

# PROTECTIVE FACTORS TO MENTAL HEALTH IN CAREGIVERS OF ONCOLOGICAL PATIENTS

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**Abstract:** The present study aimed to identify and describe the protective factors and coping strategies developed by caregivers of cancer patients. Eighteen participants who were waiting in the waiting room of a general hospital in the interior of São Paulo were interviewed. To characterize the sample, a sociodemographic questionnaire developed by the authors was used. To assess mental health, the Depression Scale “CES-D” and “Caregiver Burden Scale” were used. The analysis of the questionnaire showed that the largest number of caregivers are women (84.2%) between the ages of 50 and 60 years. The scales pointed to an important index of depression indicators (20.2), low overload, except for the isolation and general tension dimensions, with the most present aspect of protection in this sample being religious confrontation. In view of the results, it was possible to observe that the preparation for care influences the reduction of burden and better adaptation of the caregiver to their tasks.

**Keywords:** Cancer; Mental health; caregivers; Psychological Adaptation.

## INTRODUCTION

It is noticeable in contemporary society the difficulty in talking about death and about any subject associated with it, such as diseases. One of the most stigmatized diseases and associated with the issue of death is cancer. According to research data carried out by the Pan American Health Organization (PAHO-Brazil), cancer is among the second leading cause of death in the world, accounting for 9.6 million deaths in 2018 (PAHO, 2018).

Due to the high incidence, the diagnosis of the disease becomes a challenge, involving several contexts, ranging from fear of death and pain, to frustration of self-image, low self-esteem, anxiety, depression, among others.

Considered a disease of aggressive power, due to the treatment and the emotional factors involved, cancer is a barrier not only for the patient, but also for their caregivers (FARINHAS, WENDLING, DELLAZZANA-ZANON, 2013).

In this sense, a caregiver is defined as one who takes care, demonstrates zeal, diligence and care in carrying out something. Caring requires dedication, especially on the part of the “main caregivers”. The main caregiver is the one who is chosen or “summoned” to perform all or most of the tasks with the patient, and may or may not have affective bonds with the patient (SALES, SILVA, PILGER, MARCON, 2011; PERES, LOPES, 2012).

Faced with the treatment and hospitalization of the patient, caregivers undergo a great change in their routines, having to give up their jobs, home and family members, since, often, the follow-up does not occur in the city where they live (FETSCH, PORTELLA, KIRCHNER, GOMES), BENETTI et al., 2015).

Although caregivers identify positive aspects associated with their functions performed, studies show that the main caregiver’s work overload causes stress because they do not have enough time for their activities and leisure. This way, they end up putting their own health at risk, developing risk factors for depression, anxiety and affecting their quality of life. In this sense, the importance of psychological assistance and of relying on coping strategies to deal with the situation is perceived (BIANCHIN, SILVA, FUZETTO, SALVAGNO, 2015).

Coping strategies or coping in English is understood as the set of behaviors, feelings and emotional factors that are developed by people to adapt to stressful factors, with the aim of mitigating their impact (FOLKMAN, 1984; MELO, CARLOTTO, RODRIGUEZ, DIEHL, 2016, MURTA, TÓCCOLI, 2007;

POCINHO, PERESTRELO, 2011; ROCHA-SOBRINHO, PORTO, 2012; KLEINUBING, GOULART, SILVA, UMANN, GUIDO, 2013).

Other studies have shown that caregivers feel more comforted and strengthened when they have protective aspects, such as support from other family members, friends and religiosity. Among these aspects, the importance of religiosity is perceived, as it serves as an important form of anxiety relief and helps in facing difficulties (PEREIRA, DIAS, 2007).

On the other hand, even in the face of assistance, most basic tasks such as food, hygiene and medication continue to be the responsibility of the main caregiver. Making the overload continue to exist (IGNACIO, STORTI, BENNUTE, LUCIA, 2011). Therefore, the present study aims to investigate what are the protective aspects that caregivers of cancer patients develop to face treatment and identify the main risk factors, as well as possible impacts on mental health.

