Research Article

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Anxiety, Depression, and The Burden of Caring for Patients with Palliative Needs-Prospective Longitudinal Study

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Abstract

Objectives: *This study aims to measure the primary caregiver's (PrC) anxiety, depression and burden of care and to identify the correlation between the outcomes.*

Material and Methods: *This prospective observational longitudinal study assessed the burden of care for patients with palliative needs comparatively between two groups: caregivers of patients with cancer and caregivers of patients with non-malignant diseases. At the same time, the score of anxiety and depression of these caregivers was measured. The researcher used the Burden Scale for Family Caregivers (BSFC) to measure the burden of care and Hospital Anxiety and Depression Scale (HAD) to measure the anxiety and depression of primary caregivers. These questionnaires were applied at the initial moment (T0) and periodically for three months. If the patient died in this period, the caregivers were evaluated two months after the event. Statistical analysis used the Mann Whitney U test and the Wilcoxon test to compare the two groups and Pearson test to assess the correlation between burden and anxiety/ depression.*

Results: *The burden assessment of caregivers for cancer patients showed a statistically significant increase over 3 months (p=0.001). At the initial moment (T0), a statistically significant difference is observed between the burden of the oncological group and the non-oncological one. The correlation between the caregiver's burden and anxiety/ depression was statistically significant (p = 0.001).*

Conclusions: *The load had a direct and statistically significant impact on the PrC's psycho-emotional state, and there is a strong link between it and the caregiver's anxiety and sadness when caring for a palliative patient. From a practical point of view, it is important to early identify the burden of care and to know how the PrC is relating to it, as well as to assess his/her psycho-emotional state in order to act through appropriate and individualized interventions.*

Introduction

Patients suffering from a life-threatening illness who need palliative care experience multidimensional suffering: physical, psycho-emotional, social and spiritual. In most cases, there is a person called the primary caregiver (PrC) who is close to the patient, who is actively involved in the care process and who is not being paid [1]. Most of the time, this person is a family member (spouse or son/daughter), but the position can be filled in by anyone close to the patient (e.g., friend, neighbour). PrCs play a multitude of roles during care and are often unprepared to face the new challenge of delivering care while concomitantly adjusting to the psycho-emotional impact of the diagnosis and the prognosis of a life-threatening illness of the loved one.

Among caregivers, 60% experience insomnia, 35% experience a depressive state at least once a week, and 11% require the consultation of a psychiatrist [2]. The level of caregiver burden is closely associated with depression, which affects the level of care given to the patient [3]. A 12-week longitudinal study found that 96% family caregivers for advanced cancer patients reported significant stress, and 80-83% of them experienced sadness and grief due to exhaustion and moderate (43%) or severe (41%) anxiety [4].

The prevalence and intensity of psycho-emotional symptoms among caregivers differ throughout the trajectory of the care process. The period before the death of the loved one and the one after the death are the most emotionally demanding. A previous study found that the prevalence of major depressive syndrome was 21.8% in the period before death, increased to 34.8% in the first 6 months after death, and remained at 24.7% 13 months after death [5]. Because the psycho-emotional impact of caregiving is long lasting and intense, PrCs may become patients themselves.

Although there is literature and research data on this matter, there isn't sufficient data regarding the emotional overload of the primary caregiver in this geographical region.

Study Aim
This prospective longitudinal study aimed to analyse the burden and the psycho-emotional impact of caring for patients in need of palliative care on primary caregivers. The PrCs recruited in the study were divided in two groups: PrC of oncological and non-oncological patients. The first step of the study consisted in measuring and comparing the burden, anxiety and depression of the two groups of patients, while the second step implied correlating these three variables between them.

Material and Methods
Study Design and Recruitment Strategy
The main objective is to measure the burden among PrCs caring for a palliative patient and to identify the correlations of this burden with anxiety and depression among PrCs.

This is a prospective observational longitudinal study comparing the difficulty of caring for patients with palliative requirements in two groups: primary carers of palliative patients with non-malignant disease (PrC1) and primary caregivers of palliative patients with cancer (PrC2).

All primary caregivers of patients with palliative care needs who were sent to a district hospital's palliative care unit for hospitalization or consultation were included in the study. The primary caregiver (PrC) was the person named by the patient who was involved directly in the patient's care. The persons included in the study had to meet the following eligibility criteria.

