

## STRESSED CAREGIVERS. AN OBSERVATIONAL STUDY IN A REHABILITATION CARE HOME IN WESTERN SICILY

OMAR ENZO SANTANGELO<sup>1\*</sup>, SANDRO PROVENZANO<sup>1\*</sup>, DOMIZIANA GIORDANO<sup>1</sup>, ENRICO ALAGNA<sup>1</sup>, ROBERTA ALCAMO<sup>2</sup>, FRANCESCO ARMETTA<sup>1</sup>, CLAUDIA GLIUBIZZI<sup>1</sup>, DIMPLE GRIGIS<sup>3</sup>, NATHALIE SALA<sup>4</sup>, FABRIZIO MARRUSICH<sup>4</sup>, SALVATORE LO SCIUTO<sup>4</sup>, FRANCESCA CRAPAROTTA<sup>4</sup>, MANUELA PERUZZA<sup>4</sup>, CLARA FERRARA<sup>5</sup>, ANNA PROCLAMÀ<sup>4</sup>, ALBERTO FIRENZE<sup>1</sup>

<sup>1</sup>Department of Health Promotion, Maternal-Infant, Internal Medicine and Specialization of Excellence "G. D'Alessandro", University of Palermo, Palermo, Italy - <sup>2</sup>Polyclinic University Hospital "P. Giaccone", Palermo, Italy - <sup>3</sup>University of Bergamo, Bergamo, Italy - <sup>4</sup>Casa di Cura Riabilitativa "Vittoria", Castelvetro, Italy - <sup>5</sup>ARNAS Ospedali Civico Di Cristina Benfratelli, Palermo, Italy

\*Equally contributor

### ABSTRACT

**Introduction:** Caregiver is the person who takes care of the patient from the practical point of view, helping him in managing the disease and carrying out daily activities, but also supporting him on an emotional level. Caregiver burnout is a state of physical, emotional, and mental exhaustion that may be accompanied by a change in attitude from positive and caring to negative and unconcerned. The aim of the study was to understand what factors were associated with having panic attacks or crying crises in the caregivers of our study population.

**Materials and methods:** The study design is observational. An anonymous questionnaire was administered to caregivers of the patients of a hospital for the intensive post-acute rehabilitation from April 2016 to December 2018. The statistical significance level chosen for the entire analysis was 0.05. The covariates to be included were selected using a stepwise backward selection process, with a univariate *p*-value <0.25 as the main criterion. Results are expressed as adjusted Odds Ratio (aOR) with 95% Confidence Intervals (CI).

**Results:** The sample consists of 302 caregivers (60.93% was females and 39.07% was males). The mean age of the sample is 53.42 years old (SD ± 12.19). The multivariable logistic regression model shows that the risk to have panic or crying crisis is significantly associated with the following independent variables: female gender (aOR 27.06); living with the patient (aOR 4.38); had claimed that the problems related to the illness of their family member is a source of stress (aOR 23.54), smoking cigarettes (aOR 14.68); had claimed that taking care of their client affected their personal financial statement/career (aOR 5.95), having free time (aOR 7.68).

**Conclusions:** In our study we found a greater probability of having panic attacks or crying crises in female subjects, smokers, who think they have sacrificed their careers to take care of the person they follow from a welfare point of view. Certainly in the light of what has emerged it is necessary to dedicate and pay close attention to the psychological and social aspects of the caregiver.

**Keywords:** Caregiver, burden of care, stress, assistance, Sicily.

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### Introduction

The caregiver is the person who takes care of the patient from the practical point of view, helping him in managing the disease and carrying out daily activities, but also supporting him on an emotional level. Most of the time the caregiver is a family member (usually spouse or child) or a friend, but the term is also used with reference to a person assisting the patient with payment of a fee (caregiver). Taking care of a sick person is not easy and requires the ability to adapt continuously to their changing needs according to the evolution of the disease.

Often the caregiver must reconcile the responsibility of care towards the sick person with work commitments, family duties and other needs<sup>(1)</sup>. All of this absorbs a lot of energy on a physical and mental level, especially as the caregiver does not necessarily have the skills and/or knowledge necessary to deal with the problems that may arise during a long illness.

