

A Model for Quality of Life Measures in Patients with Dementia: Lawton's Next Step

C. Jonker^{a,b} D.L. Gerritsen^b P.R. Bosboom^c J.T. Van der Steen^b

^aDepartment of Psychiatry and ^bInstitute for Research in Extramural Medicine, VU University Medical Center, and ^cDepartment of Clinical Neuropsychology, VU University, Amsterdam, The Netherlands

Key Words

Dementia · Quality of life · Well-being · Broadness · Domains · Subjectivity · Model

Abstract

The introduction of drugs that are claimed to improve cognitive function and activities of daily living in patients with Alzheimer's disease raises the question of whether these drugs also influence dementia patients' quality of life (QOL). We describe a hierarchic model of QOL of dementia patients, which can guide the development of measurement instruments. After initially discussing broadly QOL research, we focus on two highly important characteristics of the concept, its broadness and subjectivity, against the background of the relevant literature on QOL in dementia. Dementia-specific dimensions and domains are presented. We identify psychological well-being as the core dimension for QOL of patients with dementia.

Copyright © 2004 S. Karger AG, Basel

Introduction

The introduction of drugs aimed at treating Alzheimer's disease has markedly increased interest in measuring quality of life (QOL) in dementia patients [1–4]. Despite ongoing

controversy about the definition and operationalization of QOL, measures for numerous diseases have been developed both in the physical and psychiatric domains [5, 6]. Nevertheless, until recently, only a few measures were available to evaluate intervention effects on the QOL of dementia patients. This field of research remained poorly developed due to the assumption that dementia patients were not able to reliably report on their QOL. Yet, it was demonstrated that patients with early stages of dementia and, more generally, elderly people with cognitive disorders are able to accurately report on this [2, 7, 8]. This development has initiated new and important research in this field. However, recent research mainly focused on the development of new scales [1–4, 9], as well as on the agreement between patients' and proxies' report of QOL in dementia [10–12]. The few researchers presenting a conceptual framework for QOL in dementia [1, 9, 13, 14] often based their concepts on Lawton [15]. However, none of them presented a model that made explicit what the dominant causal associations are between QOL and, for example, well-being or environment.

In this paper, we review conceptual developments in QOL research concerning dementia. Although, in our view, QOL consists of multiple *dimensions* (called 'sectors' by Lawton [15]) that may consist of multiple *domains*, we follow the original terminology when discussing the different approaches. We then propose a model that might be useful in the formulation of strategies to

KARGER

Fax +41 61 306 12 34
E-Mail karger@karger.ch
www.karger.com

© 2004 S. Karger AG, Basel
1420–8008/04/0182–0159\$21.00/0

Accessible online at:
www.karger.com/dem

Prof. Dr. C. Jonker, Behavioral Neurologist
Department of Psychiatry and EMGO Institute
VU University Medical Center, Van der Boechorststraat 7
NL–1081 BT Amsterdam (The Netherlands)
Tel. +31 20 4446770, Fax +31 20 4446775, E-Mail c.jonker.emgo@med.vu.nl

improve QOL in dementia patients. The model can guide the choice of instruments for specific intervention goals.

Developments in QOL Research

In order to understand developments in QOL research in dementia, a short overview will be given on two central aspects of QOL research in general: broadness and subjectivity.

