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**The burden of distress in caregivers of elderly demented patients and its relationship with coping strategies**

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## **Abstract**

**Objective:** Previous studies have shown that taking care of elderly, demented patients carries a high cost to caregivers' health, and is associated with negative consequences on physical and mental health. The aim of this study is to investigate which socio-demographic and clinical variables are significantly associated with higher levels of distress in caregivers, and the relationship between caregivers' levels of distress and the coping strategies they adopt. **Patients and participants:** The study samples 112 caregivers of demented patients, consecutively admitted to the Department of Neurology of San Raffaele-Turro Hospital (Milan, Italy). **Measurements and results:** Caregivers were asked to complete the CBI and the Italian version of the COPE. The main result is that caregivers with the highest levels of distress are characterised by an impaired physical health status. It was also found that avoidance coping may represent a risk factor associated with higher levels of distress; conversely, an active and problem-focused approach to stressful situations may act as a protective factor.

**Keywords:** Dementia, Caregiver, Burden of Illness, Coping Behavior

## **Riassunto**

**Obiettivo:** In letteratura è documentato che prendersi cura di un anziano affetto da demenza comporta per il caregiver un prezzo molto elevato da pagare, e si associa a conseguenze negative sul piano della salute fisica e psichica. Obiettivo della presente ricerca è stato quello di valutare quali variabili socio-demografiche e cliniche possano essere significativamente associate ad elevati livelli di stress nel caregiver stesso, e la relazione esistente tra i livelli di stress del caregiver e il ricorso alle strategie di coping. **Pazienti e partecipanti:** Lo studio ha coinvolto 112 caregiver di altrettanti pazienti dementi consecutivamente ammessi presso il Reparto di Neurologia dell'Ospedale San Raffaele Turro di Milano. **Risultati:** I caregiver hanno compilato il CBI e la versione italiana del COPE. I risultati indicano che i caregiver soggetti ad elevati livelli di stress si caratterizzano per uno stato compromesso di salute fisica. Uno stile di coping centrato sull'evitamento delle situazioni problematiche può costituire un fattore di rischio per elevati livelli di stress nel caregiver; il ricorso a strategie attive focalizzate sulla risoluzione del problema può configurarsi come fattore protettivo.

## Introduction

There is ample evidence that taking care of dependent elderly people comes at a very high cost to caregivers' health; more specifically, caregiving affects their physical and psychological health both directly and indirectly [1,2].

In Italy, family members are the principal caregivers to elderly, non self-sufficient people. Caregivers are mostly spouses or daughters who decided to take care of the patients in a direct way, that is by living with them [3]. On average, three quarters of their daytime is spent responding to the patients' needs; the amount of time devoted to the patient is inexorably destined to increase as the illness worsens [1].

Previous studies have underlined that some characteristics, of both patients affected by Alzheimer's Disease (AD) or other forms of dementia and of their caregivers are associated with a higher risk of developing stress in caregivers; the most distinctive features are:

- gender: it has been highlighted [4-9] that women who take care of demented patients are at higher risk for stress than men carrying out the same assistance role. This can be due to different reasons: social and gender issues make them more likely to assume a fuller role as a caregiver; moreover, women tend to spend more time with the patient which leads them to feel more burdened;
- caregiver's age: several studies [4,10] recognize the age of the family member in charge of the patient as a risk factor for distress: in particular, caregivers over 70 years of age are more likely to experience stress than younger ones. Such vulnerability could be explained both by difficulties in assuming such a demanding role and by the caregiver's own physical and psychological problems;
- caregiver's physical and mental health status: some studies pointed out that a poor physical and mental health status can put caregivers at risk for stress and depressive symptoms [9-14];
- caregiver's employment status: higher levels of stress and suffering have been found in unemployed caregivers [15];
- familial relationship between patient and caregiver: several studies [11,15] suggest that spouses and sons/daughters are more likely to undertake the role of caregivers, and that this inevitably leads to a higher risk for stress. Rinaldi et al. [4] showed that female spouses complain more about their role as caregivers and, together with sons/daughters, are most exposed to distress and suffering. Sons and daughters, because of their young age, are likely to be involved in their own social and working activities and can consequently rely on wider social networks; on the contrary, spouses, especially if

elderly, have less recreational activities and are consequently almost completely devoted to caregiving. Other studies support these results [7], suggesting that “wife” caregivers experience more strain than “husbands”. “Wife” caregivers seem to be pushed by a stronger sense of duty and are inclined to care more scrupulously for their husband, but at the same time, they would like to desert this role; all this contributes to a growing sense of guilt and uneasiness. Gonzales-Salvador et al. [16] and Waite et al. [17] found no impact whatsoever of familial relationship on caregivers’ stress levels;

