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Research paper

Health-related quality of life in community dwelling patients with mild-to-moderate Alzheimer's disease

A. Raggi [a,*], D. Tasca [b], P.M.D. Lupica Capra [b], S. Panerai [b], W. Neri [a], R. Ferri [c]

[a] Unit of Neurology, G.B. Morgagni–L. Pierantoni Hospital, Forlì, Italy
[b] Unit of Psychology I.C., Oasi Institute for Research on Mental Retardation and Brain Aging (IRCCS), Troina, Italy
[c] Unit of Neurology I.C., Oasi Institute for Research on Mental Retardation and Brain Aging (IRCCS), Troina, Italy

A B S T R A C T

Background: Given the complexity of Alzheimer's disease (AD), it is a key object to explore broad outcomes, such as patient health-related quality of life (HRQoL) in relation to other variables including the feeling of burden experienced by caregivers.
Methods: Validated tests and questionnaires were used in this survey for the assessment of clinical variables of patients, the severity of the caregiver burden, and the measurement of the HRQoL of mild-to-moderate AD patients. This study was carried on also in order to evaluate the appropriateness of the questionnaires (DEMQOL and DEMQOL-Proxy) utilized in measuring HRQoL in AD and of their capability to identify whether there is agreement between ratings obtained by patients and caregivers.
Results: The amount of burden for caregivers was found to be positively correlated with several measures of cognitive, psychological, behavioral, and motor impairment of the patients. Carers evaluated HRQoL worse than AD sufferers. A significant correlation was demonstrated between the caregiver stress and severity of depressive symptoms in the patients. The DEMQOL-PROXY was found to be significantly correlated with the patient level of depressive symptoms.
Conclusions: Depressive symptoms mostly worsen the caregiver tolerability of the patient mental impoverishment. It is of great importance to assess patients with mild-to-moderate AD carefully in terms of depressive symptoms because they may have a great clinical implication. There was relatively low agreement between ratings concerning HRQoL obtained by patients and caregivers despite the capacity of the questionnaire to yield many clinical shades concerning the patient HRQoL.

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1. Introduction

Dementia causes progressive decline in global intellectual, social, and physical functioning. Alzheimer's disease (AD) represents the most common cause of this irreversible pathology [1,2]. Most patients with dementia live in the community and depend on a family member for assistance [3] with consequent distress, which was found to be correlated with specific coping strategies [4,5].

Broad outcomes including health-related quality of life (HRQoL) need to be studied [6] in order to reinforce as much as possible the support for patients and formation of caregivers. Moreover, because no cure is available for AD at present, the optimization of quality of life (QoL) represents the best possible outcome attainable in all stages of the disease, making QoL assessment mandatory. In fact, QoL is a main endpoint of health and social service interventions [7]. Differently from other clinical conditions, including pain and diseases implying physical limitations, in dementia QoL is not an easily measurable clinical variable [8–11]. Obstacles are represented by anosognosia, difficulties in understanding questionnaire items, lack of objective data despite the presence of caregivers. Nevertheless, some studies suggest that meaningful measures can be made using subjective and proxy instruments [6,12–14]. The questionnaires are more likely suitable for patients with mild-to-moderate dementia. Previous data suggest that behavioral and psychological impairment and patient age are more strongly associated with QoL than cognition or functional limitation [15]. This finding suggests that cognitive improvement might be a poor proxy for QoL grading in dementia. A research demonstrates that caregiver distress was the most consistent predictor of QoL rating discrepancy between the patient

* Corresponding author. Unit of Neurology, G.B. Morgagni–L. Pierantoni Hospital, 34 Via Carlo Forlanini, 47121 Forlì, Italy. Tel.: +39 543 735 264; fax: +39 543 738 617.
 E-mail address: albertoraggi@libero.it (A. Raggi).

and caregiver, and patient depressive disorder was the most significant predictor of QoL [16]. The evaluation of patients living in the community showed a negative relationship of QoL, measured by means of the QoL-AD [17], with depressive mood and a positive relationship with functioning, whereas the QoL ratings of the caregivers showed a negative relationship with depressive mood and behavioral disturbances of AD sufferers. Some other studies showed discrepancies between patient and caregiver perspectives [18,19]. Therefore, there is no plentiful evidence about QoL of community dwelling patients and many aspects concerning of patient and caregiver point of view need to be developed. The up-to-date methodology substantially offers two different approaches: caregivers may be instructed to rate their relative current situation answering to questionnaire as they see it according to QoL-AD or just giving the answer that they feel their relative would provide as in the current study.

The first aim of this study was to measure HRQoL in mild-to-moderate AD patients living in the community and to compare it with that of normal controls from the same social environment. Moreover, another goal was to correlate the patient self-made evaluation of QoL with that made by the respective caregivers, in order to understand some features of the patient–caregiver interactions with possible effects in this domain. Finally, the last aim was to evaluate the correlation between the caregiver evaluation of the patient QoL, burden of distress and multidimensional neuropsychiatric status and the expert score of different neuropsychological and functional domains of the patients.

