EQ-5D as a Quality of Life Measure in People with Dementia and Their Carers: Evidence and Key Issues

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A B S T R A C T

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Objectives: This article analyzes published studies on the application of the EQ-5D for the assessment of quality of life in patients with dementia and their carers. The EQ-5D, a generic instrument for measuring health-related quality of life, is widely used for economic evaluation in many areas of health research. However, there is considerable debate about the appropriateness of the EQ-5D for people with impaired cognition.

Methods: We conducted a systematic review of research studies published in the past 10 years that either used the EQ-5D as an outcome measure or investigated different aspects of the performance of the EQ-5D in studies of dementia.

Results: This study demonstrates that despite good feasibility and reliability of the EQ-5D instrument, there are problems with the validity of self-rated data because of a lack of association between patient and proxy ratings. There is a substantial ceiling effect for patient ratings. The visual analogue scale has poor reliability, even in patients with mild and moderate dementia. Different proxies (e.g., family carers, institutional carers, and health-care professionals) provide different ratings for patients' health.

Conclusion: Careful selection of assessment mode and appropriate proxies is important to ensure the EQ-5D validity in studies of patients with dementia. Because the cost of informal patient care represents a significant proportion of total costs of dementia treatment, the impact of dementia on carer's quality of life should be included in economic evaluation.
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Introduction

Dementia is a progressive disorder characterized by impairment of memory and other cognitive functions, a loss of social and functional abilities, and emotional disturbance [1]. The prevalence of dementia is increasing largely attributed to an increase in life expectancy and an aging population in the United Kingdom (UK). The Dementia UK Report 2007 [2] estimated that there were approximately 700,000 people with dementia in the UK, and this number is expected to increase to one million by 2021 and to 1.7 million by 2051. Dementia is a major cause of morbidity among elderly people and accounts for 60,000 deaths per year. The estimated financial cost of dementia to the UK is more than £17 billion per year [2].

Assessing health-related quality of life (HR-QoL) is one of the major challenges facing the economic evaluation of pharmacological and psychosocial interventions in dementia studies [3,4]. HR-QoL evaluates the impact of physical and mental disorders and disability on the general well-being of a person [5]. HR-QoL instruments can be disease specific (applicable to a sin-

gle illness or condition) or generic (can be used in a wide range of subgroups of the population). Disease-specific HR-QoL instruments include questionnaires such as the Diabetes-39 (D-39) [6], Rheumatoid Arthritis Quality of Life Questionnaire [7], and, for dementia, the QoL-AD [8]. Generic HR-QoL instruments, such as Health Utilities Index (HUI) [9], the Quality of Well-Being (QWB) scale [10] and the EQ-5D [11] allow a comparison of health outcomes among different disorders, different groups of patients, and the general population. Expressed as quality-adjusted life-years (QALYs), the HR-QoL utilities provide a universal outcome measure in the economic evaluation of health-care interventions [5,12]. The performance of every HR-QoL instrument can be characterized in terms of feasibility, precision, reliability, responsiveness, and validity [13,14].

A number of generic instruments have been developed to measure HR-QoL in elderly people. Haywood et al. [15] reviewed 15 of the most frequently used generic instruments for HR-QoL assessment in people with mean ages of 60 to 86 years. Eleven instruments were applied to generate health profiles and four to produce health utilities. Measuring health profiles allows respondents to be classified with respect to a broad spectrum of quality-of-life domains (e.g., pain, physical functioning, and mental health). The most frequently used instruments for measuring health profiles in elderly people were the Short Form-36 (SF-36) health survey and the Sickness Impact Profile. The most often used utility instruments were the HUI, the QWB scale, and the EQ-5D [15].