- living arrangement: living with the patient is highlighted by most studies as a risk factor for caregiver suffering [4,11,18], though not all reach the same conclusion [19,20];
- support in patient’s care and availability of help: several studies [21,22] underlined that poor social support is frequently associated with higher caregiver’s stress levels;
- severity of cognitive impairment: this issue remains controversial. While some studies report a positive correlation between the patient’s cognitive status and the caregiver’s burden of distress [23-26], others did not find any association between the two variables [9,15,22,27-29];
- behavioural disorders: Donaldson et al. [6] found that non-cognitive features of Alzheimer’s disease, such as psychotic symptoms, depressive features and behavioural disturbances were the most stressful manifestations for carers, resulting in feeling of burden. Yet, Zarit et al. [27] reported that the severity of behavioural problems was not associated with high levels of burden;
- patient’s functional impairment: Braithwaite [30] found that the caregiver’s workload (in the form of bathing, household activities, supervision and decision-making) was unrelated to burden, though a large proportion of carers experienced burden in relation to being constantly on call, being unable to get household chores completed, and having to change plans at the last minute.

Apart from socio-demographic and anamnestic indexes, researchers have investigated which psychological variables may act as either risk factors for, or protective factors against, caregivers’ burden of distress; although most studies focused mainly on psychopathological indexes (i.e. anxiety or depression), a large body of evidence points out a possible role of coping strategies adopted by the caregivers.

Coping strategies refer to the specific efforts (behavioural and psychological) that people rely on to master, tolerate, reduce, or minimize stressful events. Two general coping strategies have been distinguished: problem-solving strategies are efforts to do something active to alleviate stressful circumstances, whereas emotion-focused coping strategies involve efforts to regulate the emotional consequences of stressful events. Research

indicates that people use both types of strategies to combat most stressful events [31]. The predominance of one type of strategy over another is determined by personal characteristics (e.g., some people cope more actively than others) and also by the type of stressful event (i.e. potential controllable or uncontrollable problems). Further distinctions have been proposed in the coping literature between active and avoidant coping strategies. Active coping strategies are efforts designed to change the nature of the stressor itself or how one thinks about it, whereas avoidant coping strategies lead people into activities (such as alcohol use) or mental states (such as withdrawal) that keep them from directly addressing stressful events. Active coping strategies, whether behavioural or emotional, are thought to be better ways to deal with stressful events, and avoidant coping strategies appear to be a psychological risk factor or marker for adverse responses to stressful life events [32].

Studies of demented patients' caregivers pointed out that practical forms of coping (i.e. adaptive coping) are negatively associated with lower levels of perceived burden [33]. A review on this topic [34] showed that, in spite of some methodological limitations, focusing on problematic situations and acceptance are the most functional and adaptive coping strategies. The findings have relevant clinical implications as they suggest that caregivers need help, where possible, to find solutions to problems emerging from their care of the patient; when no solution can be found, acceptance turns out to be the most successful strategy. These findings are, on the whole, supported by recent studies [35] suggesting a possible link between avoidant coping and depression [36], and dysfunctional coping strategies and anxiety symptoms in caregivers [37].

This study aims to:

- evaluate how socio-demographic variables (referring both to the patient and the caregiver) and medical condition (caregivers' physical health, severity of cognitive impairment in the patient) impact the burden of distress as assessed through the Caregiver Burden Inventory [38];
- investigate the role of coping strategies adopted by caregivers as a possible risk factor for, or a protective factor against, distress.

