A simple approach to the measurement of quality of life (QOL) would entail each individual describing what the concept means and determining the extent to which the described prerequisites for QOL are being met. This approach is limited for people with dementia whose cognitive impairments often diminish their capacity to communicate their QOL. Direct interviews using simple yet explicit questions have been successfully used with people in the early to middle stages of dementia.1–3 However, there are obvious limits to the usefulness of direct interviews as cognitive and verbal abilities decline over time. Both proxy interviews involving family or professional caregivers4,5 and observational procedures by trained observers6,7 provide alternative opportunities to assess QOL among people with dementia.

In this article, the approach of 2 groups of researchers/practitioners to identify, develop, and adapt reliable and valid measures of dementia-specific QOL for use in care settings is described. Examination of a number of dementia-specific measures of QOL eventually led to
the decision to develop and test a new approach to measuring dementia-specific QOL. The first section of this article describes a 3-phase program of research that led to the development of OQOLD—Observing Quality of Life in Dementia—a tool that can be used to assess and compare QOL across people with various stages of dementia.

This program of research included the following objectives: (1) assess a variety of existing dementia-specific QOL measures to identify relationships among these measures; (2) develop and test a new observational procedure; (3) enable practitioners to implement dementia-specific QOL measures; and (4) identify the ways in which practitioners implemented OQOLD. Throughout this work, practitioners were integral to the research process and their perspectives on the measures and methods were elicited at each phase.

The second section of this article focuses on the development and testing of Observed QOL in Dementia Advanced (OQOLDA), a derivative of OQOLD. The ‘A’ stands for ‘advanced,’ as the tool was designed specifically to assess the QOL of people with advanced dementia. The OQOLDA scale was developed by a group of researchers and practitioners who saw the need for a tool to assess the QOL of people with advanced dementia residing in nursing facilities. Finally, the discussion section describes future directions for both OQOLD and OQOLDA.

OBSERVING QOL IN DEMENTIA

Background

The 3-phase program of research was instigated by the first author’s dissatisfaction with available methods of assessing the QOL of people with dementia. He experienced this dissatisfaction during a study in which he assessed the impact of a training program to facilitate successful visits between family caregivers and their relatives living in a dementia-specific residential care setting. Thereafter, work focused on developing a reliable and valid tool that was both useful and usable. The concepts of “reliable” and “valid” refer to standard goals in research. However, the concepts of “useful” and “usable” refer to practice in real-world settings. To be “useful,” the tool would have to facilitate the improvement of care practices. To be “usable,” the tool would have to be practical for use by direct care staff. We believe that the resulting tool and methodology serves the needs of both researchers and practitioners.

Throughout the 3 phases of this research program, background characteristics of people with dementia were collected consistently across different types of care settings. Most of these care settings were located in suburban locations near Chicago but in each of the 3 phases, at least 1 rural site was included.

Phase 1: Assessing relationships among dementia-specific QOL measures

Objectives

In the initial phase, a variety of existing dementia-specific QOL measures were assessed quantitatively in 3 types of dementia-specific care settings to identify relationships among these measures. Qualitatively, the perspective of practitioners regarding each measure and the information gained was used to determine the usefulness and usability of each measure.

Methods

Participants in this phase included residents and staff of 2 dementia special care nursing facilities (SCFs) and 3 assisted living facilities (ALFs), and clients and staff of 3 adult day centers (ADCs). See Table 1 for characteristics of study participants. Residents/clients with mild, moderate, and severe dementia were included. Dementia-specific QOL data were collected using 2 direct interviews with residents/clients, 2 staff proxy surveys, and 2 observational procedures. Research staff collected resident interview and observational data and site staff provided proxy data. Observational data were recorded every 5 minutes for 6 hours for each resident/client using each of the

| Resident/client characteristics: Phase 1 (N = 166) |
|-----------|---------|
| Age       | 83.5 (6.1) |
| % Female  | 75      |
| % White   | 96      |
| MMSE score| 10.6 (7.1) |
| Count of dependent ADL | 2.4 (2.2) |
| Depression | 0.3 (0.3) |
| Count of mild to severe comorbidities | 2.7 (1.8) |
| Length of stay, y | 2.0 (1.8) |

Abbreviations: ADL, activities of daily living; MMSE, Mini-Mental State Examination.

