

# Evaluating the Quality of Life of Long-Term Care Residents With Dementia

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**Purpose:** This study's purpose was to better understand existing measures of quality of life in dementia residents of long-term care facilities. **Design and Methods:** We gathered data from 421 residents in 45 facilities. Analyses determined the psychometric properties of each measure, estimated the relationship between measures, and identified the extent to which resident characteristics predicted scores. **Results:** Most instruments had good to excellent dispersion and interrater reliability, and most scales had good to excellent internal consistency. Proxy measures tended to correlate best with each other, less well with observational measures, and least well with resident measures. Resident cognition and activities of daily living (ADLs) function were associated with most quality-of-life measures but predicted no more than a quarter of the observed variance in any measure. **Implications:** Various measures and sources of data provide different perspectives on quality of life. No "gold standard" exists; so a combination of methods and sources is likely to provide the most complete picture of quality of life.

*Key Words:* Quality of life, Long-term care, Dementia, Assisted living, Nursing homes

In recent decades, the focus of long-term care evaluation and research has gradually shifted from how care is delivered (process of care) to how care affects residents (outcomes of care). Accompanying this shift has been the recognition that the primary outcome of interest should not be quality of care provided by the facility but quality of life achieved by its residents. Defining and measuring quality of life has proved complex, however, especially when the concept is applied to individuals with Alzheimer's disease and related dementias.

Most definitions of quality of life are broad. The Institute of Medicine, for example, defined it as "subjective or objective judgment concerning all aspects of an individual's existence, including health, economic, political, cultural, environmental, aesthetic, and spiritual aspects" (Institute of Medicine, 2001). In a similar vein, M. Powell Lawton (1991) defined quality of life as "the multidimensional evaluation, by both intrapersonal and social-normative criteria, of the person-environment system of the individual" (p. 6). Some authors have tried to narrow the concept by considering only those aspects of quality of life that can be affected by health care interventions, using the term *health-related quality of life* to describe this construct (Noelker & Harel, 2001; Testa & Simonson, 1996). However, because long-term care facilities are therapeutic living environments in which the majority of resident activities involve and/or are structured by facility staff, health-related and overall quality of life may differ little in these settings. Another approach to narrowing the conceptualization of quality of life is to focus on a specific illness and the aspects of quality of life most affected by that illness, thereby creating a *disease-specific quality-of-life* measure.

A variety of theoretical models describe and organize the components of quality of life in ways

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that are relevant to the study of quality of life in long-term care settings. Bennett (1980) portrayed long-term care quality of life in terms of satisfaction of basic human needs: physiological, safety and security, social, self-esteem, and accomplishment. Lawton (1994) proposed four general sectors of quality of life: psychological well-being, behavioral competence, objective environment, and perceived quality of life. This and other writings by Lawton advanced the notion that quality of life has both an objective component (what the person experiences and does) and a subjective one (how the person feels about it) and concluded that quality of life would best be assessed from multiple perspectives. In contrast, Brod, Stewart, and Sands (2000) argued that the subjective element is the only "true" aspect of quality of life, and other aspects (e.g., environment, individual function, and behavior) are determinants of this subjective quality of life. Kane and colleagues (2003), building on the work of Lawton (1991), subscribed to the broader view and identified the following domains of long-term care quality of life: emotional health, physical health, functional status, comfort and security, social function, and self-worth or personal agency.

In addition to deciding what to assess, quality-of-life measurement in long-term care involves the issue of whose point of view to consider. Among the available options are resident report, staff report, family report, and direct observation. Deciding which point of view is most valid is particularly challenging in that quality-of-life assessments from different sources correlate poorly and exhibit systematic biases (Schnelle, 2003). Some have argued that the resident's subjective point of view should take precedence, and several instruments have been developed specifically for administration to persons with the disease (Brod et al., 2000; Logsdon, Gibbons, McCurry, & Teri, 2000). However, a significant proportion of persons with Alzheimer's disease—and the majority of long-term care residents with the disease—either cannot respond or provide responses of questionable validity due to lack of memory, inability to concentrate, lack of the capacity for introspection, unawareness of their impairments and disabilities, inadequate or absent language skills, thought disorders (e.g., psychosis), and/or acquiescent response bias (the tendency to be reluctant to complain; Kane et al., 2003; Lawton, 1994; Rabins, Kasper, Kleinman, Black, & Patrick, 2000; Schnelle). Because of these problems, many instruments to evaluate quality of life of individuals with Alzheimer's disease in long-term care use proxy respondents. Others have attempted to circumvent respondent bias by focusing on direct behavioral observation; but these, too, have limitations and inherent biases. Lawton (1997) elegantly argues that no "gold standard" measure of quality of life in dementia exists and that quality-of-life assessment should take into account both subjective and

objective data from multiple sources. Thus, according to Lawton, understanding of quality of life "will be enhanced by looking for congruence and incongruence" between sources, and by attempting to explain observed differences in quality-of-life scores.

An additional area of controversy involves whether to report the components of quality of life separately or to combine them into a more global scale or index. According to Lawton (1997), reporting the components individually is more valid and clinically relevant than aggregating them into a composite score. This is because the components of quality of life are often considered to be independent of each other (Kane et al., 2003), and the relative value assigned to individual components varies markedly among the individuals whose quality of life is being assessed (Whitehouse & Rabins, 1992). For research and program-evaluation purposes, however, global measures are at times preferable, and researchers often attempt to combine multiple dimensions into a single scale.

The past decade has seen elaboration of a variety of instruments that were designed to measure quality of life for persons with Alzheimer's disease. They range from single-component measures to those that evaluate multiple domains. They include instruments that involve resident report, staff report, and direct observation. To date, with the exception of one other report in this issue (Edelman, Fulton, Kuhn, & Chang, 2005), no efforts have comprehensively evaluated these new measures against one another to identify if one is optimal for evaluating quality of life among persons with Alzheimer's disease who reside in long-term care.

This article reports the results of a comparative study of many of the existing disease-specific quality-of-life measures for Alzheimer's disease. The study was undertaken to better understand the contributions of existing measures to the description and evaluation of quality of life among persons with Alzheimer's disease who reside in long-term care facilities. The measures we studied include those administered directly to residents, those that question staff proxies, and those that involve direct observation. The study was designed to address the following questions: What are the completion rates and psychometric properties of different measures in long-term care settings? To what extent are scores on the various instruments correlated? How do responses from different sources compare? And, finally, given the effort involved in collecting quality-of-life data, to what extent do these instruments provide information beyond what can be predicted using easily obtained information on resident health status?

