

## CAREGIVERS HELP-SEEKING RELATED TO PHYSICAL AND MENTAL BURDEN

Carmela Mento, Amelia Rizzo, Salvatore Settineri

### Abstract

*Objective:* Several studies addressed the psychological and physical consequences of caregiving. Literature suggests that the majority of caregivers would benefit from a psychological support. Despite this evidence, lots of caregivers are reluctant in seeking psychological help. The aim of the present study is to identify the sociodemographic characteristics and the psychological motivations of caregivers who request a support, in terms of gender, age, occupation, type of recipient pathology, perceived burden and experienced emotions.

*Method:* Two hundred ninety-three caregivers, 70.4% females, aged between 20 and 80 years, were interviewed with a Questionnaire for Caregiver and the Caregiver Burden Inventory (CBI).

*Results:* Findings show that factors associated with caregivers help-seeking are not the objective ones (time spent in care, age, occupation), with the exception for gender. The reasons are rather traceable in the type of pathology (physical vs. mental), the level of burden and the negative affects experienced.

*Conclusions:* Focusing on the demand analysis could contribute in the clinical practice to better specify the objectives of the psychological and psychotherapeutic interventions.

**Key words:** caregiver, psychological support, motivation

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### Introduction

When a patient expresses a request for counseling brings to our attention a question. The way in which the question is treated lays the foundation of clinical psychology. It may have a therapeutic, training, diagnosis or intervention aim, to modify the functioning of specific structures. In all such circumstances, the demand is analyzed by reading the motivational dynamics and the relationship between a user, consultant and client (Carli, 2013).

The "analysis of demand" is configured, then, as the exploratory phase on which psychologists can and must build the professional performance. Technically, the analysis of demand implies a shift in focus from the symptoms declared to the reasoning on suffering, which led the patient to ask for our help (Carli & Giovagnoli, 2011).

This also means that the demand should be analyzed,

interpreted, and understood by the psychologist and the applicant together. The transition from a passive request for external help to an active involvement of the patient in his own situation is mediated by processes of awareness and metacognition (Sifneos, 1968; Dimaggio et al., 2006).

The first step is therefore to analyze the condition of the applicant. The caregiver, term introduced by Pearlin et al. (1990), is who takes care of a person with limitations in personal autonomy, due to a particular form of chronic disease or long-term symptomatic remission, by virtue of an emotional and/or family bond.

The role they have taken provides for different tasks: (a) Take care of someone who has a chronic illness or disease; (b) Manage medications or talk to doctors and nurses on someone's behalf; (c) Help bathe or dress someone who is frail or disabled; (d) Take care of household chores, meals, or bills for someone who

cannot do these things alone (Levine & Barry, 2003).

Several studies have focused on the effects of physical and psychological burden and many reviews and meta-analysis were carried out (Zarith et al., 1980; Siegel et al., 1991; Huges et al., 1999; Kasuya et al., 1999; Adelman et al., 2014).

Among authors, there is strong consensus that caring for an individual with a disability is burdensome and stressful to many family members and contributes to morbidity. Researchers have also suggested that the combination of loss, prolonged distress, physical demands of caregiving and biological vulnerabilities of older caregivers may compromise their physiological functioning and increase their risk for physical health problems, leading to increased mortality (Shultz & Blach, 1999).

More recent studies have also employed to assess the effectiveness of caregivers support with psychological treatments and psychotherapy, through longitudinal studies (Foster et al., 2014; Rico-Blazquez et al. 2014) and structured programmes (Lui, 2014; Keech et al., 2014) and the introduction of several online support proposal (Pagan-Ortiz et al., 2014; Kwok et al. 2014).

On the opposite side, when caregivers don't get the help they need, or if they try to do more than they are able, either physically or financially burnout can occur. Caregivers who are "burned out" may experience fatigue, stress, anxiety, and depression. Many caregivers also feel guilty if they spend time on themselves rather than on their ill or elderly loved ones (El Nady, 2012).