There is therefore a risk that the caregiver will neglect himself, developing insomnia, fatigue, anxiety, depression and social isolation<sup>(1,2)</sup>. To prevent the onset of these problems, it's essential to have proper self-care to promptly recognize any

symptoms (insomnia, loss of appetite, headache) and manifestations of discomfort (feelings of impotence and/or guilt, anger, nervousness). In this situation, it is important to ask for help: recognizing one's limits is essential to keep up with one's physical and mental energies and be helpful to others<sup>(3,4)</sup>. It is necessary to know how to listen to the sick person: before the diagnosis of a tumor, a chronic-degenerative disease, the patient can have reactions ranging from the initial disbelief and denial of the problem to the subsequent manifestation of a strong anger, letting go to emotional outbursts with others or closing in on itself<sup>(5)</sup>.

Sometimes he can experience feelings of resignation, discomfort and profound sadness. Once this phase is over, he can enter the acceptance phase and look for a new adaptation with and in the disease<sup>(3)</sup>. These emotional states profoundly affect the relationship with the caregiver, which can manifest feelings similar to those of the patient. It is essential to recognize and share these feelings so as not to hinder communication and relationships. This is why the caregiver must be a "good listener" by acknowledging what the patient reports without magnifying it or minimizing it<sup>(4,5)</sup>. The caregiver and the sick person must understand and accept that all emotional reactions are part of the process of adapting to the disease and that, through their sharing, the balance necessary to face the experience of illness and care can be maintained<sup>(4,5)</sup>. So taking care of a sick or dying person can certainly be rewarding, but it can also be stressful. In fact, almost half of all family caregivers say they are "a little stressed" and more than a third "very stressed", according to the report of the National Caregiving Alliance<sup>(6)</sup>/AARP "Caregiving in the United States 2015". The caregivers of patients with dementia are the vast majority. They are generally women (74%), of whom 31% under the age of 45, 38% aged between 46 and 60, 18% between 61 and 70 and 13% over 70 years<sup>(6)</sup>. Being in a position to assist a loved one means, therefore, running the risk of being often faced with moments of difficulty, the commitment is often difficult and burdensome and there will certainly be moments of tiredness<sup>(2,4)</sup>.

The American association "National Family Caregivers Association" provides a list of guidelines to those preparing to assist their loved ones: among these, the caregiver must not allow the illness of their loved one to be constantly the center of attention of the caregivers; the caregiver is carrying out a very demanding task and has the right to find spaces and

moments of leisure; the caregiver must always be vigilant about the moments of depression he may face; must accept the help of other people, who can perform specific tasks on his behalf<sup>(4,6)</sup>. In this context it assumes particular importance the caregiver burnout syndrome. Caregiver burnout is a state of physical, emotional, and mental exhaustion that may be accompanied by a change in attitude from positive and caring to negative and unconcerned. Burnout can occur when caregivers don't get the help they need, or if they try to do more than they are able either physically or financially. 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. More than half of the familial caregivers of patients with dementia report that they suffer from some kind of burden, which is frequently associated with depression, anxiety, higher physical morbidity and mortality in this group<sup>(7)</sup>. The aim of the study was to understand what factors were associated with having panic attacks or crying crises in the caregivers of our study population.

## Materials and methods

The study design is observational. The study period was from April 2016 to December 2018. The questionnaire was created by the authors for this study and consists of 20 questions. The 20 questions asked in the questionnaire are shown in Table 1. Data collection was self-completed, anonymously and voluntarily. The paper questionnaire, after informed consent, was administered to the caregiver identified on arrival in the patient's structure.

302 questionnaires were given to caregivers of the patients who had access to the "Vittoria" Rehabilitation Care Home, in Castelvetro, Western Sicily, Italy, a hospital for the intensive post-acute rehabilitation of disabilities resulting from

- vertebrobasilar circulatory disorders;
- degenerative diseases of the nervous system in the acute phase;
- traumatic and non-traumatic musculoskeletal system diseases;
- bedding syndromes in patients with diseases affecting the cardiovascular and respiratory systems;
- bedding syndromes in patients with metabolic, oncological and urological diseases.

The institute is ISO 9001: 2015 certified.

The variable "Degree of kinship" have been

dichotomized in “Relative 1st degree” and “Not a relative”; the variable “Educational level” have been dichotomized in “High” (if high school graduation or university degree) and “Low” (if middle school, elementary school or none).The statistical significance level chosen for the entire analysis was 0.05. For all the qualitative variables, absolute and relative frequencies were calculated. The results were analysed using the STATA statistical software version 14<sup>(8)</sup>. The covariates to be included into the final model were selected using a stepwise backward selection process, with a univariate p-value <0.25 as the main criterion<sup>(9)</sup>. Results are expressed as adjusted Odds Ratio (aOR) with 95% Confidence Intervals (CI).

