

Definition, Measurement, and Correlates of Quality of Life in Nursing Homes: Toward a Reasonable Practice, Research, and Policy Agenda

Rosalie A. Kane, PhD¹

Purpose: This article identifies challenges in defining, measuring, and studying quality of life of nursing home residents. **Design and Method:** A theoretical analysis was conducted based on literature and the author's own large-scale studies of quality of life of nursing home residents. **Results:** Measuring quality of life is a relatively low priority in nursing homes because of focus on markers of poor quality of care, pervasive sense that nursing homes are powerless to influence quality of life, and impatience with research among those dedicated to culture change. The research argues that the resident voice must be sought in reaching operational definitions for quality of life and as reporters on the quality of their own lives, and that resident burden is a spurious concern that should not deter direct interviews with residents. Five challenges in measuring quality of life were identified: (a) designing questions with appropriate response categories and time frames, (b) developing a sampling strategy, (c) aggregating information at the individual and facility level, (d) validating what are ultimately subjective constructs, and (e) developing an approach using observations and proxies to assess

quality of life for approximately the 40% of the residents who will be impossible to interview. **Implications:** Although residents' perceived quality of life is partly a product of their health, social supports, and personalities, nursing homes can directly influence quality of life through their policies, practices, and environments, and, indirectly, through their approaches to family and community. A research agenda is needed, which includes both methodological research and studies of the correlates of quality of life.

Key Words: Quality of life, Quality of care, Measures, Indicators, Direct interviews, Nursing home residents, Cognitive impairment

Despite widespread beliefs among lay and professional people alike that life in nursing homes is miserable, quality of life (QOL) hardly makes it to the political and policy radar screen. Arguably, QOL will receive sustained attention only with a multi-pronged approach that includes both methodological development and an action agenda.

Why QOL in Nursing Homes is a Low Priority

First, those who believe that nursing home QOL ranges from bad to unspeakably abysmal rarely focus on improving it. They tend to accept the litany of problems in nursing home life as a given: hospital-like physical settings, rigid routines for daily life, general lack of privacy, lowest-common denominator programming, and perennial evidence that staff are too few and too poorly trained to meet the residents' physical needs, let alone their higher-order needs that affect their perceived QOL. The metaphor of incarceration is accentuated by locked doors, and the historical metaphor of the poor house is accentuated by the wide variety of physical and

This article was prepared for the Pepper Center, Florida State University/NIA Conference, "Challenges in Nursing Home Care," Tallahassee, Florida, March 19-21, 2002. The author's empirical research in this area is largely conducted under contract from the Centers for Medicare and Medicaid Services (Master Contract 500-96-008), but the conclusions and ideas in this article are those of the author and are not necessarily those of CMS or its employees. Rosalie Kane has also received support for conceptual work in this general arena under a Robert Wood Johnson Foundation Investigator Award in Health Policy. The author thanks her research colleagues who provided insight into this topic: Boris Bershadsky, Lois J. Cutler, Howard B. Degenholtz, Katherine Giles, Robert L. Kane, Kristin C. Kling, and the late M. Powell Lawton.

Address correspondence to Rosalie A. Kane, PhD, Division of Health Services Research and Policy, School of Public Health, University of Minnesota, 420 Delaware Street, S.E., Box 197, D-527 Mayo Building, Minneapolis, MN 55455. E-mail: kanex002@umn.edu

¹Division of Health Services Research and Policy, School of Public Health, University of Minnesota, Minneapolis.

mental disabilities of the residents, most of them poor and the rest without easy access to their resources, who are crammed into close quarters. Disability activists express little interest in marginally improving institutions they are trying to eliminate, especially because a relationship can be shown between dollars spent on nursing homes and dollars left over for other forms of care (Kane, Kane, & Ladd, 1998). Their recipe for QOL of older people requires staying out of nursing homes.

Second, those most involved in changing nursing home culture are not measurement-oriented. Recently, attention to QOL in nursing homes has been catalyzed by the Nursing Home Pioneers, later the Pioneer Network in Long-Term Care (Fagan, Williams, & Burger, 1997; Lustbader, 2000), which seeks a radical transformation in the relationships and structure that prevail in nursing homes and affect both residents and staff. A related movement, the Eden Alternative, outlines an approach for ending boredom, loneliness, and lack of meaning in nursing homes through creating a habitat in which all life can flourish (Thomas, 1999). Themes in recent culture change efforts include empowerment of nurse's aides and development of universal workers, breaking down of hierarchical management; modifying physical space by creating smaller residential areas, sometimes called households, neighborhoods, or clusters; emulating homes by giving residents in their households access to kitchens, laundry rooms, and the like; extending the times and choices for dining and improving ambience; respecting and enhancing individuality and individual interests rather than striving for high counts at large organized activities; regular community meetings of the resident group, along with resident input into governance and decisions affecting everyday life; and provision of a range of supportive practices for dying residents designed to help the resident, staff, other residents, and family, including individualized memorials after a resident's death. Each step toward culture change is celebrated, but the inclination is to forego formal tests of whether resident QOL has been affected. The very act of measuring QOL may seem to the reformers to be a dehumanizing activity.