One of the least studied aspect, to our knowledge, regards the factors which may somehow affect the caregiver decision to request for help. From literature evidence, it can be said that the majority of caregivers would benefit from a psychological support (Gallagher-Thompson & Coon, 2007). Despite this evidence, instead, because of the indirect nature of the perceived discomfort, lots of caregivers are reluctant in seeking psychological help.

The present study is focused on the missing link between studies that have shown, on one hand, the physical and psychological discomfort experienced by the caregiver and, on the other hand, the effectiveness of psychological support and the negative consequences of its lack.

We wondered if there are some specific types of a caregiver who access to the psychological services and what motivations and characteristics could contribute to the expression of the need for psychological support.

From these premises, the general aim of this study is to explore if there are differences between caregivers who request vs. not request psychological support. In particular, we aim to verify if these differences could depend on the gender, the type of recipient pathology or other caregiver's conditions. Furthermore, we want to verify if caregivers who request vs. not request a psychological support differ in the caregiver's burden level and the quality of the perceived emotional states.

## Methods

### Participants

Subjects were recruited from several rehabilitation centers of the provinces of Messina, Catania, Syracuse and Reggio Calabria, from December 2012 to June 2013. Each subject signed an informed consent, containing the general purpose of the research and the guarantee of anonymity, following the Ethical Principles of the

Declaration of Helsinki about the research on human subjects. The administration required for each participant between 15 to 30 minutes in a single session. Each participant signed an informed consent with research purpose and anonymity was granted according to the Italian law for personal information treatment.

Participated at the study 293 caregivers, 206 females (70.4%) and 87 males (29.6%) aged between 20 and 80 years, of which 57.5% from 26 to 55 years, 32% from 56 to 70 years, 6.5 % with less than 25 years and 4% with more than 70 years. To verify the presence of differences about the caregivers help-seeking intentions, the whole sample has been divided into two subgroups: (1) Requesting psychological support (N=111); (2) Not requesting psychological support (N=182). As stated before, the aim is to verify if these differences could depend on the gender, the type of recipient pathology or other caregiver's conditions. The second aim is instead to verify if caregivers who request vs. not request a psychological support differ in the caregiver's burden level and the quality of the perceived emotional states.

### Instruments

For the evaluation of the motivations and burden of caregivers, the instruments described below were used.

The informative *Questionnaire for Caregivers* has been developed within the project of support to caregivers DA.LIA realized with the contribution of the Ministry for Equal Opportunities in the Region of Emilia Romagna. It consists of 29 items that collect demographic information, concerning the frequency and intensity of the care, motivation at care, knowledge, and use of educational, psychological and social support.

The Italian version of *Caregiver Burden Inventory* (CBI) is a 24-item multi-dimensional questionnaire measuring caregiver burden with 6 subscales: (a) Time Dependence; (b) Developmental; (c) Behaviour; (d) Physical Burden; (e) Social Burden; (f) Emotional Burden. Scores for each item are evaluated using a 5-point Likert scale ranging from 0 (not at all disruptive) to 4 (very disruptive). All of the scores on the 24-item scale are summed and a total score >36 indicates a risk of "burning out" whereas scores near or slightly above 24 indicate a need to seek some form of respite care (Novak & Guest, 1989).

### Statistical methods

Data were analyzed using SPSS version 17.0. Chi-square was performed to identify the associations between the variables considered. Student's t-test for an independent sample was instead performed to verify any difference between groups. For reliability of instruments, we performed Cronbach alpha value. Caregiver Burden Inventory (CBI) obtained an alpha = .79, for the informative Questionnaire for Caregivers alpha was .73.

## Results

### *The characteristics of caregivers who request psychological support*

Analyzing the group of caregivers requesting a psychological support, emerges that males are under-represented, while females are over-represented, compared to the frequencies that would be expected if the null hypothesis of no association was true. Females, therefore, more easily than males, express the need for a psychological support, while for caregivers who

don't request psychological support can be observed the opposite.