**Results**

The sample consists of 302 individuals, of whom 184 (60.93%) are females and 118 (39.07%) are males. The mean age of the sample is 53.42 ± years (SD ± 12.19). The mean number of family members was 3.33 (SD ± 1.29). 280 (95.89%) participants were relative 1st degree, 12 (4.11%) were not relative. 192 (88.89%) did not work and 156 (53.98 %) did not live with the patient.147 (55.68%) declared that the patient managed by others family private collaborators. 249 declared that become a caregiver was a free choice. 224 (78.60%) had health problems and 179 (72.76%) claimed that their relatives' illness was a source of stress. 74 (25.87%) claimed that had panic or crying crisis. For others variables see Table 1.

Table 2 shows adjusted Odds Ratio (aOR). A multivariable logistic regression model was used based on 97 observations. Stepwise backward selection process, with a univariate p-value <0.25 as the main criterion. Each independent variable has been adjusted for all the other independent variables. The analysis shows that the risk to have panic or crying crisis is significantly associated with the following independent variables: female gender (aOR 27.06, 95% CI 3.76-194.91, p<0.001); living with the patient (aOR 4.38, 95% CI 1.10-17.42, p<0.036); had claimed that the problems related to the illness of their family member is a source of stress (aOR 23.54, 95% CI 4.13 -134.19, p<0.001), smoking cigarettes (aOR 14.68, 95% CI 2.55-84.52, p<0.003); had claimed that taking cre of their client affected their personal financial statement/career (aOR 5.95, 95% CI 1.16-30.36, p<0.032), having free time (aOR 7.68, 95% CI 1.27-46.49, p<0.027).

Variables		N	%
Gender	Female	184	60.93
	Male	118	39.07
Single or Engaged?	Single	82	28.17
	Engaged	209	71.82
Educational level	High	183	61.62
	Low	114	38.38
Degree of kinship	Relative 1st degree	280	95.89
	Not a relative	12	4.11
Do you currently work?	Yes	192	88.89
	No	24	11.11
Do you live with the patient?	No	156	53.98
	Yes	133	46.02
How long does it take to get to the patient's home or to the nursing home?	Minutes	228	85.71
	Hours	38	14.29
Is the patient managed by you or does he use other family private collaborators?	With others	147	55.68
	Alone	117	44.32
Did you choose to become a caregiver or was it forced by events?	Free choice	249	87.68
	Forced	35	12.32
How much time do you spend or can you dedicate to your family career?	≤12h hours a day	102	39.53
	>12 hours a day	156	60.47
Do you have health problems?	No	224	78.60
	Yes	61	21.40
Are the problems related to the illness of your family member a source of stress?	No	188	66.90
	Yes	93	33.10
Do you have relatives or friends who support you at this time of high stress?	Yes	179	72.76
	No	67	27.24
Do you smoke cigarettes?	No	237	79.80
	Yes	60	20.20
Do you drink wine or spirits?	No	245	87.19
	Yes	36	12.81
Do you have free time to dedicate to yourself?	No	114	44.71
	Yes	141	55.29
Has taking care of your client affected your personal financial statement/your career?	No	221	79.78
	Yes	56	20.22
Have you had panic or crying crisis?	No	212	74.13
	Yes	74	25.87
Mean Number of family members and Standard Deviation		3.33 ± 1.29	
Mean Age and Standard Deviation		53.42 ± 12.19	

**Table 1:** Description of the sample

The analysis shows instead that the risk to have panic or crying crisis is statistically significant lower for the following independent variables: drinking wine or spirits (aOR 0.80, 95% CI 0.01-0.96, p<0.046).

Independent variable	Dependent variable: Have you had panic or crying crisis? Yes			
		aOR	95% C.I.	p-value
Gender	Male	1		
	Female	27.06	3.76-194.91	0.001
Single or Engaged?	Single	1		
	Engaged	4.08	0.88-18.99	0.073
Do you live with the patient?	No	1		
	Yes	4.38	1.10-17.42	0.036
Do you have health problems?	No	1		
	Yes	5.56	0.86-35.69	0.071
Are the problems related to the illness of your family member a source of stress?	No	1		
	Yes	23.54	4.13-134.19	<0.001
Do you smoke cigarettes?	No	1		
	Yes	14.68	2.55-84.52	0.003
Do you drink wine or spirits?	No	1		
	Yes	0.80	0.01-0.96	0.046
Do you have free time to dedicate to yourself?	No	1		
	Yes	7.68	1.27-46.49	0.027
Has taking care of your client affected your personal financial statement/your career?	No	1		
	Yes	5.95	1.16-30.36	0.032

**Table 2:** Multivariable logistic regression. Stepwise backward selection process, with a univariate p-value <0.25 as the main criterion. Adjusted Odds Ratio are presented. Each independent variable is adjusted for all the other independent variables. Based on 97 observations.