The EQ-5D is a standardized, nondisease-specific instrument for evaluating HR-QoL. It was developed in the late 1980s by an international research group EuroQol [11] to complement rather than replace other HR-QoL measures. The instrument is based on a descriptive system that defines health in five dimensions: mobility, self-care, usual activities (e.g., work, study, household, family or leisure activities), pain/discomfort, and anxiety/depression. Each dimension has three response categories: no problem, some problem, and severe problem. The descriptive system defines a total of 243 (3^5) possible states with 2 additional states (dead and unconscious). The questions are complemented by a visual analogue scale (VAS), sometimes called a feeling thermometer, with 0 representing worst imaginable health and 100 representing best imaginable health. The instrument captures a respondent's health status at the time of completion. EQ-5D output includes health profiles (derived from the descriptive system), self-rated health status (derived from the VAS), and a weighted index (derived using preference weights for 243 health states). The EQ-5D includes the least number of attributes and is faster to complete compared to other frequently used utility measures, such as HUI and QWB scale. For example, HUI2 contains seven domains with three to five response levels, HUI3 includes eight domains with five or six response categories [9]. The QWB scale comprises 4 domains with 3 to 5 categories, and the domain symptoms and medical problems with 27 response items [10].

The EQ-5D is widely used in the clinical and economic evaluation of health-care interventions because of its high reliability, responsiveness, good validity, and short completion time. To date, it has been used in 1252 studies registered with the EuroQol Group. The EQ-5D has been translated into more than 100 languages and national reference values have been derived in 8 European countries, including the UK [11]. The EQ-5D is recommended for use in cost-effectiveness studies in the United States (US) by the Washington panel on Cost Effectiveness in Health and Medicine [16], and in the UK by the National Institute for Health and Clinical Excellence (NICE) [17].

The assessment of HR-QoL in dementia patients presents a significant challenge. Although the EQ-5D has been included as an outcome measure in the number of clinical trials and psychosocial interventions for dementia in the UK [18], there are concerns that the validity of the EQ-5D in patients with dementia may be limited. In common with dementia-specific instruments, there are concerns about the level of dementia severity at which patients are able to provide valid ratings [19–23]. There are also questions regarding who the appropriate proxy should be: carer or health professional [19,21,24], and the importance of obtaining data from both the carer and medical specialist rather than relying on a single proxy has been emphasized [19]. There is also a wider debate about the validity of proxy ratings in general [25] because there is a discrepancy between proxy and patient ratings for dementia-specific instruments, such as the QoL-AD [26]. The feasibility of incorporating a cognitive component into generic HR-QoL instruments and development of scoring algorithm including a cognitive dimension has also been discussed [27].

This review summarizes the existing literature on the application of the EQ-5D in dementia research. We then discuss a number of methodological issues concerning the use of the EQ-5D as a quality-of-life instrument in future studies.

Methods

A database search was conducted for the period 1990 to 2009 to identify peer-reviewed publications on the application of the EQ-5D in dementia studies. The search included electronic databases EuroQol, Medline, Caredata, CAB direct, CINAHL, Cochrane Library, Emerald, PsycINFO, and BIOSIS previews. The full text of articles was searched for the terms "EQ-5D," "dementia," "Alzheimer's" (Alzheimers, Alzheimer), and "quality of life." In addition, a broad search across all disciplines and sources was performed using the Google Scholar advanced option including "all the words" and "everywhere in the article" for "EQ-5D and dementia" and "EQ-5D and Alzheimer's" (Alzheimers, Alzheimer). Articles were included in this review if they fulfilled the following criteria: 1) were published in the past 10 years, 2) represented an original research study, 3) used the EQ-5D as primary or secondary outcome measure, 4) were published in English.

Results

Database search results

The search identified 21 papers that fulfilled the inclusion criteria (Table 1). These papers cover 18 studies, 2 of which are randomized, controlled trials [28,29]. Of the 21 papers, 17 focus on dementia patients and 4 on carers of people with dementia [28,30–32]. Ten papers address questions of validity of the EQ-5D in dementia patients [19,20–25,27,33,34]. Four studies