Third, concomitant with improvement and standardization of resident assessment, attention has been riveted on markers of poor health care, such as dehydration, urinary tract infections, malnutrition, bedsores, excessive use of hypnotics and antipsychotic medications, undertreatment of depression, weight loss, uncontrolled pain, and the like. With frequent reports that nursing homes are providing substandard care on these parameters (General Accounting Office, 1999a, 1999b; Office of the Inspector General, 1998, 1999a, 1999b), some policy makers consider QOL concerns frivolous. For example, an Institute of Medicine (IOM) committee described some improvements but found substantial problems remaining in

nursing home care even since regulatory reforms of 1987 ushered in by a previous Committee (IOM, 1986). Although the new Committee acknowledged that QOL in nursing homes was a problem, it recommended increases in nursing staff and stronger enforcement of care standards rather than tackling QOL head-on (Wunderlich & Kohler, 2001).

Need for Priority Shifts

In the U. S. regulatory context, QOL is ostensibly an important value for nursing home residents, but is typically modified heavily by safety concerns. Since 1987, nursing homes have been explicitly enjoined to provide the best QOL and the most personal autonomy possible for residents consistent with health and safety outcomes (IOM, 1986). But, consider if the constraint were reversed. Then, facilities would be expected to provide the safest circumstances and the best health outcomes that are consistent with residents living meaningful lives that they themselves perceive as having a good quality.

Compelling reasons remain for health and human service professionals to focus on QOL in nursing homes. In the name of health care, residents have altered the conditions of their lives for long periods of time, often forever. Health professionals and the society that urges such dramatic shifts in life conditions for seniors have some responsibility for residents' QOL. Furthermore, older people with disabilities and the financial means to afford it are attracted to assisted living apartments in large part because of presumed QOL benefits. To avoid recreating within assisted living the aspects of nursing homes that most negatively impinge on QOL, we need to understand the phenomenon of QOL better. Trying to improve QOL is ethically superior to creating a societal institution that is often seen as worse than death (Mattimore et al., 1997) and then suggesting, as sometimes is done with the concept of quality-adjusted life years, that living in nursing homes is de facto a dependent and devalued form of life. Rather than empathizing with that position (and with those who chose physician-assisted suicide instead of nursing homes), we surely should endeavor to understand and improve QOL in nursing homes or other residential organizations.

Defining QOL

QOL is the territory of novelists and philosophers. In the waning decades of the 20 years of the 20th century, it also became the province of psychometricians, health services researchers, and health policy makers, who have tried to translate the construct into one or more scales to use to measure the deliberate outcomes of health interventions or consequences of health care gone wrong. QOL is sometimes contrasted with more narrow outcomes

related to physical health. Some simply use QOL as summary term, connoting a multidimensional appraisal of a variety of important aspects of life, including health outcomes (Arnold, 1991). When used this way, QOL is either summarized into a single score or profiled in a series of scores reflecting different components or domains of QOL. The term health-related QOL (HRQOL) narrows the QOL concept to aspects of life affected by a person's health condition and its treatment; literally hundreds of HRQOL measures are available, some relating to general health-related QOL and some to QOL related to a specific disease. Thinking about adults of all ages, some commentators state that the agreed upon domains of HRQOL are: physical health and functioning, emotional health, cognitive functioning, role performance and work productivity, sexual functioning, and life satisfaction. To reduce such dimensions to a smaller number of items, the SF-36 measure was created; it has been further shortened, and its various versions are frequently used to measure QOL (McHorney, Ware, Lee, & Sherbourne, 1994; Ware & Sherbourne, 1992). In the same vein, the World Health Organization (WHO) has created the WHOQOL, a 28-item questionnaire that includes items tapping a wide range of physical, functional, psychological, social, and satisfaction elements (Kuyken & Orley, 1999) and the EuroQol reduces HRQOL to five items, each tapping one domain: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression (Dolan, 1997).

In some health contexts, HRQOL is narrowly interpreted. For example, in the 1960s, measures of the ability to perform activities of daily living (ADL) was proposed as a way of looking at outcomes for rehabilitation patients that went beyond disease parameters to consider QOL (Katz, Ford, Moskowitz, Jackson, & Jaffee, 1963). Four decades later, the widespread acceptance of ADL scales remains a substantial accomplishment, yet the ability to toilet, eat, transfer, dress, and bathe independently should hardly be equated with having a good QOL. Similarly, in the oncology literature, a disease-free interval sometimes stands in for QOL, but now broader applications in oncology look to psychological well-being and social involvement as signifying QOL. Because the condition of the lives of older people is significantly altered when they move to nursing homes, a broader concept of QOL is indicated than mere HRQOL.

QOL for Older People

What would be the relevant dimensions of a broad concept of QOL for older people? Three edited volumes have appeared since 1991 summarizing QOL for elders (Abeles, Gift, & Ory, 1994; Birren, Lubben, Rowe, & Deutchman, 1991; Noelker &