## **CASUISTRY AND METHOD**

This is a cross-sectional study with a quantitative and qualitative approach carried out in a general hospital in the interior of São Paulo, in the chemotherapy ward.

### **PARTICIPANTS**

Informal caregivers of patients undergoing chemotherapy treatment at a General Hospital in the interior of São Paulo were invited to participate in the study. A total of 18 caregivers participated.

### **INSTRUMENTS**

To characterize the individuals and identify protective factors, the researchers developed a sociodemographic questionnaire (name, age, kinship, religion, city of residence, etc.), followed by a semi-structured interview composed of nine open questions on the

following topics: relationship with the patient, time spent as caregiver, assistance in the process, reduction of working hours for the task, loss of privacy, strategies that help them to cope with the situation.

For quality of life variables, the “Caregiver Burden Scale” questionnaire was used. Composed of 22 items that comprise Quality of Life in 5 dimensions (General Tension, Isolation, Disappointment, Emotional Involvement and Environment). To measure caregiver burden, the total score is obtained from the arithmetic mean of the values equivalent to the answers to the twenty-two questions, and the individual score is obtained from the arithmetic mean of the values equivalent to the answers to the specific questions of each dimension. There is no cut-off point to classify overload (Valer, Aires, Fengler, Paskulin, 2015).

Aiming to identify risk factors and overload, such as depression, the CES-D scale, composed of twenty items, evaluates on a four-point Likert scale, with 1=rarely or never (less than 1 day), 2= Few times (1-2 days), 3=A considerable time (3-4 days), 4=All the time (5-7 days) (Batistoni & collaborators, 2007).

## **ETHICAL ASPECTS**

This research was approved by the Research Ethics Committee of Faculdades Integradas Padre Albino – (FAMECA) – SP, under opinion 3,238,072.

## **PROCEDURE FOR DATA COLLECTION**

Caregivers present in the waiting room were invited to participate in the research, where they were presented with the objectives of the study as well as the ethical aspects present in the Free and Informed Consent Form. The term included the provision of psychological support, if necessary, by the psychologist responsible for the chemotherapy sector. After

signing, the sociodemographic questionnaire was applied, followed by the two scales. Both instruments are self-administered, except for the sociodemographic questionnaire with the guiding questions, which was recorded to later be transcribed and analyzed in full.

## **PROCEDURE FOR DATA ANALYSIS**

The information obtained by the sociodemographic questionnaire and the scales were distributed in tables in numbers and frequency, using descriptive analysis. The interviews were recorded and transcribed in full, and then the descriptive analysis was carried out.

The Reports were analyzed based on the phenomenological modality, according to Amatuzzi (2009), which consists of four distinct moments: Transcription in full and ample reading of the caregivers' Reports, in order to understand the general meaning of the researched phenomenon. Elaboration and discrimination of the "units of meaning", after reading and re-reading the testimonies. Such units do not exist by themselves, they are extracted after the researcher asks about the phenomenon that is intended to be understood. Grouping into categories the units of meaning that express the psychological insight found in the contributor's discourse. Synthesize and integrate the insights into categories seeking to identify their convergences and divergences, and the understanding of the collaborators' speeches, which will lead to a better understanding of the general structure of the phenomenon in question.

For correlations, the Spearman test was used, with a confidence interval of 95% (95%CI), also considering a significant p-value  $\leq 0.05$ . Analyzes were performed using GraphPad Prism version 7 software.

## **RESULTS AND DISCUSSIONS**

The sample consisted of 18 caregivers, predominantly aged between 50 and 60 years, with a minimum of 24 years and a maximum of 63 years. Profile also observed in a study where the sample of caregivers of the elderly had an average age of 50 and 60 years, being predominantly composed of women, representing 80.7% of the sample, while in this study the representation is 84.2%. (ARAÚJO, VIDAL, BRITO, GOLÇALVES, LEITE et al., 2013) (Table 1).