## Design and Methods

As part of a study of dementia care in residential-care and assisted-living facilities and nursing homes,

**Table 1. Measures Studied and Domains of Quality of Life Addressed by Each Measure**

Instrument	Data Source	Domains of Quality of Life
Quality of Life in Dementia (QOL-D; Albert)	Care provider and/or resident (two versions)	Activity participation (both versions) Positive and negative affect (care-provider version only)
Quality of Life in Alzheimer's Disease (QOL-AD; Logsdon)	Care provider and/or resident (two versions)	Relationships with family and friends, concerns about finances, physical condition, mood
Alzheimer's Disease Related Quality of Life (ADRQL; Rabins)	Care provider	Social interaction, awareness of self, feelings or mood, enjoyment of activities, response to surroundings
Dementia Quality of Life (DQoL; Brod)	Resident	Self-esteem, positive affect or humor, negative affect, feelings of belonging, sense of aesthetics (enjoyment from five senses)
Dementia Care Mapping (DCM)	Observation	Activity, well- and-ill-being
Resident and Staff Observation Checklist (RSOC-QOL)	Observation	Agitation, physical contact, and engagement
Philadelphia Geriatric Center Affect Rating Scale (PGC-ARS)	Observation	Positive and negative affect

*Notes:* Because the names and acronyms of the QOL-D, QOL-AD, ADRQL, and DQoL are so similar, for clarification they are referred to in this and subsequent tables by the name of their primary author as well as their name.

we gathered data from 421 residents in 45 facilities in four states.

### *Facility Sample and Study Participants*

Study participants were enrolled from a purposive sample of 45 facilities in four states: Florida, Maryland, New Jersey, and North Carolina. We selected facilities from an existing cohort of 233 facilities, with additional facilities recruited at the recommendation of an advisory committee from the Alzheimer's Association, toward the overall goal of including a wide range of facilities in terms of licensure, structure, and process of care. Of the facilities enrolled, 35 were licensed as residential-care and assisted-living facilities, defined as any facility licensed by the state at a nonnursing home level of care that provided room and board, assistance with activities of daily living (ADLs), and 24-hr supervision or oversight. Of these residential-care and assisted-living facilities, 14 were "small" (< 16 bed) homes, 10 were new-model facilities ( $\geq$  16 beds, built after 1987, and exhibiting one or more characteristics associated with the care of higher-acuity residents), and 11 were traditional facilities ( $\geq$  16 beds, not meeting the new-model criteria). The remaining 10 study facilities were nursing homes. Descriptions of the typology are available elsewhere (Zimmerman et al., 2001).

Within our 45 study facilities, all residents who were aged 65 years or older and had a diagnosis of dementia were identified. To limit the sample to the common forms of age-related dementia, residents were excluded if they had a primary diagnosis of Huntington's disease, alcohol-related dementia, schizophrenia, manic-depressive disorder, or mental retardation. To maintain representation across

facility types, we targeted a maximum of 4 residents per smaller facility and 19 residents per larger facility for enrollment; we approached eligible residents in each facility in random order until the maximum was reached. We obtained consent directly from residents who were judged by facility staff to have the capacity to consent; for those too cognitively impaired to provide their own consent, we approached a guardian or responsible party for consent. Of 575 eligible residents approached for consent, 421 (73%) agreed to participate, 66 (11%) refused, and 88 (15%) were unable to provide consent and had responsible parties who were unreachable. Participant enrollment and consent followed guidelines approved by the Institutional Review Boards of the School of Medicine of the University of North Carolina at Chapel Hill and the School of Medicine of the University of Maryland–Baltimore.

### *Measures*

Table 1 displays the quality-of-life measures studied and data sources and provides an overview of the domains of quality of life addressed by each. The instruments are described below.

*Quality of Life in Dementia (QOL-D; Albert et al., 1996).*—This instrument was developed based on the assumption that the experience of living was the key component of quality of life and that readily observable behaviors would offer insight into the experiential world of persons with dementia. It measures two dimensions: activity and affect. The activity component was derived from Teri and Logsdon's Pleasant Events Schedule-AD (Logsdon

& Teri, 1997; Teri & Logsdon, 1991). It contains 15 items, 5 of which involve travel outside. Each item is rated over a one-week timeframe for opportunity and engagement in the activity. Response categories are frequently ( $\geq 3$  times per week), occasionally ( $\leq 3$  time per week), or never. The activity variables can be combined into a summary activity measure, which ranges from 0 to 30, with higher scores indicating more activity.

The affect component of the QOL-D was derived from Lawton's Affect Rating Scale (Lawton, Van Haitsma, & Klapper, 1996); it contains 6 items, 3 of which measure positive affect and 3 of which measure negative affect. Each item is coded for its average frequency during the previous 2 weeks. Frequency is coded on a 5-point format, ranging from never (coded as 1) to 3 or more times a day (coded as 5). Summary positive and negative scores (each ranging from 3 to 15) are calculated.

Two versions of the instrument exist: a care provider version, which is completed by a proxy and rates both activity and affect; and a resident version, which is completed by the person with dementia and rates only activity. Both versions were independently administered and evaluated in this study. For the caregiver version of the affect items, test-retest reliability was reported to be between 0.53 and 0.92; for 12 of the 15 activity items, Kappas were above 0.60 (Albert et al., 1996).

*Quality of Life in Alzheimer's Disease (QOL-AD; Logsdon et al., 2000).*—This instrument evaluates one's physical condition, mood, interpersonal relationships, ability to participate in meaningful activities, and financial situation. The original measure had 13 items; however, the measure evaluated in this study was a 15-item modification for use in long-term care, in which "relationships with people who work here" was substituted for "marriage relationship," "ability to keep busy" was substituted for "ability to do chores," and "ability to take care of self" was substituted for "ability to handle money;" "ability to make choices in (one's) life" and "ability to live with others" were added as new items (Edelman et al., 2005). Each item is rated on a 4-point scale (1 = poor and 4 = excellent), yielding a summative score ranging from 15 to 60.

