Correlates of Caregiver-Rated Quality of Life in Assisted Living: The Maryland Assisted Living Study

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We used a cross-sectional study to examine the correlates of caregiver-rated quality of life (QOL) in 198 randomly selected residents from a stratified random sample of 22 assisted living facilities in central Maryland. We measured QOL by using the Alzheimer's Disease-Related Quality of Life Questionnaire. In general, despite cognitive impairment, residents in assisted living were rated as having a high QOL. In a multivariate regression, we found that nonmood neuropsychiatric symptoms were the strongest correlate of QOL, explaining 37% of the variance. Depressive symptoms, functional dependence, marital status, and cognition also contributed to the model, but only minimally. Because of the strong association of neuropsychiatric symptoms with QOL, special attention should be given to their recognition and amelioration.

Assisted living (AL) has emerged as an alternative to more traditional forms of residential long-term care for older persons. As of 2002, nearly 1 million elders were living in 36,399 licensed AL facilities (Mollica, 2002). As the population ages and there is an increased demand for residential health care services that preserve the autonomy of older consumers, AL will likely become more popular (American Association for Retired People, 2002).

AL is typically conceptualized as a residential setting primarily serving the elderly population that provides personal care, 24-hr supportive service, limited medical care (such as medication administration), and food service (National Center for Assisted Living, 2001). Its mission is the maximization of resident quality of life by encouraging autonomy, dignity, privacy, and choice, in a supportive homelike environment (American Association for Retired People, 2002).

The examination of quality of life (QOL) in AL is vital to the continued evolution of AL as a long-term-care system. Prior research on QOL in AL has been limited by difficulties in defining and operationalizing QOL in cognitively heterogeneous populations. QOL is a complex, multidimensional construct and traditionally involves a subjective component. Dementia, a common condition of residents in AL (Rosenblatt et al., 2004), impairs language function, memory of past events, and the ability to reflect on internal states, which compromises the accuracy and reliability of self-report. In response to this issue, researchers have developed dementia-specific QOL assessment tools, which utilize specialized self-assessment (Logsdon, Gibbons, McCurry, & Teri, 2002), direct observational techniques (Kitwood & Bredin, 1997), and proxy ratings (Rabins et al., 1999).

Data on QOL in AL are few, and such data have typically segregated AL residents with and without dementia. Studies of self-reported QOL in AL residents without dementia have found perceived social support (Cummings, 2002) and social cohesion (Mitchell & Kemp, 2000) to be the strongest predictors of psychological well-being and QOL, respectively. In contrast, investigations focused on observed or proxy-rated QOL of long-term-care residents with dementia have reported that being depressed (Borowiak & Kostka, 2004; Gonzalez-Salvador et al., 2000; Nagatomo, Nomaguchi, & Matsumoto, 1993), having a physical dependency (Ballard et al., 2001; Gonzalez-Salvador et al.), being socially withdrawn, taking psychotropic medications (Ballard et al.), and living in a smaller, dementia-specific AL facility (Kuhn, Kasayka, & Lechner, 2002) predict lower QOL.

Our aim in this study was to examine QOL in a cohort of randomly selected cognitively normal and cognitively impaired AL residents. We attempted to estimate the contributions to caregiver-rated QOL of the following key domains: cognition, functional dependence, physical health, depression, nonmood neuropsychiatric symptoms, and activity participation.

Methods

Participants

This study was part of Phase 1 of the Maryland Assisted Living study, a cross-sectional investigation of the prevalence rates of dementia and other psychiatric disorders in a stratified random sample. The study design was described in detail in an earlier report (Rosenblatt et al., 2004). The study sample consisted of 198 AL residents who resided in 22 AL facilities, including 10 large facilities (16 beds or more) and 12 small facilities (15 beds or fewer). Informed consent was obtained from all residents. All participants received a clinical examination. A series of quantitative instruments were used to rate physical health, functional dependence, cognition, depression, QOL, neuropsychiatric disturbances, and activity participation.

Diagnoses of psychiatric illness, including dementia, were adjudicated during a consensus conference involving
a multidisciplinary panel of experts using all data collected. One hundred and thirty-four participants (68%) met the criteria given by the fourth edition, revised, of the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 1994) for dementia, and 18 (9%) met criteria for other cognitive disorders (Rosenblatt et al., 2004).