These results can be attributed to the fact that the act of caring has historically belonged to women. Similar results were found in a survey where women occupied a percentage of 76.8% as caregivers (GUTIERREZ, FERNANDES, MASCARENHAS, 2017).

The predominance of caregivers was 79% married, being spouses or children of patients, none received remuneration for this task. According to Cattani and Girardon-Perlini (2004), the spouses are the main ones to assume this care, since it is a "marital obligation", in addition to the fact that the care to be exercised and spent is imposed as an obligation of the family.

Regarding religion, it is known that in Brazil there is a diversity of religions, it is observed that in the study, 11 of the caregivers (57.8%) are Catholic, 3 evangelical (15.8%), only 1 agnostic (5.3%) and the others are of another religion (21.1%). This index can be determined by the fact that the Catholic religion is adhered to by most of the population. As pointed out in a survey carried out by the Brazilian Institute of Geography and Statistics (IBGE) in 2010, where the Catholic religion represented 65% of the Brazilian population (IBGE, 2010).

Other results found in the present study were those of the CES-D Depression Scale, which aimed to assess the impacts of the task of caring on the Participants, as shown in Table 2.

	n	(%)
<b>Gender</b>		
Male	03	15,8
Female	16	84,2
<b>Religion</b>		
Catholic	11	57,8
Evangelical	03	15,8
Agnostic	01	5,3
Other religions	04	21,1
<b>Marital status</b>		
Single	04	21
Married	15	79

Table 1: Description in frequency (n) and percentile (%) of the sociodemographic characteristics of cancer caregivers at a general hospital in the interior of São Paulo, Brazil, 2019.

Depression Indicators (CES- D)	Caregiver
$\geq 20$	
28	A1
38	A3
39	A6
25	A10
23	A11
48	A12
29	A13
43	A15
25	A16
21	A17
46	A18
$\leq 20$	
16	A2
15	A4
12	A5
15	A7
16	A8
15	A9
19	A14

Table 2 – Indicators of the Depression Scale (CES-D) in the caregivers of the sample, according to the score greater or less than 20.

The average score was 20.2, with high indicators in this sample, considering that the percentage for depression indicators corresponds to >20.

As shown in Table 2, more than half of the caregivers showed indicators of depression. This can be explained by the predominance of the sample composed of women, as presented in the study on burden and depression factors in caregivers of elderly people with Alzheimer's, in which women presented more depressive symptoms, being related to the fact that the woman's role plays in society, having to take care of the patient and also manage a home (CRUZ, LECHETA, WACHOLZ, 2009).

On the other hand, a survey carried out with 50 informal caregivers shows an average of 17.52 on the CES-D scale, that is, less than half of the caregivers (42%) had depressive symptoms. Result that differs from the present study. However, the caregivers presented had a social support network focused mainly on family members, who corresponded to 98% of the sample. (SANTOS, GUTIERREZ, 2011).

On the other hand, the "Caregiver Burden Scale" Quality of Life Questionnaire, in which on a scale from 1 to 4 the average score was 1.6, caregivers had minimal burden on quality of life, except in two dimensions as shown in Table 3.

The dimensions with the highest overload values were general voltage 1.7 and insulation 1.9. Higher values when compared to the results obtained by a survey with primary caregivers of paraplegics using the same instrument, where isolation and general tension had scores of 1.43 and 1.59 (BLANES, 2005).

Another study brought the result of 0.48 for insulation and 0.41 for general voltage. Results below those found in the sample of this study, but these data were correlated with the caregivers' variables. In the isolation dimension, it was concluded that there was a relationship with the health of these caregivers, that is, the average scores are higher in caregivers who report health problems when compared to those who do not. As for the general tension dimension, the highest results were found in caregivers who administered the patients' food. Thus, it can be concluded that the greater the number of tasks performed, the greater the burden score on caregivers (LEMOS, GAZZOLA, RAMOS, 2006).