*Values given are mean (SD), unless otherwise indicated.
observational procedures. Data were analyzed and findings were discussed with practitioners at each study site. Practitioners were also asked to share their opinions about the utility of each measure. The measures and specific procedures employed are described elsewhere.9,10

Findings

Quantitative: Staff proxy surveys and observational data were available for 166 residents/clients; 88 people with a Mini-Mental State Examination (MMSE)11 score of 10 or more were able to complete direct interviews. The 2 direct interviews were strongly correlated with each other (r = 0.70, P < .001), but weakly or uncorrelated with either staff proxies or the observational measure (correlations ranged from 0.01 to 0.27, P values ranged from not significant to 0.01). One of the observational measures, the Affect Rating scale,8 was dropped from the quantitative analysis because it was not possible to develop an appropriate summary score for comparison with other measures. The 2 staff proxy surveys were moderately or strongly correlated with each other and the objective measure (correlations ranged from 0.44 to 0.62, P < .001 for all). Also, when the Dementia Care Mapping (DCM)7 observational measure was regressed on the other measures, 1 staff proxy and 1 resident interview each explained a small but significant amount of variance of the objective measure (r² = 0.12, P = .05 and r² = 0.05, P = .06, respectively). This finding that 2 types of measures helped to explain variance in a third type was not found when either the resident interviews or the staff proxies were used as dependent variables, suggesting that the observational procedure may be more inclusive in that it reflects the perspectives of people with dementia and staff, as well as the observer.

Qualitative: Following data collection, 1 or 2 staff members at each participating setting were asked to review each measure item by item and describe problems or concerns they had regarding specific items. In addition, staff members were asked to share their opinion of the utility of the information provided by each measure and the ease with which each measure could be implemented. Suggestions for wording changes and elimination of specific items in the direct interviews and staff proxies were provided. Staff varied in their preference for each of these measures. With regard to the observational procedures, staff preferred DCM because of the “richness” of the information it provided, but expressed major concerns regarding the time required to learn and to use the procedure.

Phase 2: Practitioner implementation of QOL measures

Objectives

The first objective in this phase was to develop and test a new observational procedure that practitioners would find useful in terms of improving dementia care, but would be deemed more usable than DCM in terms of its practical application and the resources required. The second objective was to enable practitioners to implement the 3 types of dementia-specific QOL measures: direct interviews, staff proxy surveys, and observations. The assumption was that staff would make more informed recommendations regarding the usefulness and usability of each measure after having the experience of collecting the data and evaluating findings on the basis of these data.

Methods

Residents/clients and staff of 2 SCFs, 2 ALFs, and 2 ADCs participated in this phase of the study. Dementia-specific QOL data were collected using the same direct interviews with residents/clients and the same staff proxy measures as in phase 1. DCM was retained, the Affect Rating scale was dropped, and a new observational procedure was introduced—OQOLD.

Data relevant to residents/clients at each site were collected on 3 occasions approximately 3 to 4 months apart (Table 2).

| **TABLE 2.** OQOLD resident/client characteristics: Phase 2 (N = 79)* |
|----------------------|------------------|
| **Age**              | 81.2 (6.7)       |
| % Female             | 61               |
| % White              | 99               |
| MMSE score           | 14.8 (6.8)       |
| Count of dependent ADL | 2.3 (1.9)      |
| Depression           | 0.3 (0.3)        |
| Count of mild to severe comorbidities | 2.9 (1.6) |
| % Length of stay     |                  |
| <1 y                 | 51               |
| 1–3 y                | 34               |
| >3 y                 | 15               |

Abbreviations: ADL, activities of daily living; MMSE, Mini-Mental State Examination.

*Values given are mean (SD), unless otherwise indicated.
Practitioners were trained to collect all data and they received booster training in the observational procedures prior to the second and third data collection periods. During data collection days, each observational procedure was completed using DCM and half were completed using OQOLD. Observational data were collected using the DCM methodology, that is, every 5 minutes for 6 hours, a score was recorded that reflected the status of the person with dementia during most of the 5-minute period.

The data were analyzed and detailed findings for residents/clients were presented to 2 participating staff members, the data collector, and her supervisor, during a debriefing session after each data collection period. Staff reviewed findings and discussed their interpretation of specific findings in light of their knowledge of residents/clients.

