Duplicate see CI3 blue binder

The Gerontologist
Vol. 45, Special Issue I, 27–36

A Comparison of Three Methods of Measuring Dementia-Specific Quality of Life: Perspectives of Residents, Staff, and Observers

Perry Edelman, PhD,[1] Bradley R. Fulton, PhD,[1]
Daniel Kuhn, MSW,[1] and Chih-Hung Chang, PhD[2]

Purpose: This exploratory study compared three methods of assessing dementia specific quality of life, corresponding to the perspectives of residents, staff members, and trained observers. ***Design and Methods:*** We collected data on 172 residents with dementia in four special care nursing facilities and three assisted living facilities. Analyses assessed the relationship of each quality-of-life method or perspective to the others and to resident characteristics such as cognitive and functional status. ***Results:*** The relationship of staff quality-of-life measures to resident characteristics varied by care setting while no significant relationships were found for resident quality-of-life measures. Staff and observational measures were moderately correlated in both settings. Moderate correlations of resident measures with staff and observational measures were found in the assisted living sample. ***Implications:*** Each perspective is relatively independent and somewhat unique. Measures that focus on specific aspects of quality of life may be more appropriate to use with assisted living residents than with residents of special care facilities.

Key Words: Dementia, Alzheimer's disease, Long-term care, Proxy questionnaires, Direct interviews, Observation

Whitehouse and Rabins (1992) argue that the quality of life of persons with dementia is "not an isolated concept to be included as one of many measurements of the benefits of our care, but rather that it is the central goal of our professional activity" (p. 136). Although good care may be a necessary condition for good quality of life, it is possible to provide good care without residents experiencing good quality of life. Thus, assessment of residents' quality of life should be a high priority in order to address unmet needs. In American nursing homes, information is routinely collected on quality-of-care indicators through the Minimum Data Set, but no data are collected related to quality of life. A major reason is the lack of knowledge about how to best measure the quality of life of persons with dementia, who constitute the majority of nursing home residents and a large and growing minority in assisted living facilities.

Assessment of dementia-specific quality of life in residential care facilities could have many benefits. The very act of inquiring about the quality of life of persons with dementia recognizes them as individuals rather than merely as care recipients. Staff also could use quality-of-life measures to identify the impact of interventions on residents. Relatives of individuals with dementia could better understand the status of their loved ones beyond the physical health indicators that are the basis of most care plans. Regulators could use quality-of-life measures to make their assessments more relevant in terms that make a difference in the lives of residents.

A number of dementia-specific measures have been developed over the past decade that attempt to assess

---

We are grateful for the cooperation of the staff, families, residents, and clients of Brentwood North Healthcare Center, Riverwoods, IL; Brighton Gardens, Orland Park, IL; The Hannah Friend Center of the Council for Jewish Elderly, Deerfield, IL; Harbor House at New Perspectives, Wheeling, IL; Lutheran Home and Services, Arlington Heights, IL; Mather Pavilion, Evanston, IL; and The Wealshire, Lincolnshire, IL. We also thank Roseanne Kasayka of Heather Hill Hospital and Healthcare Partnership, Carolyn Lechner of Case Western Reserve University, Diana Jean Kulczyk, and Cathleen Stenger for their assistance with data collection.

Address correspondence to Perry Edelman, PhD, Director of Outcomes Research, Mather LifeWays Institute on Aging, 1603 Orrington Avenue, Suite 1800, Evanston, IL 60201. E-mail: pedelman@matherlifeways.com

[1] Mather LifeWays Institute on Aging, Evanston, IL.

[2] Buehler Center on Aging, Feinberg School of Medicine, Northwestern University, Chicago, IL.

quality of life from three different perspectives. First, structured interviews have been developed that enable persons with mild to moderate dementia to self-report their quality of life (Brod, Stewart, Sands, & Walton, 1999; Kane et al., 2003; Logsdon, Gibbons, McCurry, & Teri, 2000, 2002). Second, questionnaires completed by family members and professionals have been developed to assess the quality of life of persons with dementia who are too impaired to communicate on their own behalf (Albert et al., 1996; Logsdon et al., 2000; 2002; Rabins, Kasper, Kleinman, Black, & Patrick, 1999). Third, measures of direct observation have been developed in which trained observers assess the quality of life of persons with dementia in congregate care settings (Bradford Dementia Group, 1997; Kitwood & Bredin, 1992; Lawton, Van Haitsma, & Klapper, 1996).

Despite progress in developing measures from these three perspectives, there has been little effort to simultaneously compare these perspectives and related measures. A quality-of-life study by Thorgrimsen and colleagues (2003) of 60 persons with dementia living in care facilities or attending day hospitals in the London area showed significant correlation between two self-report measures ($r = .69$, $p < .001$) and borderline correlation between a self-report measure and an observational measure ($r = .39$, $p = .051$). A study by Edelman, Fulton, and Kuhn (2004) of 54 individuals with dementia participating in adult day centers in the Chicago area found that the same two self-report measures used in the above study were significantly correlated ($r = .56$, $p < .0005$) but were not correlated with two staff proxy measures or an observational measure.

Given the absence of a "gold standard" for assessing quality of life among persons with dementia, a comparison of quality-of-life methods to one another can be informative. Patterns of differences and similarities in how methods "perform" can indicate the usefulness of various methods for different individuals in different care settings. This article reports findings of an exploratory study of three methods of measuring dementia-specific quality of life representing three different perspectives in two types of residential care settings. In order to identify appropriate revisions to the measures based on the study sample, we first analyzed the distribution and factor structure of the items and the psychometric properties of the measures. We then examined the relationship between dementia-specific quality-of-life measures and four measures of cognitive and functional impairment. Finally, we assessed the relationships among the quality-of-life measures.