The concept of QOL was introduced at the end of the 1950s because some investigators perceived that social improvement not only included material prosperity but also a general feeling of wellness [16]. From the beginning, a differentiation was made between social and psychological indicators. The QOL of the general population was estimated on the basis of social indicators, such as income, employment, living conditions and social services [17]. In contrast, the individual's perspective on his or her QOL was based on psychological indicators, such as satisfaction and happiness [18, 19]. Gradually, QOL research split: the social sciences mostly pursued a general concept while medical researchers developed disease-related models [20]. Based on the WHO definition [21], which defines health as a state of physical, psychological, and social well-being (not just as the absence of disease or handicap), various generic scales were developed to measure health status, such as the Sickness Impact Profile [22], the Nottingham Health Profile [23], and the Medical Outcome Study Short Form-36 [24]. They suggest a more limited view of QOL – mainly health-driven – rather than seeing perceived health as part of a more inclusive view on life. As such, the QOL approach based on the WHO definition can be considered 'health-related QOL'. Focusing on the health-related concept has often led, in spite of the WHO definition, to focusing on aspects that are affected by disease and thus mostly address limitations and handicaps. Moreover, attempts to increase the specificity of such instruments have led to the further restriction of developing disease-specific instruments. Such *disease-specific scales* cover QOL aspects that relate to a specific disease or to the effects of one specific therapy, for instance the evaluation of cancer therapy [5]. In some disease-specific scales general items on QOL in addition to disease-specific items have been included to get a more general evaluation of QOL [25]. Assessing respondents' QOL with general measures of how happy and/or satisfied they are with their life as a whole is assumed to represent a synthesis of a wide range of experiences and feelings that people have [20]. As such, they should be related both to

health-related QOL and to other salient life circumstances and experiences and can be thought of as a summary measure of QOL. Opposed to the tendency in health-related and disease-specific QOL research to include only health-related items, the literature on QOL of *chronic mental patients* also mentions domains concerning personal characteristics and environmental factors (and thus holds a broader QOL concept), arguing that these domains are closely related to psychopathology [6, 26]. In short, different approaches to QOL vary in the broad QOL concept.

Another widely discussed subject in QOL research concerns the subjectivity of QOL. Most authors agree that QOL is a personal, subjective perception of an individual's life situation, which can only be described by the individual in question and is strongly influenced by the individual pattern of standards and values [27–29]. This focus on the individual's perception influences QOL research in two ways. First, a position must be taken concerning the idiosyncratic or normative character of the concept. In other words, who determines what QOL is? The more idiosyncratic the approach, the more the meaning of the concept is determined by the individual in question, while the normative perspective assumes certain standards across a category of patients. Most investigators take a normative view with regard to patients with dementia. They look at similarities within this category of patients, which is necessary if one aims to study the effect of an intervention on one or more aspects of QOL. As a consequence, they do not allow individual patients to determine what QOL means to them. The second position that has to be taken with regard to the individual perception is: who determines the level of QOL? Most authors consider QOL to be a subjective evaluation by definition, and consequently consider the individual himself to be the best source of information. In contrast to the general belief, research has demonstrated that patients at early stages of dementia can often reliably express a personal view about their QOL, and therefore might be reliable sources of judgment [2, 7, 8]. Other investigators [1, 2] demonstrated that two self-rating instruments for QOL of patients with mild to moderate dementia exhibited good test-retest reliability: reliabilities for the QOL-AD and the D-QOL varied from 0.64 to 0.90.

Conceptual Approaches to QOL in Dementia

Concerning dementia, Lawton [15, 30–32] has most extensively explored the concept of QOL. He adapted his original framework for 'the good life' to 'frail elderly', and

Table 1. Domains in QOL approaches in dementia, grouped by Lawton's sectors

Lawton's sectors	Domains			
	Lawton [15, 30–32]	Brod et al. [1, 7]	Rabins et al. [9]	Volicer and Bloom [13]
Psychological well-being		positive affect negative affect	feelings and mood	
Behavioral competence	health functional health cognition time use social behavior	interaction capacity	social interaction awareness of self	medical issues psychiatric symptoms meaningful activities
Objective environment			response to surroundings	
Perceived QOL		sense of aesthetics feelings of belonging	enjoyment of activities	
Personal characteristics ¹		self-esteem		

¹ Added to Lawton's sectors.

later to older people with dementia. He defined QOL as the 'multidimensional evaluation, by both intra-personal and social normative criteria, of the person environment system of an individual in time past, current, and anticipated [31, p. 6]. On theoretical grounds, Lawton [15] distinguishes four sectors of QOL, which overlap to a certain extent: (a) '*Behavioral competence*', including physical health, daily activities (activities of daily living, ADL; instrumental activities of daily living, IADL; work, recreational activities), cognitive functioning and social behavior. In fact, these are the aspects of functioning that are strongly influenced by illness (i.e. dementia). (b) '*Objective environment*', including material possessions, social support and network. Both sectors generate objective data that, according to Lawton [15], can be provided by caregivers or family members. (c) '*Domain-specific perceived QOL*', the degree of satisfaction with all important (life) domains, such as social functioning, leisure activities, living accommodation and income. (d) '*Psychological well-being*', 'the weighted evaluated level of a person's competence and perceived quality in all domains of contemporary life' [31, p. 11]. The last two sectors (c and d) concern the subjective perception of the individual.