2. Material and methods

2.1. Participants

Consecutive mild-to-moderate AD outpatients living in the community were recruited who were followed up at the at the Institute for Research on Mental Retardation and Brain Aging of Troina and the G.B. Morgagni – L. Pierantoni Hospital of Forlì. Institutionalized or community dwelling moderate or severe AD patients and those with any other variety of dementia were not recruited for this study. Non-demented controls were recruited in the local community of the health districts where the two institutes are located.

2.2. Clinical assessment

Demented patients were considered suitable for full assessment if they met DSM-V criteria for Neurocognitive Disorders due to AD [20]. A structured medical history collected from the patient and the primary caregiver, a neurological examination, a neuropsychological assessment, routine laboratory analysis and neuroimaging studies had been previously performed, and were consistent with the diagnosis of AD [21]. The assessment of the staging of dementia was done by means of the Clinical Dementia Rating Scale (CDR) [22]; comorbidity was identified and quantified using the Cumulative Illness Rating Scale (CIRS index) [23]; cognitive status was evaluated by means of the Mini-Mental State Examination (MMSE) [24]; the functional status was evaluated according to the Activities of Daily Living ADL [25] and Instrumental Activity of Daily Living [26], and depressive symptoms were assessed with the short form of the Geriatric Depression Scale (GDS) [27]. The overall psychopathological assessment was based on the Neuropsychiatric Inventory (NPI) [28]; this questionnaire includes a set of screening questions for ten behavioral (delusions, hallucinations, dysphoria, anxiety, agitation/aggression, euphoria, disinhibition, irritability/lability, apathy, aberrant motor activity) and two neurovegetative (sleep and night time behavior disorder, appetite and eating disorder)

features potentially present in the past four weeks. If a positive response was obtained, then that behavioral domain was explored with standardized questions on specific aspects of that disturbance. The caregiver than rated the frequency (score range 1–4) and severity (score range 1–3) of the symptom. A composite score of each domain was the product of the frequency and severity sub scores, with a maximum of 12. Mobility problems were assessed with the Tinetti Scale [29]. Treatments were also taken into consideration.

For each subject, the family primary caregiver was recruited. Caregivers were asked to complete a form sheet to collect information about sociodemographic data (age, gender, occupational status) and health status. The presence of the availability of support (formal or informal) was also verified. The Caregiver Burden Inventory (CBI) [30] was used, which is aimed at a multidimensional assessment of caregiver burden of distress. This self-report questionnaire was purposely designed for caregivers of subjects with dementia, and addresses the person who mostly takes care of the patient. It is a 24-item multidimensional questionnaire measuring caregiver burden with five subscales: Time dependence (referring to time demands and restrictions that patients impose to caregivers), Developmental (referring to the caregiver feeling of being "off-time" in their development with respect to their peers), Physical burden (referring to the strain associated with demands on caregiver physical health), Social burden (referring to the caregiver conflicts between different roles such as work and family), Emotional burden (referring to the caregiver negative feelings depending upon the patient unpredictable and often bizarre behavior). Scores for each item are evaluated using a 5-point Likert scale ranging from 0 (not at all disruptive) to 4 (very disruptive). All the scores on the 24-item scale are summed up and a total score > 36 indicates a risk of "burning out" whereas scores near or slightly above 24 indicate the need to take a break and rest. The caregiver distress score was assessed also by the NPI-Caregiver Distress Scale [31].

Quality of life indicators in this study were the Dementia Quality of Life (DEMQOL) and DEMQOL-Proxy. DEMQOL is a patient reported outcome measure (PROM), which is designed to enable the assessment HRQoL of people with dementia [14,32,33]. DEMQOL is designed to work across dementia subtypes and care arrangements. DEMQOL is indicated for patients with mild-to-moderate dementia whilst DEMQOL-Proxy can be used at all stages of cognitive/behavioral decline. The measure consists of two questionnaires: DEMQOL, which is a 28 item interviewer-administered questionnaire answered by the person with dementia (score range 28–112, with a higher score indicating better HRQoL), and the DEMQOL-Proxy which is a 31 item interviewer-administered questionnaire answered by a caregiver (score range 31–124, with a higher score indicating better HRQoL). In order to make DEMQOL and DEMQOL-Proxy scores comparable, in this study, we normalized them as ranging between 1 and 100, and called these normalized values nDEMQOL and nDEMQOL-Proxy, respectively. The questionnaire was very carefully introduced by an interviewer to both patient and caregiver in order to:

- ensure that the person was happy to participate;
- reiterate that there were not right or wrong answers;
- explain the contents of the collection of questions (for example about the activities that the people do during the day);
- show the person the response card and encourage to hold it if appropriate;
- read the instructions on the front of the questionnaire;
- read aloud the practice questions, such as asking to point the response card or say the answer chosen;
- providing breaks when the subject was struggling.