**Measurement of Quality of Life**

We chose the Alzheimer Disease-Related Quality of Life Scale (ADRQL), a proxy-rated measure designed for use in dementia, as the primary measure of QOL (Rabins et al., 1999). We did consider dementia-specific self-report QOL measures, but there were few available at the time and their validity and reliability had not been tested in later stages of dementia. We had the ADRQL administered to the resident’s formal caregiver, identified by the facility director as the staff member most involved in the resident’s day-to-day care. We used private-duty caregivers if residents were receiving one-on-one care. We had 93 formal caregivers interviewed. Most of them were Black (74%), and there were more women (94%) than men. Of the caregivers, 80% were facility staff and had worked there for a mean of 6 years. Most were either certified nursing assistants (62%) or medical assistants (9%).

The ADRQL consists of 47 true–false items in five domains: social interaction, awareness of self, feelings and mood, enjoyment of activities, and response to surroundings. Responses are based on the occurrence of observable behaviors over the preceding 2 weeks. Internal consistency reliability for the instrument in this study was good (Cronbach’s α = 0.85). Scores are expressed as percentages, with higher scores reflecting a better QOL.

We assessed the concurrent validity of the proxy-rated ADRQL by testing the strength of its association with the Medical Outcomes Study Short Form Health Survey (SF-12; Ware, Kosinski, & Keller, 1996), a widely accepted self-assessment measure of health-related QOL. Because of the subjective and retrospective nature of the items in the survey, we had the SF-12 administered exclusively to residents without dementia. We weighted and summed the 12 items to produce a physical component summary score and a mental component summary score. The SF-12 mental component summary score correlated significantly with the ADRQL total percentage score ($r = .613, p < .001$) for residents without any cognitive disorder ($n = 41$) and moderately for residents who did not meet criteria for dementia ($n = 53$) but may have suffered from other cognitive disorders ($r = .483, p < .001$).

**Independent Variables**

The Neuropsychiatric Inventory (NPI), administered to the formal caregiver, assesses frequency and severity of mental and behavioral symptoms in 12 domains (Cummings, 1997). The measure has good interrater and test–retest reliability and content and concurrent validity (Cummings et al., 1994). We extrapolated the seven nonmood domains (i.e., delusions, hallucinations, agitation or aggression, euphoria, apathy, disinhibition, and aberrant motor behavior) to calculate an NPI nonmood total symptom score (NPI-NM). Other researchers have done this to minimize the problem of collinearity with other measures of mood such as the Cornell Scale of Depression in Dementia (CSDD) (see Lyketsos et al., 2003).

Other measures that we considered in this analysis are as follows: (a) the Mini-Mental State Exam (MMSE) (Folstein, Folstein, & McHugh, 1975); (b) the Psychogeriatric Dependency Rating Scale–Physical Dependency subscale (PGDRS-P) (Wilkinson & Graham-White, 1980), administered to formal caregivers to rate overall functional impairment in activities of daily living; (c) the General Medical Health Rating (Lyketsos et al., 1999) of global medical comorbidity, with scores ranging from 1 (poor) to 4 (excellent); and (d) the CSDD (Alexopoulos, Abrams, Young, & Shamoian, 1988), a measure of depressive symptom severity.

We measured activity participation by asking residents and caregivers to estimate the number of hours in the past month they had engaged in structured group activities (e.g., discussions, clubs, games, and trips) and in solo activities (e.g., hobbies, reading, and crossword puzzles).

We examined all continuous variables for fit to the normal distribution. We log-transformed the following variables because of significant positive skew: the CSDD total score, the NPI-NM total score, and the length of stay in AL.

**RESULTS**

The majority of residents were women (79%), widowed (71%), and Caucasian (83%). Seventy-six percent were living in large facilities. The mean age was 85.7 years (SD = 8.2), and residents had an average of 13.6 years of education (SD = 3.1). Residents had lived in their AL facility for a mean of 2.1 years (SD = 1.9), and the facility cost per month averaged $2,983 (SD = 1357.9).

AL residents had a mean ADRQL total percentage of 80.7% (SD = 13.5), which was comparable with the previously reported 77.2% in an AL sample of residents with dementia (Gonzalez-Salvador et al., 2000). The mean MMSE score of the participants was 18.2 (SD = 8.8); 25% of the participants had a score of 12 or less. Average physical dependency scores (PGDRS-P) were 12.3 (SD = 8.5). The majority of residents (79%) were rated as having good or fair health; 18% had excellent health, and 3% had poor health. The mean CSDD score was 5.3 (SD = 4.5), and the mean NPI-NM score was 5.5 (SD = 7.7). Residents spent an average of 76.5 hr a month participating in activities (SD = 67.4).