Several other investigators have elaborated on Lawton's [15, 30–32] framework to study QOL of patients with dementia or developed distinctive approaches, based on different theoretical assumptions or on focus groups, consisting of professional caregivers, informal caregivers and patients [7, 9]. Table 1 provides an overview of the

dimensions and domains discussed in the literature. As Lawton was the first to describe an approach to QOL and other authors are indebted to his work [7], his sectors form the structure to compare the other approaches.

Volicer and Bloom [13] identify three domains of QOL of patients with moderate to severe dementia. The first of their domains concerns *meaningful activities* involved in the physical and social environment. Volicer and Bloom [13] believe this to be the most important factor for QOL of patients with dementia. The second domain concerns the *medical aspects*: problems with eating, infections, chronic physical diseases etc. Finally, the third domain concerns *psychiatric symptoms*: changes in behavior, including psychiatric symptoms.

Gurland and Katz [14], on theoretical grounds, consider inability to adapt as the central aspect of QOL of patients with dementia. They base their view on a 'deficit' model by considering limitations that are characteristic of patients with dementia, such as the inability to perform ADL that require cognitive skills, the inability to adapt, and (subjective) feelings of discomfort in performing cognition-related activities. Their assessment of QOL is based on 19 domains or adaptive tasks that focus particularly on functional skills, such as (I)ADL functioning. It ignores the possibility that subjective QOL can be high although functional skills decrease, a phenomenon that is known as the disability paradox [33].

Brod et al. [7] also introduced a conceptual framework for QOL of demented persons. Based on focus group dis-

cussions, they identified the domains of QOL that are relevant for dementia patients. They stressed the importance of individual characteristics and social support. Two factors were found to be important to persons with dementia that can be considered newly formulated domains: *interaction capacity*, interactive skills, referring to the degree of confusion and psychopathology caused by the cognitive impairment, and *sense of aesthetics*, the ability to enjoy sensory stimuli, such as listening to music, enjoying nature.

Based on discussions in focus groups with professional care providers, Rabins et al. [9] include five domains in their disease-specific instrument to assess the QOL of patients with Alzheimer's disease. Three of these domains, i.e. *social interaction*, *awareness of self*, and *mood and feelings*, are also included in generic instruments to measure QOL. According to these authors, the other two domains are more disease-specific, or in any case much more important for patients with dementia: *enjoying recreational activities* and *response to surroundings*, i.e. interaction with the home environment.

Considering table 1, *personal characteristics* (such as age, religion, coping style) may be added to complete Lawton's dimensions in line with Brod et al. [1]. It may apply to patients with dementia as it applies to chronic mental patients [6]. For instance, not only religion, also age and coping style are relevant to QOL of patients with dementia.

In most of the dementia-specific literature, 'psychological well-being' is a central outcome for QOL [1, 32]. Psychological well-being concerns the question of 'how good a person feels'. We classify this issue as one concerning the strictly personal life situation. Brod et al. [1] describe five indicators of psychological well-being: 'sense of aesthetics', 'positive and negative affect', 'self-esteem' and 'feelings of belonging'. In this respect, Rabins and Kasper [34] emphasize 'feelings and mood' and 'enjoyment of activities'. These indicators of psychological well-being are related to the personal evaluation of certain specific domains of life.

Relationships between Dimensions and Domains

The multidimensional composition of QOL gives rise to the question of how these dimensions are related. We follow Lawton [31], who considers, in agreement with the existing literature on QOL in physical and mental disorders [6, 20], psychological well-being to be the central indicator and 'ultimate outcome in a causal model of the open type'. However, the question that remains is: how are the dimensions related to psychological well-being and to each other?