Harel, 2001). Taken together, these chapters cover a wide variety of topics, including social, psychological, environmental, functional, health, and family dimensions. In the first of these volumes, Lawton proposed a model of QOL that would include behavioral competence (assessed by third parties); perceived QOL (with items paralleling behavioral competence spheres, but assessed through the subjective appraisal of the older person); environmental dimensions (i.e., objective features of the social and physical environments that might influence outcomes); and psychological well-being, the latter perceived as "the ultimate outcome in a causal model" (Lawton, 1991, p. 11). In this formulation, Lawton also stressed that QOL has temporal dimensions, including reflection on the past and expectation of the future, as well as appraisal of the present, a comment also made by Atchley (1991) in his emphasis on the need for cues in the present that reinforce identity, and by Svensson (1991) in his claim that people who evaluate their QOL "must engage in some form of autobiographical process with the intention of evaluating and synthesizing the meanings and involvements that have been experienced so far" (p. 258); and that those who compose a successful synthesis are most likely to experience a good QOL. Similarly, Katz and Gurland (1991) posit a holistic concept that they call "an irreducible network of interwoven parts, encompassing the elders themselves (mind, body, and spirit), their animate and inanimate environment, their life experiences in time and space, and the functions or powers created by the interwoven parts" (p. 341). One proposed conceptual framework lays out 14 domains of QOL for older people: physical functioning, self-maintenance, usual activities, social functioning, sexual functioning and intimacy, psychological well-being and distress, cognitive functioning, pain and discomfort, energy/fatigue, sleep, self-esteem, sense of mastery, perceived health, and life satisfaction; many of these domains were organized into subcategories (Stewart & King, 1994). QOL is clearly a multidimensional construct, but which and how many dimensions are appropriate to tap when considering the well-being of older individuals who receive long-term care is less clear.

QOL for Nursing Home Residents

In 1998, the University of Minnesota was contracted to develop and test measures and indicators of QOL for nursing home residents. As part of the nursing home regulatory reforms of 1987, Centers for Medicare and Medicaid Services (CMS) previously had commissioned the development of a standardized Minimum Data Set (MDS) to assess nursing home residents (Morris et al., 1990). By 1998, all nursing homes accepting federal funds were mandated to collect MDS data from all residents at

mandated intervals and to submit these data electronically to CMS. By that time, too, CMS had gained considerable experience with constructing MDS-derived quality indicators to help guide its inspection process (Zimmerman et al., 1995). Therefore, our work at the University of Minnesota called for developing QOL measures that reflected domains that were either omitted from or not especially emphasized in the MDS. Adding to the complexity of QOL assessment by and about residents with moderate-to-severe cognitive impairment for whom inference about important aspects of their QOL is difficult, we need to ask what elements should be examined for nursing home residents with reasonably good cognitive functioning.

The inquiry needs to be brought to older long-term care consumers themselves. The exercise of asking older people what is important to them with reference to their QOL is an essential step in defining the constructs, but is fraught with peril. If older people with no need for long-term care are polled, they may have different and higher expectations for their QOL than their more frail counterparts. They may also be more willing to perceive that a decent QOL is possible even when one has contracted difficult conditions (e.g., stroke, Parkinson's disease, severe arthritis, dementia) that create the need for long-term care. Given problems in learning directly about the values and preferences of nursing home residents, the information is most often gathered on small samples of the residents easiest to interview or engage in focus groups. These limitations notwithstanding, research evoking the resident voice on the elements of a good QOL tends to find that residents care about aspects of relationships, activity, stimulation, and security (Abt Associates, Inc., 1996; Cohn & Sugar, 1991; National Citizens' Coalition for Nursing Home Reform, 1985). Commentators also stress the importance of control and autonomy, bringing both theory and empirical findings to buttress that contention (Abeles, 1991; Kane et al., 1997).

New standards on Quality of Life and on Residents' Rights were promulgated in 1987. These standards emphasize the maintenance of the dignity of the individual, provision for individual choices, opportunities for residents' participation in their own care planning, resident choices about how to spend their time, resident involvement in facility governance, and staff respect for each resident's individuality and preferences. The Residents' Rights standard additionally asserts rights to association, privacy, information, and the full gamut of civil rights of citizens. Because these elements have been associated with nursing home QOL, they should be incorporated into QOL measures.

No single correct solution is possible in selecting domains for a comprehensive view of QOL for nursing home residents. The number of domains used to assess QOL in operational programs will depend as much on the data collection budget as on any

theory of human development. In our own recent work, we identified 11 previously unmeasured aspects of QOL for which we attempted to develop measures: autonomy, dignity, privacy, individuality, security, comfort, relationships, meaningful activity, enjoyment, functional competence (defined as being as independent as one wishes within the constraints of one's physical and mental abilities), and spiritual well-being (Kane, 2004). In proposing these domains, we had no illusion of being exhaustive. Certainly, extant self-report tools can measure emotional well-being, functional abilities, perceived health, and life satisfaction as candidate additional domains. With these four additions, a broad array of important elements would be covered, but decisions are still needed about the boundaries for each domain. For example, we omitted sexual functioning, which could be perceived as an important relevant domain in its own right or as a subdomain under the relationships domain. Such omissions may be justified by awareness that selective optimization leads many nursing home residents to abrogate their sexual lives (Baltes, 1994). Similarly, we might have explored the entire arena of productive activity in employment and volunteering sectors, but, assuming little opportunity or ability for such activity, we merely included one item about help to others inside and outside the nursing home as a type of meaningful activity. Also, we excluded financial security, which community-dwelling seniors view as important to QOL and which is far from irrelevant to nursing home residents, many of whom express anxiety over the costs of care. In specifying the financial security domain in nursing homes, it would be necessary to decide how to treat the spend-down phenomenon; those who spend their resources to be eligible for Medicaid experience some relief of financial worries, but becoming pauperized could surely lead to a reduction in perceived QOL for those residents who are conscious of their dependent financial status.