We used simple linear regression models to estimate the relationship between the independent variables and ADRQL total score (Table 1). Better cognition, physical health, and hours spent in activity were significant predictors of better QOL ratings. Increased functional dependence, depressive symptoms, and nonmood mental and behavioral psychiatric symptoms (NPI-NM) predicted lower QOL ratings. Being widowed ($p = .056$) and Caucasian ($p = .087$) reached near significance in predicting better QOL. Age, sex, education, length of residence, cost, and size of the facility did not contribute significantly to QOL score.

We estimated a multivariate regression model by stepwise methodology to determine the relative contribution of each variable with a value of $p < .10$ in the univariate regression models (Table 1). The variables entered in the equation accounted for almost half (49.2%) of the variance in QOL ratings, with $F(5, 183) = 37.5, p < .001$. The presence of nonmood neuropsychiatric symptoms was the largest single
true activity levels. We concede that facility size may be an unsatisfactory proxy for quality of environment. Future analyses of specific environmental features may better elucidate any association between facility-level factors and QOL.

There were several limitations of this study. Because this was a cross-sectional investigation, we could not draw causative conclusions. We are currently in the process of making a longitudinal follow-up of this cohort that can better address how these variables predict caregiver-rated QOL over time. Second, the ADRLQ is a proxy-rated measure of QOL that does not include a subjective component. We were able to demonstrate, however, that for participants without dementia, the ADRLQ significantly correlated with a self-report QOL measure (i.e., the SF-12). Third, the use of caregiver ratings on both the NPI and ADRLQ may inadvertently introduce bias. Caregivers of residents with more severe behaviors may have rated the residents’ QOL lower because of their own sense of burden. Nevertheless, the structure of the ADRLQ was intended to reduce potential caregiver bias by focusing on observable behavior rather than asking the respondent to rate her or his perception of resident functioning (Rabins et al., 1999).

In conclusion, psychiatric symptoms, which are prevalent in AL (Rosenblatt et al., 2004), contribute to lower QOL ratings. The appropriate detection and treatment of psychiatric symptoms is likely to enhance QOL for residents of AL. Facility-level and individual-level interventions such as more focused staff training, use of evidence-based screening approaches, increased communication and collaboration with primary care physicians, and optimization of dementia care treatment strategies, including appropriate behavioral and pharmacological management of neuropsychiatric symptoms, might be considered.

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References

Table 1. Results of Univariate and Multivariate Linear Regression Models

<table>
<thead>
<tr>
<th>Independent Variable</th>
<th>B</th>
<th>SE</th>
<th>p</th>
<th>Adj. R²</th>
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<tr>
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<tr>
<td>Age</td>
<td>0.06</td>
<td>0.12</td>
<td>.626</td>
<td>.004</td>
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<tr>
<td>Female (vs male)</td>
<td>2.58</td>
<td>2.35</td>
<td>.273</td>
<td>.001</td>
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<td>Caucasian (vs non-Caucasian)</td>
<td>4.35</td>
<td>2.53</td>
<td>.087</td>
<td>.010</td>
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<tr>
<td>Widowed (vs other)</td>
<td>4.03</td>
<td>2.09</td>
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<td>Education</td>
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<td>Length of residence</td>
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<td>Cost</td>
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<td>0.001</td>
<td>.285</td>
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<td>Living in a large (vs small) facility</td>
<td>3.14</td>
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<td>-.005</td>
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<td>MMSE</td>
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<td>PGDRS-P</td>
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<td>0.10</td>
<td>&lt;.001</td>
<td>.173</td>
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<td>GMHR</td>
<td>3.02</td>
<td>1.21</td>
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<td>CSDD</td>
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<td>.192</td>
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<td>Activity participation</td>
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<td>0.01</td>
<td>&lt;.001</td>
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<tr>
<td>NPI-NM</td>
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<td>&lt;.001</td>
<td>.369</td>
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<td><strong>Multivariate model</strong></td>
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<tr>
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<td>&lt;.001</td>
<td>.372</td>
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<tr>
<td>CSDD</td>
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<td>PGDRS-P</td>
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<tr>
<td>MMSE</td>
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<td>&lt;.05</td>
<td>-.492</td>
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</table>

Notes: Values for significance (p values) are based on two-tailed tests. MMSE = Mini-Mental State Examination; PGDRS-P = Psychogeriatric Dependency Rating Scale–Physical Dependency subscale; GMHR = General Medical Health Rating Scale; CSDD = Cornell Scale for Depression in Dementia; NPI-NM = Neuropsychiatric Inventory (nonmood); SE = standard error.


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