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Abstract: Objectives: We aimed to examine the discrepancy between patients and caregivers’ ratings of quality of life in terms of accuracy and precision, and identify factors associated with it, in order to facilitate the use of this scale as dementia progresses. Design: Cross-sectional analytic study. Setting: Day care centres. Participants: Community-living patients with Alzheimer’s disease in early or moderate stage and their principal caregivers. Measurements: Participants rated patients’ quality of life using DEMQOL. The discrepancy was assessed using the individual difference score and the residuals for each domain of DEMQOL. The scores on Mini-Mental State Examination, Geriatric Depression Scale, Neuropsychiatric Inventory, Clinical Insight Rating Scale, Cumulative Illness Rating Scale, Health Utilities Index Mark 3 and Zarit Burden Interview were considered as possible predictors of the discrepancy. Results: A total of 276 subjects participated in the study (138 patients with Alzheimer’s disease and their caregivers). Discrepancy measured by individual difference score was lower than that measured by the residuals. Burden and mood-related symptoms explained the positive differences and residuals, while pain, self-perceived depression and cognition determined the negative ones. Conclusions: Differences exist between patients and caregivers’ perceptions about subjective states. The evaluations of each informant seem to be influenced by their own emotional state and the inner experience of the effects of the disease. Caregivers’ ratings on DEMQOL could be useful to monitor the efficacy of any treatment whenever burden is low and patients have no great physical or emotional suffering.

Key words: Quality of life, discrepancy, Alzheimer’s disease, DEMQOL.

Introduction

Alzheimer’s disease (AD) is increasingly prevalent in aging societies (1). Therefore, there is increasing interest in developing cost-effective strategies to improve the health-related quality of life (HRQoL) of these patients (2). Although HRQOL definitions vary widely, there is general agreement that it implies a subjective perception of the impact of health status on physical, psychological, and social functioning. In cognitively impaired patients, HRQoL has been assessed using self-reports, caregiver-reports and observational measures. There is general agreement that subjective evaluation should rely, as far as possible, on the patients’ perspective, especially in early stages of AD (3). Several studies have reported notable differences between patients and caregivers’ perceptions of HRQoL. Caregivers’ ratings are, on average, lower than patients’ ratings, and the agreement between observers is moderate at best (3-4). This discrepancy has been associated to characteristics of the patients such as lack of insight, severity of cognitive impairment or behavioral disorders (5), but also to caregivers-related factors such as depression, health or burden (6). These data suggest that proxy’s report, though necessary in advanced stages, may not be a good substitute for the patient’s report. Determining the factors that contribute to the discrepancy could help assess HRQoL more reliably. Little research has been conducted on this topic using DEMQOL scale (7-8). This study aimed to measure the discrepancy between patients and caregivers DEMQOL ratings and identify the factors potentially contributing to it. We used two methodological approaches to assess the discrepancy, and established comparisons between them. The results could be of practical importance, since we have considered a wide set of clinical variables as predictors and separately analyzed the discrepancy in different domains of HRQoL.

Methods

Participants

Patients were recruited from day centres in the area of Murcia, Spain. They were required to meet criteria for possible or probable AD (9), have a score of 4 or 5 in the Global Deterioration Scale score (10) and be residing with a caregiver in a community dwelling. Caregivers were selected from people who provide daily care to the patients and supervise them at home. They were non-professional caregivers.

Measures

Dementia specific HRQoL measure

DEMQOL (4). The DEMQOL system consists of two interviewer-administered instruments (DEMQOL and DEMQOL proxy) that measure the HRQoL of dementia
patients. DEMQOL is reported by patients and DEMQOL proxy is completed by caregivers, both have proved to have good psychometric properties in mild to moderate dementia patients (4). DEMQOL consists of 28 items answered on a 4-point Likert scale (a lot/quite a bit/a little/not at all). Total score ranges from 28 to 112, with higher scores indicative of better HRQoL. DEMQOL proxy has 31 items, some of which are different from DEMQOL items. Since we intend to measure the patient-caregiver agreement and to predict patients’ ratings, we administered DEMQOL to both patients and caregivers and studied its psychometric properties. Studies about the factorial structure of DEMQOL have proposed solutions with three, four and five factors (4, 11). We choose the solution proposed by Lucas et al. (11) because this study was conducted with the Spanish version of the scale. This version has three factors: feelings, everyday life and memory. The “feelings” factor includes items 1 to 13 and item 27; “everyday life” includes items 20 to 26 and 28 and “memory” items 14 to 19.