**Description of OQOLD**

OQOLD observers make systematic assessments of the QOL of people with dementia on the basis of verbal and nonverbal cues, and indicators of engagement and affect. To facilitate the most accurate judgments of QOL possible, to serve as an observer. This coding system is composed of a 7-point scale ranging from +3 (an extremely pleasant experience) to −3 (an extremely unpleasant experience). For the purpose of training and interobserver reliability, an information sheet is provided on which each point on the 7-point scale is formally defined. Definitions are accompanied by illustrations of faces that represent the experience as well as examples. Verbal anchors are also attached to the midpoint and endpoints of the scale (+3 = excellent, 0 = neutral, −3 = terrible). Below is an example for the highest possible OQOLD score.

**EXCELLENT.** An extremely pleasant experience. A very enjoyable OR high level of verbal or nonverbal engagement with others or an activity.

**Examples:** Having a very enjoyable conversation with another person(s), OR a very enjoyable interaction with a pet, OR a very enjoyable or high level of engagement in talking, singing, or playing games.

**Findings**

**Quantitative:** Quantitative findings focusing on the validity and reliability of OQOLD are described. Training of OQOLD observers was accomplished in 4 hours. Training included a discussion of person-centered care, a description of the OQOLD scoring procedure, role-playing of resident/client-staff interactions by trainers followed by a discussion of how to score each interaction, and observation/scoring of people with dementia in a skilled care setting followed by discussion of proper OQOLD scoring. Observations and scoring of residents followed by discussion continued until trainees’ OQOLD scores matched those of trainer’s scores 80% of the time during 10 consecutive observations. Reliability of trainees was usually attained in an hour. The same minimum 80% reliability with the trainer was achieved at each booster training session.

The validity of OQOLD was tested by comparing OQOLD scores to DCM scores. Observations using each method were conducted by 1 staff member at each site. Both OQOLD and DCM observations were conducted during alternate hours on each day of data collection. A strong correlation between the 2 observational procedures supported the validity of OQOLD (r = 0.75, P < .001). In a separate study of 11 residents/clients in an SCF and an ADC, a trained observer made 558 observations and coded residents/clients using both OQOLD and DCM simultaneously. The extremely high correlation provided further support for the validity of OQOLD (r = 0.98, P < .001). In addition, OQOLD was moderately/strongly correlated with the 2 staff proxy surveys (r = 0.62, P < .001 and r = 0.55, P < .001, respectively) and 1 of the direct interviews (r = 0.50, P < .001). It was also significantly correlated with related constructs such as number of dependent activities of daily living (r = −0.36, P = .003), cognitive functioning (r = 0.36, P = .003), and depression (r = −0.49, P < .001).

Finally, when OQOLD scores were validated against an adapted version of the Engagement scale using 2 independent observers (one used OQOLD and the other used the Engagement scale), an 89% match in scoring was achieved over 141 observations of nursing home residents.
Qualitative: Detailed findings from the 6 measures were presented to 2 staff members at each setting (the data collector and her supervisor) during debriefing sessions that followed each data collection period. Practitioners were asked to interpret the data in light of their knowledge of residents’/clients’ behavior and condition, as well as events that may have occurred at the time of data collection. In general, OQOLD scores accurately reflected residents’/clients’ condition and practitioners’ knowledge of residents/clients. For instance, at an ADC (described elsewhere in this issue), a decrease in OQOLD scores was attributable to a staffing shortage, resulting in the inability to provide small group activities to the most impaired participants.

A pilot test of the revised OQOLD procedure was conducted, followed by a study to attain phase 3 objectives. Residents/clients and staff of 2 SCFs, 2 ALFs, and 2 ADCs participated in the pilot test, and a new group of 6 dementia care settings participated in this phase. Staff collected OQOLD data for 20 residents/clients at each site in the pilot test and 10 residents/clients in this phase on 2 occasions, approximately 3 to 4 months apart. Practitioners received booster training in the use of OQOLD prior to the second data collection period. Following each data collection period, staff participants were asked how they had used the data or how they anticipated using data.

Phase 3: Adopting and adapting OQOLD

Objectives

Phase 3 objectives included determining which care settings adopted OQOLD into their practices and the ways in which practitioners implemented OQOLD. A final aim was to obtain the perspectives of practitioners about the benefits of OQOLD vis-à-vis their dementia care practice.