In data obtained through the CBS scale in a study that sought to assess the psychological stress of caregivers of pediatric patients with Juvenile Idiopathic Arthritis (JIA), the general tension dimension reached a score of 1.75,

Scale Domains	Means (Standard Deviation)	Minimum - Maximum
General tension	1,7 (0,77)	1,0 - 3,8
Isolation	1,9 (0,78)	1,0 - 3,6
Disappointment	1,9 (0,67)	1,0 - 3,4
Emotional Involvement	1,2 (0,49)	1,0 - 2,6
Environment	1,7 (0,47)	1,0 - 2,6
Global	1,6 (0,28)	1,2 - 1,9

TABLE 3- Mean global score and in each dimension of the Caregiver Burden Scale questionnaire in caregivers of cancer patients (n=18) at a general hospital in the interior of São Paulo, Brazil, 2019.

Overhead dimensions	Depression		Age	
	R	<i>p</i>	R	<i>P</i>
General tension	0,5875	0,0103*	-0,1231	0,6265
Isolation	0,2031	0,4190	0,0356	0,8883
Disappointment	0,0457	0,8569	-0,1855	0,4613
Environment	0,5416	0,0203*	-0,1569	0,5340
Involvement	0,0257	0,9193	-0,2011	0,4237

Subtitl: \**p* significant  $\leq 0.05$ ; CI: Confidence interval (95%); Spearman's Test.

TABLE 4: Correlation between the indicators of the Caregiver Burden Scale questionnaire, in each dimension, CES-D Depression Scale and current age of caregivers in the oncology sector of a general hospital, Brazil, 2019.

while the isolation dimension reached 1.35. The comparison of the general average of stress was related to the gender of the caregiver, in which female caregivers were more stressed than male caregivers, despite the male representation having only five individuals compared to 35 female ones (IWAMOTOL, SANTOS, SCARELL, SPELLING, 2008).

This could have been an important influencer for the highest flows in these dimensions. Since the predominance of this present study was of female caregivers compared to male.

Through the correlation between the two scales, a significant index between depression and general tension can be observed. That is, the higher the number of general tension, the greater indicators of depression. The general tension dimension was also presented with greater burden on caregivers of children undergoing renal therapy, where depression and anxiety were evaluated in these caregivers, as well as quality of life, and the depression results were 18.4%. This again correlates to the overload of the high general tension dimension, together with the depression index (LIMA, SALES, SERAFIM, 2019).

Another dimension with significant statistics was the environment and indicators

of depression. This correlation indicates that the environment is an important influencer in the increase of depression indicators. As corroborated by the literature, a study was found in which the Environment dimension had a higher score for caregivers who work or study outside and who manage food. However, in relation to age, this study points out that the older the caregivers, the lower the score for the Environment dimension (LEMONS, GAZZOLA, RAMOS, 2006).

Following the objective of the study, from the phenomenological analysis of the qualitative data obtained through the interview and faithfully transcribed, four categories of meaning emerged, which are: Changes in activities, Coping Strategies, social support to the caregiver and Perception of preparation for the task to take care.

### Category 1: Changes in activities

Changes in activities include any change in the caregiver's routine that is spent on the process of caring for the patient. Whether distance from other family members, reduced working hours, or dismissal, lack of time for leisure activities, moving house to better adapt to patient care, etc.

Participants	Report
P4	Yes, I needed it, but I have a very large collaboration, I work in a closed condominium, so the staff gave me this certain ease, right, so I come here, I get a certificate from a companion, and we see that everything is fine, who know it's a serious health issue, so they understand (sic).
P9	I reduced the dose, I do nails, you know, then I only do it on Thursday, Friday and Saturday, I don't usually do the days that I have to come here for the chemo, I don't work anymore (sic).
P12	I stopped all my life, I had a store, yeah, everything stopped for his life.