To add complexity, what constitutes a good QOL in a nursing home may vary from culture to culture and from country to country. For example, privacy and autonomy may be more important values in the United States, Canada, and much of Europe than in many other countries, particularly than in less affluent ones. Differences also are likely, of course, within subgroups within a country. Most work on QOL in nursing homes in the United States has been done in the English language. Moreover, given that relatively few persons of color reside in nursing homes, research samples usually have too few members of minority groups to develop information about their preferences.

Challenge of Assessing QOL

Source of Data

QOL can be assessed directly by asking questions of residents themselves. It can also be assessed

through proxy informants, such as staff members or family members who are presumed to know the resident well, or be inferred by observing the resident's behavior, or by collecting information about the physical, social, and care environments thought to be related to QOL. Each type of inference moves further away from the individual self-report, which arguably is at the heart of QOL assessment. Attributes of the environment, program, and services are better seen as indicators rather than measures. Good indicators show a statistically significant relationship to QOL, but they cannot predict any given individual's QOL.

When data from both the subject and a proxy are available for comparison, correlations are often poor. Research is now available about the adequacy of proxy informants, which can be summarized optimistically or pessimistically depending on how exact a concordance the researcher seeks. However the data are summarized, they cast enough doubt to make it seem unjustified to use proxies as the sole source of data when residents themselves can self-report. Proxy inaccuracy may be compounded for nursing home residents if families visit infrequently or staff are not well acquainted with residents. In our CMS study, family and staff appraisals of the QOL of specific residents were significantly correlated with the residents' own appraisals, but substantial differences occurred in matched-pairs item responses (Kane et al., 2000). Additionally, a small test showed substantial variation between two staff members reporting on the same resident, suggesting that staff reports would be influenced by the idiosyncracies of the choice of reporter.

Several researchers have successfully rebutted the claim that people with dementia cannot reliably report their QOL (Brod, Stewart, Sands, & Walton, 1999; Logsdon, Gibbons, McCurry, & Terri, 1999). We, too, found that substantial numbers of residents who scored poorly on a cognitive score derived from their MDS assessment were able to respond to a rather long QOL interview. We are working with parallel response formats to permit residents who resist the oversimplification of a yes/no response to use Likert scales, whereas others may opt for binary response formats (Kane et al., 2000; Kane et al., 2003).

Despite concerns about respondent burden because of fatigue levels, hearing and speech difficulties, and poor health, ample evidence attests that nursing home residents typically like having their opinions solicited and enjoy taking part in interviews. Some will be impatient and unfamiliar with fixed response categories so that interviewers need considerable skill and training to avoid biasing the interview or exhausting the resident. Patience is also needed to wait while the respondents process their experiences to choose their best response for an item. Arguably interviewer burden is a more likely deterrent than resident burden. Identifying the problem as interviewer burden would be more

forthright than making a virtue out of avoiding direct interviews with residents so as not to burden them. Far too little conversation and real communication occurs between residents and others, whether in unstructured form or structured by the use of questionnaires.

Instrument Design

Issues arise about the level of detail desirable, which can range from short scales that attempt to touch on multiple elements of QOL with a few questions, to multidimensional scales that use multiple questions for each domain. Variation is present also in the metric for eliciting information (e.g., satisfaction, need for improvement, or some other approach). The way questions are has been shown to influence the likelihood of negative responses (Simmons et al., 1997). The number of response options is also an important decision. Offering a broader range (e.g., a 5-point scale) may make residents more comfortable criticizing because they can avoid going to the extreme, but such scales are more difficult for residents with cognitive impairment. Also, it is necessary to decide whether and how to balance negative and positive items related to QOL. If the purpose is to identify sentinel negative feelings and reactions (being fearful, feeling neglected, being in pain), an all negatively worded item set may suffice. However, with only negatively slanted items, one would never be able to test the positive end of QOL (being stimulated and engaged, having meaningful friendships, having fun, making contributions to others). A QOL tool that operationally defines a good QOL as an absence of bad things sets forth low expectations for nursing home life. Other issues concern the time frame of the inquiry: does one ask about a short recent time span to aid recall or does one ask about a longer time frame to include events that happen rarely? If one wishes a snapshot of the QOL of the residents in the entire facility, then a short time frame can be used. If feedback is to be used to improve a specific resident's QOL, a time frame of the past few weeks may be too short to capture his or her experience.

Sampling Strategy

For clinical purposes, caregivers need to know how to ask about and assess an individual resident's QOL. But, for quality assurance, quality improvement (quality indicator [QI]) efforts, or public reporting, it is necessary to characterize QOL in the whole facility. Thus, the sample must be large enough to permit a stable estimate of QOL in the facility, and it usually must not be biased toward residents who are likely to have a good or a poor QOL. The exception is when a QI intervention effort is being targeted at those at risk of a poor QOL (e.g.,

persons who are bedbound or have sensory impairments may be more likely to experience boredom and a poor outcome on a meaningful activity domain; persons who have no visitors from the outside are at greater risk of a poor score on a relationships domain). Although on some quality-of-care measures, any bad result should be taken seriously (e.g., one death as a result of the wrong medication signals poor quality), a finding that three residents reported happiness (or conversely, unhappiness) is not a useful signal of QOL in a nursing home with 100 residents. Based on our ongoing work, we think a sample of 20 or more residents would be needed in a 100-resident nursing home before comparing nursing homes on QOL. Some sample stratification should also be used to ensure a mix by gender, cognitive status, functional status, and length of stay. At present, information is insufficient to design an ultimate sampling strategy. It is likely, however, that the experience and the willingness to report perceptions of the experience will be different for a newly admitted versus a long-stay resident; furthermore, the newly admitted resident who expects a short course of rehabilitation and discharge may differ from the newly admitted resident who is expected to stay forever on a long-stay unit. Also, if the facility is divided into rather different wings or nursing units, it is possible that the circumstances of residents' life and care vary with the physical and social environments of the unit, suggesting a sampling frame that accounts for the geography of the facility. Sampling also has a time dimension. Facility QOL may be better at the time of a major holiday. It may be worse during flu season, when both residents and staff have high illness rates. How often to assess QOL to capture changes is also important.