Methods

Participants

We recruited a convenience sample of seven sites in a metropolitan area of the United States. Sites included four special care facilities that are dementia-specific nursing homes and three assisted living facilities with dementia-specific programs and staff trained in dementia care. We obtained informed consent from a key family member or legal representative of each study participant. Informed consent also was obtained directly from individuals with a Mini-Mental State Examination (MMSE; Folstein, Folstein, & McHugh, 1975) score of 10 or greater. We obtained complete quality-of-life data from 172 people including 117 residents of special care facilities and 55 residents of assisted living facilities (91.5% of those for whom family member or legal representative consent was obtained).

Quality of Life Measures

We used three types of measures to assess dementia-specific quality of life: two direct interviews (with residents whose MMSE scores were 10 or higher), two questionnaires completed at each site by a staff person, and observations of residents by trained observers. Higher scores indicated a higher quality of life.

Direct interviews.—The Quality of Life–Alzheimer's Disease (Resident QOL-AD; Logsdon et al., 2000) is a 13-item structured interview to assess issues such as one's relationship with friends and family, physical condition, and mood. It was originally developed and tested for use among community-dwelling individuals with dementia and their primary family caregivers. Based on unpublished work by Edelman and Fulton, the QOL-AD was adapted for people in residential settings by dropping two items (money and marriage), and adding four items (people who work here, ability to take care of oneself, ability to live with others, and ability to make choices in one's life). The wording of three items was changed ("self as a whole" was changed to "self overall," "ability to do chores" was changed to "ability to keep busy," and "life as a whole" was changed to "life overall"). The adapted 15-item scale (used in the current study) was rated by residents using the original 4-point scale (poor, fair, good, excellent). We examined the internal consistency of the adapted scale ($\alpha = .92$). Scale scores were computed as the mean of nonmissing items. If more than 20% of the items of any case were missing, we excluded the case from the analyses.

The Dementia Quality of Life instrument (DQoL; Brod et al., 1999) is a 30-item interview consisting of five subscales. The internal consistency (range of $\alpha = .67$ to $.89$) and test–retest reliability (range of $r = .64$ to $.90$) of these subscales were reported. Items are rated on one of two 5-point scales (ranging from not at all to a lot, and never to very often). We excluded an optional single item that assesses overall dementia-specific quality of life from the analyses.

Scale scores were computed as the mean of nonmissing items. If more than 25% of the items of any case were missing, we excluded the case from the analyses.

Staff proxy reports.—The Staff QOL-AD (Logsdon et al., 2000) is the staff questionnaire version of the Resident QOL-AD interview. The internal consistency for the present study was .88. The Alzheimer's Disease-Related Quality of Life instrument (ADRQL; Rabins et al., 1999; Black, Rabins, & Kasper, 2000) is a 47–item measure consisting of five subscales (range of α = .77 to .85). The dichotomous response option is agree/disagree. Scale scores were computed as the mean of nonmissing items. If more than 25% of the items of any case were missing, we excluded the case from the analyses.

Observation.—Dementia Care Mapping (DCM; Bradford Dementia Group, 1997) involves making detailed observations of up to eight persons at 5-minute intervals for up to 6 continuous hours in public areas only. DCM data collection ("mapping") involves recording a "behavior category code" (BCC), which defines the type of behavior or interaction that is being observed, and a well-being/ill-being (WIB) value, which indicates the level of well-being or ill-being observed (possible values = −5, −3, −1, +1, +3, +5). For each participant, we calculated the mean of all WIB values, which will hereafter be referred to as a "WIB score." Beavis, Simpson, and Graham (2002) reviewed the methodological literature related to dementia care mapping and concluded that DCM has good face validity and reliability, and based on other aspects of validity, DCM should be regarded as a moderately valid instrument. A full description of DCM appears in this issue (Brooker, 2005).

Independent variables.—We collected information related to age, gender, ethnicity, length of stay, dementia severity, function, depression, and comorbidity. The MMSE employs a 30-point scale to assess dementia severity. We used the 6-item Activities of Daily Living scale (ADL; Katz, Ford, Moskowitz, Jackson, & Jaffe, 1963) to measure residents' functional impairment (e.g., toileting, bathing, dressing, etc). Scale scores, which we computed as a count of the total number of dependent ADLs, range from 0 to 6.

The Cornell Scale for Depression in Dementia (CSDD; Alexopoulos, Abrams, Young, & Shamoian, 1988) contains 19 items indicative of depressive symptoms (α = .86). Possible responses on a 3-point scale were: 0 = absent, 1 = mild or intermittent, and 2 = severe or chronic. (The descriptor "chronic" was added for this study.) We computed the sum of all 19 items to determine prevalence of depression. Depression was operationalized as a score > 7 points, based on a cutoff score adopted by other researchers (Teresi, Lawton, Holmes, & Ory, 1997; Watson, Garrett, Sloane, Gruber-Baldini, & Zimmerman, 2003). In addition, we computed the mean of the items for use as a covariate in the analyses.

We assessed comorbid medical conditions using the 11-item Cumulative Illness Rating Scale–Geriatrics (Miller et al., 1992). We assessed severity of comorbid conditions using a 5-point scale ranging from none to extremely severe. We computed the scale as the number of conditions rated with at least a mild degree of impairment.

Procedure

An experienced nurse at each site collected data on age, gender, race, length of stay, ADLs, depression, and comorbidity. Information was derived from medical charts, administrative records, clinical judgment, and personal knowledge about residents. Staff questionnaires were completed for all residents by a staff member at each site who was most familiar with residents. A research assistant assessed each resident's dementia severity using the MMSE and conducted interviews using both the QOL-AD and DQoL if the MMSE score was ≥ 10 ($n = 65$). Two highly trained and experienced mappers conducted observations of all residents using DCM. Interrater reliability for these mappers was examined (> 85% exact agreement for BCCs and WIB values). We observed each of the residents continuously on a weekday, typically between 9:00 a.m. and 3:00 p.m., for an average 6.1 hr or 73.3 5-min time frames. Per DCM scoring guidelines, we did not make observations when a resident was situated in a private area such as a bedroom or bathroom. Thus, the average number of usable observations per resident was 4.7 hr or 56.8 time frames.