## **Materials and methods**

### Caregivers' sample

Our research sampled 112 primary caregivers providing assistance to an equal number of patients affected by dementia; patients were consecutively admitted to the Neurological Ward of the San Raffaele-Turro Hospital in Milan (Italy) during the period from December 2004 to June 2006.

The department is highly specialized in diagnosis and treatment of degenerative disorders and, in liaison with the Division of Clinical and Health Psychology, offers caregivers participation to supportive psycho-educational groups.

Nine caregivers were excluded from analysis because of the high number of missing data; no caregivers refused to participate.

The caregivers' sample was composed of 82 women (73%) and 30 men (27%); mean age was 58.94 years ( $SD = \pm 12.05$  ys; range: 32-81 ys). These data are in line with previous Italian studies [3].

As far as occupational status is concerned, 47.3% of caregivers were retired, 23.2% employees, 17% housewives, 8.9% professionals and 0.9% unemployed. Three caregivers (2.7%) did not provide information on occupation.

As for familial relationship between patients and caregivers, the sample distribution was as follows: 50% of caregivers were sons or daughters, 41.1% spouses, while the remaining 8.9% had other degrees of relationship.

At time of assessment, 17.9% of caregivers were affected by some physical ailment. The most frequent disorders were cardiovascular diseases (33.3%), followed by rheumatic (19%), endocrinological (14%) and neurological (9%) disorders.

As for the caregivers' domicile, 54.5% of caregivers claimed they lived with the patient, while the remainder (45.5%) lived elsewhere.

The availability of additional supports in caregiving (additional helpers, other family members and friends) was also investigated. In particular, 14.3% of caregivers refer to a helper, 33.9% can rely on family members and friends' help, and 14.3% can rely on both a helper and other supports. Taken together, these data suggest that a considerable percentage of caregivers (i.e. 37.5%) cannot take advantage of any kind of support.

#### Patients' sample

The patients' sample was mainly composed of females ( $N=67$ ; 59.8%). Age ranged between 52 and 92 years (mean age= 76.20 ys;  $SD = \pm 7.85$  ys). The most common cause of dementia was probable AD (60%); other diagnosis were dementia associated with Parkinson's disease (18%), vascular dementia (8%), mixed dementia (6%), fronto-temporal dementia (4%), Lewy Body dementia (4%).

Mini Mental State Examination (MMSE) [38] mean score at time of admission was 17.82 ( $SD = \pm 5.34$ ; range: 6-24); MMSE data were not available for 12 patients (10% of the total sample) who were untestable at admission.

Each caregiver received a set of questionnaires including:

- 1) The *Caregiver Burden Inventory* [38]: it is a self-report questionnaire consisting of 24 items aimed at a multidimensional assessment of caregivers' burden of distress. It was purposely designed for caregivers of patients with AD and other forms of dementia and addresses the primary caregiver, i.e. the person who mostly takes care of the patient. The CBI provides burden profiles, allowing "tailored" counselling interventions and monitoring of variations over time. The original version of the scale consists of 5 subtests covering both subjective and objective indexes of distress:
- *Time dependence* (items 1-5): referring to time demands and restrictions that caregiving imposes on caregivers;
  - *Developmental burden* (items 6-10): referring to the caregivers' feelings of being "off-time" in their development with respect to their peers;
  - *Physical burden* (items 11-14): referring to the strain associated with demands on caregivers' physical health;
  - *Social burden* (items 14-19): referring to the caregivers' feelings and conflicts between different roles (e.g. work and family);
  - *Emotional burden* (items 20-24): referring to the caregivers' negative feelings (e.g. shame, embarrassment) towards the care receiver, which may result from the patient's unpredictable and often bizarre behaviour.

Subjects are asked to rate each item on a 5-point Likert scale (0= not at all; 4= very much).

2) Coping strategies were evaluated through the Italian version of the COPE (*Coping Orientation to Problem Experienced*) [40,41]. The questionnaire is composed of 60 items divided in 15 subscales; the subject is asked to rate their level of endorsement of each item on a 4-point Likert scale (1= "I usually don't do this at all"; 4 = "I usually do this a lot"), referring to what they generally do or feel "when experiencing stressful events". The scoring procedure adopted in the present study was derived from the validation study of the Italian version of the scale [41]; a second-order factor analysis on the 15 original subscales mean scores yielded five factors. The factors are the following: *Social support, Avoidance coping, Positive attitude, Focus on problem, Religion*.