## Discussions and conclusions

Caregivers of individuals in rehabilitation operate as extensions of health care systems (performing complex medical and therapeutic tasks and ensuring care recipient adherence to therapeutic regimens) and have unique needs and concerns that should be addressed in rehabilitation and in community-based programs.

Their concerns have a direct bearing on their health and on the health and well-being of their care-recipients<sup>(10)</sup>. The responsibilities of caregiving (and corresponding lack of preparation, guidance and support) erode their physical and emotional health<sup>(11)</sup>. The results of this study are based on 302 caregivers (60.93% females and 39.07% males). In relation to the planned aim of study, we are found that female are higher risk of experience panic or crying crisis. This result could be connected to the fact that, how Barbola et al<sup>(12)</sup> detected in

their study, female caregivers have an higher burden than male caregivers; in the same way an higher burden is also correlated to live with the patient that, according to our results, is an another important factor that increase the risk of panic crisis. It's also important to underline that more than 95% of cases caregivers and recipients are relatives and so we have to add to the physical burden the psychological stress derived from the illness of a family member as found in other studies<sup>(7)</sup>. To alleviate the burden the 55,68% of our sample decide to be supported by others private collaborators that help them in the management of the patient.

This decision certainly affects the financial statement, that is another important source of stress. Quite the opposite, whom who can't or don't want assistance by others collaborators have to spend a lot of time for the patient needs and even if this decision can preserve their money, obviously affect the time they can dedicate to their career that it's an additional stress factor. All of these findings are logical and can be easily understood. Instead two of our results could appear curious; we found that smoking cigarettes and having free time are two factors related to a major risk of panic or crying crisis. As Choi et al<sup>(13)</sup> have already shown in their study cigarette smoking perhaps can relieves stress, so we could imagine that those who have higher level of stress and as result suffer more from panic or crying crisis, are also those who consume more tobacco.

According to this hypothesis Stubbs et al<sup>(14)</sup>, in a cross-sectional study conducted among 41 countries, found that an increased level of self-reported stress was positively associated with daily smoking, and the association was statistically significant. Evidence indicates that perceived stress may comprise a barrier for smoking cessation<sup>(14)</sup>.

Why having free time is correlated with an higher risk of panic or crying crisis is hardly explainable; maybe for those who work as caregivers is not possible to release their stress during work time; instead those who take care of a family member don't want to show that this activity is a source of stress to avoid anxieties or guilty conscience in the patient, contrary to what one might think, free time would seem to increase crying crises because the caregiver feels guilty in not spending this free time on patient care. Finally we found that the risk of panic or crying crisis is lower for those who drink wine or spirits.

The relation between alcohol and aggregate wellbeing is already known in literature: Parackal et al<sup>(15)</sup> showed that low-risk drinkers affected aggregate happiness positively, so we could say that a moderate consumption of alcohol could help caregivers to manage their stress. Before to generalize our results some limitations need to be taken in account. The questionnaires were paper based so there have been some missing as some questions had not answer or the answers given were not complete. In addition the response rate has been lower than we expected. Certainly others researches are essential to study the psychological status of caregivers and how to improve it for the wellbeing both of themselves and, as result, of their patients. Caregiver burnout is a relevant issue that very often is inadequately considered in rehabilitation units.

In our study we found a greater probability of having panic attacks or crying crises in female subjects, smokers, who think they have sacrificed their careers to take care of the person they follow from a welfare point of view. All this can be even more exacerbated by the fact of living with the patient, and by the fact that they consider the patient's illness to be a source of stress. Further investigations are necessary to evaluate other stress-related variables not considered in the questionnaire used for the study.

Certainly in the light of what has emerged it is necessary to dedicate and pay close attention to the psychological and social aspects of the caregiver, as their discomfort not only goes to the detriment of the caregiver itself but also to the quality of care given to the patient that they follow, risking to create a spiral that worsens the situation, like the "serpent that bites its tail".

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*Acknowledgements*

*Casa di Cura Riabilitativa "Vittoria", Castelvetro, Italy.*

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*Corresponding Author:*

DR. FRANCESCO ARMETTA

Dipartimento di Scienze per la Promozione della Salute e Materno Infantile "G. D'Alessandro"

Via del Vespro, 129

90127 Palermo (PA)

E-mail: francesco.armetta03@gmail.com

(Italy)