Analyses

We examined demographic and other characteristics for the total sample and for the subsample of residents who provided direct interviews; differences between residents in special care facilities and assisted living facilities were analyzed. To explore the possibility that Resident and Staff QOL-AD subscales existed, or that existing subscales (DQoL subscales and ADRQL subscales) could be combined into general quality-of-life scales, we conducted exploratory factor analyses. Unless otherwise indicated, we extracted factors using maximum likelihood estimation and rotated using direct oblimin (an oblique rotation) with $\delta = 0$. We examined eigenvalues and scree plots to determine the number of factors to retain. For all analyses, factor loadings of 0.3 or higher were considered salient. We assessed the internal consistency of these scales by computing Cronbach's coefficient alpha and by examining inter-item and item-total correlations. To ensure adequate power, factor analyses and internal con-

Table 1. Resident Characteristics

	Total Sample			MMSE = 10+		
Variable	All Study Participants (*N* = 172)	SCF (*N* = 117)	ALF (*N* = 55)	All Study Participants (*N* = 65)	SCF (*N* = 38)	ALF (*N* = 27)
Age	85.8 (6.4)	86.0 (6.8)	85.3 (5.4)	85.6 (5.8)	85.3 (6.2)	86.1 (5.1)
Female (%)	83.7	85.5	80.0	81.5	86.8	74.1
White (%)	97.0	96.5	98.1	100	100	100
Length of stay (in days)	729.9 (581.1)	748.5 (593.3)	695.5 (561.7)	607.3 (543.4)	671.8 (618.9)	518.1 (412.5)
MMSE	9.0 (6.9)	7.9 (6.8)**	11.1 (6.8)**	15.6 (3.8)	15.1 (4.0)	16.5 (3.5)
Count of dependent ADLs	3.4 (2.2)	3.8 (2.2)**	2.5 (2.0)**	1.9 (1.9)	2.1 (2.2)	1.6 (1.3)
Depression	0.3 (0.3)	0.3 (0.2)	0.3 (0.4)	0.2 (0.3)	0.2 (0.2)	0.2 (0.3)
Prevalence	26.2%	21.4%	36.4%	18.5%	18.4%	18.5%
Count of mild to severe comorbidities	3.1 (1.7)	2.8 (1.5)*	3.6 (2.0)*	3.4 (1.9)	2.8 (1.5)**	4.3 (2.0)**

Notes: SCF = special care facilities; ALF = assisted living facilities; ADLs = activities of daily living; MMSE = Mini-Mental State Exam. For the table, data presented are *M* (*SD*) or % of total.

*$p < .05$; **$p < .01$.

sistency analyses were not conducted separately for residents in special care facilities and assisted living facilities.

To examine individual differences between the Resident and Staff QOL-AD, we computed difference scores by subtracting the Staff QOL-AD scale scores from the Resident QOL-AD scale scores and assessed the distribution of these difference scores by care setting. We computed Pearson correlation coefficients between the quality-of-life measures and MMSE, ADLs, depression, and comorbidities.

To examine differences among the more comprehensive quality-of-life scales (subscales that focused on specific components of quality of life were excluded), we conducted a repeated measures MANOVA with two factors: care setting (between subjects; special care and assisted living), and quality-of-life measure (within-subjects; four levels representing four measures). We conducted planned comparisons between the two resident measures and between the Staff QOL-AD and WIB scores. To determine differences between the Staff QOL-AD and WIB scores, we conducted a second multivariate repeated measures analysis of variance with the larger sample, not limited to residents who provided an interview.

To enable comparison and interpretation of findings using repeated measures multivariate analysis of variance, we recoded the scales into a common unit of measure. Because the Staff and Resident QOL-AD interviews share the same response options (1 to 4), the other scales were recoded into this response scale. The procedure used to recode scales changed the unit and origin of these scales and did not affect the distribution of the data or the relationships within the data (McCall, 2001). We also examined differences by care setting and used hierarchical multiple linear regression to determine the extent to which dementia-specific quality-of-life measures from each perspective could be predicted by measures from the other two perspectives.

Results

Resident Characteristics

As shown in Table 1, the sample consisted of 117 special care facility residents and 55 assisted living residents; data from 65 residents with MMSE scores of ≥ 10 were used for analysis of the two resident interviews. Residents were primarily female and Caucasian. The mean age was 85.8 years, and the average length of stay was about 2 years. Dementia severity, the number of dependent ADLs, depression severity, and the number of comorbidities are reported in Table 1. Special care residents were significantly more cognitively impaired, had more dependent ADLs, but had fewer comorbidities than assisted living residents.

Item Analysis

We found adequate use of the full range of potential responses, and response variability, as indicated by standard deviations, for the quality-of-life measures. The only exception was that some of the dichotomous items from the ADRQL had limited variability (up to 97.7% of the respondents chose one response option). Mean scores and standard deviations of the quality-of-life scales and subscales appear in Table 2.

Factor Analysis

DQoL.—The 29 items from the DQoL were factor analyzed. Because the rotated factors were