Methods

The OQOLD methodology was changed per suggestions of staff participants in phase 2. Rather than observing clients/residents every 5 minutes over a period of 6 hours, as in DCM, residents and clients were observed while participating in selected activities. Researchers and practitioners identified 5 broadly defined activities for each resident/client: (1) lunch; (2) a one-on-one activity; (3) a small group activity; (4) a large group activity; and (5) moving someone from one space or room to another and/or putting on or removing coats/sweaters (in ADCs). The OQOLD scale was used to assess QOL during these types of activities for each resident/client.

Another concern of phase 2 staff participants was that the data be accessible via a user-friendly system to facilitate timely decision making regarding care practices. Therefore, a Microsoft Access—based computer program was developed for data entry and information retrieval. Additional data in terms of the usefulness of the information may have occurred at the time of data collection. In general, OQOLD scores accurately reflected residents’/clients’ condition and practitioners’ knowledge of residents/clients. For instance, at an ADC (described elsewhere in this issue), a decrease in OQOLD scores was attributable to a staffing shortage, resulting in the inability to provide small group activities to the most impaired participants.

Practitioners indicated a strong preference for observational data in terms of the usefulness of the information and its potential to improve dementia care practice. However, they considered DCM to be too labor intensive because of the requirement of recording observations every 5 minutes for 6 continuous hours. Moreover, the fact that DCM did not provide feedback directly linked to the impact of staff-led activities was considered a major drawback. On comparing the 2 observational procedures, staff members were in agreement that OQOLD was more practical and less time-consuming to implement than DCM. Thus, OQOLD was targeted for further testing in phase 3.

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Findings

Although the phase 3 study has not concluded, findings from the pilot test and debriefings with staff participants identified some of the benefits of implementing OQOLD. Most of these initial findings relate to staff training:

- Data collected during lunch were presented to other staff to identify ways to improve the dining experience for residents.
- Observation of personal grooming of residents led to the conclusion that the activity was strictly task-oriented and opportunities for socialization were being missed.
- During a staff-led group activity, the observer noticed a resident who was not participating in staff-led activities, but was “doing his own thing.” Staff recognized that staff-led activities should be assessed in terms of actual impact on each individual rather than assuming that everyone benefits from the same activity conducted in the same way.
- A certified nursing assistant who collected OQOLD data reported that observing residents’ engagement and affect in a systematic manner gave her a new appreciation of her residents and the impact of staff on residents’ behavior and mood. As a result, the manager of the care setting expressed interest in training all certified nursing assistants and activity staff to use OQOLD to afford them the same learning experience.
- At one site, staff used OQOLD to conduct a small experiment that influenced an individual’s care plans. A married couple lived in a retirement community and the husband’s dementia had worsened to the point that staff wanted him to eat his meals at the care center instead of the main dining room. His wife did not want to take her meals apart from her husband, nor did she want to eat meals in the care center. The staff decided to observe the husband using OQOLD in both dining rooms and determined that eating in the main dining room was indeed beneficial to him, and consequently the husband and wife continued eating meals together.

Summary

This 3-phase research program has demonstrated the validity of OQOLD when compared with dementia-specific measures that employ direct interviews, staff proxy interviews, and other observational procedures. Inter-rater reliability was obtained after approximately 4 hours of training and practice. Practitioners who helped develop OQOLD attested to its usefulness and usability for their care settings. Initial benefits from the use of OQOLD have been identified and additional applications will be reported in the future.

The usefulness of OQOLD has been demonstrated for individuals with mild, moderate, and severe dementia. A potential limitation to the applicability of OQOLD is for those individuals who are so severely impaired that both interaction and affect are minimal. The OQOLD scale may be inadequate for detecting very subtle signs and indicators of mood and engagement that are present in people with dementia near the end of life. The next section of this article describes the adaptation of OQOLD to address this issue.

Observing QOL in Dementia Advanced

Little attention has been given to measuring QOL in persons with advanced dementia—those who are unable to express or interpret language, no longer can walk independently, and require total care. It is difficult for caregivers to determine whether or not their efforts and interactions optimize comfort and QOL in these individuals. Persons with advanced dementia typically demonstrate a blunted or flattened affect, and struggle to convey thoughts and feelings. Traditional methods of assessing affect, language, and engagement to evaluate the subjective experiences of the person with advanced dementia are limited. Thus, caregivers must be sensitive to subtle indicators of a person’s pleasure, comfort, level of engagement, and affect related to QOL.