Finally, caregivers were asked to complete a form-sheet to collect information like socio-demographic data (age, gender, occupational status), physical and mental health status (presence of any serious or long-term health problems or mental health disorders) and caring routine.



Each caregiver completed the questionnaires individually; a research assistant was always present at testing sessions to provide clarification when necessary. Given the caregivers' mean age, this procedure was deemed necessary. In order to be included in the sample, caregivers signed a written informed consent and no reward was given for participation in the study.

## **Results**

A factor analysis followed by Oblimin rotation was performed on the correlation matrix of all CBI items. The number of factors to retain was determined through Cattell's scree test, which suggested a three-factor solution explaining 53.12% of total variance.

The first factor (10 items, 34% of variance) is highly consistent with the second and third subtests in the original version of the scale by Novak and Guest [38]; this factor reflects emotional exhaustion, impairment of caregiver's health and general functioning.

The second factor (6 items, 12.46% of variance) is consistent with the fifth subtest in the original version of the scale; it reflects emotional distress in the caregiver (e.g. embarrassment, shame, resentment) and impact of caregiving on the family.

The third factor (8 items, 6.46% of variance) overlaps the first subtest in the original version of the scale. It emphasizes the patient's dependence on the caregiver's support and the time demands and restrictions that caregiving imposes on caregivers. It is therefore suggestive of the caregiver's objective level of distress.

The three factors showed satisfactory internal coherence (Cronbach's alpha: 0.89, 0.74, and 0.85, respectively).

### Impact of socio-demographical and anamnestic variables on CBI mean scores

In order to assess the impact of socio-demographical and anamnestic variables on CBI mean scores, a multivariate analysis of variance (MANOVA) on the three CBI scales was carried out with the following variables entered simultaneously as fixed factors: patients' gender, caregivers' gender, patients' age (categorized as 70 ys or younger; between 71 and 80 ys; 81 ys or older); caregivers' age (categorized as 50 ys or younger; between 51 and 60 ys; between 61 and 70 ys; 71 ys or older); familial relationship between patient and caregiver (spouse, son/daughter, other); cohabitation/non-cohabitation; availability of support in caregiving; presence/absence of health disorders in the caregiver.

A significant overall effect of caregivers' health problems emerged (Wilks' Lambda=0.847;  $F_{(3,96)}=5.781$ ;  $p<0.001$ ), but not for any of the other variables. Univariate protected F-tests with Bonferroni corrections



For both Factor I and Factor II CBI scores, two coping strategies were selected as significant predictors: avoidance coping (Factor 2) and problem-focused coping (Factor 4). The coping strategies adopted by the caregivers appear therefore correlated to two dimensions of burden strictly connected to psychological distress. In particular, as suggested by beta values, avoidance coping is connected to an increase in CBI Factor I and Factor II scores, while focus-oriented coping is associated to a decrease.

No coping strategies have been selected as significant predictors for CBI Factor III scores.

## **Discussion**

### Impact of socio-demographic and anamnestic variables on caregivers' strain

In line with previous researches [9-13], our study supported the hypothesis that a somatic disorder in the caregiver is associated with a significant increase in burden of distress. A possible explanation is that a somatic disorder, which is functionally impairing per se, may deprive the caregivers of energies and capacity to provide assistance to the demented patient, thus leading them to perceive a sense of higher strain.

However, some other variables which have been associated with higher levels of distress in previous researches showed no significant effects on CBI mean scores in the present study. This is the case for gender, the caregivers' and patients' age, cohabitation, and the availability of supports for caregivers.

For some of these variables (i.e. caregiver's age), it is plausible that previous studies, ignoring the possible role of the caregivers' physical health status, pointed out a spurious association between burden of distress and age, suggesting that the older is the caregiver, the higher is the burden.

Moreover, as for availability of external supports, it would have been advisable to collect more reliable indexes, such as the mean amount of time helpers provide assistance to the patient, thus allowing the primary caregiver to take some time off. It is plausible that, being asked whether they could rely on any form of external support, caregivers may have included people that seldom or marginally provide assistance to the patient.

