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Featured Article

Assessing Alzheimer's disease patients' quality of life: Discrepancies between patient and caregiver perspectives

Sandrine Andrieu[a,b,*], Nicola Coley[a,b], Yves Rolland[a,c], Christelle Cantet[a,c],
Catherine Arnaud[a,b], Sophie Guyonnet[a,c], Fati Nourhashemi[a,c], Alain Grand[a,b], Bruno Vellas[a,c],
and the PLASA group[1]

[a]*Inserm-Toulouse University UMR1027, Toulouse, France*
[b]*CHU Toulouse, Department of Epidemiology and Public Health, Toulouse, France*
[c]*Gerontopole, CHU Toulouse, Department of Geriatric Medicine, Toulouse, France*

Abstract

Introduction: Quality of life (QOL) is an important dimension to consider in Alzheimer's disease (AD), but few large-scale studies have analyzed self and caregiver reports of patient QOL.
Methods: Patient QOL was evaluated in a cohort of 574 AD patients with the QOL-AD scale over 2 years.
Results: Caregiver reports of patient QOL were lower at baseline than self reports. Older patient age was associated with overestimation of QOL by caregivers, whereas neuropsychiatric inventory score and caregiver burden were associated with underestimation. Activities of daily living limitation, depressive symptoms, and caregiver burden were systematically associated with poorer QOL, whereas caregiver relationship and apathy were associated with poorer QOL only for self reports or caregiver reports, respectively. Cognitive function and professional care were not associated with QOL. Self-rated patient QOL did not change over time, whereas disease severity markers and caregiver-rated patient QOL declined.
Discussion: It is important to assess both self and caregiver ratings when assessing patient QOL.

Keywords: Alzheimer's disease; Quality of life; QOL-AD; Caregivers; Proxy report; Longitudinal

1. Introduction

Alzheimer's disease (AD) is a chronic disease that requires care for several years and remains one the most frequent disabling diseases in aging populations [1,2]. It is a major cause of decreased quality of life (QOL) in older adults, and some studies have shown that more than the disease itself, it is its disability-related impact that affects QOL [3]. Simple measures of cognitive or functional decline are not sufficient to address the complexity of AD, and QOL is a useful additional dimension to consider as a broader outcome measure which may represent more "clinically significant" changes or benefits to the patient and caregiver [4]. QOL is a broad conceptual field, linked to physical health as well as psychological state, level of independence, social relationships, personal beliefs, and the subject's relationship with the specifics of their environment [5]. Researchers [6,7] and regulatory agencies [8] emphasize the need to take into account patient QOL in the evaluation of new drugs but stress the need for further validation work to use it as an end point in clinical trials. For example, little is known about the natural history of QOL in AD, the determinants

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There are conflicts of interest to disclose.

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[1] See acknowledgments for the list of the PLASA study group members.

*Corresponding author. Tel.: +33-5-61-14-59-50; Fax: +33-5-62-26-42-40.

E-mail address: sandrine.andrieu@univ-tlse3.fr

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of high and low QOL, or the effects of medication on QOL [9].

Caregiver ratings are frequently used as part of multidimensional evaluations of AD patients, in particular to measure patients' functional status and neuropsychiatric symptoms, and caregivers may also be asked to rate patients' QOL [4]. However, because QOL is subjective and defined as an individual perception, it should ideally be assessed from the subject's own perspective [10,11], but declining cognitive function makes this harder to do in AD [10]. Many QOL scales have been proposed in AD [12], including the QOL-AD scale which requires both the patient and caregiver to rate the same domains of patient QOL [10].

Several previous studies [13–17] have reported discrepancies between caregiver and self reports of AD patients' QOL, and some have identified factors associated with divergent ratings [15–19]. Most studies were small scale and targeted populations coming from particular settings, such as residential care homes [20], or from therapeutic trials, thus providing a selected sample with an abnormally low rate of comorbidities [21,22]. Furthermore, very few studies have examined longitudinal changes in patient and proxy QOL reports over >1 year of follow-up [18].

The primary objective of this multicentre study was to explore discrepancies between self and caregiver reports of patient QOL in a large population of well-characterized community-dwelling AD patients at baseline and during 2 years of follow-up and to determine factors associated with disagreement at baseline. The secondary objective was to assess factors explaining a low level of self- or caregiver-reported patient QOL at baseline.

2. Methods

This study includes AD patients and their primary caregivers enrolled in the Plan de soin et d'aide dans la maladie d'Alzheimer (PLASA) study, a randomized trial that tested the efficacy of a standardized care plan versus usual dementia care on functional decline over 2 years of follow-up. PLASA is described in detail elsewhere [23].

2.1. Subjects

Briefly, a total of 1131 AD patients and their caregivers were recruited in a French nationwide network of 50 memory centers. To be included, subjects had to meet the following inclusion criteria: diagnosis of probable or possible AD according to the National Institute of Neurological and Communicative Disorders and Stroke and the Alzheimer's Disease and Related Disorders Association criteria [24], mini-mental status examination (MMSE) [25] score between 12 and 26, community-dwelling, looked after by a well-identified informal caregiver, and not participating in any other research program. In the present analysis, we included only the 574 patients randomly assigned to the intervention group to be able to study the determinants of QOL and patient-proxy agreement because this group underwent more comprehensive evaluations than the usual care group (as part of the intervention). The intervention had no significant effect on any of the primary or secondary efficacy measures, including QOL.

The study was funded by the Ministry of Health and was approved by the Institutional Review Board and ethics committee of Toulouse University. Written informed consent was obtained from all patients and their caregivers. This trial was registered in clinicaltrials.gov (identifier: NCT00480220).

2.2. Measurements

Patients were evaluated every 6 months in memory centers in general or university hospitals.

2.2.1. QOL measure

Patient QOL was assessed by the QOL-AD scale [10], a 13-item questionnaire designed to provide patient and caregiver reports of the patient's QOL which covers various domains (physical health, energy, mood, living situation, memory, family, marriage, friends, self as a whole, ability to do chores, ability to do things for fun, financial situation, and QOL as a whole). Items are scored on a 4-point Likert scale ranging from 1 (poor) to 4 (excellent). Total scores range from 13 to 52 with higher scores indicating better QOL. As proposed by Logsdon [10], missing items were replaced by the mean score of the remaining items if no more than two items were missing; otherwise, the score was considered missing.

2.2.2. Other measures

Sociodemographic data (age, sex, educational level, and living arrangements), time since diagnosis of dementia as declared by the caregiver, comorbidities, use of support services, and assistance in the home (home help, supervision, meal delivery service, and nursing care) were recorded using a standardized questionnaire. Number of medications used and use of anti-AD drugs (i.e., cholinesterase inhibitors, N-Methyl-D-aspartate receptor antagonists) were recorded. Dementia severity was evaluated based on assessments of cognition (MMSE) [25], function (activities of daily living [ADL] [26], instrumental activities of daily living [IADL] [27]), and behavioral disorders (neuropsychiatric inventory [NPI]) [28]. Nutritional status was evaluated with the mini nutritional assessment (MNA) [29], and caregiver burden was evaluated using the Zarit Burden Interview [30].

2.3. Data analysis

Baseline mean total scores and individual domain scores were calculated for patient- and caregiver-rated QOL when a score was available for both members of the dyad.

To address the extent of agreement between patient and caregiver reports, Spearman and intraclass correlation coefficients (ICCs) were computed for each item at