The inclusion criteria for PrCs were as follows: over 18 years old, Romanian language speakers, did not receive money for the treatment provided, did not have a disease affecting their cognition, and gave their written agreement to participate in the study. If they did not meet all these conditions, they were excluded from the study (Figure 1).
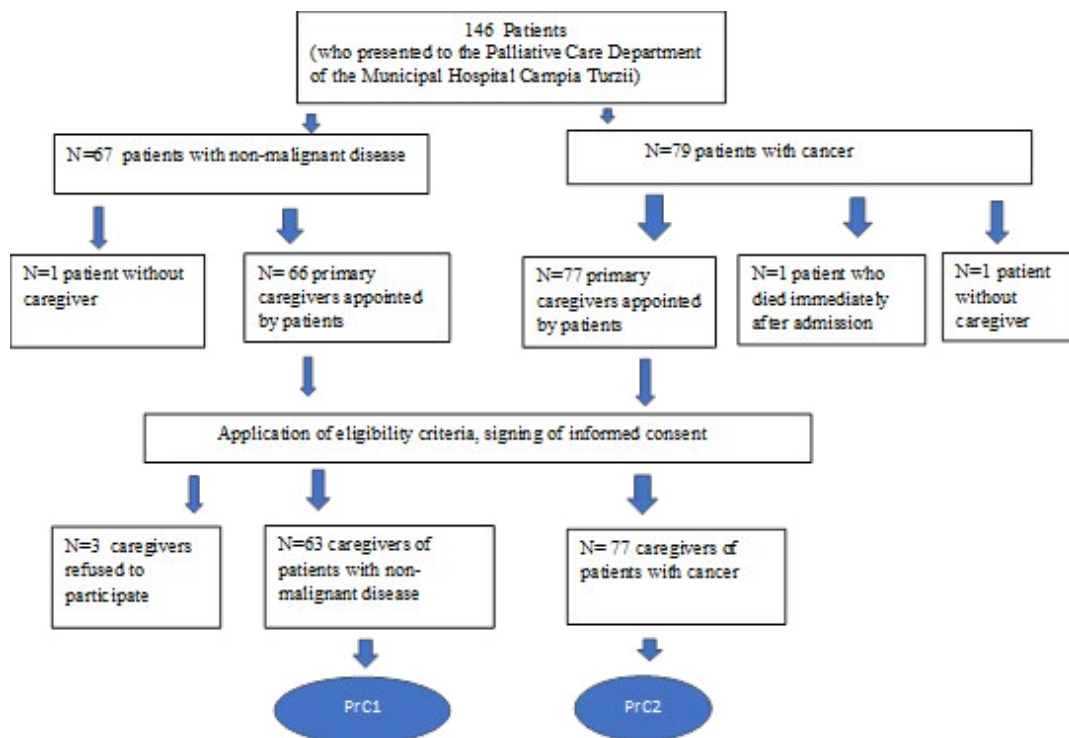
Figure 1: The algorithm for enrolling the subjects in the study

Upon enrolment in the study (T0), we assessed the demographic data of each PrC: age, gender, living environment, the distance between one's home and the patient's, the degree of kinship with the patient, level of education, occupation, and data about the number of hours spent caring for the patient. The caregiver's perception of his or her health and his or her quality of life was assessed in the same questionnaire. To measure the burden of care, anxiety and depression, two validated tools were used at the time of enrolment (T0) and monthly for a period of 3 months (T1, T2, T3). If the patient died during the study, the caregiver was assessed 2 months after the patient's death (Tf).

Measures

The two assessment tools included the Burden Scale for Family Caregivers (BSFC) and Hospital Anxiety and Depression Scale (HAD).

The BSFC (Burden Scale for Family Caregivers) is a 28-item tool that assesses the burden of caring for a patient in palliative care. Each item is scored using a Likert scale (I totally agree, I agree, I partially agree, and I do not agree; each response corresponded to scores ranging from 0 to 3 points). The total score varies between 0-64. A Cronbach's alpha coefficient of 0.92 was obtained for the scale as a whole [6]. The scale has a high level of reliability for assessing the total subjective burden, so the score obtained for this scale indicates the existence and severity of the burden [7]. On the other hand, the value obtained for each item indicates the individ-ualized subjective burden for a particular issue and allows specialized services to provide interventions to improve the situation or even secondary prevention.

The HAD (Hospital Anxiety and Depression Scale) has 14 items, of which 7 statements assess anxiety and 7 statements assess the depression. These statements are interspersed. The score of each statement ranges from 0 to 3, and the maximum score for both anxiety and depression is 21. Higher scores indicate a higher level of anxiety/depression. Scores up to a value of 7 are considered normal psycho-emotional situations; scores ranging from 8-10 points indicate anxiety or subclinical depression; and scores over 11 points indicate anxiety or clinically manifested depression.

Statistical Data Analysis

The software package IBM SPSS v26.0 for Windows was used in order to realise the statistical analysis of the data. Descriptive statistics were performed for all variables. The Mann–Whitney U test and the Wilcoxon test were used to compare the two groups. Pearson correlation analysis was used to assess the correlation between burden and anxiety and between burden and depression.

Results

Demographic characteristics show that there are no statistically significant differences between the two groups of caregivers (Table 1).