The QOL-AD has two versions; one is designed to be administered to a care provider, the other directly to the person with Alzheimer's disease. The reported coefficient alpha for the patient version is 0.88 and for the caregiver version is 0.87 (Logsdon et al., 2000). In this study, both versions were independently administered and evaluated.

*Alzheimer Disease Related Quality of Life (ADRQL; Rabins et al., 2000).*—This instrument consists of 47 items, completed by a care provider, that describe behaviors that were judged by focus

groups of family caregivers and professionals to be of importance to health-related quality of life in Alzheimer's disease. The items address the following 5 domains: social interaction, awareness of self, feelings and mood, enjoyment of activities, and response to surroundings. The various domains contain from 5 to 15 items, each of which is rated and scored as either agree or disagree. Items are assigned weights, ranging from 9.15 to 13.51, which were designed to reflect the extent to which the item influences quality of life. Summary scores are generated for each domain and for global quality of life; each is computed so as to range from 0 (lowest quality) to 100 (highest quality). The internal consistency reliability of the ADRQL domains has been reported to range between 0.77 and 0.91 (Lyketsos et al., 2003).

*Dementia Quality of Life (DQoL; Brod, Stewart, Sands, & Walton, 1999).*—This instrument was designed for direct administration to individuals with dementia to evaluate feeling states that comprise "the subjective experience of dementia." Its 29 questions address five domains: self esteem, positive affect and humor, negative affect, feelings of belonging, and sense of aesthetics. Items ask how often the respondent has experienced the feeling; responses are on a 1-point scale, ranging from 1 = never to 5 = very often. Each domain generates a scale, consisting of the mean of component items. Reported test-retest reliability for the 5 scales ranges from 0.64 to 0.90; internal consistency reliability for the scales ranges from 0.67 to 0.89 (Brod et al.). The DQoL was field tested in persons with mild and moderate, but not severe, dementia. The authors suggest that the instrument be supplemented by proxy assessment of more objective quality-of-life components, such as physical function, activity, and social interaction.

*Dementia Care Mapping (DCM; Bradford Dementia Group, 1997; Fossey, Lee & Ballard, 2002; Kitwood, 1997).*—Based on theory articulated by Kitwood, DCM records observations every 5 minutes on activities (assigning a behavior category code [BCC]) and perceived quality of life (assigning a well- and-ill-being [WIB] score). To assign a BCC, the observer selects from a list of 24 codes the one that best describes the resident's behavior during the 5-minute observation period. Most BCCs fall into two categories: Type I codes (for good behaviors, such as conversation or creative expression) and Type II codes (for bad behaviors, such as being socially withdrawn or engaging in repetitive self-stimulation). There are three additional codes that are neither Type I nor Type II because their relation to well- or ill-being depends on context: sleeping, speaking, and locomotion. To assign a WIB score, the observer follows a complex set of rules, which

are specific for each BCC. Possible WIB scores are +5, +3, +1, -1, -3, and -5, with +5 representing the highest state of well-being, -5 representing the worst state of ill-being, and +1 as a neutral score. Interrater reliability on DCM items has been calculated using the concordance coefficient, and reported concordances have ranged between 0.70 and 0.95 (Beavis, Simpson, & Graham, 2002). Test-retest reliability was estimated using the correlation of item proportions; reported values are 0.55 for the considerable (+3/+5) well-being score and 0.40 for activities (Fossey et al.). DCM was developed as a quality-improvement tool; however, interest has recently grown on its possible use as a quality-of-life measure.

The standard DCM observational protocol for quality-improvement purposes calls for 6 hr of observation during the day, without specification of the time of day, and for observations to be made only in public areas. In this study, research observations were conducted over three specified one-hr intervals and did not exclude observation in resident rooms. The following DCM-based indicators of quality of life were evaluated: mean WIB score, percent of WIB values that were +3 or +5, and the percent of BCC observations that were in Type I categories.

*Resident and Staff Observation Checklist—Quality of Life Measure (RSOC-QoL; Sloane et al., 1991; Sloane et al., 1998; Zimmerman, et al., 2001).*—The RSOC-QoL was developed over 15 years of long-term care work by the study team. The instrument uses systematic nonparticipant observation to gather and record data on the appearance, location, activity, behavior, affect, restraint use, and interactions of residents in long-term care settings. For this study, observations were made every 5 min on study participants during 3 one-hr observation periods. Three measures of resident QOL are reported here: agitation, physical contact, and engagement. Agitation was coded as present if any one of nine behaviors (e.g., pacing or repetitive mannerisms) was observed; a summary score consisted of the percent of observations during which agitation was observed. Physical contact with other residents, staff, or visitors was coded as 0 = no contact, 1 = nonintimate touch (e.g., physical assistance), or 2 = intimate touch (e.g., hand holding). Engagement was coded as 0 = idle, 1 = watching, passive, or listening (alert and observing surroundings), or 2 = active (directly participating and/or interacting with environment). Quality-of-life summary indicators for physical contact and engagement were created by summing the scores over all observation periods for which data were available and then expressing the result on a scale from 0 to 100, such that 0 = a mean score of 0 for all observations and 100 = a mean score of 2 for all observations.

Reported interrater agreement of RSOC items ranged from 0.95 to 1.00 (Sloane et al., 1998).

*Philadelphia Geriatric Center Affect Rating Scale (PGC-ARS; Lawton, 1994; Lawton et al., 1996).*—This observational instrument was developed to assess quality of life by observing and noting the facial expression, body movement, and other cues by which persons with dementia communicate their minute-to-minute feeling states. The original instrument used multiple 10-min observation periods, during which research assistants recorded the prevalence of six affect states; these were then aggregated into two scales, positive affect and negative affect. Interrater reliability, using the Kappa statistic, was reported to range from 0.76 to 0.89 (Lawton et al.).

The measure used in this study was a modification based on reliability studies and experience with videotaped ratings of persons with dementia by the project team. Its seven states are mild pleasure, high pleasure, anger, anxiety or fear, sadness, general alertness, and sleeping or dozing. Data were recorded every 5 min during 3 one-hr observation periods; only one affect (the predominant state) was recorded per observation period. For the analyses reported herein, the affect states were coded as follows: 0 for anger, anxiety or fear, or sadness; +1 for general alertness or sleeping or dozing; +2 for mild pleasure; and +3 for high pleasure. These were summed during the observation periods and expressed on a scale from 0 to 100, such that 0 = a mean score of 0 for all observations and 100 = a mean score of +3 (maximum positive affect) for all observations.

