

## ***Guest Editorials***

# **The Assessment of Quality of Life in Dementia**

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In the past decade, pharmacological, behavioral, educational, and environmental interventions for individuals with dementia have addressed a variety of goals: improving cognitive status, delaying the onset of symptoms, reducing behavioral problems such as depression and agitation, and maximizing activities of daily living. It is important not only to ameliorate symptoms but also to evaluate the extent to which an intervention improves the quality of life (QOL) of the person being treated (Logsdon et al., 2002).

In general, two concepts of QOL are distinguished: The first deals with the objective conditions of life, defining the objective aspects of the QOL, whereas the second focuses on subjective well-being and is based on a personal assessment of one's own life situation. The objective QOL of an individual can be judged according to the dimensions of the resources available to a person; that is, those resources related to that individual as well as those supplied by the environment and infrastructure. For an institutionalized person with dementia, this objective aspect of QOL might be indicated by a high staff-resident ratio, an in-service training program

that emphasizes sensitivity and individual care, or a care unit whose architectural design is homelike or that fosters social interaction. It is expected that the average well-being of the residents will improve if they are exposed to these environmental features (Lawton et al., 2000).

Especially in the field of gerontology, two different perspectives on QOL are encountered: that of the person affected and that of the outsider. Although two people may find themselves in the same objective situation, their subjective evaluations of that situation may differ strongly. Integrative approaches that consider both the objective as well as the subjective aspects of QOL predominate in current research. The coincidence of good life conditions with positive well-being is the most favorable combination and is termed "well-being." "Deprivation" is the constellation in which poor life conditions coincide with an absence of (i.e., negative) well-being. "Dissonance" or the "dissatisfaction dilemma" describes the inconsistent coincidence of good life conditions with dissatisfaction, whereas "adaptation" or the "satisfaction paradox" describes that of poor life conditions with satisfaction.

The concept of QOL is difficult to define because the perspectives on it differ, as do the cultural, social, and personal perceptions. The World Health Organization defines QOL comprehensively as individuals' perception of their position in life in the context of the culture and value system in which they live, and in relation to their goals, expectations, standards, and concerns (WHOQOL Group, 1995). Lawton (1991) has developed a broad conceptual framework for QOL in older adults that includes four domains: behavioral competence, objective environment, psychological well-being, and perceived QOL. It is generally agreed that the concept of QOL is multidimensional, comprising a person's physical health, psychological state, level of independence, social relationships, personal beliefs, and relationship with salient features of the environment.

## METHODOLOGICAL ISSUES

Rabins and Kasper (1997) have summarized several methodological issues that should be considered in measuring QOL in dementia. By definition, QOL is subject to individual interpretations. Thus there is no "gold standard" (criterion validity) against which to measure an instrument's validity. However, face validity, content validity, and predictive validity can be established. Outcome studies use QOL measurement primarily to detect change over time in response to an intervention. Therefore, an instrument's sensitivity to change is an important issue.

Another methodological issue is whether the measurement instruments should be generic or disease-specific. Generic instruments facilitate comparisons among different disease groups. Disease-specific instruments reduce the

burden on patients' assessment by focusing only on domains relevant to a particular disease. Another strength of disease-specific instruments is their ability to measure the effects of an intervention upon specific symptoms of a particular disorder. Because dementia consists of a unique set of symptoms, measures specific for dementia are needed.

Another challenge is the development of an instrument that is capable of assessing QOL at different stages of dementia, measuring the elements of capacity that are possibly retained and valued, and enabling a person other than the patient to rate their presence. Because patients with severe dementia generally have impaired language, perception, and judgment, it is unlikely that any measure can make use of a statement expressed by a patient with late-stage dementia. The objectivity (focus on externally observable events) or subjectivity (subjective response permitted) of instruments is a further general issue in the measurement of QOL.