Table 2. Means and Standard Deviations of Original Scale Scores

Scale	Total Sample (*N* = 65)	SCF (*N* = 38)	ALF (*N* = 27)
Resident QOL-AD (range = 1–4)	3.1 (0.5) [1.3–4.0]	3.1 (0.5) [1.3–4.0]	3.1 (0.4) [1.8–4.0]
DQoL subscales (range = 1–5)			
Self esteem	3.7 (0.8) [1.3–4.8]	3.7 (0.7) [1.5–5.0]	3.8 (0.8) [1.3–5.0]
Positive affect	3.5 (0.7) [1.3–5.0]	3.5 (0.7) [1.3–5.0]	3.6 (0.7) [1.8–5.0]
Negative affect	2.1 (0.6) [1.0–3.7]	2.0 (0.6) [1.0–3.4]	2.3 (0.7) [1.1–3.7]
Feelings of belonging	3.4 (0.9) [1.3–5.0]	3.2 (0.9) [1.3–5.0]	3.6 (0.8) [1.3–5.0]
Sense of aesthetics	3.1 (0.9) [1.2–5.0]	3.0 (1.0) [1.2–5.0]	3.3 (0.8) [1.2–4.6]
	(*N* = 172)	(*N* = 117)	(*N* = 55)
Staff QOL-AD (range = 1–4)	2.4 (0.5) [1.3–3.7]	2.2 (0.4) [1.3–3.2]	2.9 (0.5) [1.5–3.7]
ADRQL subscales (range = 0–1)			
Social interaction	0.8 (0.2) [0–1.0]	0.8 (0.2) [0.3–1.0]	0.9 (0.2) [0–1.0]
Awareness of self	0.7 (0.2) [0.1–1.0]	0.6 (0.2) [0.1–1.0]	0.7 (0.2) [0.3–1.0]
Feelings and mood	0.9 (0.2) [0.3–1.0]	0.9 (0.1) [0.3–1.0]	0.9 (0.2) [0.3–1.0]
Enjoyment of activities	0.7 (0.3) [0–1.0]	0.7 (0.3) [0–1.0]	0.8 (0.2) [0–1.0]
Response to surroundings	0.8 (0.2) [0.3–1.0]	0.8 (0.2) [0.3–1.0]	0.8 (0.1) [0.3–1.0]
WIB	1.0 (0.8) [–2.4–2.8]	0.7 (0.8) [–2.4–2.3]	1.5 (0.4) [0.8–2.8]

Notes: SCF = special care facilities; ALF = assisted living facilities; QOL-AD = Quality of Life–Alzheimer's Disease; DQoL = Dementia Quality of Life; ADRQL = Alzheimer's Disease-Related Quality of Life; WIB = well- or ill-being. For the table, higher scores indicate better quality of life, except for negative affect for which a higher score indicates a higher level of negative affect. Data presented are *M* (*SD*); observed ranges are presented in brackets.

uncorrelated ($r = -.01$), we reanalyzed the items using an orthogonal rotation (varimax). The pattern of factor loadings clearly identified two factors: negative affect (comprising all 11 items from the Negative Affect scale) and general quality of life (comprising the remaining 18 items). These two factors accounted for 25.1% and 20.4% of the variance, respectively. Hereafter, these two factors will be referred to as Negative Affect and General DQoL.

Resident QOL-AD.—All 15 items from the Resident QOL-AD were factor analyzed. Two factors were identified and were significantly correlated ($r = .74$). The pattern of factor loadings in the structure matrix reflected this correlation; all items loaded on both factors. The factor loadings and factor correlations suggest that these two factors are indicative of a single factor, therefore all items were reanalyzed with a one-factor solution prespecified. Items loaded (range of loadings = .54 to .85) on this single factor and accounted for 51.8% of the variance.

Staff QOL-AD.—All 15 items from the Staff QOL-AD were factor analyzed. One factor was retained and accounted for 41.8% of the variance. Because four factors had initial eigenvalues greater than 1.0, we also explored the four-factor solution. The loadings revealed significant factorial complexity; 10 of the 15 items were loaded on three or four of the factors. Factor correlations ranged from $r = .01$ to .42. The factor loadings and correlations suggest that these factors are likely highlighting different dimensions of a single factor.

ADRQL.—All 47 items from the ADRQL were factor analyzed. Three factors were identified. The pattern of factor loadings indicated a fair degree of complexity; however, there were also some clear patterns. In addition to other items, all but two of the items from the Social Interaction subscale loaded on factor one; all but one of the items from the Awareness of Self subscale loaded on factor two. Items from multiple scales loaded on factor three. Factor one was significantly correlated with factors two ($r = -.31$) and three ($r = .24$), while factor two and three were not correlated ($r = .09$). These three factors accounted for 18.0%, 6.8%, and 4.0% of the variance, respectively.

Internal Consistency Reliability

An item was considered inconsistent and removed from the scale if it had negative interitem or item-total correlations, and/or the alpha would improve if removed. An alpha $\geq .70$ is considered adequate. Table 3 presents internal consistency statistics, including alpha and interitem and item-total correlations. For the Staff QOL-AD, we observed some negative correlations, indicating a need to revise this scale. Examination of these correlations indicated that one item (family) was not consistent with the remaining items. This item was removed and the alpha recomputed; item-total correlations improved.

The item-total correlations, interitem correlations and/or internal consistency alpha for the Social Interaction, Awareness of Self, and Feelings and Mood subscale indicated a need to revise these scales. After

Table 3. Internal Consistency

Scale or Subscale	α	Correlation Ranges Interitem	Correlation Ranges Item Total
DQoL general scale and subscales			
General DQoL ($N = 58$)[a]	.90	−.09–.60	.37–.75
Self esteem ($N = 58$)	.70	.27–.46	.40–.52
Positive affect ($N = 58$)	.78	.17–.52	.44–.59
Negative affect ($N = 58$)	.95	.37–.80	.58–.84
Feelings of belonging ($N = 58$)	.61	.32–.38	.41–.45
Sense of aesthetics ($N = 58$)	.79	.27–.60	.47–.66
Resident QOL-AD ($N = 65$)	.94	.29–.74	.53–.82
Staff QOL-AD ($N = 168$)	.90	−.12–.80	−.05–.84
Revised ($N = 170$)[b]	.91	−.07–.79	.28–.85
ADRQL subscales			
Social interaction ($N = 172$)	.80	.01–.59	.11–.62
Revised ($N = 172$)[c]	.82	.07–.59	.34–.58
Awareness of self ($N = 172$)	.68	−.25–.60	−.24–.61
Revised ($N = 172$)[d]	.76	.14–.60	.30–.66
Feelings and mood ($N = 172$)	.71	−.10–.56	−.04–.56
Revised ($N = 172$)[e]	.74	.01–.56	.25–.59
Enjoyment of activities ($N = 172$)	.61	−.04–.42	.14–.55
Response to surroundings ($N = 172$)	.29	−.21–.45	−.01–.42

Notes: DQoL = Dementia Quality of Living; QOL-AD = Quality of Living–Alzheimer's Disease; ADRQL = Alzheimer's Disease-Related Quality of Life.