*Other measures.*—A variety of measures were administered to gather data on the study participants and the facilities in which they resided. For these analyses, the following measures of resident function were used: the Mini-Mental State Examination (MMSE; Folstein, Folstein, & McHugh, 1975), the Minimum Data Set Cognition Scale (MDS-COGS; Hartmaier, Sloane, Guess, & Koch, 1994), the MDS scale of activities of daily living (MDS-ADL; Morris, Fries, & Morris, 1999), the Cornell Scale for Depression in Dementia (CSDD; Alexopoulos, Abrams, Young & Shamoian, 1988), the Cohen-Mansfield Agitation Inventory (CMAI; Cohen-Mansfield, 1986), and the Philadelphia Geriatric Center Pain Intensity Scale (PGC-PIS; Parmelee, Katz, & Lawton, 1991).

#### *Data Collection*

Data were collected on-site between September 2001 and February 2003 by teams of two or three trained study research assistants, which spent between 2 and 6 days in each facility, depending

on facility size. For each resident, interviews were conducted with the resident, the direct care provider who knew him or her best (i.e., the staff member who provided the most hands-on care, usually a nursing assistant), and the care supervisor who knew him or her best (i.e., the staff member directly above the direct care provider, usually a licensed nurse). In addition, observations were conducted on study participants by trained research assistants for one day. Finally, the administrator of each facility was interviewed to obtain facility-level data.

Data on the QOL-D (Albert et al., 1996), QOL-AD (Logsdon et al., 2000), and ADRQL (Rabins et al., 2000) staff measures were gathered from the direct care provider who knew the resident best. Data on the QOL-D, QOL-AD, and DQoL (Brod et al., 1999) resident measures were gathered directly from the resident. Participants with MMSE scores less than 10 were not administered the resident version of the QOL-D or QOL-AD, and residents who failed the DQoL cognitive screen were not administered the DQoL. Data on the observational measures were collected on up to 12 study participants in each facility; in sites with more than 12 participants, observation residents were randomly selected. A data collector observed up to three residents simultaneously using a nonparticipant method that recorded observations every 5 min for 3 hr (10–11 a.m., 1–2 p.m., and 4–5 p.m.); closed doors to resident rooms were opened during data collection (once per hour), after knocking, and observations were not made on residents who were behind bathroom doors or were off the unit.

Interrater reliability data on the study measures were collected during data-collection site visits. For the care-provider-reported measures, an interrater reliability study was conducted using a convenience sample of 23 staff care providers in five facilities by having one data collector conduct the interview while another data collector observed. The responses were independently recorded and scored, and an intraclass correlation coefficient was computed for each summary quality-of-life measure. For the measures based on direct observation, two data collectors simultaneously but independently observed up to three residents at a time, recording observations every 5 min for one hr (not during mealtimes). A total of 59 pairs of one-hr observations were recorded and scored on a convenience sample of 38 residents in seven facilities, using four data collectors. Intraclass correlation coefficients were computed for each observed quality-of-life measure.

### Data Analysis

Descriptive statistics, including means, standard deviations, range, and medians were computed for all quality-of-life measures. MMSE scores were used to estimate the degree of cognitive impairment

among participants ( $\geq 17$  = mild impairment, 10–16 = moderate impairment, 3–9 = severe impairment, and  $\leq 2$  = very severe impairment); when an MMSE was not available (51 residents), corresponding ranges of the MDS-COGS were used. In order to determine whether the measures might be limited by ceiling or floor effects, the proportions of the sample scoring the minimum and maximum possible values for each measure also were calculated. For all multi-item measures, consistency reliability was estimated using Cronbach's alpha. To facilitate comparison across respondent type, for measures collected from both resident and care provider report (Albert's Patient Activities Score and Logsdon's QOL-AD), descriptive statistics were computed separately for both the full care-provider sample and the subset for which both care provider and resident data were available. To estimate the association between subscale scores and between different quality-of-life measures, Pearson correlation coefficients were computed between all measures.

To estimate the extent to which each quality-of-life measure was "explained" by commonly assessed measures of resident status, a series of seven hierarchical linear models was computed for each quality-of-life outcome measure. The first model contained no fixed effects and was used to derive an estimate of the total variance in each quality-of-life measure. Five additional models each adjusted for a single resident factor as follows: cognitive function (measured by the MMSE), disability in ADLs (number of dependencies among seven MDS-ADL items), depressive symptoms (CSDD), agitated behavior (CMAI), and pain (PGC-PIS). The final model included all five of these factors. For each model, variance reduction was computed as the percent decrease in the total variance for the model of interest from the total variance from the model without fixed effects; total variance is defined as the sum of resident, care-provider (or observer), and facility-level variances from the hierarchical linear model. For care-provider-reported quality-of-life measures, models included random effects for facility and care provider (nested within facility). For the resident-reported measures, models included a random effect for facility. For the directly observed measures, models included random effects for facility and observer.

## Results

### *Characteristics of Study Facilities and Participants*

The 35 residential care/assisted living (RC/AL) facilities in the study sample had a mean of 49 beds (range: 6–64) and a mean age of 13 years (range: 1–50), the majority (75%) were for-profit facilities, and half had a dementia special care unit. The 10 nursing homes in the sample had a mean of 114 beds (range: 50–180) and a mean age of 40 years (range: 12–105),

40% were for-profit facilities, and 80% had a dementia special care unit.

A total of 414 facility residents were included in these analyses. Residents who served as study participants had an average age of 85 years old (range: 65–101). The majority were female (79%) and White (91%). The degree of cognitive impairment among study participants was as follows: 12% were mildly impaired, 25% were moderately impaired, 27% were severely impaired, and 37% were very severely impaired. Supervisor interviews included diagnostic information on 326 participants (the remainder were either not completed or partially completed); of these, 54% had Alzheimer's disease, 4% had vascular dementia, 5% had both Alzheimer's disease and vascular dementia, and 37% had a non-specific dementia diagnosis.