**Table 1.** Help-seeking nature of caregivers according to gender

	Caregivers who request support		Caregivers who not request support	
	Males	Females	Males	Females
Frequency	24	87	118	64
Percentage	33.30%	77.70%	63.73%	35.16%

\*=statistically significant  $\chi^2=6.01$   $p<.01$

As regards the other demographic data, there are no age differences: the subjects, divided into 5 classes, are distributed randomly and similarly between the groups. The number of offspring, employment status, number of care hours, living in the same house, and the degree of relationship do not have a significant impact on the need for support (ANOVA).

What is most evident from the results is the impact due to the severity and type of disease.

For this reason, in a second step, we divided the sample in three categories, according to the pathology of the recipient: (1) physical diseases (SLA; paralysis, cerebral trauma, permanent anatomic and functional injury); (2) mental illness (schizophrenia, obsessive-compulsive disorder, mood disorders, anxiety disorders); (3) both pathological conditions (Alzheimer's disease, dementia, intellectual disability). These pathological categories derived from the ICD-10 classification and could occur in different degree of severity: mild, moderate and severe.

**Table 2** shows that caregivers who care for patients with exclusively physical disabilities, tend to not express the need for a support, on the contrary caregivers of individuals with psychopathologies and mental illnesses express a greater need. This association is evident even in those who are caring for patients with both physical and mental diseases, with a significant incidence. Similarly, as might be expected, caregivers who feel they need psychological help are the ones who take care of people with disorders of severe degree.

**Table 2.** Help seeking nature of caregivers according to the pathology

Caregivers	N	Caregivers who request support
of physical disabilities	142	43
of mental illness	88	39**
of both conditions	63	39**
of severe degree disorders	115	55*

Legend: \*\* Chi square  $\chi^2(2)=6.18$   $p<.03$  statistically significant incidence; \* Chi square  $\chi^2(2)=9.25$   $p<.01$  statistically significant incidence.

**Table 3** shows gender differences in relation to perceived burden. Women compared to men show higher levels both in the developmental dimension. The time required for the assistance that is perceived as a subtraction of personal time for self. Women also report more emotional implications related to assistance of patient.

*The role of the perceived emotional states in the help-seeking*

Eventually, to explore the impact of emotional states on the expression of the need for psychological support, we used the chi-square test. The analysis of data showed that the emotional states are significantly associated among groups. In particular, **table 4** shows the caregivers who declare to need help (N = 111) and report the emotional states listed.

Despite all the emotional states show a significant impact with the request to help, those who, from a statistical point of view, seems prevalent are the emotions of sadness and anger. Furthermore, there are differences between gender in the emotional states experienced: females, compared to males, are more likely to report higher levels of crying spells [ females M = .40 ± .49; males M = .07 ± .25; t (291) = -.600,  $p<.001$  ] and excessive fatigue [ females M = .75 ± .43; males M = .60 ± .51; t (291) = -2.45,  $p<.01$  ].

**Table 3.** Gender differences in the perceived burden among caregivers

Group	male		female		t-test for Equality of Means	
	Mean	SD	Mean	SD	t	Sig.
Time Dependence	10.04	6.124	12.79	4.910	-2.387	<b>.018</b>
Developmental	5.83	5.597	7.53	5.556	-2.613	<b>.009</b>
Physical Burden	4.94	4.654	6.48	4.550	.465	.643
Social Burden	3.80	4.267	3.56	3.921	-.388	.699
Emotional Burden	1.92	2.805	2.08	3.365	-2.736	<b>.007</b>
CBI Total	25.30	17.504	31.39	17.467	-2.387	<b>.018</b>

**Table 4.** Incidence of emotional states on requesting psychological support

Emotions	Indicators	Observed	Expected	Chi-square	Sig. (2-sided)
Sadness	Crying spells	55	33.3	32.38	.000
Aggression	Ourtbust of anger	50	32.2	22.31	.000
Fatigue	Excessive fatigue	86	77.7	4.79	.020
Tension	Insomnia	44	34.1	6.68	.010

## Discussion

The present study aimed to identify the characteristics and motivations of caregivers asking for psychological support compared to the caregivers who do not require it. In the literature, motivational aspects and the analysis of demand are poorly studied (Rosenbaum & Horowitz 1983, Ryan & Deci, 2008). This study could represent the missing link between studies that have shown, on one hand, the physical and psychological discomfort experienced by the caregiver and, on the other hand, the effectiveness of psychological support and health professionals empathy (Mento et al., 2016).

