CAREGIVERS BURDEN IN NURSING HOMES FOR PATIENTS WITH DEMENTIA: THE IMPORTANCE OF PSYCHOLOGICAL SUPPORT

IL BURDEN DEI CAREGIVER NELLE STRUTTURE RESIDENZIALI PER PAZIENTI AFFETTI DA DEMENZA: L'IMPORTANZA DEL SUPPORTO PSICOLOGICO

Pinna S\(^2\), Biagioli S\(^2\), Venuti A\(^2\), Bellomo A\(^2\), Cardarelli M\(^2\), Sepe Monti M\(^3\), Antonaci L\(^1\), Fattapposta F\(^1\), Amabile GA\(^1\), Marianetti M\(^1\)

\(^1\) Department of Sensory Organs- Neurology Section, “Sapienza” University of Rome, Italy
\(^2\) Institute San Giovanni di Dio Fatebenefratelli- Experimental Alzheimer’s centre, Genzano of Rome, Italy
\(^3\) Second Faculty of Medicine and Surgery: U.O.C. Neurology, “Sapienza” University of Rome, Italy


Key words: caregivers, dementia, nursing homes, psychological support

Parole chiave: caregiver, demenza, strutture residenziali, supporto psicologico
Abstract

Background: Family caregivers are an essential part of healthcare services for elderly with dementia. Most of them continue caregiving for their relatives after admitting them to long-term care facilities. The characteristics of this caregiving differ from those related to caregiving in home-care settings and have been rarely studied in literature.

Objective: To investigate the differences of Burden evolution between Caregivers of patients with dementia in a Nursing Home joining a support/psycho educational group and Caregivers who did not.

Methods: 29 caregivers (7 M-22F, age: 59±7.8) of demented patients who were undergoing a standard rehabilitation program in our Institute (≈ 90 days) were administered the Caregiver Burden Inventory at the beginning and at the end of hospitalization. These caregivers took part in a support/psycho educational group (two hours, twice a month) conducted by a trained psychologist. The results we obtained were compared to a control group, that did not participate to the encounters.

Results: The two groups did not differ for demographical variables; the two correspondent groups of patients did not differ for clinical/demographical and neuropsychological variables, too. Only caregivers who participated to the group reduced their burden significantly at the end of the program (p<0.001).

Conclusions: Our study supports the hypothesis that the simple absence of a patient from home is not enough to prevent and reduce caregiver burden. Support/psycho educational groups are a fundamental resource for families and should be part of their healthcare in every stage of the disease and in every context.
Introduction
Due to the consistently growing aging population, dementia is becoming a problem of significant proportions. It is estimated that in Italy there are between 600,000 and 1,000,000 people affected (6-9% of people over sixty). The critical problem of dementia is the high degree of functional impairment that severely limits the patient in carrying out daily activities. Such condition can worsen to the point of a total disability condition and to the full dependence on the caregiver. In Italy, probably due to the scarcity of formal structures and services, over 80% of people with dementia are attended in a family environment (primary caregiver) which performs this task without specific skills and usually without adequate knowledge of the disease. (1, 2, 3). Taking care of elderly people with cognitive impairment often causes physical, psychological or emotional disturbances in these individuals and also social and financial discomfort (Figure 1) (2, 4, 5).

Figure 1: Caregiving stress model (Pearlin et al., 1990)

The literature has used the term "burden" to indicate this overload work experienced by the caregiver. It varies from one situation to another depending on the complex relationships that develop between the characteristics of the person and the environment over time. Some symptoms experienced by caregivers, such as social isolation, physical and mental tension, feelings of disappointment and emotional involvement, are closely correlated with the severity of cognitive decline, with the degree of disability and behavioral disorders of patients with dementia (6, 7, 8, 9, 10). Relatives of AD patients usually ascribed to the behavioral appearance their main source of stress (11). In particular, physical aggression and mood instability often make it impossible to live together, leading to the hospitalization of
patients (4, 11, 12, 13, 14). There is also a strong correlation between mental and behavioral disorders (apathy, agitation, dysphoria, irritability) described in more than 50% of demented subjects examined and the psychosocial stress of caregivers (15, 16, 17).

Consequently, in addition to the need to increase economically affordable services, which may mitigate the weight relief, on the one hand it has been considered necessary the creation of neuropsychological scales designed to evaluate the size and characteristics of this burden while on the other emphasizing the institution of interventions targeted to those areas and those emotional skills necessary to support the role of caregivers (18, 19, 20). With regard to interventions that have proven useful in alleviating the discomfort of the caregiver, results highly diverge from various international perspectives. Interventions that have proven most effective are those adopting an approach that combines different programs in order to embrace the whole range of needs of the caregiver.

Measures to provide information only showed zero impact in decreasing the burden, demonstrating that the increase of knowledge is important but not sufficient as an adequate intervention. Combined training and education interventions (psycho education) have been proved effective in producing changes in terms of outcomes directly related to those skills that are aimed at developing competences not only among the family but also on patients (10, 16, 20, 21, 22). In Italy there are still few studies of interventions that use combined approaches, especially in particular contexts such as residential facilities. Indeed, the importance of the intervention in the cultural context has to be taken into account.