Validation

Validation of a tool measuring a subjective phenomenon is particularly challenging. Clearly, various tests of reliability must be met as a precondition for validity, but what next? A time-honored approach is to seek concurrent validity by comparison to an existing tool. For many of the QOL domains worth measuring in a nursing home, no existing tools are available. Another well-accepted approach is to validate using some expert judgment as the criterion measure. But the criterion may be less confidence-engendering than the new tool. At the individual level, one would like to see convergent validity in the form of agreement among reporters, but one cannot use family and staff as validators on whether a resident's statements about his or her pain, or happiness, or fearfulness are valid. At the facility level, an expert could spend the same amount of time in a nursing home as a person administering formal assessments, making observa-

tions and having conversations with residents. Suppose the average QOL scores gleaned from the resident sample differ from the expert's ratings of QOL in that nursing home along the same dimensions. Which is correct, the residents or the expert? Reputational surveys are even worse because added to the possible inaccuracies is the lag time before a good or bad reputation is altered with changing reality. Another approach entails brainstorming among experts to identify structural characteristics in the facility that should be associated with the QI (Abr Associates, 2001). The valid indicator is one that is associated with the expected characteristics. Analogously with QOL, one could identify factors thought to be associated with the outcomes (private rooms would be a strong candidate for several QOL outcomes) and test the strength of the association. But, this seems almost backwards. We might like to think that well-staffed activity programs are associated with resident-reported meaningful activity, or that enjoyment of food is associated with raw food expenditures, variety in menus, and the expertise of the chef. But suppose these associations did not hold up? Would that suggest the measured outcomes were faulty, or rather that the structural predictors were incorrect?

No ready answer is available for the validation question. At the very least the items should have face validity. They should seem to any sensible individual to be measuring the phenomenon, and they should be vetted by residents as related to the phenomenon.

Scoring and Reporting

Deciding how individual and facility level data will be scored, summarized, and reported is complex. The world of measurement seems divided into lumpers and splitters, (i.e., those who value the efficiency of a single summary score and those who value the added detail received by maintaining groups of scores). Whether lumping or splitting scores, decisions need to be made about weighting items. Even unweighted scales make implicit weighting decisions; either they imply all items are of equal importance to the construct or, by including multiple questions about one aspect, they give that aspect *de facto* extra weight. If multiple domains are collapsed into a single score, the issue of whether and how to weight is carried to a higher level. Many who write about QOL would join Stewart and King (1994, p. 35) in acknowledging that the domains are highly interrelated, and undoubtedly there is considerable overlap in the information across domains. The question is whether such correlations should be perceived as a problem in the construction of scales, with resultant research necessary to combine scales and to generate a group of highly independent QOL scales. Conversely, one might presume that domains of QOL are correlated just as domains of physical

health are correlated and perceive the study of those relationships to be of interest.

Facility-level QOL summaries enable providers and prospective consumers to compare across facilities. To make such comparisons fair, QOL results need to account characteristics of the resident population that might affect the outcome and are beyond the nursing home's capability to control. Just as hospital mortality rates are adjusted by various disease characteristics, QOL should be adjusted by characteristics that are known to affect QOL but are not influenced by care or the care environment. Current understanding does not yet allow for confident case-mix adjustment of QOL outcomes. Some suggested adjusters seem unwise. For example, many propose that QOL as reported by residents should be adjusted by whether the resident is depressed. Adjusting for a serious endogenous depression may be appropriate, but adjustment for depressive affect exonerates the facility for creating an environment that engenders depression and anxiety.

Residents Who Cannot Communicate

Throughout, we emphasize that many nursing home residents, including those with substantial cognitive impairment or major communication difficulties, can report on their QOL if the trouble is taken to ask them and listen to their answers, including substantial cognitive impairment or major communication difficulties. That being said, some residents simply cannot participate in any interview, however short. These include some residents in the last days before an expected death who lapse into a noncommunicative state, residents in comas or vegetative states, and, most numerous, residents whose cognitive impairment has reached the stage where verbal communication is precluded.