Up to 90% of people with advanced dementia reside in residential facilities in the final 1 to 3 years of life, as they require total care to meet their daily needs. For those living in nursing facilities, the Minimum Data Set, Version 2.0, is used to measure participation and response to staff-led activities. However, residents with advanced dementia score at the lowest levels in most of the indicators using the Minimum Data Set. Small changes in mood, affect, and behavior, which may reflect improved QOL, cannot be captured in this process. Likewise, for persons with advanced dementia who are enrolled in hospice care, benefits are tied to decline rather than capturing improvement in everyday living. Staff must provide documentation of the resident’s decline over time to ensure retention of hospice benefits from one certification period to another. Yet, individuals with advanced dementia can experience good QOL when family and professional caregivers engage them in personalized and meaningful activities. A method to capture quality moments and the impact of interventions was needed.

Background

After attending a presentation on OQOLD at a national conference, the potential benefits of this tool were...
recognized, and the decision was made by the last 3 coauthors to adapt OQOLD for use with persons with advanced dementia. The tool was modified to capture the more subtle or muted changes in affect, engagement, and body language. Thus, the OQOLDA scale was developed to measure a model of care known as “Palliative Care for Advanced Dementia.” Preintervention and postintervention data were collected on residents at 4 facilities in a major city in the southwestern United States.

### Methods

The sample consisted of 30 residents who met the inclusion criteria of advanced dementia. Participants with advanced dementia had an MMSE score of less than 10 or more and a Functional Assessment Staging Tool (FAST) score of 7a-e.18 Table 3 lists the demographic characteristics of participants.

The OQOLDA scale was modified from OQOLD by specifying subtle signs of both positive and negative affects and engagement for people with advanced dementia. These included changes in eye contact, verbalization/vocalization, facial expression, breathing, body movement/position, and social interaction. The 7-point scale from OQOLD was retained to document changes along the +3 to −3 range. However, the pictures of faces from OQOLD were eliminated, because they provided visual cues that could inappropriately be overweighted in making assessments in comparison with the verbal descriptors of each point on the scale. As with OQOLD, observers are instructed to look for any nonverbal and/or verbal forms of engagement or affect that align with points on the scale and to select the appropriate rating. Similar to the OQOLD methodology, the person being observed is assigned 3 OQOLDA scores for each activity: (1) the “most” sustained affect/engagement; (2) the “best” affect/engagement; and (3) the “worst” affect/engagement. Table 4 shows an example for the highest possible OQOLDA score.

Activities were observed for 15 minutes and included mealtime, brief change/toileting, and 1 individualized activity that caregivers determined as highly pleasurable.

### Table 3.

<table>
<thead>
<tr>
<th>OQOLDA resident/client characteristics</th>
<th>(N = 30)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, mean (SD)</td>
<td>85.0 (7.8)</td>
</tr>
<tr>
<td>Female</td>
<td>77</td>
</tr>
<tr>
<td>White</td>
<td>87</td>
</tr>
<tr>
<td>Widowed/married</td>
<td>63/20</td>
</tr>
<tr>
<td>High school diploma or less</td>
<td>70</td>
</tr>
<tr>
<td>MMSE score = 0</td>
<td>80</td>
</tr>
<tr>
<td>FAST stage = 7c(^b)</td>
<td>70</td>
</tr>
<tr>
<td>Level of consciousness: % Alert/drowsy</td>
<td>69/24</td>
</tr>
<tr>
<td>Length of stay, y, mean (SD)</td>
<td>2.4 (2.0)</td>
</tr>
</tbody>
</table>

Abbreviations: FAST, Functional Assessment Staging Tool; MMSE, Mini-Mental State Examination.

\(^{a}\)Values given are percentages, unless otherwise indicated.

\(^{b}\)A score of 7a–e classifies advanced dementia. A score of 7c is a person who is nonambulatory or unable to walk without assistance.