In particular, the presence or absence of the patient from home is not the only stress determinant in the caregiver (19). The objective of this study was to evaluate the effectiveness of supportive and informative psychological intervention group of six meetings lasting two hours each in the decrease of perceived Burden in a sample of 50 caregivers of institutionalized patients with Alzheimer’s Disease, Vascular Dementia, fronto-temporal Dementia or Mixed Dementia at our Research Centre Alzheimer’s (CSA), a residential rehabilitation center where patients are hospitalized for about 90 days to undergo cycles of reactivation cognitive therapy, music therapy, donkeys assisted therapy and occupational therapy.

Materials and methods:

50 primary consecutive caregivers of patients institutionalized at our Center for Experimental Alzheimer’s, being of age, able to understand the Italian language were enrolled. 29 of these caregivers participated in support groups-information bi-monthly and 21 did not participate. Participation in groups was voluntary. The socio demographic characteristics of caregivers divided by groups are shown in Table 1.

**Table 1: Socio demographic characteristics of the two groups of caregivers**

<table>
<thead>
<tr>
<th></th>
<th>Numbers of participants in groups n=29</th>
<th>Non participating in groups n=21</th>
<th>Total of caregivers n=50</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td>Male=7 (24%)</td>
<td>Male =5 (24%)</td>
<td>Male =12 (24%)</td>
</tr>
<tr>
<td></td>
<td>Female=22 (76%)</td>
<td>Female =16 (76%)</td>
<td>Female =38 (76%)</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td>59 years old</td>
<td>54 years old</td>
<td>57 years old (range=30-80)</td>
</tr>
<tr>
<td><strong>Family relationship</strong></td>
<td>Soon/Daughter=17 (58%)</td>
<td>Soon/Daughter =12 (57%)</td>
<td>Soon/Daughter =29 (58%)</td>
</tr>
<tr>
<td></td>
<td>Spouse=11 (38%)</td>
<td>Spouse =6 (28%)</td>
<td>Spouse =17 (34%)</td>
</tr>
<tr>
<td></td>
<td>Sister/Brother=0</td>
<td>Sister/Brother=1 (4%)</td>
<td>Sister/Brother =1 (2%)</td>
</tr>
<tr>
<td></td>
<td>Nephew=1 (3%)</td>
<td>Nephew =0</td>
<td>Nephew =1 (2%)</td>
</tr>
<tr>
<td></td>
<td>Daugher-in-law=0</td>
<td>Daugher-in-law =2 (9%)</td>
<td>Daugher-in-law =2 (4%)</td>
</tr>
</tbody>
</table>
Features such as diagnosis, level of cognitive impairment and function assessed through the Mini Mental State Examination (MMSE) and Activities of Daily Living Scale (ADL), and the origin of the patients divided according to the participation of the caregiver intervention and the non-participation are shown in Table 2 (23, 24).

Table 2: Clinical characteristics of patients

<table>
<thead>
<tr>
<th></th>
<th>Patients with caregiver taking part to the groups n=29</th>
<th>Patients with caregiver not taking part to the groups n=21</th>
<th>Total patients n=50</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosis</td>
<td>AD=6, VaD=13, FTD=2, MD=7, PDD=1</td>
<td>AD=5, VaD=11, FTD=2, MD=2</td>
<td>AD=11, VaD=24, FTD=4, MD=9, PDD=2</td>
</tr>
<tr>
<td>MMSE</td>
<td>M=8.38</td>
<td>M=6.66</td>
<td>M=7.46</td>
</tr>
<tr>
<td>ADL</td>
<td>M=2.10</td>
<td>M=1.86</td>
<td>M=2.00</td>
</tr>
<tr>
<td>Origin</td>
<td>Home=29</td>
<td>Home=20</td>
<td>Home=49</td>
</tr>
<tr>
<td></td>
<td>Hospital=0</td>
<td>Hospital=1</td>
<td>Hospital=1</td>
</tr>
</tbody>
</table>

All caregivers were subjected to the perceived burden evaluation at the beginning and at the end of the family hospitalization. To assess the burden perceived by caregivers the Caregiver Burden Inventory questionnaire was used (25, 26). Such questionnaire is a quantitative tool for assessing the burden of care, and also able to analyze the multidimensional aspect, developed for caregivers of patients with Alzheimer’s disease and dementia in general. It is a self-report instrument consisting of 24 items scale type Likert 5 points where 0 indicates the absence of the burden and 4 the maximum of burden. The questionnaire is completed by the primary caregiver, is divided into 5 domains allowing to evaluate several factors of stress: objective burden (1), psychological burden (2), physical load (3), social care (4), emotional strain (5).