Lawton [32] suggests a hierarchical view with 'behavioral competence' and 'perceived quality of life' as central sectors, 'environment' as a prerequisite or catalyst and 'psychological well-being' as the ultimate outcome. Volicer and Bloom [13] do not describe clearly how their dimensions are related. Gurland and Katz [14] suggest that the skills needed to perform the adaptive tasks are ordered hierarchically. In the work of Brod et al. [1, 7], environment and other context variables determine QOL, and they thus also suggest a hierarchical view. Therefore, based on indications in dementia-specific literature on QOL, and in line with the tradition on QOL concepts in physical diseases and chronically mentally ill patients [6, 20], we chose a hierarchical approach to explain the relations between the dimensions in dementia. This corresponds largely with Lawton's work. However, we do not consider 'behavioral competence' as a central component of QOL in dementia. Moreover, Lawton does not incorporate 'personal characteristics'. In view of the work on QOL in physical conditions and mental disorders in which personal characteristics and objective QOL indicators act as determinants of subjective health perceptions and psychological well-being, we consider dimensions that are related to dementia ('behavioral competence' in Lawton's approach) as well as the environment ('objective environment') and 'personal factors' that are not related to dementia (not in Lawton's approach) as determinants of the evaluative dimensions 'evaluation' ('domain-specific perceived QOL') and 'psychological well-being' ('psychological well-being') (fig. 1).

Figure 1 presents a hierarchical model for QOL in dementia that includes the interrelation between dimensions. It addresses all aspects of life of a dementia patient, also those not affected by dementia. Thus, our approach is disease-specific, but not in that regard that all dimensions of the model are influenced by the disease. In the model, the causal pathways that link different types of outcomes to each other are identified. The choice of the dimensions and their domains is based on the aforementioned research. Until the model is empirically tested to identify key concepts, we rely on the domains suggested by the focus groups in the studies of Brod et al. [1, 7] and Rabins et al. [9]. In addition to the domains that are related to dementia, 'environment' and the (non-dementia-related) 'personal factors' (age, sex, etc.) influence the 'evaluation of the domains' and 'psychological well-being'. Environment and personal factors also influence the domains that are in turn affected by dementia at the same level in the model (fig. 1). The personal evaluation of the life domains is on the second level 'evaluation', which can be com-

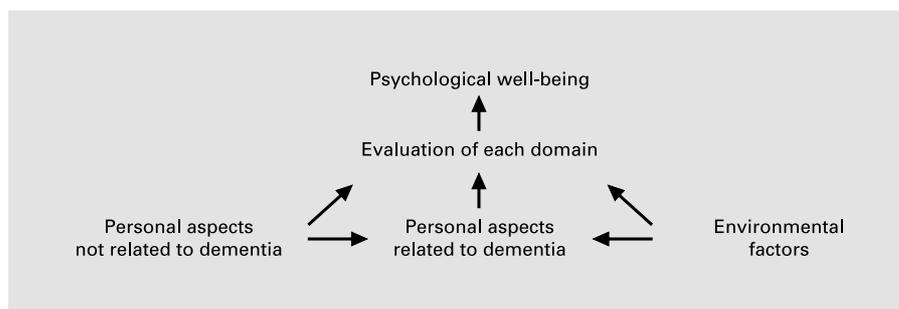


Fig. 1. Hierarchic relationships between QOL dimensions in dementia.

pared to Lawton's field 'domain-specific perceived QOL'. Also the evaluation of the domains is influenced by personal factors and environment. At the highest level in the model 'psychological well-being' is located – the central outcome measure – which can be described as the subjective evaluation of life in general, as a result of the appreciation of the various life domains. This means that the subjective evaluation of the various relevant (life) domains determines psychological well-being in general. For each individual the various domains will have their individual contribution to psychological well-being. For instance, loss of ADL functions like dressing and washing oneself may well be important for QOL for one individual, but less so or even not important for the other.