### Table 4.

<table>
<thead>
<tr>
<th>Quality of experience</th>
<th>Nonverbal engagement</th>
<th>Verbal engagement (verbal and vocal cues)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very pleasant +3</td>
<td>Eyes: Bright, prolonged direct eye-to-eye engagement</td>
<td>Intelligible/unintelligible words, phrases, or sentences or silent formation of words, which demonstrate positive meaning related to the context of the activity or stimulus (eg, laughter, singing, pleasurable sighs)</td>
</tr>
<tr>
<td>The highest level of engagement or positive affect</td>
<td>Face: Alert or animated, laughing/smiling during verbal or nonverbal engagement with others or an activity</td>
<td>Motor: Body is relaxed, demonstrates more prolonged moments and/or increased range of motion in response to the stimulus, clapping/patting, tapping, demonstrated attempt to move toward the stimulus</td>
</tr>
<tr>
<td></td>
<td>Dining: Reciprocity, giving back, feeling a connection with the dining experience and the caregiver</td>
<td></td>
</tr>
</tbody>
</table>
for the person with advanced dementia. The observation time was determined with consideration to the person’s slow reaction time and the time necessary to assess a change in affect and engagement. The OQOLDA scale was piloted using nurse practitioner students as trained observers. The tool was tested further by trained observers in the 4 skilled nursing facilities included in the study. It was also implemented to ascertain reliability and to examine the validity of OQOLDA. Observers recorded participants’ level of consciousness as alert, drowsy, stupor, or coma as a variable that could be used to validate OQOLDA scores.

Findings

Intraclass correlations were computed to examine interrater reliability. Two different models of intraclass correlations were used. First, a 1-way random effects model was used to examine differences in 6 observers’ ratings of residents participating in up to 3 activities—a meal, a favorite activity, and change of briefs. Thus, each resident could be observed on 3 occasions (specifically, 63 observations). In this model, differences in the ratings of the residents are of interest without regard to differences among observers. In the second model, a 2-way random effects model was used to examine not only the ratings but also the observers themselves. In particular, differences between all observers and the ‘master’ observer were examined. In both models, absolute agreement on individual OQOLDA ratings was evaluated. Results from the analysis of the first model suggest strong interrater reliability for “most” (0.87, P < .001), “best” (0.91, P < .001), and “worst” (0.95, P < .001). Results from the analyses of the second model are displayed in Table 5. These data also suggest strong interrater reliability. In summary, strong interrater reliability between 5 observers and a master observer, as well as generally across these observers, was demonstrated for the ratings of “most,” “best,” and “worst” OQOLDA scores.

Multiple observations for each individual related to the most frequently observed QOL, the best QOL observed, and the worst QOL observed were then aggregated to produce 3 average scores for each individual: “most,” “best,” and “worst.” The relationship of these average scores to other variables was then examined. Correlations of these 3 scores with age and length of stay indicated that age was significantly correlated with “worst” (−0.32, P = .043), marginally correlated with “most” (−0.26, P = .075), but not correlated with “best” (−0.05, P = .433). Length of stay was marginally correlated with “most” (−0.54, P = .001), “best” (−0.34, P = .038), and “worst” (−0.32, P = .046). Because of the high proportion of individuals with an MMSE score of 0, correlations of MMSE scores with “most,” “best,” and “worst” are not appropriate. Instead, MMSE scores were dichotomized (MMSE score = 0 vs 1+) and t tests conducted. No significant differences in “most” or “best” scores were identified (Table 6). There was a marginally significant difference in worst scores; those with an MMSE score of 1+ had a lower mean worst score than those with an MMSE of 0.

Similarly, the variable indicating level of consciousness was dichotomized from 4 choices (alert, drowsy, stupor, coma) to alert versus drowsy or worse, and t tests conducted. These tests indicated significant differences in most scores by level of consciousness (see Table 6). Specifically, those identified as alert had a higher mean “most” OQOLDA score than those identified as drowsy or worse. Marginally significant differences were also identified in best scores; those identified as alert had higher best scores than those identified as drowsy or worse. No differences in worst score were identified by level of consciousness. Because of a nonnormal distribution, FAST scores were

| TABLE 5. Interrater reliability: 2-way random effects model intraclass correlations |
|---------------------------------|-----------------|-----------------|-----------------|
| Master rater and N               | Most P          | Best P          | Worst P         |
| Rater 1 (N = 11)                 | 0.75 (.002)     | 0.93 (.001)     | 0.79 (.001)     |
| Rater 2 (N = 4)                  | 0.95 (.007)     | 0.73 (.08)      | 0.91 (.02)      |
| Rater 3 (N = 22)                 | 0.76 (.001)     | 0.91 (.001)     | 0.98 (.001)     |
| Rater 4 (N = 19)                 | 0.92 (.001)     | 1.00 (.001)     | 0.93 (.001)     |
| Rater 5 (N = 23)                 | 0.84 (.001)     | 0.97 (.001)     | 0.98 (.001)     |
categorized into 3 groups: (1) FAST stage = 6c, 7a, or 7b (highest functioning); (2) FAST stage = 7c; and (3) FAST stage = 7d or 7e (lowest functioning). Because only 2 individuals were in group 3, this group was not analyzed. Then, t tests were conducted to examine differences in “most,” “best,” and “worst” scores between FAST groups 1 and 2. These tests identified significant differences in “best” scores. Specifically, those in FAST group 1 (higher functioning) had higher mean “best” scores than those in FAST group 2 (again, see Table 6). No differences in “most” or “worst” scores were identified between these 2 groups.