To estimate QOL for these groups, the choices are few. One could deem their QOL unknowable and concentrate on the quality of their care and respect for their dignity (with family providing data on the latter). This may be an acceptable strategy for those who are comatose, vegetative, or so debilitated that they have no interaction with their environment. Otherwise, the choices are to obtain proxy reports, to make direct systematic observations, to rely on structure and process indicators that theoretically are related to QOL, or use physiological indicators to measure stress. Physiological measures are too intrusive and expensive for routine QOL monitoring, although useful for research to learn more about the well-being of people who cannot communicate. The proxy strategy is probably essential for residents who cannot communicate at all and still interact with their environment. Family may be the best proxy. Except in the rare case of malevolence, they have the interests of their relative with dementia

most at heart. Their satisfaction with the resident's QOL may be inherently worth knowing. Staff members may also be trained to be reliable proxies, particularly if they use a tool with clear objective parameters. One such possibility is the Multidimensional Observational Scale for Elderly Subjects (MOSES), which asks the proxy reporter to use a time frame of 1 week and report on the frequency of very specific items (e.g., how often the resident speaks of being sad, looks sad, shows signs of sadness like tears, expressed interest in the outside world, responds to contact from other residents, initiates contacts with other residents; Helmes, Csapo, & Short, 1987). The alternative approach of structured observation during a series of sampled time periods may be more objective in some ways, yet be based on a smaller sample of experience than the proxy respondent.

A variant of the proxy approach uses cognitively intact residents to report on the experience of cognitively impaired residents. This sentinel method is more plausible to obtain an aggregate impression rather than a measure of an individual's QOL. The reporters might be asked whether they believe residents are agitated, anxious, left in discomfort, and the like. No example of a systematic use of this approach was located in the literature. It has become a standard practice to use a group meeting with residents, such as resident council leaders, to comment on quality broadly. The merits of group feedback versus individual interviews has not been studied, nor has there been systematic study of how well cognitively intact residents can comment on the QOL of those who are cognitively impaired. The tendency for geographic separation in dementia units would diminish the experience base of potential sentinel reporters.

Structured direct observation should surely be part of any approach. The internal processing of some people with dementia may be mysterious, but some observable phenomena have face validity. Smiling, singing, and animated residents would appear to have a good QOL, and screaming, moaning residents wringing their hands, and pleading for help would seem to have a poor QOL. The Apparent Affect Rating Scale is an approach that rates residents' facial expressions and body language to determine happiness, anger, anxiety, and engagement during structured 5-minute observations (Lawton, Van Hantsa, Perkinson, & Ruckdeschel, 1999). This approach is promising but difficult to implement because it requires multiple observations of the same individual to achieve a stable result, and it requires extensive training to be performed to avoid the observer influencing the observation. With this and other observation approaches, one is watching for rare events: by far the most frequent observation of the first four emotions in a 5-min period is "none." Moreover, observations related to QOL cannot be limited to the working day and

week; residents' lives are shaped by what happens or does not happen in the long stretches of time when outsiders are absent.

Quality Improvement and Amenability to Intervention

Nursing homes are plagued by low expectations for what providers can do to improve QOL for residents. QOL in nursing homes is a product of at least four factors: the resident's health status, his/her social situation (including his/her family support from outside the nursing home), his/her personality; and the care and environment he/she is offered in the nursing home. Nursing homes may not be able to influence all these factors equally, but the belief that nursing homes are impotent to change QOL given the conditions that bring residents to the nursing home in the first place may be self-fulfilling and stand in the way of marginal improvements.

What, then, is the prospect of a nursing home making a difference? It could have an indirect effect on QOL through quality of care. If the nursing home affects health and functional status, these outcomes may, in turn, affect QOL. But nursing homes can influence QOL directly as well. At first blush, one might say that whether the resident has visitors seems a function of family structure. But nursing home practices, policies, and milieus can make the facility a more or less pleasant place to be, and can also influence the quality and duration of the visit. In considering what is actionable by the nursing home, a full range of efforts are relevant, including the direct care, the physical environment, and the rules and policies that affect resident life. When nursing home personnel are encouraged to think creatively about what they might do to improve QOL, imaginative ideas emerge.

Nursing homes cannot, of course, transform residents' personalities. Gubrium (1993) noted in an anthropological study that residents' appraisals of quality of care in facilities where the care seemed constant varied by the personality type of the resident. Surely the societal expectation and hope should be that the facility generate an equally good QOL for all residents regardless of personality type. Studies are needed to examine how personality interacts with health characteristics and facility characteristics to produce QOL outcomes. The first step will be to adapt personality measures so that they can be used in a self-report format and contain items pertinent to nursing home residents.

Implications for Professional Practice, Public Policy, and Research

Numerous formulas have been advanced for improving QOL in nursing homes. But the key to action is likely to be as individualized as is QOL itself. A person-by-person approach to determining

what might make the given resident appraise his or her quality of life more positively cannot be avoided. Because individualized care planning is, in theory, already being done, it would seem plausible to incorporate QOL goals into care planning, but a rather different orientation would be needed. Also, the hotel and housing attributes of a nursing home might need much more priority than they are wont to receive. Dramatic environmental changes are probably required, such as private rooms and bathrooms, which could at least be considered for new construction. Clearly, nursing-home care is labor-intensive, and staff contribute to QOL, but new configurations of personnel may be needed to deliver a better QOL.

Personnel delivering care will need more human relationship skills and more assessment skills related to QOL than they usually have. Katz and Gurland (2001) propose "better quality of life for residents through practitioner judgments." Yet, practitioner judgment and discretion, especially on the part of direct care workers without professional degrees, tends to be discouraged in the current context.

Public policy implications are also numerous. First, QOL needs priority or at least equal billing with other concerns. Current policy treats QOL as a luxury in relation to care outcomes. Then, regulations will need to be scrutinized to be sure that they do not detract from QOL. Other implications relate to the inspection process and to possible structural requirements for QOL assessment and QI related to QOL. Public bodies could, and have already begun to, provide information and ideas about how QOL might be improved. Certainly, there are implications for the future licensing and regulation of new group residential settings, such as assisted living. It would be worth considering what should be done differently than in the current nursing home context to give residents a better chance at QOL.