Three approaches to the assessment of QOL can be distinguished: self-reports by the individual with dementia (e.g., Brod et al., 1999; Logsdon et al., 2002; Selai et al., 2000), proxy reports by a family member or caregiver (e.g., Albert et al., 2000; Rabins et al., 1999), and direct observation of behaviors assumed to be related to QOL (e.g., Fossey et al., 2002; Lawton et al., 1996; Logsdon et al., 2002).

## SELF-REPORTS

Self-reports emphasize the perspective of the cognitively impaired person, taking into account his or her personal experiences. Respect for the autonomy of the individual is very important from

a clinical and ethical perspective. However, if self-reports are to be useful, it is necessary to design measures that facilitate an individual's ability to respond despite cognitive impairment and to evaluate the impact of dementia-related problems on an individual's ability to report QOL. Comprehension of questions and selection of appropriate responses can be facilitated by the use of explicit instructions, face-to-face administration by a trained interviewer, and visual cues to remind the respondent of the response options. Furthermore, an interviewer can assess a respondent's comprehension by asking follow-up questions when the response is unclear or inconsistent.

Self-ratings will be influenced by education, memory, and attention problems. Furthermore, this approach is likely to yield high levels of missing data. The format of questionnaires should be developed with care, giving preference to simple language and large font sizes, because many patients will have vision problems. In addition, short interviews should be used for patients with dementia because patients tire easily (Selai & Trimble, 1999). Face-to-face interviews are preferable to telephone interviews so as to motivate subjects and to increase their attention. Many questions have been raised about the ability of persons with dementia to make complex subjective judgments about their lives and about the point at which they become unable to do so (Rabins et al., 1999). Deficits of memory, attention, judgment, insight, and communication influence the ability of persons with cognitive impairment to comprehend questions or communicate their own subjective states. QOL ratings may also be biased by noncognitive disorders such as depressive, agitated, or psychot-

ic symptoms. Judgments about what is important to QOL may change as dementia progresses. In the early stages of dementia, preservation of intellectual capacity may be seen to be more important, whereas in later stages, safety and comfort may take on primary importance.

Examples of measures designed for direct respondent assessment in cognitively impaired populations are the Dementia QOL (Brod et al., 1999) and the Quality of Life-AD (Logsdon et al., 2002). This latter instrument assesses the patient's QOL on the basis of responses from both a patient and his/her caregiver. It covers the following domains: physical health, energy, mood, living situation, memory, family, marriage, friends, chores, fun, money, self, and life as a whole. Studies on its psychometric properties indicate that it is a reliable and valid instrument.

Studies (e.g., Brod et al., 1999; Logsdon et al., 2002) concerning the ability of persons with mild to moderate dementia to self-report QOL furnish evidence that they may be more capable of providing self-assessments than has been recognized previously.

## PROXY RESPONSES

In the later stages of dementia, proxy measures are required because patients are no longer capable of making an evaluation. Proxy responses are usually obtained from a relative or caregiver of the person with dementia. They circumvent the cognitive limitations involved with dementia and can be used throughout the course of the disease. However, studies (Bassett et al., 1990; Sainfort et al., 1996) indicate that for both cognitively intact and cognitively impaired persons,

proxies consistently rate QOL lower than do the affected individuals themselves. A disadvantage to proxy ratings is that they filter a subjective measure through the opinion of another person. These ratings may be influenced by the proxy's own expectations and belief system, the prior relationship with the person being rated, and the current burden of care. When QOL is used as a basis for decisions about treatment, residential options, or end-of-life choices, it is vital to identify the biases of proxy ratings.

A review of studies based on proxy reports indicates that the more objective the question and the more concrete the item in question is, the higher is the agreement between proxy report and self-report. Proxies are poorer reporters for symptoms that are private and not easily observed. Thus, it is not surprising that the proxy-subject agreement for ratings of affective status is inconsistent.

The Alzheimer's Disease-Related Quality of Life developed by Rabins and colleagues (1999) is a proxy instrument well designed to assess QOL in patients with Alzheimer's disease and covers the following domains: social interaction, awareness of self, feelings, and mood, enjoyment of activities, and response to surroundings.