### *Psychometric Properties of the Quality-of-Life Measures Studied*

Psychometric properties of the dementia quality-of-life measures studied are presented in Table 2. For the reported measures, the completion rate for the resident-completed instruments was 25–30%, whereas close to 100% of participants had care-provider versions completed. All of the reported measure scales and subscales demonstrated broad ranges and distributions that were approximately normal, with means and medians that were relatively similar (i.e., not markedly skewed). The three exceptions were the QOL-AD positive affect scale and two of the ADRQL subscales. Internal consistency was as follows: the QOL-D scales were largely in the good range (.57–.79); the QOL-AD was in the excellent range (.88–.92); the ADRQL overall scale was excellent (.85), but subscales ranged from fair to good (.46–.72); and the DQoL scale and subscales ranged from good to excellent (.59–.91). Interrater reliability of all reported measures was excellent.

For the observed measures (Table 2), nearly all participants (97%) selected for sampling had observations completed. Interrater reliability of the observed measures ranged from .28 (for the percentage of WIB scores in the +3 to +5 range) to .90 (for observed agitated behaviors); most were in the good to excellent range. Among the DCM measures, the mean WIB scores tended to cluster around 1 ( $M = 0.74$ ,  $SD = 0.55$ ). The percent of WIB scores of +3 or +5 demonstrated floor effects, with 68% of participants scoring 0%. In contrast, the percent of BCC Type I observations demonstrated good dispersion. Among the RSOC-QOL variables, both the agitated behaviors and physical contact demonstrated floor effects, whereas activity level or engagement and emotion or affect demonstrated more normal distribution properties.

### *Correlations Between the Quality-of-Life Measures Studied*

Tables 3–8 display correlation matrices comparing the various quality-of-life measures with each other, by data source. In general, measures generated by care-provider report demonstrated moderate correlations with each other (Table 3), as did measures generated by resident report (Table 4). Correlations were lower, however, when care-provider reports were compared with those generated by residents themselves (Table 5). Of particular note are the low correlations observed when residents and care providers were administered the same instrument (0.24 for the QOL-D activities scale and 0.02 for the QOL-AD).

Correlations between the observational measures were in the low to moderate range (Table 6). In general, the observational items tended to correlate more strongly with care-provider reports (Table 7) than with resident reports (Table 8).

### *Extent to Which Resident Factors Explain Variation in Quality-of-Life Scores*

Table 9 displays the proportion of variation in the results of each measure explained by five resident factors: cognitive function, physical function (ADLs), depressive symptoms, agitated behavior, and pain. Results are displayed as the percent of variance in each measure explained by each of these resident factors and by the combination of resident factors; they were generated by a series of hierarchical linear models in which the quality-of-life outcome was the dependent variable and the resident characteristics were the independent variable(s). For these analyses, the sample size was reduced so as to only include participants for whom data were available for all variables in the model. As a result, the total sample size is 246 for the care-provider-reported measures, 222 for the observed measures, and 78 for the resident-reported measures.

Of the five resident factors studied, cognition and ADL function were the strongest predictors of quality-of-life scores (Table 9). Nearly all care-provider-reported and observed measures tended to decline as cognitive function declined or ADL dependency rose. Depressive symptoms and agitation also were associated with many of the reported and observed measures, although the percent of variation explained was less. Pain, however, showed little association with any measure of quality of life. When all five measures of resident status were entered into predictive models, they were found to be associated with virtually all care-provider-reported and observed measures, with the proportion of variance explained being in the small to moderate range (0–27%). In contrast, little or no association was detected between any of the resident-reported measures and resident factors. Due to the small

**Table 2. Psychometric Properties of Dementia Quality-of-Life Measures Studied**

Measure	No. of Participants	Completion Rate (%) <sup>a</sup>	No. of Items	Theoretical Range	Observed Range	M (SD)	Median	Maximum (%); Minimum (%) <sup>b</sup>	Internal Consistency <sup>c</sup>	Interrater Reliability <sup>d</sup>
<b>Reported measure</b>										
QOL-D (Albert)										
Care provider (CP) report										
Activities	400	96.6	15	0-30	0-28	9.3 (5.0)	9	0; < 1	.78	0.95 (n = 18)
Positive affect	403	97.3	3	3-15	3-15	11.9 (2.9)	13	26; < 1	.66	0.99 (n = 23)
Negative affect	383	92.5	3	3-15	3-15	6.7 (3.1)	6	2; 16	.66	0.96 (n = 21)
Resident report										
Activities	110	82.1 <sup>e</sup>	15	0-30	0-25	9.5 (5.1)	9	0; < 1	.78	0.99 (n = 5)
CP-resident subset <sup>f</sup>	107	NA	15	0-30	0-26	10.1 (5.0)	9	0; < 1	.79	—
Activities	107	NA	3	3-15	5-15	11.9 (2.8)	12	25; 0	.57	—
Positive affect	103	NA	3	3-15	3-15	7.2 (3.1)	7	2; 12	.65	—
Negative affect										
QOL-AD (Logsdon)										
Care provider report	410	99.0	15	15-60	19-59	36.9 (7.9)	37	0; 0	.88	0.99 (n = 20)
Resident report	121	90.3 <sup>e</sup>	15	15-60	18-60	42.8 (8.2)	44	< 1; 0	.92	1.0 (n = 5)
CP-resident subset <sup>f</sup>	116	NA	15	15-60	24-59	41.1 (7.9)	41	0; 0	.89	—
ADROL (Rabins)										
Social interaction	413	99.8	12	0-100	0-100	78.4 (18.5)	84	16; < 1	.69	1.00 (n = 23)
Awareness of self	410	99.0	8	0-100	9.3-100	66.7 (23.4)	73	9; 0	.62	0.90 (n = 20)
Feelings and mood	412	99.5	15	0-100	14.4-100	76.8 (18.0)	81	11; 0	.72	0.98 (n = 23)
Enjoyment of activities	411	99.3	5	0-100	0-100	68.1 (26.2)	78	24; 2	.50	0.97 (n = 22)
Response to surroundings	410	99.0	7	0-100	0-100	81.4 (18.6)	84	33; < 1	.46	1.00 (n = 22)
Total	410	99.0	47	0-100	21.0-100	75.2 (14.8)	78	1; 0	.85	0.99 (n = 22)
DQoL (Brod)										
Self-esteem	100	74.6 <sup>e</sup>	4	1-5	1-5	3.5 (0.9)	4	8; 2	.73	1.0 (n = 5)
Positive affect or humor	97	72.4 <sup>e</sup>	6	1-5	1-5	3.5 (0.9)	4	4; 2	.84	1.0 (n = 5)
Negative affect	97	72.4 <sup>e</sup>	11	1-5	1-5	3.6 (0.8)	4	2; 1	.88	1.0 (n = 5)
Feeling of belonging	100	74.6 <sup>e</sup>	3	1-5	1-5	3.3 (0.9)	3	4; 1	.59	1.0 (n = 5)
Aesthetics	97	72.4 <sup>e</sup>	5	1-5	1-5	3.6 (1.0)	4	13; 2	.83	1.0 (n = 5)
Total	100	74.6 <sup>e</sup>	29	5-25	7-25	17.5 (3.5)	18	2; 0	.91	1.0 (n = 5)
Observed measure										
DCM										
Mean WIB Score	333	97.1	1	-5-+5	-2.15-+2.60	0.74 (0.55)	0.89	0; 0	—	0.70 (n = 56)
% WIB +3 or +5	333	97.1	1	0-100	0-80	4.0 (9.0)	0	0; 68	—	0.28 (n = 56)
% BCC Type I	333	97.1	1	0-100	0-100	35.4 (25.6)	30.8	2; 6	—	0.80 (n = 59)
RSOC-QOL										
Agitated behaviors <sup>g</sup>	333	97.1	1	0-100	0-94	11.6 (19.5)	0	0; 56	—	0.90 (n = 54)
Activity level or engagement	333	97.1	1	0-100	0-100	50.5 (25.5)	50.0	2; 2	—	0.77 (n = 54)
Physical contact <sup>h</sup>	333	97.1	1	0-100	0-38	5.6 (7.0)	3.2	0; 32	—	0.81 (n = 54)
PGC-ARS	333	97.1	1	0-100	3-71	33.6 (6.4)	33.3	0; 0	—	0.82 (n = 54)