Validity analyses showed that “most” scores were significantly related to level of consciousness, that “best” scores were significantly related to level of functioning and marginally related to level of consciousness, and that “worst” scores were marginally related to MMSE scores. These findings were all in the predicted direction. Although additional data collection is planned, these analyses provide initial support for the validity of OQOLDA.

OQOLDA case study

Mrs T was enrolled in hospice with a primary diagnosis of dementia and an MMSE score of 8. At the time of admission to hospice, she was not eating and was losing weight. When the care staff began working with Mrs T, she would ignore them or say, “I hate you—go away!” An OQOLDA score of −3 was assigned to Mrs T’s reactions to staff as she demonstrated direct, glaring eye-to-eye engagement, and repeated statement indicating an extremely unpleasant response.

The team began to give Mrs T some pleasant sensory experiences, and quickly learned that she loved chocolate. When eating chocolate, Mrs T’s OQOLDA score, which began at −3, transitioned to moments of +2. Caregivers at the facility began to notice and comment in amazement that it was possible to influence Mrs T’s reactions. However, this was short-lived and Mrs T once again began her verbal assaults and became combative with personal care (OQOLDA score = −3).

Laurie, a certified nursing assistant, learned of Mrs T’s past interest in cats and put together a poster of cats for her room. While Laurie provided personal care, she directed Mrs T’s attention to the photos and a discussion of cats. Laurie observed Mrs T slowly transition from −3 to +1 for approximately 10 minutes while completing personal care. Karen, a licensed practical nurse, asked Mrs T if she had pain to which she replied, “No.” Karen noted that Mrs T generally exhibited an OQOLDA score of −2 or −1 at best, and assessed that physical pain could be contributing to her negative experiences. Karen began routine acetaminophen for Mrs T but did not see much change. One day Mrs T said that she was having pain and the team changed her pain medication. Her verbal assaults and resistance to personal care went away, resulting in an increase in her score to 0. Staff learned to utilize Mrs T’s favorite sensory experiences to provide increased moments of enjoyment and pleasurable distracters during personal care tasks. Staff took pride in their new ability to help Mrs T achieve a score of +3. In contrast to “I hate you—go away,” Mrs T now reaches out to staff to talk with

### TABLE 6.
Significant t tests of most, best, and worst OQOLDA score by dichotomized MMSE score, dichotomized LOC, dichotomized FAST scorea

<table>
<thead>
<tr>
<th>OQOLDA score</th>
<th>MMSE = 1+ (N = 6)</th>
<th>MMSE = 0b (N = 23)</th>
<th>One-tailed significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Worst LOC Alert+ (N = 20)</td>
<td>−1.1 (1.5)</td>
<td>−0.3 (1.1)</td>
<td>.077</td>
</tr>
<tr>
<td>LOC = Drowsy or worse+ (N = 7)</td>
<td>0.9 (1.0)</td>
<td>0.3 (0.4)</td>
<td>.020</td>
</tr>
<tr>
<td>Best Higher functioning group+ (N = 7)</td>
<td>2.0 (0.7)</td>
<td>1.5 (0.6)</td>
<td>.081</td>
</tr>
<tr>
<td>Lower functioning group+ (N = 20)</td>
<td>2.5 (0.6)</td>
<td>1.8 (0.7)</td>
<td>.007</td>
</tr>
</tbody>
</table>

Abbreviations: FAST, Functional Assessment Staging Tool; LOC, level of consciousness; MMSE, Mini-Mental State Examination.

aValues given are mean (SD).

bLower functioning individuals have less ability to express negative emotions; thus, their “worst” score was expected to be closer to 0.
Experience using OQOLDA at this stage of the applied research has resulted in one refinement to the procedure. First, the decision was made to eliminate brief change/toileting from the observed activities for data collection. Although the purpose of scoring brief change was to inform caregivers that they could make this often times distressing experience more comfortable, it was found to be too intrusive of a person’s privacy. Data collection currently focuses on 2 activities: dining and ‘best activity.’ In addition, the 15-minute observation time was reduced to 5 minutes in duration after repeatedly observing that persons with advanced dementia appear to become fatigued and struggle to stay engaged in activities for longer periods.