[a] This scale is comprised of all items from the from the following subscales: self-esteem, positive affect, feelings of belonging, and sense of aesthetics.

[b] The following item was removed: family.

[c] The following item was removed: He/She pushes, grabs, or hits people.

[d] The following item was removed: He/She becomes upset by personal limitations such as forgetting, losing things, or getting confused in familiar places.

[e] The following items were removed: He/She throws, hits, kicks, or bangs objects; He/She locks or barricades himself/herself in his/her room/house/apartment; He/She says he/she wants to die; He/She resists help in different ways such as with dressing, eating or bathing, or by refusing to move; and He/She clings to people or follows people around.

Table 4. Correlations of Quality of Life Measures With Cognitive Severity, ADL Severity, Depression, and Comorbidities

Setting	N	MMSE	Count Of Dependent ADLs	Depression	Count of Mild to Severe Comorbidities
SCF					
Staff QOL-AD	117	.59*	−.58*	−.30*	.01
WIB		.42*	−.44*	−.24*	−.02
Social interaction		.38*	−.39*	−.15	−.14
Awareness of self		.62*	−.54*	.03	.03
Feelings and mood		.19	−.21*	−.30*	−.06
Resident QOL-AD	38	−.17	−.12	.08	.17
General DQoL		−.17	−.18	−.01	.19
Negative affect		−.28	.11	−.16	.19
ALF					
Staff QOL-AD	55	.22	−.21	−.68*	−.19
WIB		.30*	−.34*	−.24	.09
Social interaction		.37*	−.33*	−.76*	.18
Awareness of self		.45*	−.47*	−.11	−.01
Feelings and mood		.34*	−.29*	−.72*	.07
Resident QOL-AD	27	.01	−.07	.01	.08
General DQoL		.07	−.20	−.05	.06
Negative Affect		.08	−.06	.35	−.01

Notes: MMSE = Mini-Mental State Exam; ADLs = activities of daily living; SCF = special care facility; QOL-AD = Quality of Living–Alzheimer's Disease; WIB = well- or ill-being; DQoL = Dementia Quality of Life; ALF = assisted living facility.

*Significant at $p < .05$.

we removed inconsistent items, adequate scalar properties were achieved. The alphas of the Enjoyment of Activities and Response to Surroundings subscales were not adequate, and revisions did not substantially improve the alphas. Therefore, we did not include these subscales in the analyses. Because there is no generally accepted method of determining the internal consistency of WIB scores in DCM, we did not assess the internal consistency of these scores.

Correlations of QOL Measures With Dementia Severity, ADLs, Depression, and Comorbidities

The relationship of the quality-of-life measures to dementia severity, ADLs, depression, and comorbidities is shown in Table 4. In the special care subsample, the Staff QOL-AD and WIB scores were both significantly correlated with MMSE and count of dependent ADLs. However, in the assisted living subsample, WIB scores were significantly correlated with MMSE and count of dependent ADLs, while the Staff QOL-AD was not significantly correlated with either of these variables. Although the Social Interaction and Awareness of Self subscales demonstrated significant correlations with MMSE and ADLs in both subsamples, the Feelings and Mood subscale was significantly correlated with these variables in the assisted living subsample and was either not significantly correlated (MMSE) or not as strongly correlated in the special care subsample. Depression was significantly correlated with three of five staff/observer measures in both subsamples, but the correlations were considerably stronger in the assisted living sample. None of the quality-of-life measures were significantly correlated with the count of comorbidities. Also, none of the resident measures were significantly correlated with dementia severity, ADLs, depression, or comorbid conditions.

Table 5. Correlations Among Staff, Observer, and Resident QOL Measures

Setting	*N*	Staff QOL-AD	Social Interaction	Awareness of Self	Feelings and Mood	WIB
SCF						
Resident QOL-AD	38	.10	−.06	−.11	.25	−.00
General DQoL		.14	−.10	−.16	.08	−.03
Negative affect		−.30	−.11	−.04	−.25	.16
WIB	117	.40*	.28*	.32*	.29*	—
ALF						
Resident QOL-AD	27	.07	.26	.15	.09	.38*
General DQoL		.17	.20	.16	.18	.35
Negative affect		−.32	−.43*	−.12	−.41*	−.37
WIB	55	.31*	.22	.35*	.24	—

Notes: QOL = quality of life; QOL-AD = Quality of Life–Alzheimer's Disease; WIB = well- or ill-being; SCF = special care facilities; DQoL = Dementia Quality of Life; ALF = assisted living facilities.

*Significant at $p < .05$.

Comparison of Perspectives

Correlations among staff, observer, and resident quality-of-life measures.—Correlations among staff, observer, and resident quality-of-life measures are shown in Table 5. Because we focus on similarities and differences between perspectives in this article, correlations of measures from the same perspective are not reported. In the special care subsample, none of the resident measures are significantly correlated with any of the staff measures or WIB scores. In the assisted living subsample, however, the Resident QOL-AD is significantly correlated with the WIB; the Negative Affect subscale is significantly related to both the Social Interaction subscale and the Feelings and Mood subscale. In the special care subsample, the WIB is significantly correlated with the Staff QOL-AD, and three subscales—Social Interaction, Awareness of Self, and Feelings and Mood. In the assisted living subsample, the WIB is significantly correlated with the Staff QOL-AD and the Awareness of Self subscale. Because the special care subsample ($n = 117$) is much larger than the assisted living subsample ($n = 55$), differences between these settings in the significance of the correlations is, in part, determined by the difference in sample size.