The research agenda is a long one. Some needed research is methodological, developing and fine-tuning measures, including cross-cultural validation of QOL measures. Some needed research must examine relationships among resident QOL, and process and structure features in the facility. The ideas of all staff on all shifts will be important. Some of the needed research will test the effectiveness of interventions to improve QOL. It will be necessary to study how the mundane tasks of daily life are managed: bathing, meals, rising times, bed times, and room allocations. The physical environment, including equipment and furnishings, needs research. It is worthy of emphasis, however, that this research should not lose sight of the person at the other end of the measurement. QOL still needs to be approached in the spirit of humility, with recognition of individual differences. Easy measures that bring false reassurance need to be avoided. The subject of QOL must be elevated, not trivialized, through its study.

References

- Abeles, R. P. (1991). Sense of control, quality of life, and frail older people. In J. E. Birren, J. F. Lubben, J. C. Rowe, & D. E. Deutchman (Eds.), *The concept and measurement of quality of life in the frail elderly* (pp. 297-314). San Diego, CA: Academic Press.
- Abeles, R. P., Gift, H. C., & Ory, M. G. (Eds.). (1994). *Aging and quality of life*. New York: Springer Publishing Company.
- Abt Associates, Inc. (1996). *Evaluation of the long term care survey process* (final report). Cambridge, MA: Abt Associates, Inc.
- Arnold, S. B. (1991). Measurement of quality of life in the frail elderly. In J. E. Birren, J. F. Lubben, J. C. Rowe, & D. E. Deutchman (Eds.), *The concept and measurement of quality of life in the frail elderly* (Vols. 50-73). San Diego, CA: Academic Press.
- Archley, R. C. (1991). Influence of aging on perceptions and expressions of the self. In J. E. Birren, J. F. Lubben, J. C. Rowe, & D. E. Deutchman (Eds.), *The concept and measurement of quality of life in the frail elderly*. San Diego, CA: Academic Press.
- Baltes, M. M. (1994). Aging well and institutional life: A paradox? In R. P. Abeles, H. C. Gift, & M. G. Ory (Eds.), *Aging and quality of life* (pp. 185-201). New York: Springer Publishing Company.
- Birren, J. E., Lubben, J. F., Rowe, J. C., & Deutchman, D. E. (Eds.). (1991). *The concept and measurement of quality of life in the frail elderly*. San Diego, CA: Academic Press.
- Brod, M., Stewart, A. L., Sands, L., & Walton, P. (1999). Conceptualization and measurement of quality of life in dementia: The Dementia Quality of Life Instrument (DQoL). *The Gerontologist*, 39, 25-35.
- Cohn, J., & Sugar, J. A. (1991). Determinants of quality of life in institutions: Perceptions of frail older residents, staff, and families. In J. E. Birren, J. F. Lubben, J. C. Rowe, & D. E. Deutchman (Eds.), *The concept and measurement of quality of life in the frail elderly* (pp. 28-49). San Diego, CA: Academic Press.
- Dolan, P. (1997). Modeling valuations for EuroQol health states. *Medical Care*, 35, 1095-1098.
- Fagan, R. M., Williams, C. C., & Burger, S. G. (1997). *Meeting of pioneers in nursing home culture change*. Rochester, NY: LifeSpan of Greater Rochester.
- General Accounting Office. (GAO). (1999a). *Nursing home survey and certification: Deficiency trends* (OEI-02-98-00331). Washington, DC: Office of the Inspector General.
- General Accounting Office. (1999b). *Quality of care in nursing homes: An overview* (OEI-02-99-00060). Washington, DC: Office of the Inspector General.
- Gubrium, J. (1993). *Speaking of life*. Hawthorne, NY: Aldine de Gruyter.
- Helmes, E., Csapo, K. G., & Short, J. A. (1987). Standardization and validation of the Multidimensional Observational Scale for Elderly Subjects (MOSES). *Journal of Gerontology*, 42, 395-405.
- Institute of Medicine. (1986). *Improving the quality of care in nursing homes*. Washington, DC: National Academy Press.
- Kane, R. A. (2001). Long-term care and a good quality of life: Bringing them closer together. *The Gerontologist*, 41, 293-304.
- Kane, R. A., Caplan, A. L., Urv-Wong, F. K., Freeman, I. C., Aroskar, M. A., & Finch, M. D. (1997). Everyday matters in the lives of nursing home residents: Wish for and perception of choice and control. *Journal of the American Geriatrics Society*, 45(9), 1086-1093.
- Kane, R. A., Kling, K. C., Bershadsky, B., Kane, R. L., Giles, K., Degenholtz, H. B., et al. (2003). Measuring quality of life of nursing home residents. *Journal of Gerontology: Medical Sciences*, 58, 240-248.
- Kane, R. A., Kane, R. L., Giles, K., Lawton, M. P., Bershadsky, B., Kling, K., et al. (2000). *First findings from wave 1 data collection: Measures, indicators, and improvement of quality of life in nursing homes*. Minneapolis, MN: Division of Health Services Research, Policy, and Administration, School of Public Health, University of Minnesota.