*Notes:* For the table, a dash indicates that the task was not done or is not available for the measure.

<sup>a</sup>For completion rate, the denominator is 414 for the measures reported by the care provider, 399 for the measures reported by the resident, and 343 for the resident observation.

<sup>b</sup>Percent of participants scoring at the theoretical maximum and theoretical minimum value for the measure.

<sup>c</sup>Cronbach's alpha.

<sup>d</sup>Intraclass correlation coefficient (Shrout & Fleiss, 1979).

<sup>e</sup>Due to protocols of the instruments and/or of the project, which restricted administration of resident-responder instruments to persons with scores of  $\geq 10$  on the Mini-Mental State Examination (MMSE), only 134 participants (33.6 % of the total sample) were administered the resident instruments. Reported completion rates are only for those residents who met the MMSE criterion and were offered the instrument.

<sup>f</sup>CP-resident subset = the care-provider ratings of the subset of participants for whom resident ratings of the same instrument were collected.

<sup>g</sup>Percent of observations in which the behavior occurred.

**Table 3. Correlations (Pearson *r*) Among Dementia Quality-of-Life Measures Reported by Staff Care Providers**

Measure	QOL-D (Albert)			QOL-AD (Logsdon)	ADRQL (Rabins)					
	Activities	Positive Affect	Negative Affect		SI	AS	FM	EA	RS	Total
QOL-D (Albert)										
Activities	1									
Positive affect	0.33	1								
Negative affect	-0.09	-0.17	1							
QOL-AD (Logsdon)	0.52	0.46	-0.36	1						
ADRQL (Rabins)										
SI	0.38	0.48	-0.33	0.52	1					
AS	0.38	0.38	-0.18	0.57	0.50	1				
FM	0.24	0.37	-0.65	0.51	0.55	0.31	1			
EA	0.44	0.40	-0.25	0.51	0.50	0.40	0.44	1		
RS	0.18	0.27	-0.45	0.34	0.27	0.21	0.49	0.28	1	
Total	0.44	0.53	-0.54	0.68	0.81	0.67	0.83	0.68	0.57	1

Notes: SI = social interaction; AS = awareness of self; FM = feelings and mood; EA = enjoyment of activities; RS = response to surroundings. For the table, *n* = 374–413; sample size varies because of missing data.

sample size, however, these results should be interpreted with caution.

**Discussion**

The analyses reported in this article indicate that many instruments are now available to evaluate quality of life among persons with Alzheimer’s disease and related dementias that can be successfully used in long-term care populations and have relatively robust psychometric properties. As is clear from the analyses in Table 2, most of the instruments studied, including their component subscales, demonstrated good to excellent interrater reliability and adequate dispersion. Furthermore, the fact that the resident factors of cognition, ADL impairment, depression, agitated behaviors, and pain explained no more than 27% of the variance in any of the measures (Table 9) suggests that these measures are capturing far more than can be inferred from basic information on resident characteristics.

The issue of validity remains a challenge. As was noted by Patrick and Erickson (1993), quality of life is

based largely on theory and values, not on scientific inference. Because theories and values vary as to which elements are most important to quality of life, it is not surprising that different instruments tend to evaluate somewhat different domains and to differ in their scope (Table 1). A few investigators have attempted to empirically determine which domains of quality of life are most highly valued by persons with Alzheimer’s disease and/or long-term care residents (Cohn & Sugar, 1991; Kane et al., 2003; Rabins et al., 2000). However, as was demonstrated by Cohn and Sugar, the answers to such questions differ markedly depending on whom you ask. This tendency for different data sources to provide different answers is echoed in our data, most dramatically by the QOL-AD—one of the more comprehensive quality-of-life scales, for which the correlation between resident and caregiver ratings was .02. Prior studies have suggested that correlations between patient and provider ratings tend to be mild to moderate; for example, Logsdon and colleagues (2000) reported a correlation of .40 between resident and provider versions of the QOL-

**Table 4. Correlations (Pearson *r*) Among Dementia Quality-of-Life Measures Reported by Residents**

Measure	QOL-D (Albert) Activities	QOL-AD (Logsdon)	DQoL (Brod)							
			Self-esteem	Positive Affect	Negative Affect	Feeling of Belonging	Aesthetics	Total		
QOL-D (Albert) activities	1									
QOL-AD (Logsdon)	0.36	1								
DQoL (Brod)										
Self-esteem	0.47	0.70	1							
Positive affect or humor	0.54	0.69	0.74	1						
Negative affect	0.11	0.48	0.42	0.41	1					
Feeling of belonging	0.46	0.63	0.61	0.73	0.20	1				
Aesthetics	0.39	0.47	0.39	0.45	0.12	0.45	1			
Total	0.54	0.78	0.84	0.88	0.55	0.80	0.67	1		

Notes: For the table, *n* = 93–120; sample size varies because of missing data.

