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A Simple and Practical Index to Measure Dementia-Related Quality of Life

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ABSTRACT

Background: Research on new treatments for dementia is gaining pace worldwide in an effort to alleviate this growing health care problem. The optimal evaluation of such interventions, however, calls for a practical and credible patient-reported outcome measure. **Objectives:** To describe the refinement of the Dementia Quality-of-life Instrument (DQI) and present its revised version. **Methods:** A prototype of the DQI was adapted to cover a broader range of health-related quality of life (HRQOL) and to improve consistency in the descriptions of its domains. A valuation study was then conducted to assign meaningful numbers to all DQI health states. Pairs of DQI states were presented to a sample of professionals working with people with dementia and a representative sample of the Dutch population. They had to repeatedly select the best DQI state, and their responses were statistically modeled to obtain values for each health state. **Results:** In total, 207 professionals working with people with dementia and 631 members of the general population completed the paired comparison tasks. Statistically significant differences between the two samples were found for the domains of social functioning, mood, and memory. Severe problems with physical health and severe memory problems were deemed most important by the general population. In contrast, severe mood problems were considered most important by professionals working with people with dementia. **Discussion:** The DQI is a simple and feasible measurement instrument that expresses the overall HRQOL of people suffering from dementia in a single meaningful number. Current results suggest that revisiting the discussion of using values from the general population might be warranted in the dementia context.

Keywords: dementia, health-state valuation, health states, quality-adjusted life-years, quality of life.

Introduction

Dementia has a major impact on health-related quality of life (HRQOL), and its prevalence is expected to double or triple by 2050 [1,2]. Because of this rapid increase and the poor prospects of a cure in the near future, some governments now seek to keep people in the community as long as possible. Currently, many interventions are directed to the antiamyloidal or other pathways [3]. These trials, however, rarely use HRQOL as an outcome measure, even though maintaining or improving HRQOL is a primary goal in dementia care. In light of the current perspective, the innovative HRQOL measures [4] described in this article may give impetus to intervention (both pharmacological and psychosocial) studies with societal benefits.

Preference-based HRQOL instruments that enable the generic expression of the quality of patients' health status in a single standardized value (index) are increasingly important because these are most often used to evaluate the cost-effectiveness of interventions. Generic index instruments such as the EuroQol-5D (EQ-5D) [5], the Short-Form 6-D (SF-6D) [6], and the Health Utility Index (HUI) are already available for this purpose [7]. In the field of dementia, however, clinicians and researchers generally discredit the use of generic HRQOL index instruments because these do not specifically concern the most relevant domains affected by the disease [8–10]. The general objection is that their results are insufficiently valid. Instead, researchers suggest the use of disease-specific index instruments [11], which focus on the most relevant health domains affected by a certain disease.

All HRQOL index instruments apply valuation techniques to arrive at single HRQOL values (variously called utilities, weights, or indices) for all the health states that can be defined by these instruments. Basically, HRQOL index instruments comprise a predetermined and fixed set of health domains, each with levels that indicate the seriousness of these domains. Together that set of domains constitutes the classification system of a particular instrument. Each possible combination of domain levels is assigned a metric value expressing the overall value of a health state, which comprises the valuation stage. In this part of the task, the respondents have to assess the overall descriptions of health states instead of working through the list domain by domain (or item by item), the latter being standard procedure in descriptive HRQOL questionnaires.

Conflict of interest: The authors have indicated that they have no conflicts of interest with regard to the content of this article.

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Any HRQOL index instrument should be based on a limited set of key domains because respondents can process only a small amount of information simultaneously. As empirical studies show (and theories underpin this), a limited set of key domains may be sufficient to describe the overall HRQOL [12,13]. It is crucial to include only the most important and relevant health domains in the HRQOL index instrument. Including non-key domains might increase the content marginally but increase the difficulty of the assessment tasks substantially.

In this article, we describe the refinement of a prototype dementia-specific HRQOL index instrument specifically designed for community-dwelling people with dementia, the Dementia Quality-of-life Instrument (DQI). In previous work, we have discussed the theoretical models of HRQOL in dementia [14], discussed the need for a new instrument, and focused on the psychometric properties [15]. In this article, we focus on the derivation of health-state values, not on the psychometric properties of the DQI. Furthermore, we demonstrate how to apply this novel instrument.

Methods

Instrument

The DQI describes dementia-specific HRQOL in six domains: 1) physical health, 2) self-care, 3) memory, 4) social functioning, 5) mood, and 6) orientation. To facilitate rating, each domain consists of a limited number of levels: 1) no problems, 2) some problems, and 3) severe problems. The DQI is intended for use in community-dwelling patients. Given this number of six domains with three levels each, a total of 3^6 (729) health states can be created. Each health state can be classified by a six-digit code consisting of one digit per domain (Fig. 1).