- Kane, R. A., Kane, R. L., & Ladd, R. L. (1998). *The heart of long-term care*. New York: Oxford University Press.
- Katz, S., Ford, A. B., Moskowitz, R. W., Jackson, B. A., & Jaffe, M. W. (1963). Studies of illness in the aged. The index of ADL: A standardized measure of biological and psychosocial function. *Journal of the American Medical Association*, 185, 914-919.
- Katz, S., & Gurland, B. J. (1991). Science of quality of life in elders: Challenge and opportunity. In J. E. Birren, J. F. Lubben, J. C. Rowe, & D. E. Deutchman (Eds.), *The concept and measurement of quality of life in the frail elderly* (pp. 335-343). San Diego, CA: Academic Press.
- Katz, S., & Gurland, B. J. (2001). Better lives for elders through better practitioner judgment. In L. S. Noelker & Z. Harel (Eds.), *Linking quality of long-term care and quality of life* (pp. 204-220). New York: Springer Publishing Company.
- Kuyken, W., & Orley, J. (1999). Development of the WHOQOL: Rational and current status. *International Journal of Mental Health*, 23(2-3), 24-56.
- Lawton, M. P. (1991). A multidimensional view of quality of life in frail elders. In J. E. Birren, J. F. Lubben, J. C. Rowe, & D. E. Deutchman (Eds.), *The concept and measurement of quality of life in the frail elderly* (pp. 3-27). San Diego, CA: Academic Press.
- Lawton, M. P., Van Haitsa, K., Perkinson, M., & Ruckdeschel, K. (1999). Observed affect and quality of life: Further affirmations and problems. *Journal of Mental Health and Aging*, 5, 69-82.
- Logsdon, R., Gibbons, L., McCurry, S., & Terri, L. (1999). Quality of life in Alzheimer's disease: Patient and caregiver reports. *Journal of Mental Health and Aging*, 5, 21-32.
- Lustbader, W. (2000). The pioneer challenge: A radical change in the culture of nursing homes. In L. S. Noelker & Z. Harel (Eds.), *Quality of care and quality of life in nursing homes* (pp. 185-203). New York: Springer Publishing Company.
- Mattimore, T. J., Wenger, N. S., Cesbiens, N. A., Teno, J. M., Hamel, M. B., Liu, H., et al. (1997). Surrogate and physician understanding of patients' preferences for living permanently in a nursing home. *Journal of the American Geriatrics Society*, 45, 818-824.
- McHorney, C. A., Ware, J. E., Jr., Lee, J. F. R., & Sherbourne, C. D. (1994). The MOS 36-item short-form health survey (SF-36). III. Tests of data quality, scaling assumptions, and reliability across diverse patient groups. *Medical Care*, 32(1), 40-66.
- Morris, J. N., Hawes, C., Fries, B. E., Phillips, C. D., Mor, V., Katz, S., et al. (1990). Designing the national resident assessment instrument for nursing homes. *The Gerontologist*, 30, 293-307.
- National Citizens' Coalition for Nursing Home Reform. (1985). *A consumer perspective: the resident's point of view*. Washington, DC: Author.
- Noelker, L. S., & Harel, Z. (Eds.). (2001). *Linking quality of long-term care and quality of life*. New York: Springer Publishing Company.
- Office of the Inspector General. (OIG). (1998). *California nursing homes: Care problems persist despite federal and state oversight*. Washington, DC: Author.
- Office of the Inspector General. (1999a). *Nursing homes: Additional steps needed to strengthen enforcement of federal standards*. Washington, DC: General Accounting Office.
- Office of the Inspector General. (1999b). *Nursing homes: Complaint investigation process often inadequate to protect residents* (Publication No. GAO-HEHS-99-80). Washington, DC: Author.
- Simmons, S. E., Schnelle, J. F., Uman, G. C., Kulvicki, A. D., Lee, K. O., & Ouslander, J. G. (1997). Selecting nursing home residents for satisfaction surveys. *The Gerontologist*, 37, 543-550.
- Stewart, A. L., & King, A. C. (1994). Conceptualizing and measuring quality of life in older populations. In R. P. Abeles, H. C. Gift, & M. G. Ory (Eds.), *Aging and quality of life* (pp. 27-54). New York: Springer Publishing Company.
- Svensson, T. (1991). Intellectual exercise and quality of life in the frail elderly. In J. E. Birren, J. F. Lubben, J. C. Rowe, & D. E. Deutchman (Eds.), *The concept and measurement of quality of life in the frail elderly* (pp. 256-275). San Diego, CA: Academic Press.
- Thomas, W. H. (1999). *The Eden alternative handbook: The art of building human habitats*. Sherburne, NY: Summer Hill Company, Inc.
- Ware, J. E., Jr., & Sherbourne, C. D. (1992). The MOS 36-item short-form health survey (SF-36). I. Conceptual framework and item selection. *Medical Care*, 30(6), 473-483.
- Wunderlich, G., & Kohler, P. (2001). *Improving the quality of long-term care*. Washington, DC: National Academy Press.
- Zimmerman, D. R., Karon, S. L., Arling, G., Clark, B. R., Collins, T., Ross, R., et al. (1995). Development and testing of nursing home quality indicators. *Health Care Financing Review*, 16(4), 107-127.

Received May 14, 2002

Accepted October 31, 2002

Decision Editor: Laurence G. Branch, PhD