TABLE 1: Changes in the activities of caregivers of cancer patients.

A large part of the sample says they have no changes in their routine due to the fact that they are retired. With this, it can be understood that since most Participants are between 50 and 60 years old, they would already be retired and would not feel the impact of the change in routine in this aspect. Since the number of elderly people being cared for by other elderly people is growing in Brazil due to the increase in longevity, as explained in the study on the profile of elderly people who care for other elderly people (SANTOS-ORLANDI, BRITO, OTTAVINI, ROSSETTI, ZAZZETTA et al., 2017).

On the other hand, another study shows that elderly caregivers have greater complaints of insomnia and depressive symptoms compared to elderly non-caregivers. This worsening in quality of life is probably derived from pressures related to the act of care (TOMOMITSU, PERRACINI, NERI, 2013).

The answers to this interview may have been influenced by the environment in which the research took place, in the waiting room, with the other caregivers. And this category mainly, because when asked about the changes in activities and the loss of

privacy due to the care, several caregivers felt difficulties in expressing themselves for fear of being implying that the patients disturbed them, as in the case of one of the caregivers. answers where, when questioned, the answer given by the caregiver was: "no, he does not disturb me".

Another possible reason is that even in the face of some difficulties that are faced in the care process, there are studies that prove the positive aspects of the act of caring. It improves in three aspects: it makes the caregiver feel good about himself, feel more useful and give greater value to life (CARVALHO & NERI, 2019).

However, these changes in activities make the individual, to a greater or lesser extent, have to adapt to the patient's new routine, such as medication schedules, commuting to treatment, hygiene habits, etc. Therefore, it is necessary to emphasize that, along with this process, caregivers develop protective aspects and coping strategies that help them to rebalance and mitigate the impact generated by stress.

### Category 2: Coping Strategies

Coping strategies are a set of factors and resources developed to mitigate the impact of stressful situations, there are several ways of coping, but having the perception of what they are is something important and that needs to be strengthened. The table below shows three reports from caregivers that describe the strategies developed and used.



Participants	Report
P4	This we have hope in the word of God, right, and the bible promises there in Revelation 21:3,4 that there will be no more death, there will be no more pain, no more crying, the past things will pass away, so we it is very attached, has a lot of faith, and another strategy that I use is that the patient is a human being, so we need strength, to vent, then I usually take the bike for a ride, a little cry and then it goes away.
P12	I pray, right, I take the bible, I pray, I talk to God and He has been my balm, right, he has strengthened me, held me, given me strength, right, only he himself to strengthen us.
P9	Yes, I'm going to church now, evangelical, I'm getting very attached to God.

TABLE 2: Coping Strategies used by caregivers of cancer patients.

Among the various coping strategies that can be developed, religion is among them, and it was the most prominent among the Participants in the sample. Another study carried out with 113 participants whose objective was to examine the effects of religiosity on the outcome of depression in the elderly found that religious patients had a faster remission of depression. In the same study, when 87 patients were asked what enabled them to deal with stress and the depressing factors of the disease, a third (32.6%) gave religious answers such as “God”, “the Lord”, “my faith”, “prayer”, “Jesus”. (KOENING, GEORGE, PETERSON, 1998).

The same is possible to perceive through the present research when questioning what helped them to face the moment was cited the church, God, prayer, bible. It can then be understood that religion was one of the factors that helped caregivers in this process. Being cited directly or indirectly in the Reports.

To understand the strategies developed, it is also necessary to know the social support provided to this caregiver, since, when there is some type of help, stress and overload can be

reduced, being also a protective aspect.

### Category 3: Social Support for the Caregiver

The category of social support is focused on the help network that this caregiver perceives, whether through family members or friends, people who help them in the care process, either emotionally or physically.

Participants	Report
P5	Brothers-in-law and brothers
P12	No, no one, no one volunteered. just me, just me.
P6	There is all my Family, yes, there is.
P1	There is all my family.