The final DQI differs from its prototype [15] in several ways. The prototype was restricted to five domains because the feasibility of five domains had been found acceptable for people with dementia as well as their caregivers [16]. In the AD Euro study [17], the DQI prototype showed a similar level of feasibility among people with dementia and their caregivers [18]. In addition, the EuroQol five-dimensional questionnaire with the cognitive dimension [19] has been used to measure the HRQOL in people with dementia and their proxies. That study suggested that it may be feasible to allow for a sixth DQI domain. The refinement of the prototype was based on unpublished data [20] that takes into account expert opinion, a literature review, and an additional empirical study, which indicated that professionals working with people with dementia regarded physical health as the most relevant domain of HRQOL. Therefore, this domain was added to the classification system. The new selection of domains allowed a broader coverage of HRQOL. In addition, the prototype underwent minor changes to improve consistency and uniformity throughout the domains and levels. The current selection of domains makes the DQI suitable for community-dwelling people with dementia because all domains are considered relevant for such people. We do caution about implementation in other populations because this might decrease the content validity.

Health-State Assessment

Conventionally, values for health states are derived from members of the general population [21]. Respondents who evaluate hypothetical health states, however, might not be familiar with dementia. It seems reasonable to assume that healthy people have insufficient information or imagination to make a valid judgment about the impact of dementia in its various stages [22,23]. The best judges of a health state are presumably those who have actually experienced it. In the case of dementia, however, their judgments about their own health state are probably biased because of their loss of insight. An alternative would be to question informal caregivers or professionals working with people with dementia because both groups have regular contact with people with dementia and are familiar with its impact on HRQOL. For this reason, the present study investigates values derived from professionals working with people with dementia and laypersons. On the basis of the literature [22,23], we hypothesized that it would be likely for the judgments of these two groups to differ substantially, in which case we would advocate using the values of the professionals.

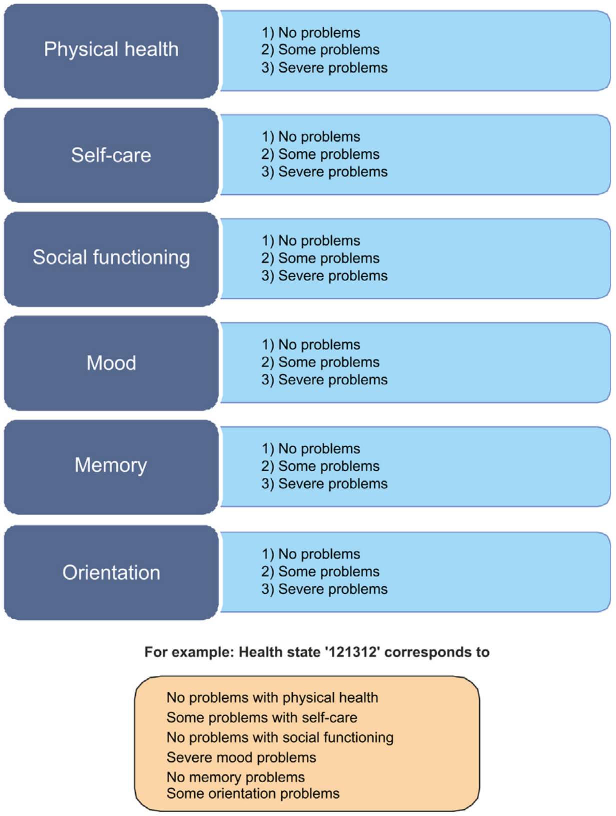

Fig. 1 – The Dementia Quality of Life Instrument. (Color version of figure is available online.)

Respondents from the professional panel and the general population were repeatedly presented with two health states (paired comparisons) and asked to indicate which one they preferred. The DQI classification system allows for 729 health states, which makes it impractical to conduct a valuation study in which all states are assessed (full factorial design). Instead, a near-orthogonal main effects design was generated (Sawtooth software, complete enumeration option) to meet certain methodological criteria (minimal overlap, level balance, and orthogonality) [24,25]. This orthogonal design allowed the estimation of main effects independent of one another. All presentations of health states (paired comparisons) were randomized while the order of domains was kept constant.

The designs also contained some paired comparisons (~4%) in which one of the two health states was dominant. A dominant comparison means that one health state was equal to or less severe on each of the domains compared with the other health state. Such comparisons served as a validity check; the number of “wrong” answers on such tasks indicates how well the respondents paid attention and understood the paired comparison task.

The survey started with demographic questions (e.g., age, sex, and location). Respondents were also asked about their