily functioning at home (e.g., visual cues, removal of unnecessary objects). Nevertheless, given the high number of hazards observed, caregivers appear to need professional assistance to optimize patient safety at home. The home environment as a facilitator of safe patient functioning and effective care provision remains understudied in dementia care although its importance is well recognized in residential care settings.

Consistent with previous research, we found discordance between patient caregiver ratings with most patients perceiving higher QoL than their caregivers.^{13,18} A little over one-third of patients and caregivers had similar QoL ratings; ratings by two-thirds of the dyads were discordant. Although patient anosognosia may explain discordance in part, previous research suggests otherwise.¹⁸ It appears that patients and caregivers evaluate QoL differently. Lower caregiver ratings of patient QoL (45%) may be due in part to viewing patients as suffering; higher caregiver ratings (18%) may be due in part to viewing patients as having greater capacity than they may have.⁵¹ Either way, discordance suggests that both patient and caregiver perspectives need to be considered and that caregivers may benefit from interventions which enhance their understanding of patients' needs, self-appraisals, and capabilities.

For patients, health conditions and unmet environmental needs were the only two factors associated with QoL in separate regressions. Although patients had multiple chronic conditions, it is not possible to determine which condition(s) nor aspects of conditions contribute to perceived diminished QoL. Research on older adults with physical impairments suggests the limitations imposed on activity participation by health conditions are the most distressful.⁵² The same may be the case for people with dementia. Chronic comorbidity is common in dementia; nursing home research suggests high frequency of multiple health problems that are poorly managed.⁵³ Other studies show patients living at home with undetected yet treatable medical conditions.^{50,54} A study of 15,022 people in developing countries found high prevalence of pain, hearing, visual, and mobility impairments, among other conditions.⁵⁵ Clearly, there is a critical need to develop physical health management protocols for dementia patients to ease the excess burden of common diseases of old age.

Noteworthy is that having difficulty navigating or accessing rooms impacts patients' appraisals of QoL, although unmet need did not remain significant when number of health conditions was entered in the regression analysis. Nevertheless, unmet needs may have an important role in patients' home life. Navigational challenges may constrict life space and prevent effective engagement in daily activities and in this way contribute to poor perceived QoL. Studies of older adults with physical disabilities have linked home environmental conditions to diminished competencies and accessibility challenges.²⁹ As involvement in pleasant events and meaningful activities positively impact behavioral symptoms, particularly depression and agitation,^{56,57} greater consideration to the role of the home environment in supporting navigation, accessibility, and activity engagement is warranted.

Correlates not associated with patient QoL are also instructive to consider. These included specific environmental (hazards, adaptations), patient (sleep, behaviors, fall risk) and caregiver (mood, communication) characteristics. Whereas previous studies^{14,54} report an association between pain and QoL, that was not the case for this sample, due possibly to a limited range in pain scores or small sample size. Although previous research suggests disruptive behaviors affect QoL,⁵⁸ patients in this sample did not perceive that to be the case. Similarly, the social environment (caregiver mood, communication) did not impact patient self-ratings.

For caregivers, select patient and caregiver characteristics were more important than home conditions in rating patients' QoL. Caregiver appraisals were related to perceived negative caregiving experiences, suggesting they may project their own perceived diminished QoL on that of patients. In both the separate regressions and multivariate model, caregiver appraisals were related to greater frequency of patient behaviors and health conditions. These conditions may be perceived by caregivers as evidence of patients' suffering and, hence, lower appraisals of patient QoL.⁵¹

One study limitation is that not all modifiable and theoretically relevant factors could be included in this study given the sample size. Rather, these results provide preliminary insights as to specific home, patient, and caregiver conditions hitherto not considered that may infringe upon perceived QoL. Only a limited number of the conditions considered appeared to affect appraisals, suggesting that further exploration of contributors be pursued. Another limitation is the small sample size and cross-sectional design. Studies with diverse and larger samples and that examine other modifiable factors and their role over time are warranted.

