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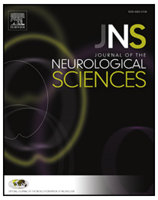

# The burden of distress and related coping processes in family caregivers of patients with Alzheimer's disease living in the community

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## ABSTRACT

*Background:* Many patients with dementia live in the community and depend on a family member for assistance. Taking care of non-self-sufficient people such as those with dementia causes distress. This study concerns factors contributing to feelings of burden and consequent coping strategies adopted by family caregivers of patients with Alzheimer's disease living in the community.

*Methods:* The severity of the caregiver burden (Caregiver Burden Inventory and the Neuropsychiatric Inventory Caregiver Distress Scale) was evaluated in relation to the cognitive, behavioral, functional, mood, motor and comorbidity status in 73 consecutive patients with Alzheimer's disease. The type of coping processes (Coping Orientation to Problem Experienced), and psychosocial and medical variables of caregivers were also investigated and correlated with the degree of their distress.

*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. The severity of caregiver distress was correlated with specific coping strategies, such as seeking for social support, using avoidance behaviors and focusing on problems. Finally, caregivers needing higher levels of familial and/or social support had also higher levels of distress.

*Conclusions:* Higher cognitive, psychological, behavioral, and motor impairment of patients with Alzheimer's disease are associated with increasing levels of burden and distress in their caregivers, who need to adopt adequate coping strategies and to seek for familial and social support.

## 1. Introduction

Alzheimer's disease (AD) represents the most common cause of dementia [19,34], and is a public health problem that will intensify as the population ages. Most patients with dementia live in the community and depend on a family member for assistance [23].

Taking care of non-self-sufficient people such as those with dementia causes stress [12]. Higher levels of stress have been found in aged caregivers [35], female spouses [9,13,18,35], those with low levels of informal social support [8], and sufferers of poor physical or mental health status [6]. Patient's functional impairment [5] has been reported to be very stressful for caregivers. As for cognitive impairment, some studies report a positive correlation between the patient cognitive status and the caregiver burden of distress [14,27,31,33], while others failed to demonstrate an association between these conditions [8,15,43]. The same discordance has been seen for the severity of behavioral disorders with [2,13] and without [43] association between the severity of psychopathology and levels of caregiver burden.

Coping consists in expending conscious effort to solve personal and interpersonal problems, and to tolerate stress. The term coping as used in psychology refers to adaptive or constructive coping strategies and, in these cases, the strategies should reduce stress levels. However, some coping strategies can be considered to be maladaptive, provoking an increase in stress level [24]. People usually adopt both problem-solving and emotion-focused strategies [16] with the predominance of one form over the other determined by personal characteristics [20]. Emotion-focused and avoidance coping may represent a risk factor associated with higher levels of distress while an active and problem-focused approach to stressful conditions may act as a protective factor for caregivers of patients with dementia [12].

The main scopes of this study were to define the severity of the caregiver burden in relation with the cognitive, behavioral, functional, mood, motor, and comorbidity status of the patients, to investigate coping strategies adopted by caregivers as a function of their distress, and to evaluate the caregiver psychosocial and medical variables related to the burden of distress.

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## 2. Material and methods

### 2.1. Patients

Consecutive outpatients living in the community were recruited who were followed up at the Morgagni–Pierantoni Hospital of Forlì and at the Institute for Research on Mental Retardation and Brain Aging of Troina. Patients were considered suitable for full assessment if they met DSM-V criteria for Major Neurocognitive Disorder due to AD [3]. 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 [39]. The assessment of the staging of dementia was done by means of the Clinical Dementia Rating Scale (CDR) [21]; comorbidity was identified and assessed using the Cumulative Illness Rating Scale (CIRS index) [32]; cognitive status was evaluated by means of the Mini Mental State Examination [17]; the functional status was evaluated according to the Activity of Daily Living (ADL) [22] and Instrumental Activity of Daily Living [25], and depression was assessed with the short form of the Geriatric Depression Scale (GDS) [40]. The overall psychopathological assessment was based on the Neuropsychiatric Inventory (NPI) [10]; 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 [41].