In addition to this change in procedure, an additional change is being considered. A difference between observers’ use of OQOLDA has been noted. For example, observer #1 might rate the person’s worst OQOLDA score a ‘+1’ and the ‘best’ response a ‘+3.’ At the same time, observer #2 might rate the worst score a ‘0’ and the ‘best’ response a ‘+2.’ Although the difference between the worst and best scores is the same, the absolute value of the scores is different. Accordingly, a 5-point OQOLDA scale (−2 to +2) is being tested as an alternative.

DISCUSSION

Observational tools such as OQOLD and OQOLDA are critical for a number of reasons. First, the ability to reliably and validly assess QOL refutes the lingering myth that people with dementia lose their identity or their capacity for enjoyment. Specific changes in affect and engagement reflect their reactions to care practices and the overall environment. Assessing the impact of interventions among people with dementia is challenging, but it is clear that there is a link between care practices by staff and QOL of people with dementia. Even people with advanced dementia continue to reflect and communicate the impact of caregiving interactions. Although their expressions may not be the same as they were earlier in dementia, they still provide valuable clues that inform and direct caregiving efforts.

QOL information is also needed to ensure that programs and services maximize the QOL of people with dementia. Creating the proper environment (physical, social, spiritual, programmatic, etc) where people with dementia can thrive requires an understanding by caregivers about the impact of the environment. Structured observations such as those required by both OQOLD and OQOLDA are often enlightening to caregiving staff. The observational experience enables them to carefully focus on engagement and affect of residents/clients and see the immediate effects of interactions.

The data obtained from these procedures have been successfully used to test new interventions and adjust care plans, as well as to identify the consequences of ongoing care practices. The quantitative data that these methods provide, especially in combination with qualitative feedback from staff, may be more comprehensible to family members who are trying to understand their relatives’ dementia and plan for their care. In addition, both OQOLD and OQOLDA might be helpful to assessors from regulatory and accrediting agencies, as well as in evaluating the impact of drug trials and other interventions.

Assessing the well-being of residents and clients is a natural component of the work of most practitioners. Knowledgeable and caring staff members possess crucial information related to the QOL of people with dementia. The tools described in this article provide systematic information that complements what staff know and feel. Both OQOLD and OQOLDA provide information that differs from the qualitative perspective of staff, enabling care decisions to be based on valid and reliable data.

While the effort to validate OQOLD has been extensive, validation is continuing with OQOLDA. To further increase the utility of OQOLD, a data entry system for hand-held personal computers is in the planning stage. Also, a video is available to train staff in dementia care settings to use OQOLD. The video includes interactions between staff and people with dementia that were scored by the developers of OQOLD. These scored interactions can be used to conduct booster training and ensure reliability among staff as well as with the developers of OQOLD.

Future research is needed to identify at what point in the disease process OQOLD is less useful in comparison with OQOLDA. When do the signs and indicators of affect and engagement become too subtle for observers using OQOLD to distinguish different levels of QOL? A comparison study of OQOLD and OQOLDA with individuals in advanced dementia will answer this key question.

These 2 observational procedures provide researchers with a new methodology for data collection that has demonstrated advantages over other methods. Moreover, because the development of these procedures was guided by the experience, advice, and hands-on use by practitioners in different care settings, the tools are both useful and usable.

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to practitioners. Both OQOLD and OQOLDA can help professional caregivers understand and experience the numerous opportunities they have to profoundly impact the QOL of people with dementia. These tools illuminate opportunities to affirm, enhance, and optimize well-being. Furthermore, by enabling staff to measure their impact, these tools invite practitioners to experiment with and expand care approaches. Caregivers may gauge the impact of their interactions, feel more confident in their abilities, and find personal rewards in their work. Most importantly, people with dementia may receive care that upholds their personhood and may experience QOL that transcends the boundaries of their impairments.

This article is dedicated to the memory of Dr Roseann Kasayka who assisted with data collection and was a pioneer in person-centered care.

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Address correspondence to: Perry Edelman, PhD, Mather LifeWays Institute on Aging, 1603 Orrington Ave, Suite 1800, Evanston, IL 60201 (pedelman@matherlifeways.com).

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