Important clinical implications can be derived. First, as others have suggested, QoL is a subjective state that can inform patient management.⁵⁹ The findings of patient caregiver discordance and distinct QoL correlates for patients and caregivers highlight the need to consider appraisals from both patients and caregivers in clinical encounters. Second, the one factor significant to both patients and caregivers was number of patient health conditions, suggesting that careful monitoring of health in dementia care is important. Third, the good news is that the QoL correlates considered were either modifiable (unmet environmental needs, negative communications), or their impact could be minimized (patient comorbidities, negative appraisal of caregiving) through ongoing, comprehensive dementia care. Fourth, over half of the caregiver sample indicated using one or more negative communications, suggesting that improving caregiver skills in communicating effectively is key. Finally, this exploratory study suggests that QoL improvement interventions need to be multi-component and address the similar and unique concerns of patients and caregivers. Nevertheless it is difficult to determine the clinical meaning of QoL. The total QoL scores for this sample are similar to those reported elsewhere but score interpretation is imprecise. There are no cutoff scores indicative of clinically poor outcomes, an area of investigation important to pursue.

In conclusion, we do not have a dementia cure, and helping patients enhance and maintain QoL is an important treatment goal. This study provides new insights concerning the home

conditions in which patients live and the modifiable factors that may attenuate or support QoL from which to design and test beneficial care interventions. The study also shows that for this sample, patients lived at home with risk factors that can be ameliorated through assessment, intervention, and monitoring. The study highlights the urgent need to develop a comprehensive approach to dementia care that includes addressing co-morbidities and home environmental conditions along with providing caregiver education, support, and communication training to improve and maintain the QoL of this growing clinical population.

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TABLE 1

Patient and Caregiver Characteristics

Characteristics	Patients (N = 88)	Caregivers (N = 88)
Age (years), Mean $\pm$ SD (range)	81.7 $\pm$ 8.0 (56–97)	65.8 $\pm$ 12.2 (38–89)
Race, N (%)		
White	67 (76.1)	68 (77.3)
African American	20 (22.7)	18 (20.5)
Other	1 (1.1)	2 (2.3)
Sex, N (%)		
Female	46 (52.3)	78 (88.6)
Male	42 (47.7)	10 (11.4)
Marital status, N (%)		
Married	51 (58.0)	66 (75.0)
Not married	37 (42.0)	22 (25.0)
MMSE, Mean SD $\pm$ (range) ^a	17.7 $\pm$ 4.6 (10–28)	
Observed function, Mean $\pm$ SD (range) ^b	4.1 $\pm$ 0.5 (3–5.2)	
1 Falls in past 6 months, N (%)	36 (43.3)	
Relationship to patient, N (%)		
Spouse		49 (55.7)
Non spouse		39 (44.3)
Education, N (%)		
High school		2 (2.3)
>High school		86 (97.7)
Years caregiving, Mean $\pm$ SD (range)		5.1 $\pm$ 3.5 (0.5–22)
Financial difficulty, N (%)		
Not difficult at all		36 (40.9)
Not very difficult		21 (23.9)
Somewhat difficult		28 (31.8)
Very difficult		3 (3.4)

Notes: MMSE: Mini Mental Status Examination; Observed function: Allen diagnostic tests.

Results expressed as mean, standard deviation (range) or frequency (percentage of total). Percentages may not sum to 100 due to rounding error.

^aN 87.

^bN 84.

