Differences between physician and caregiver evaluations in Alzheimer’s disease

Elena Sinforiani, MD
Chiara Pasotti, PsyD
Laura Chiapella, PsyD
Paola Malinverni, PsyD
Chiara Zucchella, PsyD

Alzheimer’s Disease Assessment Unit/Laboratory of Neuropsychology, IRCCS “C. Mondino National Institute of Neurology” Foundation, Pavia, Italy

Correspondence: Elena Sinforiani
Laboratory of Neuropsychology, IRCCS C. Mondino
Via Mondino 2, 27100 Pavia, Italy
E-mail: elena.sinforiani@mondino.it

Summary

In Alzheimer’s disease (AD) differences are often reported between caregivers’ and physicians’ aims and evaluations. The aim of this study was to investigate the presence of discrepancies between the evaluations of caregivers and physicians. Two hundred and eighteen caregivers of outpatients diagnosed with mild-to-moderate AD, referred to our Alzheimer’s Disease Assessment Unit, entered the study. Caregiver burden was investigated using the Caregiver Burden Inventory (CBI) and the Neuropsychiatric Inventory Caregiver Distress Scale (NPIDS). Caregivers were also administered a four-point scale to assess quantitatively whether their expectations in relation to the efficacy of the pharmacological treatment had been satisfied and a scale exploring clinical global impression of change. Caregivers whose expectations had not been satisfied had significantly higher CBI and NPIDS scores and a lower level of education; moreover, caregivers tended to overestimate the degree of cognitive decline during the course of the disease. These results underline the importance of correct and constant communication with AD patients and their families.

KEY WORDS: Alzheimer’s disease, caregiver burden, caregiver expectations, clinical impression of change

Introduction

Alzheimer’s disease (AD) is a chronic disease, characterised by a progressive loss of cognitive and functional abilities. The AD patient’s increasing care needs as the disease progresses and the consequent impact on the caregiver’s life are well known. The term “caregiver burden” was coined to define “a multidimensional response to physical, psychological, emotional, social and financial stresses associated with the caregiving experience” (1). Many studies have investigated this phenomenon. Various patient and caregiver variables (type and severity of dementia, comorbidities, pharmacological treatment, sociodemographic conditions, pre-morbid personalities and relationships) have been studied in order to identify possible predictors of caregiver burden and thus to allow the implementation of effective coping strategies and psychosocial interventions (2-6). Of the milestones liable to significantly increase caregiver burden, the onset in the AD patient of behavioural and psychological disturbances (BPSDs) is considered the most important (7-9). Moreover, specific caregiver characteristics, such as relationship to the patient (10), gender (11,12) and culture (13), have been reported to be associated with the presence of BPSDs, independently of patient characteristics including dementia severity (14). The presence of a caregiver is fundamental throughout the course of AD, including the early stages; indeed, medical interventions in AD are always decided on the basis of both the physician’s direct assessment and the caregiver’s report. However, discrepancies may exist between the objective assessment and the caregiver’s report, possibly related to personal characteristics of the caregiver (15,16); moreover, differences have been reported between physician and caregiver expectations of treatment and evaluations of treatment results (17,18).

In Italy, most people with dementia live at home, even in the advanced stages of the disease (19). The majority of caregivers are women (20), even though, as a result of changes in population socio-demographics, men are increasingly assuming prominent roles as caregivers (2). In this study we investigated caregiver burden in a large population of AD patients referred to our Alzheimer’s Disease Assessment Unit. In particular, we set out to explore the extent to which caregiver expectations as regards the efficacy of the pharmacological treatment had been satisfied, whether there were discrepancies between the caregivers’ and physicians’ clinical impressions; and whether caregiver impressions correlated with objective evaluations. Moreover, we tried to identify which caregiver characteristics might influence these aspects.