## OBSERVATIONAL METHODS

Given the problem of self-rating and the potential bias of proxy reports, observational methods may be helpful. Direct observation of behaviors believed to be associated with QOL has the advantage that it can be based on predefined behaviors and rated consistently over time. Evaluations of observed affect (Lawton et al., 1996, 2000) and pleasant

events (Logsdon & Teri, 1997) have been proposed to measure observable attributes of QOL. Limitations of this approach include uncertainty about whether what is being observed is what an individual considers to be important to his or her QOL. Direct observations may also be subject to many of the biases associated with proxy ratings. In addition, some raters are very alert and attuned to subtle nuances of affect and behavior, whereas others are not. Thus, the training of raters is an important component of observational studies.

One of the most sophisticated QOL observational instruments, the Apparent Affect Rating Scale, was developed by Lawton and colleagues (1996). Their approach is based on the conviction that the signs of emotions can be read in the observable nonverbal behaviors of people and that these signs can be learned. Furthermore, practice in observation can make most of us into reliable observers of emotional states in patients with dementia. The scale focuses on three negative emotions (anxiety, anger, sadness or depression) and two positive emotions (pleasure, interest). Ratings are based on a defined time period, usually 5 minutes. Its reliability and validity have been established in different settings. An advantage of this measure is that it can be applied to all levels of dementia severity.

Kitwood and Bredin (1992) were among the first to employ an observational method among people with dementia in institutional care. After many years of observing people with dementia in congregate settings, they developed a list of 12 indicators of relative well-being that could be identified among people with dementia: (a) the

assertion of desire or will, (b) the ability to experience and express a range of positive and negative emotions, (c) initiation of social contact, (d) affectionate warmth, (e) social security, (f) self-respect, (g) acceptance of other people with dementia, (h) humor, (i) creativity and self-expression, (j) showing evident pleasure, (k) helpfulness, and (l) relaxation. The Dementia Care Mapping (DCM) tool consists mainly of the Behavior Category Codes, which focus on 24 domains concerning what a person with dementia is doing or not doing, and a well-being scale that assesses each behavior observed in a 5-minute time frame. DCM involves a series of detailed observations of a resident's well-being and activities over a period of 6 hours with good face validity among staff working in the field of dementia care. In clinical practice, DCM has been mainly used as a tool for practice development, but its potential utility is much broader. A number of articles have demonstrated its usefulness in service evaluation and as an audit tool. However, a drawback to DCM is the time-consuming nature of the evaluation. A study by Fossey and colleagues (2002) indicates that the hour before lunch could be used as a reliable assessment period indicative of the day. This could substantially reduce the recommended assessment period of 6 hours and may facilitate its wider use.

## CONCLUSION

People who have dementia need adequate and continuing treatments in a stable, safe, and stimulating environment. Evaluating service and intervention effectiveness requires outcome measures on

several dimensions. These include objective measures of mortality, morbidity, and disability, as well as of changes in QOL from a patient's perspective.

Recently increased attention has been paid towards improving the assessment of the QOL among cognitively impaired persons. Evaluation of QOL provides older adults with cognitive impairment and their caregivers with information on whether an intervention has made an important difference in a patient's life. Conclusions can be drawn about the extent to which interventions provide significant benefits. Monitoring changes in QOL in patients with dementia may suggest new areas of intervention to maintain or enhance life quality.

Dementia confronts us with the situation of most individuals with severe cognitive impairment who can no longer speak with words or are unable to use self-report instruments. Therefore, in addition to self-report measures, proxy responses and observational methods are needed in order to assess QOL in dementia adequately. Instruments with established psychometric properties are available for all three methodologies. Each of these approaches is important in its own right and should be further explored. An optimal study design would incorporate the use of multiple methods of data collection. Albert and Logsdon (2000) have provided a comprehensive overview on both conceptual and practical issues in the measurement of QOL in dementia.

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