Individual differences between Resident and Staff QOL-AD scores.—For this analysis, we retained the item in the Staff QOL-AD scale identified as inconsistent in the internal consistency reliability analyses to ensure that the Staff and Resident QOL-AD scales included equivalent items. Difference scores, computed by subtracting the Staff QOL-AD from the Resident QOL-AD, ranged from −1.1 to 1.6 ($M = 0.4$, $SD = 0.6$). Most of the differences scores (69.2%) were positive, indicating the residents rated their own quality of life higher than staff rated them. To determine if these difference scores were related to dementia severity, we correlated difference scores with MMSE and found a significant correlation ($r = -.38$, $p = .002$).

Table 6. Means and Standard Deviations of Recoded Scale Scores

	Total Sample		Subsample With Resident Interviews	
QOL Measure	SCF ($N = 117$)	ALF ($N = 55$)	SCF ($N = 38$)	ALF ($N = 27$)
Staff QOL-AD	2.2 (0.4)	2.9 (0.5)	2.4 (0.4)	2.9 (0.4)
WIB	2.7 (0.2)	2.9 (0.1)	2.8 (0.1)	3.0 (0.1)
Resident QOL-AD	—	—	3.1 (0.5)	3.1 (0.4)
General DQoL	—	—	2.8 (0.5)	2.9 (0.5)

Notes: QOL = quality of life; SCF = special care facility; ALF = assisted living facility; QOL-AD = Quality of Living–Alzheimer's Disease; WIB = well- or ill-being; DQoL = Dementia Quality of Life.

For the special care and assisted living subsamples, difference scores ranged from −.9 to 1.6 ($M = 0.6$, $SD = 0.6$) and −1.1 to 1.4 ($M = 0.2$, $SD = 0.6$), respectively. These means were significantly different; $t(63) = 3.141$, $p = .003$, $d = 0.8$. Most difference scores (81.6% and 51.9%, respectively) were positive. Difference scores were significantly correlated with MMSE in the special care subsample ($r = -.53$, $p = .001$) but not in the assisted living subsample ($r = -.07$, $p = .738$).

Differences among the means of quality-of-life measures.—We conducted a repeated measures MANOVA to compare each of the two comprehensive resident measures with the Staff QOL-AD and WIB scores. We also examined differences by care setting (special care vs assisted living). The omnibus test indicated multivariate significance, $F(3, 61) = 17.829$, $p < .0005$; as well as a significant interaction, $F(3, 61) = 5.302$, $p = .003$. Planned comparisons indicated a significant interaction in which Staff QOL-AD scores were lower than General DQoL scores for residents of special care facilities but not for residents of assisted living facilities ($p = .013$, $\eta^2 = .095$). Similarly, Staff QOL-AD scores were lower than Resident QOL-AD scores for special care residents but not for residents of assisted living facilities ($p = .002$, $\eta^2 = .140$). There was also a significant difference between the Resident QOL-AD and WIB scores ($p = .002$, $\eta^2 = .144$) but no interaction with type-of-care setting. Examination of the means in Table 6 demonstrated that residents rated their quality of life higher than staff did in special care facilities but not assisted living facilities.

Due to the violation of certain assumptions of repeated measures MANOVA, we examined differences between the Staff QOL-AD and WIB scores using the nonparametric Wilcoxon Signed Ranks test. We conducted two tests, one for residents of assisted living facilities and one for residents of special care facilities. These tests indicated no significant differences in the assisted living sites ($p = .621$) but did indicate significant differences in the special care sites ($p < .0005$). Specifically, for 104 special care residents, the mean Staff QOL-AD score was less than the mean WIB score; for 13 residents the opposite was true. Means and standard deviations are reported in Table 6.

Predicting quality of life.—We used hierarchical multiple linear regression to examine the extent to which quality-of-life measures from each perspective could be predicted by measures from the other two perspectives. The three quality-of-life measures to be predicted include the Staff and Resident QOL-AD and WIB scores. We conducted three regressions. For these regressions, we dummy coded care setting, which was significantly associated with MMSE and ADLs (t tests, $p < .0005$), and tested on the first step, followed by the measures on the second step. We used forward entry in both steps.

Results of the first regression indicated no significant predictors of the Resident QOL-AD. In the second regression, after removing one outlying case ($n = 64$), care setting ($\beta = -.435$, $p = .001$) and the Awareness of Self subscale ($\beta = .247$, $p = .033$) were both significant predictors of WIB scores. Care setting (adjusted $r^2 = .15$) accounted for much more of the variance than the Awareness of Self subscale (adjusted $r^2 = .05$). However, a normal P-P plot indicated a potential problem with nonnormality in the distribution of WIB scores. Transformations of the data were unsuccessful in correcting this problem; thus, caution should be used when interpreting these results.

In the third regression, after removing one outlying case ($n = 64$) whose standardized residual was -3.5, care setting ($\beta = -.540$, $p < .0005$) and WIB scores ($\beta = .227$, $p = .033$) were both significant predictors of the Staff QOL-AD. However, care setting (adjusted $r^2 = .39$) accounted for much more of the variance than WIB scores (.04). We reran the second and third regression analyses with all independent variables tested on the first step; the results were the same as in the original analyses.

Discussion

This article compared and contrasted three methods of assessing dementia-specific quality of life corresponding to the perspectives of residents, staff, and observers. Our goal was to identify similarities and differences that would provide a better understanding of the extent to which each measure estimates quality of life.

We conducted psychometric analyses to identify the most appropriate scales to use in the sample. Factor analysis indicated that the DQoL resident interview (Brod et al., 1999) could be represented by two subscales: Negative Affect and General DQoL. We identified a single factor for the Resident and Staff QOL-AD scales; thus, they were used unaltered with the exception of dropping one item from the Staff QOL-AD. The internal consistency reliability of two of five of the original ADRQL subscales was unacceptable. Therefore, we included the following subscales and scores in the analyses: three ADRQL subscales (Social Interaction, Awareness of Self, and Feelings and Mood), Negative Affect, General DQoL, Resident QOL-AD, Staff QOL-AD, and WIB scores.