**Table 5. Correlations (Pearson *r*) Between Dementia Quality-of-Life Measures Reported by Staff Care Providers and Residents**

Measure Reported by Care Providers	Measures Reported by Residents							
	QOL-D (Albert) Activities	QOL-AD (Logsdon)	DQoL (Brod)					Total
			Self-esteem	Positive Affect	Negative Affect	Feeling of Belonging	Aesthetics	
QOL-D (Albert)								
Activities	0.24	0.18	0.09	0.20	0.08	0.14	0.19	0.20
Positive affect	0.19	0.07	0.11	0.21	0.03	0.27	0.16	0.20
Negative affect	-0.09	-0.03	-0.02	0.01	-0.26	0.11	0.01	-0.05
QOL-AD (Logsdon)	0.24	0.02	0.04	0.18	0.06	0.17	0.07	0.14
ADRQL (Rabins)								
Social interaction	0.10	0.09	0.07	0.17	0.05	0.15	0.16	0.19
Awareness of self	0.13	0.03	0.23	0.18	0.03	0.32	0.15	0.27
Feelings and mood	0.03	0.06	0.05	0.12	0.21	0.10	0.11	0.17
Enjoyment of activities	0.31	0.20	0.17	0.23	0.01	0.21	0.24	0.23
Response to surroundings	0.18	0.08	0.11	0.17	0.25	0.16	0.12	0.22
Total	0.19	0.12	0.18	0.25	0.17	0.26	0.20	0.30

Notes: For the table, *n* = 84–117; sample size varies because of missing data.

AD, and Thorgrimsen and colleagues (2003) reported a correlation of .69 between resident scores on the QOL-AD and staff scores on the DQoL. While more study is clearly needed on the degree and causes of nonagreement between residents and caregivers, findings from a study of schizophrenics suggest that residents' and providers' judgments are least likely to coincide on activity and social aspects of quality of life and more likely to agree on function and symptom-related domains (Sainfort, Becker, & Diamond, 1996).

A logical solution to the dilemma of validity might be to consider the resident's own opinion to be the "gold standard" (Brod et al., 2000). Unfortunately, study results suggest that the majority of residents with Alzheimer's disease in long-term care have cognitive decline so severe that they may be unable to be administered measures of quality of life. In our stratified random sample, the majority of whom were from RC/AL facilities, between 70% and 76% of participants failed cognitive screening criteria and,

therefore, were not administered the resident measures. Quite possibly, some of these individuals could have provided at least some data; according to Thorgrimsen and colleagues (2003) and Logsdon, Gibbons, McCurry, & Teri (2002), MMSE scores between 3 and 10 define a gray zone in which some individuals can complete quality-of-life measures and others cannot. Similarly, Mozley and colleagues (1999), in conducting in-depth quality-of-life interviews of long-term care residents with dementia, concluded that an MMSE cutoff of 9–10 defined "interviewability" but that some respondents with even lower scores might have been interviewable. When and how to best elicit self-reported quality-of-life data from persons with severe cognitive impairment is a critical one for current practice (Schnelle, 2003), and one for which further research is needed.

Do observational measures provide a superior alternative to proxy measures? While direct observation has theoretical advantages, the state of

**Table 6. Correlations (Pearson *r*) Among Directly Observed Dementia Quality-of-Life Measures**

Measure	DCM			RSOC			PGC-ARS <sup>a</sup>
	WIB Mean	% WIB +3 or +5	% BCC Type I	% Any Agitation	% Physical Contact	Activity or Engagement	
DCM							
Mean WIB	1						
% WIB +3 or +5	0.49	1					
% BCC Type I	0.39	0.12	1				
RSOC							
% any agitation	-0.23	-0.07	-0.16	1			
% physical contact	0.00	0.00	0.10	0.17	1		
Activity or engagement	0.44	0.33	0.49	0.19	0.07	1	
PGC-ARS	0.52	0.58	0.15	-0.34	-0.15	0.21	1

Notes: WIB = well- and ill-being score; BCC = behavior category code. For the table, *n* = 333.

**Table 7. Correlations (Pearson  $r$ ) Between Dementia Quality-of-Life Measures Reported by Staff Care Providers and Those Directly Observed**

Measure Reported by Care Providers	Directly Observed Measures						
	Dementia Care Mapping			Resident-Staff Observation Checklist			
	WIB Mean	% of WIB +3 or +5	% BCC Type I	% Any Agitation	% Physical Contact	Activity or Engagement	PGC-ARS
QOL-D (Albert)							
Activities	0.25	0.17	0.32	-0.12	-0.03	0.25	0.23
Positive affect	0.30	0.12	0.20	-0.20	0.03	0.19	0.20
Negative affect	-0.09	0.02	-0.18	0.23	0.10	-0.03	-0.16
QOL-AD (Logsdon)	0.33	0.17	0.25	-0.16	-0.18	0.30	0.26
ADRQL (Rabins)							
Social interaction	0.33	0.17	0.32	-0.34	-0.09	0.21	0.25
Awareness of self	0.33	0.16	0.22	-0.19	-0.13	0.30	0.21
Feelings and mood	0.20	0.08	0.23	-0.29	-0.08	0.06	0.22
Enjoyment of activities	0.28	0.08	0.29	-0.16	-0.03	0.25	0.20
Response to surroundings	0.10	-0.02	0.19	-0.13	-0.03	0.02	0.14
Total	0.35	0.14	0.35	-0.33	-0.11	0.23	0.29

Notes: WIB = well- and ill-being score; BCC = behavior category codes. For the table,  $n = 302-327$ ; sample size varies because of missing data.

development of observational instruments is much more primitive than that of proxy-report measures. As is clear from Tables 1 and 2, the observational instruments studied had numerous disadvantages. These include floor effects (agitated behavior and physical contact), lack of variation (WIB scores), poor interrater reliability (the percentage of WIB scores of +3 or +5), and lack of multidimensionality (all measures). Furthermore, the fact that the observational measures tended to correlate more strongly with care-provider-report measures (Table 7) than with resident-report measures (Table 8) suggests that observation may carry with it many of the same inherent biases of proxy reports.