1 - the objective burden (items 1-5), depending on the time required on hand describes the load associated with the restriction of time for the caregiver, the sense of failure on their hopes and expectations;
2 - the burden of evolution (items 6-10), assumed as the perception of the caregiver to feel cutting off from the expectations and opportunities of their peers;
3 - the physical burden (items 11-14) describes the feelings of chronic fatigue and somatic health problems;
4 - the social burden (items 15-19) on the possible presence of conflict within the family and work;
5 - the emotional burden (items 20-24) describes the negative emotions (embarrassment, resentment, etc.) tested against the patient.
The score of each domain is given by the sum of the items except for the physical domain, which is calculated with the sum multiplied by 1.25. The total score is calculated by the sum of domains. The total range varies from 0 to 100, the range of domains varies from 0 to 20. The time of administration is about 15 minutes. To check the existence of a significant difference in perceived burden among caregivers who participated in the meetings of psychological intervention-support information and those who did not participate, Univariate analysis of variance (ANOVA) and Student's paired t test (Student's t paired groups) were conducted.

Results
The two groups did not differ significantly for sociodemographic variables and for clinical and neuropsychological characteristics of patients. From the analysis of the performed data the total score of the burden showed a statistically significant difference (p <0.001) with regard to the increase of the burden between the first and second administration of the CBI solely in those who did not participate in intervention support. Instead, there has been a statistically significant decrease (p <0.001) in the burden of the group following the treatment. Regarding the individual domains, among the treated group the major influences are related to the objective and evolutionary burden, while among the untreated group to all but the load objective (Table 3, Figure 2-3).

Table 3: t di Student CBI domains and CBI total

<table>
<thead>
<tr>
<th></th>
<th>AVERAGE SCORES</th>
<th>AVERAGE SCORES</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Treated t0</td>
<td>Treated t1</td>
</tr>
<tr>
<td>OBJECTIVE LOAD</td>
<td>17,18</td>
<td>15,12</td>
</tr>
<tr>
<td>EVOLUTIONARY</td>
<td>15,12</td>
<td>12,85</td>
</tr>
<tr>
<td>PHYSICAL</td>
<td>14,99</td>
<td>13,68</td>
</tr>
<tr>
<td>SOCIAL</td>
<td>8,37</td>
<td>6,99</td>
</tr>
<tr>
<td>EMOTIONAL</td>
<td>5,58</td>
<td>4,32</td>
</tr>
<tr>
<td>TOTAL BURDEN</td>
<td>60,5</td>
<td>52,84</td>
</tr>
</tbody>
</table>
Figure 2: Pre-post total and single domains CBI scores of caregivers who participated to the psychoeducational-support group

![Bar chart showing burden in caregivers who participated to the group](image)

Figure 3: Pre-post total and single domains CBI scores of caregivers who did not participate to the psychoeducational-support group

![Bar chart showing burden in caregivers who did not participate to the group](image)
Conclusions
The described data are in line with the literature, providing the profile of the average caregiver as a woman, daughter, aged at 57 and without employment. The significant prevalence of women who assume the role of caregiver is usually traced back to the female culture of taking care of people inside the family(1, 5). There were no significant differences in sociodemographic variables between the two groups of caregivers, also the two corresponding groups of patients did not differ in sociodemographic, clinical and neuropsychological variables. Caregivers who participated in the support intervention and information show a decrease of the total burden. This decreasing trend contrasts with the control group which worsened their perceived burden. In these caregivers all variables tend to improve, in particular the objective and evolutionary burden. This result confirms the importance of a vision of the burden as a global phenomenon and not as sectorial (2). The support and information action aims both to support and taking into consideration the here and now and also facilitating the role of caregiver and the relative acceptance of the disease, as well as expanding the knowledge and skills to better manage the care service. Therefore it sets objectives in both the short and long term.
In this piece of work, the support and information action has been proven effective in helping caregivers to express and process emotions, regain their identity and learn to listen to their needs. The caregiver, during three months of intervention, does not provide direct assistance to relatives with dementia, because in that period relatives are hospitalized. However, it has not been still clarified whether the caretakers once back in their home, would be able to keep the level of burden reached with the intervention, or once starting taking care of the patient they would go back again to the initial state of burden. The evidence that those who do not take part in the groups do not reduce, but significantly worsen the burden would seem to direct more toward the first hypothesis. We must also emphasize the need for additional tools in the detection of bio-psycho-social status of the caregiver in order to produce a complete view of them and not omit important aspects. The use of the isolated CBI does not allow to become aware of any concomitant psychopathological states and / or pre-existing illness that may be affect the caregiver. In our view, finally, the contribution of this study is important to stress again the need to increase on a national scale interventions aimed at caregivers of dementia patients and the need to validate its actual effectiveness. Dementia has increased significantly and the majority of caregivers at this moment might experience social isolation and a perception that there are no resources to deal with the situation, adding all negative consequences on their physical and mental health status.

References


Corresponding Author: Massimo Marianetti
Department of Sensory Organs-Neurology Section, "Sapienza" University of Rome, Italy
e-mail: info@preventionandresearch.com

Autore di riferimento: Massimo Marianetti
Dipartimento di Organi di Senso-Sezione Neurologia, “Sapienza” Università di Roma
e-mail: info@preventionandresearch.com