According to figure 1, QOL can be measured at three levels. Although the relative importance of the domains may vary across individuals, it is assumed that, for all patients with dementia, a number of these are important, and contribute to psychological well-being.

What Our Model Adds

The relationships between traditional clinical variables of dementia and health status measures has not been conceptualized in much of the research done to date on dementia. Our model facilitates the understanding of these associations, essentially based on the dimensions presented by Lawton. This model should be useful in the formulation of strategies to improve QOL in dementia. Changes in the disease process (e.g. progression of dementia) would be reflected in changes on dimensions and domains. Our model adds to the existing literature an approach to the relationship between the dimensions. Lawton's description of these relationships is not complete and Brod et al. [1, 7], although they differentiate between determinants and components, do not describe the relationships between the components of QOL.

Conclusion

In this article we present a hierarchical model for QOL of patients with dementia that identifies relationships between the dimensions in the model and can be used to develop and study the effect of QOL interventions. The starting point for QOL in this model is psychological well-being. Psychological well-being is considered to be the central indicator for QOL of patients with dementia. Second, we advocate that QOL in dementia should not be based on domains that are influenced by dementia exclusively. Our approach is based on the view that all life domains do have an important role in QOL in dementia, not only environmental characteristics, but also non-dementia-related personal factors, such as religion and income.

Therefore, when developing an adequate QOL model for dementia the selection of the domains is the most crucial, but also a highly controversial step. The model should be empirically tested to determine – preferably in an alternative way to the earlier used method of the focus groups – what domains are lacking in the model. A major issue of assessing QOL is being able to measure the effects of treatment. Small effects might be found lower in the hierarchy in the specific dementia-related domains but also in the objective environmental domain. Nevertheless, depending on the individual domains, small effects might also have considerable consequences for the central outcome measure, 'psychological well-being'. For this reason it is important to consider effects of interventions at various levels in the hierarchy.

Acknowledgments

We thank Dr. David R. Mehr, Department of Family and Community Medicine, University of Columbia, Mo., for his supportive critical review of an earlier version of this article.