In conclusion, it appears that, while many

measures now exist that provide windows to the quality of life of long-term care resident with dementia, no single instrument can claim superiority, and, indeed, no instrument adequately captures the broad canvas of quality of life. Certainly, the science is improving, yet the field is still underdeveloped. One direction that needs to be explored is the use of multiple instruments and sources, to better understand the experiences of persons with dementia (Lawton, 1997). Another is the individualization of assessment, based on the individual and family's values, experiences, and expressed wishes. Given the progressive, terminal nature of Alzheimer's disease, being able to capture a clearer image of quality of life throughout the illness will help guide treatment and,

**Table 8. Correlations (Pearson  $r$ ) Between Dementia Quality-of-Life Measures Reported by Residents and Those Directly Observed**

Measure Reported by Residents	Directly Observed Measures						
	Dementia Care Mapping			Resident-Staff Observation Checklist			
	WIB Mean	% WIB +3 or +5	% BCC Type I	% Any Agitation	% Physical Contact	Activity or Engagement	PGC-ARS
QOL-D (Albert) activities	0.13	0.09	0.00	0.26	0.08	0.03	0.14
QOL-AD (Logsdon)	0.13	0.12	0.07	0.13	0.07	0.00	0.20
DQoL (Brod)							
Self-esteem	0.22	0.13	0.06	0.03	0.09	0.18	0.19
Positive affect or humor	0.26	0.18	0.17	0.00	0.05	0.19	0.26
Negative affect	0.17	0.10	0.12	-0.08	-0.17	0.06	0.23
Feeling of belonging	0.08	0.13	-0.01	0.13	0.06	0.04	0.10
Aesthetics	0.19	0.22	0.14	0.05	0.07	0.24	0.27
Total	0.24	0.21	0.11	0.04	0.02	0.18	0.29

Notes: WIB = well- and ill-being score; BCC = behavior category codes. For the table,  $n = 72-88$ ; sample size varies because of missing data.

Table 9. Percent of Variance in Quality-of-Life Measures Explained by Resident Factors

Measure	Models With Single-Resident Factors (% of Variance Explained by Resident Factor[s] <sup>a</sup> )					Model With All 5 Resident Factors
	Cognitive Function	ADLs	Depressive Symptoms	Agitated Behavior	Pain	
Proxy-reported measure ( <i>n</i> = 246)						
QOL-D (Albert)						
Activities	9.3***	8.8***	0.6	1.4**	0.8	11.9***
Positive affect	6.3***	2.7*	7.6***	2.8***	0	9.4***
Negative affect	6.0***	4.2*	7.4***	9.4***	0	13.5***
QOL-AD Logsdon	19.8***	21.4***	2.8**	2.0**	0.1	26.8***
ADRQL (Rabins)						
Social interaction	15.4***	13.3***	4.0**	3.5***	0	18.7***
Awareness of self	21.8***	16.0***	0.7	3.1**	0	24.4***
Feelings and mood	8.0***	4.7*	9.7***	10.8***	0	15.6***
Enjoyment of activities	6.1***	7.3	1.3	1.9*	0	8.2***
Response to surroundings	1.5	0	4.7**	7.4***	0	7.4***
Total	18.4***	16.4***	8.5***	10.2***	0	24.8***
Observed measure ( <i>n</i> = 222)						
Dementia Care Mapping						
Mean WIB Score	8.2***	11.7***	0.2	0.7	0	11.8***
% WIB +3 or +5	0.1	1.8*	0	0	0	0
% BCC Type I	19.3***	7.1**	1.4	2.6	0	18.1***
RSOC-QOL						
% Agitated behaviors	17.0***	8.4***	1.9	11.0***	0.8*	20.9***
Activity level/engagement	9.0***	13.0***	0.6	0	1.0	14.9***
% Physical contact	14.5***	10.6***	0	5.1**	2.4	19.4***
PGC-ARS	7.8***	6.9***	2.7	2.7*	0	9.4**
Resident-reported measures ( <i>n</i> = 78)						
QOL-D (Albert) Activities	0	0	0	2.3	0	0
QOL-AD (Logsdon)	0	0	0	0	2.3	0
DQOL (Brod)						
Self-esteem	0	0	0.2	0	1.9	0
Positive Affect/Humor	0	0	2.5*	0	0	1.9
Negative Affect	0	3.3	0	1.5	0	1.2
Feeling of Belonging	1.1	0	0	4.0*	0	3.8
Aesthetics	0	0	0	0	0	0
Total	0	0	0	0	0	0

Notes: ADLs = activities of daily living. All regression models are hierarchical linear models with the specified global quality-of-life measure as the dependent variable. For care-provider-reported quality-of-life measures, models included random effects for facility and care provider (nested within facility). For the directly observed measures, models include random effects for facility and observer. For the resident-reported measures, models include a random effect for facility. Sample size is restricted to those with data on all resident factors (*n* = 246 for quality-of-life measures reported by care provider, *n* = 222 for directly observed measures, and *n* = 78 for measures reported by resident). An entry of 0 indicates that the estimate of variance reduction was either very small or negative, the latter occurring occasionally in small samples due to uncertainty in estimation even though a nonnegative estimate was expected.

<sup>a</sup>Variance reduction is the percent decrease in the total variance for the model of interest, when compared with the total variance of the model without fixed effects; total variance is defined as the sum of resident, care provider (or observer), and facility-level variances from the hierarchical linear model.

\**p* < .05; \*\**p* < .01; \*\*\**p* < .001. Statistical significance is based on *T* statistics for individual fixed effects in the single-factor models and on an *F* test for the joint effects of all resident factors in the full model.

ultimately, improve the experience of persons with the disease, their families, and those who provide their care.

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