Correlations Among Quality-of-Life Measures and With Other Measures

Because there is no "gold standard" against which to compare the dementia-specific quality-of-life scales, we examined the relationships of each scale to other measures. Correlations of the scales to measures of dementia severity and ADL impairment provided insight into the meaning and potential uses of the quality-of-life scales. In special care facilities, Staff QOL-AD was more strongly correlated with MMSE and ADLs than were the staff subscales Social Interaction and Feelings and Mood. This finding may reflect the greater challenges faced by special care staff to engage more impaired residents and to notice variability in residents' emotions. By contrast, in assisted living facilities, higher correlations with MMSE and ADLs were found for Social Interaction and Feelings and Mood than with Staff QOL-AD. Assisted living residents, who are typically less impaired than special care residents, may have more opportunities for social engagement and communicating their feelings. Therefore, in contrast to special care facilities, it is likely that staff members of assisted living facilities will be more aware of residents engaging with others and take notice of their feelings and mood.

The staff measure Awareness of Self was most highly correlated with dementia severity and ADLs in both subsamples, suggesting that this scale is particularly sensitive to impairment level. Given the strong correlation between MMSE and ADLs ($r = .70$; $p < .0005$) and that the items comprising the Awareness of Self subscale reflect cognitive performance, it is likely that the relationship of Awareness of Self to impairment is driven by dementia severity.

Depression was more strongly correlated with staff measures in the assisted living subsample than in the special care subsample. Distinguishing between symptoms of depression and dementia may have been a difficult task for staff in special care facilities whose residents demonstrated greater dementia severity. On the other hand, depression may have been more easily recognized in assisted living residents who were less impaired and had a better capacity to communicate.

None of the dementia-specific quality-of-life scales were significantly correlated with the count of comorbid conditions. Most of the comorbid conditions were mild in nature; thus, these conditions may have had little impact on residents' quality of life.

By contrast to the staff and observer measures, none of the resident scales were correlated with dementia severity, ADLs, depression, or comorbidities. A statistical explanation is not likely because we found the resident measures to have adequate distributional properties. As a result, limited variance in the measures is not an explanation for the low correlations. In this study, residents' self-perceived quality of life was unrelated to their cognitive and functional impairment. An explanation for residents' self-perceptions of quality of life remains to be determined.

Our finding that dementia severity and ADLs are correlated with staff and observer estimates of quality of life should not be interpreted to mean that moderately to severely impaired persons are limited to a poor quality of life. First, the limited amount of variance ($r^2 = .08$ to .22) accounted for by most of the significant correlations (16 of 23) suggests that much about residents' quality of life is not explained by dementia severity and ADLs. Secondly, a resident's perspective of one's own quality of life is not necessarily influenced by dementia severity and ADLs. Clearly, there is much to be learned about determinants of dementia-specific quality of life and how residents, staff, and observers gather and process information about quality of life.

Difference Between Resident and Staff/Observer Perspectives

Differential patterns of correlations among dementia-specific quality-of-life measures suggest that the perspectives of staff and observers were more closely aligned with each other than the perspective of residents in special care nursing facilities. For instance, we found moderate correlations between staff measures and WIB scores. In contrast, none of the correlations between resident measures and staff measures/WIB scores were significant (see Table 5). In that care setting, the perspective of residents was quite different than the perspectives of staff and observers.

Multivariate comparisons among all the quality-of-life measures revealed significantly lower scores on the Staff QOL-AD than on the General DQoL or the Resident QOL-AD, but only in the special care subsample. WIB scores were significantly lower than Resident QOL-AD across both settings. Thus, the staff and the observer perspective indicated lower quality of life than did the residents' perspective, especially among the more cognitively impaired special care sample.

While it is tempting to assume that residents' with greater cognitive impairment were less able to make accurate judgments regarding their quality of life, it is also possible that staff were unable to make accurate estimates of residents' quality of life as they became less communicative due to dementia. Perhaps the criteria upon which staff made their quality-of-life judgments (e.g., engagement and positive affect) were not appropriate from the perspective of residents. For example, is the resident who is sitting quietly experiencing poor quality of life or is he or she simply meditating? Although this study cannot answer this question, a study that uses residents' physiological state as an outcome measure could be helpful.

Multiple regression findings indicated that type of care setting was a better predictor of WIB scores and Staff QOL-AD than other quality-of-life measures. This remained true when care setting was tested on the first step of the analysis followed by the quality-of-life measures or when all independent variables were tested together on the first step of the analysis. Strong associations of care setting with MMSE and ADLs (significant t tests, $p < .0005$), suggest that care setting may serve as a proxy for these variables. Resident QOL-AD was not predicted by any other variable. Thus, each of these three perspectives—resident, staff, and observer—remain fairly distinct with only a small proportion of the variance of staff or observer measures accounted for by the other quality-of-life measure.

Limitations

We should note several limitations of this study. The observed range of the WIB scores, the ADRQL subscale scores, the count of dependent ADLs, and the depression scores is somewhat limited; this may be limiting their correlations with other variables. The sample size was relatively small and confined to seven sites in a specific region of the United States and included a limited number of men and persons of color. These analyses need to be replicated with a larger, more representative sample. Another limitation is that the perspectives of those making quality-of-life judgments are confounded with the methods. Although the data-collection methods tested in this study represent the best means currently available, differences found could reasonably be attributed to either the method or the perspective. For instance, DCM uses trained observers to estimate quality of life in real time during a number of hours of observations, staff questionnaires provide judgments of quality of life based on staff members' overall estimate over a period of time, and residents' may respond in terms of their status at the moment they are interviewed.