Materials and methods

Two hundred and eighteen caregivers (M/F: 75/143) of consecutive outpatients with mild-to-moderate AD (diagnosed according to the NINCDS-ADRDA criteria) (21), referred to the Alzheimer’s Disease Assessment Unit of the IRCCS “C. Mondino National Institute of Neurology”, Pavia, Italy, from January 2003 to December 2004, entered the study. Formal caregivers were excluded. All the patients had been receiving pharmacological treatment with cholinesterase inhibitors and/or memantine for at least four years.
The staff members involved in conducting the study were one physician (neurologist) and two psychologists with considerable experience (more than 10 years) of working with AD patients. The patients' cognitive and functional status was assessed using the following measures:
- Mini-Mental State Examination (MMSE) (22), to obtain a global cognitive evaluation;
- Activities of Daily Living (ADL) (23), to evaluate basic everyday activities (the score ranges from 0 to 6, with higher scores corresponding to higher levels of independence);
- Instrumental Activities of Daily Living (IADL) (24), to evaluate more complex activities (the score ranges from 0 to 8, with higher scores corresponding to higher levels of independence);
- Neuropsychiatric Inventory (NPI) (25). This scale assesses the frequency and severity of 12 psychological and behavioural symptoms; the score ranges from 1 to 144 with higher scores indicating greater behavioural disturbances.

The caregivers were instead administered the following instruments:
- Caregiver Burden Inventory (CBI) (26): this is a self-administered, 24-item questionnaire assessing the caregiver's perception of the burden of care in different domains. It is divided into five sections: objective burden, relating to the restrictions placed on the family member's time; developmental burden, relating to the caregiver’s feelings of being "left out", i.e. unable to enjoy the same expectations and opportunities as his or her peers; physical burden, which relates to tiredness and somatic health problems; social burden, which relates to conflicts with work and with family life arising as a result of the caregiving role; and emotional burden, which is generated by negative feelings towards the patient (shame and embarrassment).

Each item is rated on a five-point Likert scale ranging from 0 to 4 and the caregiver is required to tick the box (number) that most closely corresponds to his or her own condition or personal impression; higher scores on the CBI indicate greater levels of perceived burden.
- Neuropsychiatric Inventory – Caregiver Distress Scale (NPIDS) (27). This instrument, developed as an adjunct to the NPI, is a tool for assessing the impact of AD patients' neuropsychiatric symptoms on caregiver distress; the score ranges from 0 to 60, with higher scores indicating greater distress.

In order to establish whether caregivers felt that the patient’s disease had evolved according to their expectations, the following question was put to them: "Thinking back to what you knew at the time of the diagnosis, would you say that the patient's disease has evolved as you expected?". A four-point scale (0=no; 1=partially; 2=moderately; 3=completely) was used. The question was formulated in writing but the clinicians also explained it to the subjects orally; in the event of doubt, the question was rephrased and re-explained to caregivers in order to avoid possible misunderstandings.

Finally, in order to evaluate changes in their impressions of the patient’s clinical picture over time in relation to pharmacological treatment, both physicians and caregivers were administered the Clinical Global Impression of Change scale (CGIC) (28). This scale is used to indicate the extent to which a patient’s illness is deemed to have improved or worsened in relation to baseline (status at the beginning of the intervention): 1=very much improved, 2=much improved, 3=minimally improved, 4=no change, 5=minimally worsened, 6=much worsened, 7=very much worsened.

The patients and caregivers were seen regularly and answered the questionnaires every six months; however only the scores obtained from the evaluation measures at baseline, i.e. before beginning the pharmacological treatment, and at the end a four-year follow up were considered in the statistical analysis. Patients who presented clinical disturbances were administered these surveys more frequently. However, even if they completed the questionnaires, these subjects' data were not included in the study.

The main characteristics of the patients and their caregivers at baseline are reported in table 1.

Statistical analysis

Descriptive statistics were used to analyse the demographic characteristics of the caregivers and patients. The results were analysed using one-way ANOVA, followed by pairwise post-hoc comparison using the Bonferroni procedure to account for multiple comparisons, and correlation analysis. The initial value for statistical significance was set at p<0.05 for all measures. The SPSS version 16.0 for Windows was used for the analysis.