### 2.2. Caregivers

For each patient, the family primary caregiver was recruited. Caregivers of institutionalized AD patients and those of sufferers of any other dementia were not recruited for this study. Caregivers were asked to complete a form sheet to collect information about socio-demographic 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 caregivers' 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 multi-dimensional questionnaire measuring caregiver burden with five subscales: Time Dependence (referring to time demands and restrictions that patients impose to caregivers), Developmental (referring to the caregivers' feeling of being “off-time” in their development with respect to their peers), Physical Burden (referring to the strain associated with demands on caregivers' physical health), Social Burden (referring to the caregivers' conflicts between different roles such as work and family), Emotional Burden (referring to the caregivers' negative feelings depending upon the patient's 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 [11]. The assessment of coping strategies was based on the Coping Orientation to Problem Experienced questionnaire (COPE) [7], which is composed of 60 items. The subjects are required to rate their level of endorsement of each item of a 4-point Likert scale where the score of 1 is for “I usually don't do this at all” and that of 4 is for “I usually do this at all” referring to how they usually act or feel when experiencing stressful events. The scoring procedure adopted here refers to the validation study of the Italian version [37] in which a second-order factor analysis of the fifteen original subscales mean scores yielded five factors used to identify both dysfunctional and functional responses: Social Support, Avoidance Coping, Positive Attitude, Focus on Problem, Religion. The study was approved by the local Ethics Committee and all volunteers signed an informed consent according to the declaration of Helsinki before entering the study.

### 2.3. Data analysis

Due to the non-normal distribution of data, results were reported as frequencies or median and interquartile range and statistical analyses were performed by means of nonparametric tests [38]. In particular, the Spearman rank correlation coefficient “rho” and the Kruskal–Wallis ANOVA were used, as appropriate. Finally, due to the numerous correlations and comparisons performed, the Bonferroni correction for multiple testing was applied to the resulting p values [4].

## 3. Results

Table 1 reports the descriptive statistics of demographic and clinical features of the AD patients recruited for this study. It can be noticed that they were characterized by a low number of comorbid conditions which also showed a relatively low degree of severity while all other measures were typical for patients with AD. Finally, almost all patients (only one had no drug therapy) were taking some medication, with the most frequent being anticholinesterases.

The descriptive statistics of demographic and clinical features of caregivers are reported in Table 2. In particular, the results obtained at the CBI were characterized by a high level of burden felt by the caregivers with a median score of 33 and 32 of them (43.8%) reporting

**Table 1**
Descriptive statistics of demographic and clinical features of patients.

| Sex (M/F) | 28/45 | |
|---|---|---|
| | Median (interquartile range) | |
| Age, years | 75 (68.5–78.5) | |
| Education, years | 5 (4–8) | |
| Months from onset | 48 (36–72) | |
| Months from diagnosis | 20 (6–36) | |
| Clinical Dementia Rating | 2 (1–2) | |
| Mini-Mental State Evaluation | 16 (11–19) | |
| Cumulative Index Rating Scale, severity | 1.07 (1–1.23) | |
| Cumulative Index Rating Scale, comorbidity | 0 (0–1) | |
| Geriatric Depression Scale | 4 (2–7) | |
| Activity of Daily Living | 4 (3–6) | |
| Instrumental Activity of Daily Living | 3 (1–4) | |
| Neuropsychiatric Inventory | 18 (8.5–33) | |
| Tinetti scale | 27 (26–28) | |
| Drug therapy | n. | % |
| Antidepressant | 28 | 38.4 |
| Benzodiazepine | 11 | 15.1 |
| Neuroleptic, typical | 8 | 11.0 |
| Neuroleptic, atypical | 3 | 4.1 |
| Anticholinesterase | 58 | 79.5 |
| Memantine | 8 | 11.0 |
| Antiplatelet | 40 | 54.8 |
| Anticoagulant | 7 | 9.6 |
| Oral antidiabetic | 4 | 5.5 |
| Insulin | 2 | 2.7 |
| Antihypertensive | 55 | 75.3 |
| Statin | 24 | 32.9 |
| L-thyroxine sodium | 5 | 6.8 |
| Mood stabilizer | 19 | 26.0 |

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