The factors associated with the expression of a request for psychological help in caregivers, who are suffering in an indirect way the pathology of the care recipient, are different.

We observed that women find easier the psychological help-seeking. This could be linked to the difference found between males and females on the reported emotional states. In particular, emerged a higher level of crying spells (sadness) and excessive fatigue among females.

From the literature, it is well known that women have a greater vulnerability to depression and many different explanations for the gender difference in depression have been offered, even if none seems to fully explain it (Nolek-Hoeksema, 2001). Some of the most important explanations of gender differences in depression concern the model of stress, vulnerability and life events (Hankin & Abramson, 2001) and the influence of personality variables (Goodwin & Gothib, 2004), such as the temperamental traits (Rizzo, 2013). The difference would seem, therefore, a product of a different cognitive and emotional processing of the stressful event.

As regards the level of perceived fatigue, coherently with other studies on non-clinical samples, fatigue is found more frequently among women than men. In particular, fatigue is related to more acute health complaints, more psychosocial problems and a lower level of perceived health in both men and woman. Instead, women are more likely to report higher levels of fatigue in association with gender-specific biological complaints and psychosocial problems (Bensing et al., 1999). This explanation emphasizes that fatigue is perceived differently according to gender, not only as a biological but also as a psychological factor.

The results also show that request for psychological support occurs more frequently in the group of caregivers caring for someone with a mental illness, compared to those who assist someone with physical problems, probably because, it is more stressful in relational terms (Settineri et al., 2014) despite do not involve directly the illness stigma (Lannin et al., 2014), but the relational sphere (Cheng et al., 2015).

This finding suggests that taking care of a person with psychopathology involves a greater emotional burden and a worse mood for the intervention of relational factors, unlike the care of people with exclusively physical disorders, despite the burden being similar and quality of life reduced for both groups. These results are coherent with the study of Provencher (1996) who underlined how the most common negative consequences of caring were the primary caregiver's emotional problems, the disturbance in the caregiver's performance of work, and the disruption in the lives of other adults in the household (Greenberg et al., 1997).

In conclusion, the most interesting aspect is that are not so much the objective factors to affect the help-seeking (eg, occupation, number of children, hours

of caregiving, living with the care recipient), but the subjective ones, i.e. the emotional states and the burden perceived. In particular, we found that despite all the emotional states show a significant impact on the request to help, those who seem prevalent are the emotions of sadness and anger. If the presence of depressive feelings has already been widely demonstrated (Gallagher et al., 1989; Stommel et al., 1990; Brendgen et al., 2001; Lee & Farran, 2004) the emotion of anger is instead less studied (Coon et al., 2003).

In particular has been most studied aggression against the caregiver (O'Leary et al., 2005), especially when assisting Alzheimer's patients (Deutsch et al., 1991) with dementia (Sloane et al., 2004) or schizophrenic (Lauber et al., 2003; Chan, 2008). Nevertheless, Tabak et al. (1997), examined the caregiver's feelings of anger, the causes of these feelings as described by the caregivers and their reactions. By observing a caregiver support group for 3 years, authors found that frequently anger was raised as a major issue in the caregiving.

## Conclusion

Caregivers who more easily wish to contact a psychologist are those who feel a greater burden of time required, both physical and psychological and feel that taking care of the assisted has affected their social relationships and has prevented a serene development over life.

The emotional burden and the pathological relational experience are hence associated with the help-seeking; plausibly the mental illness, compared to the physical one, may be more difficult to manage in terms of emotional stress. The second indication, very useful to a finalized psychotherapeutic path, is the presence of two prevailing emotions: sadness and anger, toward the situation, the infirm and toward self, because of the major limitation of the caregiver life and the mixed feelings of duty and affection. Understanding the reasons for the psychological help request may, therefore, be a useful first step in identifying specific treatments.

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