Future Considerations

This study demonstrated the relative uniqueness of each perspective of quality of life. Different measures assessing the same perspective were not directly compared. Such a comparison could enable care providers to select the resident or staff measure that is most appropriate for regularly assessing quality of life. Ideally, a profile of quality-of-life scores across multiple perspectives could provide a complete picture of residents' quality of life, or an index could be developed which combines elements of multiple perspectives into a single score. To maximize the usefulness of quality-of-life measures in residential care settings, a national database of dementia-specific quality-of-life data should be developed that would refine measures in terms of psychometric properties, benchmark dementia care programs, and provide normative data. These data would not only be useful to service providers to better understand the impact of their programs but also would provide information for family members and potential residents to help them make informed choices regarding residential care options. To accomplish this goal, two parallel efforts should be undertaken. First, comparison studies, like the one presented in this article, need to be conducted with larger samples to further specify the properties of these measures and their relationship to each other and to quality of life. Second, service providers must be incentivized to collect quality-of-life data using one or more measures and contribute to a centralized data bank.

Maximizing the quality of life of persons with dementia should be a high priority for care providers. Utilization and further development of measures that account for multiple perspectives is critical to better understand how to best meet the needs of persons with dementia. Measuring quality of life enables care providers to focus on each person with dementia as a unique individual and provide the highest level of care in residential care settings.

References

Albert, S. M., Castillo-Castenada, C., Sano, M., Jacobs, D. M., Marder, K., Bell, K., et al. (1996). Quality of life in patients with Alzheimer's disease as reported by patients' proxies. *Journal of the American Geriatrics Society, 44,* 1342–1347.

Alexopoulos, G. S., Abrams, R. C., Young, R. C., & Shamoian, C. A. (1988). Cornell scale for depression in dementia. *Biological Psychiatry, 23,* 271–284.

Beavis, D., Simpson, S., & Graham, I. (2002). A literature review of dementia care mapping: Methodological considerations and efficacy. *Journal of Psychiatric and Mental Health Nursing, 9,* 725–736.

Black, B. S., Rabins, P. V., & Kasper, J. D. (2000). *Alzheimer disease related quality of life user's manual.* Baltimore: DEMeasure.

Bradford Dementia Group. (1997). *Evaluating dementia care: The DCM method* (7th ed.). Bradford, England: University of Bradford.

Brod, M., Stewart, A. L., Sands, L., & Walton, P. (1999). Conceptualization and measurement of quality of life in dementia: The dementia quality of life instrument (DQoL). *The Gerontologist, 39,* 25–35.

Brooker, D. (2005). Dementia Care Mapping (DCM): Changing and evaluating the culture of care for people with dementia. *The Gerontologist, 45*(Special Issue 1), 11–18.

Edelman, P., Fulton, B. R., & Kuhn, D. (2004). Comparison of dementia-specific quality of life measures in adult day centers. *Home Health Care Services Quarterly, 23,* 25–42.

Folstein, M. F., Folstein, S. E., & McHugh, P. R. (1975). "Mini-mental state": A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research, 12,* 189–198.

Kane, R. A., Kling, K. C., Bershadsky, B., Kane, R. L., Giles K., Degenholtz, H. B., et al. (2003). Quality of life measures for nursing home residents. *Journal of Gerontology: Medical Sciences, 58A,* M240–M248.

Katz, S., Ford, A. B., Moskowitz, R. W., Jackson, B. A., & Jaffe, M. W. (1963). Studies of illness in the aged. The index of ADL: A standardized measure of biological and psychosocial function. *Journal of the American Medical Association, 185,* 914–919.

Kitwood, T., & Bredin, K. (1992). A new approach to the evaluation of dementia care. *Journal of Advances in Health and Nursing Care, 1,* 41–60.

Lawton, M. P., Van Haitsma, K., & Klapper, J. (1996). Observed affect in nursing home residents with Alzheimer's disease. *Journal of Gerontology: Psychological Sciences, 51B,* P3–P14.

Logsdon, R. G., Gibbons, L. E., McCurry, S. M., & Teri, L. (2000). Quality of life in Alzheimer's disease: Patient and caregiver reports. In S. Albert & R. G. Logsdon (Eds.), *Assessing quality of life in Alzheimer's disease* (pp. 17–30). New York: Springer Publishing Co.

Logsdon, R. G., Gibbons, L. E., McCurry, S. M., & Teri, L. (2002). Assessing quality of life in older adults with cognitive impairment. *Psychosomatic Medicine, 64,* 510–519.

McCall, R. B. (2001). *Fundamental statistics for the behavioral sciences* (8th ed.). Belmont, CA: Wadsworth/Thomson Learning.

Miller, M. D., Paradis, C. F., Houck, P. R., Mazumdar, S., Stack, J. A., Rifai, A. H., et al. (1992). Rating chronic medical illness burden in geropsychiatric practice and research: Application of the Cumulative Illness Rating Scale. *Psychiatric Research, 41,* 237–248.

Rabins, P., Kasper, J. D., Kleinman, L., Black, B. S., & Patrick, D. L. (1999). Concepts and methods in the development of the ADRQL: An instrument for assessing health-related quality of life in persons with Alzheimer's disease. *Journal of Mental Health and Aging, 5,* 33–48.

Teresi, J. A., Lawton, M. P., Holmes, D., & Ory, M. (1997). *Measurement in elderly chronic care populations.* New York: Springer Publishing Co.

Thorgrimsen, L., Selwood, A., Spector, A., Royan, L., de Madariaga Lopez, A., Woods, R. T., et al. (2003). Whose life is it anyway? The validity and reliability of the Quality of Life-Alzheimer's Disease (QOL-AD) Scale. *Alzheimer's Disease and Associated Disorders, 17,* 201–208.

Watson, L. C., Garrett, J. M., Sloane P. D., Gruber-Baldini, A. L. & Zimmerman, S. (2003). Depression in assisted living: Results of a four-state study. *American Journal of Geriatric Psychiatry, 11,* 534–542.

Whitehouse, P. J., & Rabins, P. V. (1992). Quality of life and dementia. *Alzheimer's Disease and Associated Disorders, 6,* 135–137.

Received April 6, 2004
Accepted November 30, 2004
Decision Editor: Richard Schulz, PhD