TABLE 3: Social support to the caregiver.

From the sample, 72% of caregivers reported having the help of other people in the task of caring, predominantly from family members. The same data is obtained in a study where the type of support received was informal help from relatives (57.8%) (AMENDOLA, OLIVEIRA, 2011).

In view of such a result of the sample in question, it is possible to observe a certain distinction from what is found in much of the literature. In a study with a sample of 33 participants, it was observed the presence of stress in 81.8% of the evaluated caregivers. Through the Informal Caregiver Burden Assessment Questionnaire (QASCI), a significant association was found between stress and emotional burden related to the patient ( $p=0.007$ ) (SOUZA, HANUS, LIBERA, SILVA, MANGILLI, 2015).

It is noted that even in the face of the perception of social support obtained by these caregivers, the depression index was high according to the applied scale, scoring 20.2.

This may have been an important bias, because when addressing this issue, it was not

asked how often this help was exercised, since even if the family support was identified, the greatest care provided continued to belong to the main caregiver.

It is important to know the social support provided to the caregiver, as well as the subjective experience of this task of caring. As seen in the first category, the caregiver is often chosen due to availability, but he is not always prepared for such a role, which can lead to higher rates of overload and stress in this process.

#### Category 4: Perception of readiness for the task of caring

In this category, we sought to identify whether or not caregivers were prepared for the task of caring, and their perceptions of this task.

Participants	Report
P1	I thought I wasn't, but I am, thank God (sic).
P18	I didn't feel it, now I feel it.
P17	Yes, until I did better than I imagined.
P16	Now, it is ok.
P13	No.

TABLE 4: Perception of readiness for the task of caring.

As observed, caregivers reported not being prepared for this task at first, but adapting to this condition. According to Laham (2003), the caregiver adapts to their care roles and the patient's illness over time.

On the other hand, a survey carried out with caregivers of the elderly points out that it is necessary for the caregiver to meet with himself, before taking care of the other, to know his own feelings, tastes, having greater empathy for the other. In addition, in this same research, caregivers emphasized the lack of more in-depth knowledge to deal

with certain situations in the care process, especially when patients are discharged from the hospital and this care is exercised at home, generating greater insecurity in caregivers (MOREIRA, SANTOS), COUTO, TEIXEIRA, SOUZA, 2013).

Given this argument, one might think that if the general population had contact with some type of preparation, if one day they need to be someone's caregiver, this task could be lighter, and their adaptation could occur faster. Precisely with the aim of helping family members, the Caregiver's Practical Guide was developed, seeking to guide the health care of people of any age, with the objective of clarifying home care, helping the caregiver and the person cared for. However, this guide is little publicized, being unknown by many (BRASIL, 2008).

## CONCLUSION

Cancer is one of the most stigmatized and complex diseases, also becoming a challenge for caregivers who are subjected to stressors that affect their quality of life and mental health.

The profile of caregivers was predominantly female, aged between 50 and 60 years, which brings the reflection that the act of caring belongs to women, as a result of the sociocultural construct.

Regarding the protective aspects, religious was identified as a frequent strategy in this population. Through the reports, it was also possible to observe that social support can be understood as an important protective factor in this study.

The high indicators of depression can be explained by the fact that most of the sample is composed of women. On the other hand, overload indicated low levels, except for the isolation and general tension dimensions, which are generally associated with the health of care and the tasks performed in the

act of caring. In view of the results, further studies need to be carried out to investigate whether depression in these individuals was present before the act of caring or not, as this may have been a bias in this study.

In the correlation between the two scales, there was statistical significance between indicators of depression and general tension and depression and environment. This may be related to the caregivers' advanced age and the accumulation of tasks, since most of them have other work activities besides the act of caring.

Preparation for care was reported and related to influence on overload, as it provides caregivers with a better adaptation to their tasks.

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