Results

In order to answer our first question, i.e. whether caregiver’s expectations in relation to the efficacy of the treatment had been satisfied, we subdivided the caregivers into four groups: Group 1 (not satisfied); Group 2 (partially satisfied), Group 3 (moderately satisfied); Group 4 (completely satisfied). As reported in table II, the majority of subjects were moderately or completely satisfied, while only 17 (8%) and 35 (16%) were not at all or partially satisfied, respectively; these subjects had significantly higher scores on the CBI (objective: p<0.09; developmental: p<0.0001; physical: p<0.0001) and NPIDS (p<0.02) and a lower level of education (p<0.03) compared with the other two groups. The first two groups were also older, but this difference was only a trend which did not reach statistical significance.

In order to answer the second point, i.e., whether there were discrepancies between the caregivers’ and physicians’ impressions, we examined the correlation between physician and caregiver CGIC scores. The correlation was found to be positive and significant (r=0.602, p<0.003), i.e. no discrepancy was detected.

Finally, to answer to the third question, whether caregiver impressions correlated with objective evaluations, we calculated the differences between the MMSE, ADL, IADL and NPI scores obtained at baseline (i.e. before beginning treatment) and the MMSE, ADL, IADL and NPI scores obtained after four years of therapy (ΔMMSE, ΔADL, ΔIADL, ΔNPI, respectively). These differences were then correlated with the caregivers’ CGIC scores; the correlation proved to be significant for ADL (r=0.665, p<0.002), IADL (r=0.473,
### Table I - Caregivers’ and AD patients’ demographic and clinical characteristics

<table>
<thead>
<tr>
<th></th>
<th>AD patients</th>
<th>Caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number (males/females)</td>
<td>218 (81/137)</td>
<td>218 (75/143)</td>
</tr>
<tr>
<td>Mean age, years (mean±SD)</td>
<td>72.4±7.9</td>
<td>56.9±8.6</td>
</tr>
<tr>
<td>Level of education, years (mean±SD)</td>
<td>4.9±3.6</td>
<td>8.5±4.6</td>
</tr>
<tr>
<td>Disease duration, years (mean±SD)</td>
<td>5.8±1.9</td>
<td>–</td>
</tr>
<tr>
<td>Therapy duration, years (mean±SD)</td>
<td>4.1±1.7</td>
<td>–</td>
</tr>
<tr>
<td>Family history, n (%)</td>
<td>28 (7%)</td>
<td>–</td>
</tr>
</tbody>
</table>

**Relationship to the patient, n (%):**
- Spouse: 108 (49%)
- Son/daughter: 82 (38%)
- Other relative: 28 (13%)

**Living with the patient, n (%):**
- 125 (57%)

**Mini Mental State Examination**
- 18.1±4.7

**Activities of Daily Living**
- 5.5±0.7

**Instrumental Activities of Daily Living**
- 4.2±1.1

**Neuropsychiatric Inventory**
- 8.7±5.3

**Caregiver Burden Inventory domains**
- Objective: 7.2±1.9
- Developmental: 2.6±0.7
- Physical: 2.1±0.5
- Social: 2.0±0.7
- Emotional: 2.3±1.1

**Neuropsychiatric Inventory - Caregiver Distress Scale**
- 7.5±3.8

### Table II - Division of caregivers according to level of satisfaction with treatment outcome

<table>
<thead>
<tr>
<th></th>
<th>Group 1</th>
<th>Group 2</th>
<th>Group 3</th>
<th>Group 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Four-point scale</td>
<td>not satisfied</td>
<td>partially satisfied</td>
<td>moderately satisfied</td>
<td>completely satisfied</td>
</tr>
<tr>
<td>Number, n (%)</td>
<td>17 (8%)</td>
<td>35 (16%)</td>
<td>85 (39%)</td>
<td>81 (37%)</td>
</tr>
<tr>
<td>Males/females</td>
<td>7/10</td>
<td>14/21</td>
<td>28/57</td>
<td>26/55</td>
</tr>
<tr>
<td>Age, years (mean±SD)</td>
<td>58.5±7.6</td>
<td>59.7±8.1</td>
<td>56.0±7.7</td>
<td>56.3±8.5</td>
</tr>
</tbody>
</table>