References

- 1 Brod M, Stewart AL, Sands L, et al: Conceptualization and measurement of quality of life in dementia: The dementia quality of life instrument (DQOL). *Gerontologist* 1999;39:25–35.
- 2 Logsdon RG, Gibbons LE, McCurry SM, et al: Quality of life in Alzheimer's disease: Patient and caregiver reports. *Ment Health Aging* 1999;5:21–32.
- 3 Selai CE, Trimble MR, Rossor MN, Harvey RJ: Assessing quality of life in dementia: Preliminary psychometric testing of the Quality of Life Assessment Schedule (QOLAS). *Neuropsychol Rehabil* 2001;11:219–243.
- 4 Ready RE, Ott BR, Grace J, Fernandez I: The Cornell-Brown scale for quality of life in dementia. *Alzheimer Dis Assoc Disord* 2002;16:109–115.
- 5 de Haes JCJM, van Knippenberg FCE: The quality of life of cancer patients: A review of the literature. *Soc Sci Med* 1985;20:809–817.
- 6 Lehman AF: The well-being of chronic mental patients: Assessing their quality of life. *Arch Gen Psychiatry* 1983;40:369–373.
- 7 Brod M, Stewart AL, Sands L: Conceptualization of quality of life in dementia. *Ment Health Aging* 1999;5:7–19.
- 8 Mozley CG, Huxley P, Sutcliffe C, et al: 'Not knowing where I am doesn't mean I don't know what I like': Cognitive impairment and quality of life responses in elderly people. *Int J Geriatr Psychiatry* 1999;14:776–783.
- 9 Rabins PV, Kasper JD, Kleinman L, Black BS, Patrick DL: Concepts and methods in the development of the ADRQL, an instrument for assessing health-related quality of life in persons with Alzheimer's disease. *Ment Health Aging* 1999;5:33–48.
- 10 Novella JL, Jochum C, Jolly D, Morrone I, Ankri J, Bureau F, Blanchard F: Agreement between patients' and proxies' reports of quality of life in Alzheimer's patients. *Qual Life Res* 2001;10:443–452.
- 11 Karlawish JH, Casaret D, Klocinski J, Clark CM: The relationship between caregivers' global ratings of Alzheimer's disease patients' quality of life, disease severity, and the caregiving experience. *J Am Geriatr Soc* 2001;49:1066–1070.
- 12 Logsdon RG, Gibbons LE, McCurry SM, Teri L: Assessing quality of life in older adults with cognitive impairment. *Psychosom Med* 2002;64:510–519.
- 13 Volicer L, Bloom CL: *Enhancing the Quality of Life in Advanced Dementia*. Philadelphia, Brunner/Mazel, 1999.
- 14 Gurland B, Katz S: Quality of Life and Mental Disorders of Elders; in Katschnig H, Freeman H, Sartorius N (eds): *Quality of Life in Mental Disorders*. New York, Wiley & Sons, 1997, pp 193–212.
- 15 Lawton MP: Quality of life in Alzheimer disease. *Alzheimer Dis Assoc Disord* 1994;8 (suppl 3):138–150.
- 16 Zautra A, Goodhart D: Quality of life indicators: A review of literature. *Community Ment Health Rev* 1979;4:1–10.
- 17 Schuessler KF, Fisher GA: Quality of life research and sociology. *Annu Rev Sociol* 1985;11:129–149.
- 18 Diener E: Subjective wellbeing. *Psychol Bull* 1984;95:542–575.
- 19 Diener E: Assessing subjective wellbeing: Progress and opportunities. *Soc Indicators Res* 1994;31:103–157.
- 20 Wilson IB, Cleary PD: Linking clinical variables with health-related quality of life: A conceptual model of patient outcomes. *JAMA* 1995;273:59–65.
- 21 World Health Organization: *Constitution of World Health Organization; Basic Documents*. Geneva, 1948.
- 22 Bergner M, Bobbit RA, Kressel S, Pollard WE, Gilson BS, Morris JR: The *Sickness Impact Profile: Conceptual formulation and methodology for the development of a health status measure*. *Int J Health Serv* 1976;6:393–415.
- 23 Hunt SM, McKenna SP, McEwen J, Backett EM, Williams J, Papp E: A quantitative approach to perceived health status. *J Epidemiol Community Health* 1980;34:281–286.
- 24 Ware JE, Sherbourne CD: The MOS 36-Item Short-Form Health Status Survey (SF-36). I. Conceptual framework and item selection. *Med Care* 1992;30:473–483.
- 25 Patrick DL, Erickson P: *Health Status and Health Policy: Quality of Life in Health Care Evaluation and Resource Allocation*. New York, Oxford University Press, 1993.
- 26 Katschnig H: How useful is the concept of quality of life in psychiatry? Anniversary editorial. *Curr Opin Psychiatry* 1997;10:337–345.
- 27 Guyatt GH, Feeny DH, Patrick DL: Measuring health-related quality of life. *Ann Intern Med* 1993;118:622–629.
- 28 Gill TM: Quality of life assessment: Values and pitfalls. *J R Soc Med* 1995;88:680–682.
- 29 Hunt SM: The problem of quality of life (editorial). *Qual Life Res* 1997;6:205–212.
- 30 Lawton MP: Environment and other determinants of well-being in older people. *Gerontologist* 1983;4:349–357.
- 31 Lawton MP: A multidimensional view of quality of life in frail elders; in Birren JE, Lubben JE, Rowe JC, Deutchman DE (eds): *Quality of Life in the Frail Elderly*. San Diego, Academic Press, 1991, pp 3–27.
- 32 Lawton MP: Assessing quality of life in Alzheimer disease research. *Alzheimer Dis Assoc Disord* 1997;11(suppl 6):91–99.
- 33 Carr AJ, Higginson IJ: Are quality of life measures patient centred? *BMJ* 2001;322:1357–1360.
- 34 Rabins PV, Kasper JD: Measuring quality of life in dementia: Conceptual and practical issues. *Alzheimer Dis Assoc Disord* 1997;11 (suppl 6):100–104.