Clinical measures of the participants

MINI-MENTAL STATE EXAMINATION (MMSE) (12). MMSE is a 30-point instrument widely used as a rough measure of cognitive severity. We used the score of a short version of MMSE (SMMSE) built from six memory items of MMSE, which has proved to be useful in screening dementia (13).

GERIATRIC DEPRESSION SCALE SHORT FORM (SGDS) (14). SGDS is a 15-item self-report questionnaire that has been validated to assess depression in both cognitively intact and demented elderly (15).

NEUROPSYCHIATRIC INVENTORY (NPI) (16). NPI is an interview-based tool designed for comprehensive evaluation of behavioral disturbances in patients with dementia. The 12-item version evaluates the frequency and severity of delusions, hallucinations, agitation, depression, anxiety, euphoria, apathy, nighttime behaviour disturbances, appetite disorders, disinhibition, irritability and aberrant motor behaviour. The score for each item is obtained by multiplying frequency (1-4) by severity (1-3). The total NPI score is the sum of the individual item scores. Recently, a study using confirmatory factor analysis has proposed a three-factor model for the 12-item NPI: mood (depression, apathy, eating disturbances, nighttime behaviour disturbances and anxiety), psychosis (delusions, hallucinations) and behavioral disturbances (anxiety, agitation, disinhibition, irritability, aberrant motor behaviour) and the item euphoria (17).

CLINICAL INSIGHT RATING SCALE (CIR) (18). CIR is a 4–item instrument that measures four components of insight: the awareness of the situation, cognitive deficits, functional disability, and progression of the disease. Each item is rated from 0 (totally unaware) to 2 (totally aware).

ZARIT BURDEN INTERVIEW (ZBI) (19). ZBI is an instrument for measuring caregivers’ perceived burden of providing family care. It has 22 items and is self-administered. ZBI scores range from 0 (no burden) to 88 (highest burden).

HEALTH UTILITIES INDEX MARK 3 (HUI 3) (20). HUI 3 is a generic multi-attribute preference-based measure of health status and HRQoL widely used as an outcome measure in clinical and economic studies. HUI 3 includes 8 attributes of health status: vision, hearing, speech, ambulation, dexterity, emotion, cognition, and pain with 5 or 6 levels per attribute, varying from highly impaired to normal. HUI 3 is scored using single- and multi-attribute utility as described by Ruiz et al. (21). In this study, we used the score of the pain attribute.

CUMULATIVE ILLNESS RATING SCALE (CIRS) (22). The modified Cumulative Illness Rating Scale was used to measure the total burden of medical illness. The questionnaire consists of 14 domains related to different body systems. Scoring on the different domains is weighted by the severity of the comorbid condition. Severity scores range from 0 (none) to 5 (extremely severe). The illness severity index is the average score of all the items, excluding the domain “psychiatric or behavioral disturbances”. CIRS has proved to be valid and reliable in the geriatric population (23).

Procedures

Written informed consent was obtained from both patients and caregivers. Patients and caregivers were administered the tests separately to avoid the possibility of influence. Patients were interviewed about their quality of life (DEMQOL) and depressive state (SGDS). The severity of the dementia was assessed by using the MMSE and the GDS. A physician quantified medical comorbidity using the Cumulative Illness Rating Scale. Caregivers completed HUI 3, NPI and ZBI and were asked to rate the patients’ HRQoL (DEMQOL) as a substituted judgment. Researchers completed CIR based on their judgments of patients’ insight after the interviews with the patient and the relative.

Statistical Analyses

The internal consistency of DEMQOL and its domains was calculated with Cronbach’s alpha coefficient (24). The factor structure of the DEMQOL was examined by means of exploratory factor analysis using the using principal component analysis with varimax rotation.

The analysis of the discrepancies proceeded in several steps. First, we examined whether there were significant differences in both DEMQOL total and each domain scores between patients and caregivers using the ANOVA test. Where significant differences were found, we assessed the discrepancy by two statistical methods: individual difference score and regression residuals. Individual difference score was calculated by subtracting caregiver’s rating score from the patient’s rating score. Predictors were selected from the variables that correlate significantly with the difference score and with the scores of either patients or caregivers, as did Huang et al. (6). We used a Bonferroni adjustment to control for Type I Error.

The second method to assess the discrepancy is based on the