### Coping strategies

Regarding coping strategies and their relationship to burden of distress, our data support the hypothesis that a coping style characterized by an effort to minimize, avoid or ridicule the entity and impact of stressors may predispose caregivers to higher levels of burden of distress; conversely, making use of an active, planned and problem-focused coping style (not simply acceptance) may act as a protective factor.

As for CBI Factor III scores, no regression model has been selected to explain a significant proportion of its variance; this result may be explained by the assumption that this subscale may represent an “objective” index of the caregivers’ burden. It is plausible that the use of functional or dysfunctional coping strategies may have no impact on the third CBI Factor which is rather connected to the caregiver’s perception of the patients’ degree of autonomy and self-sufficiency in everyday activities.

However, as the study design is cross-sectional in nature, it can not provide an answer regarding the direction of causality in the relationship between coping strategies and distress levels. The results can in fact be interpreted in a different way, i.e. high levels of burden of distress may influence the coping strategies adopted by the caregiver, promoting the use of avoidance coping. Further studies are necessary since, as it has been pointed out [34], longitudinal studies relating coping strategies and burden of distress in caregivers are limited in number.

Finally, we assessed coping strategies with the use of an a-specific instrument which collects information on the frequency of use of different strategies in situations generically defined as “stressful”. It therefore does not take into account the specific problems and stressors that caregivers of demented patients have to face, nor other possible coping strategies they can rely on.

This study suffers from several limitations. Besides those already mentioned, it was not possible to control the effect of other potentially significant variables on CBI mean scores: the caregivers’ knowledge of the patients’ disease, the caregivers’ level of education, participation to support groups for caregivers of demented patients, duration of illness, presence and clinical relevance of specific cognitive symptoms (i.e. prosopagnosia for family members, etc.) or behavioural disorders (i.e. agitation, wandering, psychotic symptoms) in the patients.

Our results suggest, in terms of clinical implications, the need to provide psychological support to caregivers with an impaired health status. Psychological interventions should focus on the acquisition and enhancement of functional coping strategies (i.e. active and problem-focused coping) and on the modifications of dysfunctional ones (i.e. avoidance coping).

Several different psychosocial intervention programmes have been proposed so far for caregivers of people with dementia [42,43], though meta-analytic studies showed that their efficacy in reducing caregivers’ burden is questionable [44]. However, a recent study based on group interventions consisting of general education followed by group discussion has provided encouraging results [45]. The aim of the intervention is to allow caregivers to cope better with their own emotional states and deal with difficult and challenging circumstances, including providing advice about more effective ways of responding to problematic behaviours and feelings of

loss concerning changes in the patients or changes to their own quality of life. The best effect on caregivers was found early in the progression of dementia and, remarkably, in caregivers with impaired health.

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**Table 1. Effect of caregivers' physical health status on CBI mean scores: descriptive statistics**

	<b>Physical problems (N=20)</b>	<b>No physical problems (N=92)</b>
<b>CBI Factor I</b>	2.22 ± 1.06	1.29 ± 0.88
<b>CBI Factor II</b>	1.15 ± 0.97	0.69 ± 0.57
<b>CBI Factor III</b>	2.76 ± 0.90	1.88 ± 0.96

**Table 2. Burden of distress and cognitive impairment: correlation (Spearman's rho) matrix (N=100)**

	<b>CBI Factor I</b>	<b>CBI Factor II</b>	<b>CBI Factor III</b>
<b>MMSE</b>	-0.046, NS	0.104, NS	-0.089, NS

**Table 3. Coping strategies and burden of distress: regression analysis**

<b>CBI subscales</b>	<b>COPE</b>	<b>B</b>	<b>T</b>	<b>p</b>
<b>CBI Factor I</b> R <sup>2</sup> =0.218; F(2,106)=14.799; p<0.001	1) Factor 2	0.428	4.982	0.000
	2) Factor 4	-0.188	-2.194	0.030
<b>CBI Factor II</b> R <sup>2</sup> =0.089; F(2,106)=5.164; p=0.007	1) Factor 2	0.229	2.471	0.015
	2) Factor 4	-0.191	-2.059	0.042