**Relationship to the patient, n (%):**
- Spouse: 9 (53%)
- Son/daughter: 5 (30%)
- Other relative: 3 (17%)

**Living with the patient, n (%)**: 125 (57%)

**Level of education, years (mean±SD):**
- 6.5±2.8

**Caregiver Burden Inventory domains**
- Objective: 8.3±1.7
- Developmental: 2.7±0.8
- Physical: 2.4±0.4
- Social: 2.1±0.7
- Emotional: 2.4±1.3

**Neuropsychiatric Inventory - Caregiver Distress Scale**: 8.6±2.3

* Groups 1 and 2 vs Groups 3 and 4 (p<0.03), ** Group 1 vs Group 3 (p<0.009), *** Group 1 vs Groups 2,3,4 (p<0.0001), § Group 2 vs Groups 3 and 4 (p<0.0001), ° Group 1 vs Group 3 (p<0.02)
Discussion

The results of our study revealed the presence of greater care burden and distress in caregivers whose expectations were less satisfied; these subjects also had a lower educational level. The clinical impression of change over time was the same for both caregivers and physicians; however, when this impression was correlated with the data obtained from the objective evaluation, it emerged that caregivers tended to overestimate the degree of cognitive change. It may be argued that a low level of education is a negative factor capable of interfering with level of information and with management strategies; instead, the data concerning the caregivers’ overestimation of cognitive deficits are not easy to interpret. Physicians see patients only sporadically, whereas caregivers have regular and continuous contact with them and, even taking into account their emotional involvement, may thus have a more accurate view of the situation; moreover, we used a gross measure, namely the MMSE, to evaluate cognitive status. This study undoubtedly presents some methodological limitations; in particular one might ask why we put the question “Thinking back to what you knew at the time of the diagnosis, would you say that the patient’s disease has evolved as you expected?” and whether caregivers were able to understand it in the right way. We put this question because, in our clinical practice, we have often noticed that patients and caregivers have little information and are unaware of how the disease will evolve, particularly if they have a low level of education; for this reason, they may harbour unrealistic expectations. During the course of the disease physicians’ and caregivers’ aims and evaluations may be different, primarily because of the caregivers’ emotional involvement: while a clinical stabilisation is, per se, a positive result for a physician, it may not be seen as such by a caregiver, particularly in the early and middle stages, when patients’ and caregivers’ expectations are greater (29). We consider this a crucial point in a longlasting, chronic disease like AD, which is why we set out to obtain a better understanding of this topic. Our results support the concept that the role of information is fundamental from the time of diagnosis and throughout the course of the disease: physicians must always ensure correct and continuous communication with patients and their carers, in particular in specific situations when important decisions are required (changing or stopping pharmacological treatment, introduction of drugs for behavioural disturbances, institutionalisation). In this sense, a higher level of education can help a caregiver to understand better the complexity of the disease and to implement more effective management strategies, thereby reducing the level of burden and distress (6). In our study, too, the patients with a lower educational level showed a higher level of burden.

In conclusion, we think that a more exhaustive evaluation of caregiver burden is needed not only in everyday clinical practice but also in randomised clinical trials, in order to increase and improve our knowledge and achieve a more individualised vision of the single patient and his/her needs.

References

15. Zanetti O, Geroldi C, Frisoni GB, Bianchetti A, Trabucchi M. Contrasting results between caregiver’s report and direct assessment of activities of daily living in patients af-
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Lawton MF. Scales to measure competence in everyday activities. Psychopharmacol Bull 1988;24:609-614


Novak M, Guest C. Application of a multidimensional Caregiver Burden Inventory. Gerontologist 1989;29:798-803