TABLE 2

Potential Correlates of Quality of Life (N = 88)

Factors	N (%)	Mean ($\pm$ SD)	Min–Max
Home Environment ^a			
#Hazards		8.1 (5.2)	1–27
#Adaptations		5.4 (4.1)	0–23
Unmet needs			
0 unmet needs	42 (48.3)		
1 unmet need	31 (35.6)		
2 unmet needs	14 (16.1)		
Patient			
Behavior frequency ^b		2.5 (0.6)	1.0–3.75
Timed Up and Go ^c			
10 seconds (normal)	16 (19.5)		
11–13 seconds (good mobility)	8 (9.8)		
14–20 seconds (potential risk for falls)	34 (41.5)		
21 seconds (problems, needs assistive device)	24 (29.3)		
Sleep Quality ^d		.73 (.70)	0–2.8
Pain ^a		1.5 (2.2)	0–10
Health Conditions ^a		6.0 (3.1)	0–15
High blood pressure	57 (65.5)		
Arthritis	40 (46.0)		
Depression	40 (48.8)		
Nervousness	38 (43.7)		
Heart trouble	37 (42.5)		
Hearing loss	37 (42.5)		
Cataracts	35 (40.2)		
Bladder problems	30 (34.5)		
Diabetes	23 (26.4)		
Circulation problems	23 (26.4)		
Foot problems	29 (33.3)		
Insomnia	26 (29.9)		
Caregiver related factors			
Depressive symptoms (CES D)		11.4 (9.7)	0–42
Positive aspects of caregiving		2.8 (0.9)	0–4
Negative communication style		2.0 (0.7)	1–4.5

Notes: CES D: Center for Epidemiologic Studies Depression.

^a N 87.^b N 84.^c N 82.

^dN 86.

TABLE 3

Comparison of Patient and Caregiver Ratings on Single Global Patient QoL Item

Caregiver Rating	Patient Self Rated QoL				Total	Summary
	1	2	3	4		
1	0	1	3	3	7	Patient = CG N = 32
2	3	4	14	7	28	Patient > CG N = 39
3	2	3	24	11	40	CG > Patient N = 16
4	1	0	7	4	12	
Total	6	8	48	25	87	

TABLE 4
Associations of Factors with Patient and Caregiver Perceived Quality of Life of Patient

Factors ^d	Patient Perceived Quality of Life				Caregiver Perceived Quality of Life of Patient					
	B	95% CI		t	p value	B	95% CI		t	p value
		Lower Bound	Upper Bound				Lower Bound	Upper Bound		
Home Environment										
Unmet needs	2.314	4.370	0.258	2.240	0.028*	1.474	3.425	0.476	1.505	0.136
# Adaptations	0.284	0.647	0.079	1.558	0.123	0.172	0.516	0.172	0.996	0.322
# Hazards	0.002	0.292	0.296	0.016	0.987	0.078	0.354	0.197	0.567	0.573
Patient										
# Health conditions	0.707	1.161	0.253	3.101	0.003*	0.690	1.110	0.269	3.265	0.002*
Behavioral frequency	0.772	3.203	1.659	0.633	0.529	4.058	6.021	2.094	4.117	0.000*
Pain	0.723	1.462	0.016	1.948	0.055	0.120	0.828	0.588	0.338	0.737
Sleep quality	1.523	3.650	0.604	1.425	0.158	1.753	3.721	0.215	1.774	0.080
Fall risk (TUG)	0.057	0.129	0.016	1.556	0.124	0.018	0.087	0.052	0.504	0.616
Caregiver										
Positive aspects of caregiving	0.072	1.773	1.628	0.085	0.933	2.000	0.476	3.523	2.613	0.011 ^b
Negative communication	1.027	3.182	1.129	0.948	0.346	3.120	5.013	1.226	3.280	0.002 ^b
Depressive symptoms	0.006	0.161	0.149	0.078	0.938	0.100	0.243	0.043	1.389	0.169

Notes: TUG: Timed up and Go; N 84 except for Behavioral frequency (N 81), Sleep quality (N 83), and Fall risk (N 79). Degrees of freedom for t tests for patient QoL regressions were 79 except for Behavioral frequency (df 76), Sleep quality (df 78), and Fall risk (df 74). Degrees of freedom for t tests for caregiver perceived QoL of patient regressions were df 78 except for Behavioral frequency (df 75), Sleep quality (df 77), and Fall risk (df 73).

^aEach factor in Block II was entered into a separate linear regression which included the set of covariates from Block I.

^bDenotes statistically significant p value.