Table 1: Demographic characteristics of the two groups

Parameter	Category	Nononcological group (PrC1) N=63 (%)	Oncological group (PrC2) N=77 (%)	Total N=140 (%)	p
Gender	Male Female	20 (31.74) 43 (68.26)	23 (29.87) 54 (70.13)	43 (30.71) 97 (69.29)	0.81
Living environment	Rural Urban	17 (26.99) 46 (73.01)	21 (27.27) 56 (72.73)	38 (27.14) 102(72.86)	0.96
Degree of kinship	Husband/wife Brother/sister Son/daughter Nephew/niece Others	15 (23.8) 2 (3.18) 34 (53.97) 4 (6.35) 8 (12.7)	20 (25.97) 3 (3.90) 40 (51.95) 5 (6.50) 9 (11.68)	35 (25) 5 (3.57) 74 (52.85) 9 (6.44) 17 (12.14)	0.99
Occupation	Employee Retired Unemployed	22 (34.92%) 32 (50.8%) 9 (14.28%)	38 (49.35%) 35 (45.45%) 4 (5.20%)	60 (42.85%) 67 (47.86%) 13 (9.29%)	0.83
Level of education	Primary education Gymnasium studies High-school (college) Higher education	2 (3.18%) 9 (14.28%) 36 (57.14%) 16 (25.40%)	4 (5.20%) 15 (1.48%) 31 (40.25%) 27 (35.05%)	6 (4.29%) 24 (17.14%) 67 (47.86%) 43 (30.71%)	0.3
Living place	Similar from the patient's Different from the patient's	40 (63.49%) 23 (36.51%)	38 (49.35%) 39 (50.65%)	78 (55.71%) 62 (44.29%)	0.93

Distance between the patient's home and the caregiver	Under 1 km 1-10 km 10-30 km Over 30 km	41 (65.08%) 12 (19.05%) 4 (6.35%) 6 (9.52%)	46 (59.74%) 16 (20.78%) 6 (7.80%) 9 (11.68%)	87 (62.15%) 28 (20%) 10 (7.14%) 15 (10.71%)	0.92
The initial state of health of the care-giver	Very good Good Bad Very bad	8 (12,70%) 40(63.49%) 14 (22.22%) 1 (1.59%)	17 (2.07%) 47 (61.03%) 9 (11.68%) 4 (5.22%)	25 (17.86%) 87 (62.15%) 23 (16.43%) 5 (3.56%)	0.14
The time spent caring for the patient	Less than 3 hours Between 3-10 hours Over 10 ore	8 (12.70%) 25 (39.68%) 30 (47.62%)	16 (20.78%) 32 (41.55%) 29 (37.67%)	24 (17.14%) 57 (40.72%) 59 (42.14%)	0.33
The time spent for oneself	Less than 3 hours Between 3-10 hours Over 10 hours	37 (58.73%) 23 (36.51%) 3 (4.76%)	37 (48.06%) 30 (38.96%) 10 (12.98%)	74 (52.86%) 53 (37.86%) 13 (9.28%)	0.18
The time spent with other family members	Less than 3 hours Between 3-10 hours Over 10 hours	38 (60.32%) 21 (33.33%) 4 (6.35%)	36 (46.75%) 29 (37.66%)	74 (52.86%) 50 (35.71%)	0.13
Number of days late from work	Without days of delay Up to 10 days Over 10 days	51 (80.95%) 8 (12.70%) 4 (6.35%)	65 (84.42%) 11 (14.28%) 1 (1.30%)	116 (82.86) 19 (13.57) 5 (3.57)	0.27
Number of days off work	Without days off from work Up to 10 days Over 10 days	49 (77.78%) 10 (15.87%) 4 (6.35%)	62 (80.52%) 10 (12.98%) 5 (6.50%)	111(79.29) 20 (14.28) 9 (6.43)	0,88
Leaving work	Yes No	3 (4.76%) 60 (95.24%)	6 (7.79%) 71(92.21%)	9 (6.43) 131(93.57)	0.46

One hundred forty caregivers were recruited and divided into two groups: PrC2, which includes the primary caregivers of patients with malignancies (n = 77), and PrC1, which includes the primary caregivers of patients with non-oncological illnesses (n = 63). The mean age was 54.77 years (minimum 26 and maximum 78 years) in the PrC1 group and 58.33 years (minimum 29 and maximum 92 years) in the PrC2 group.

Over two-thirds of the caregivers were women (70.13% in the group of oncology patients and 68.26% in the group of non-oncological patients). In half of the cases, the care of the patient was taken over by the patient's son or daughter (51.95% in the group of oncological patients and 53.97% in the group of non-oncological patients), and in a quarter of the cases, care was provided by the spouse (25.97% in the PrC2 group and 23.8% in the PrC1 group).

In 49.35% of cancer patients, the caregivers lived in the same house as the patient. The situation differed in the case of the non-onco-logical group, but the different was not statistically significant (p = 0.93): 63.49% of caregivers lived with the patient, while 36.51% did not live with the patient. Domiciles in the same locality or in the neighbouring locality (expressed by a distance of less than 10 km) were identified in most cases (80.52% in the oncological group and 84.13% in the nononcological group).

The need for more than 10 hours of care per day was reported by 37.67% of oncological patients and 47.62% of nononcological patients (p = 0.33). Most caregivers did not have time off and did not give up their day jobs (92.21% in the PrC2 group and 95.24% in the PrC1 group).

A total of 49.35% of caregivers in the PrC2 group and 34.92% of caregivers in the PrC1 group were employed; this difference was not statistically significant (p = 0.83). The proportion of retired people involved in care was 45.45% in the PrC2 group and 50.8% in the PrC1 group.
Most of the people included in this study had a secondary degree (40.25% in PrC2 and 57.14% in PrC1) and higher education (35.05% in PrC2 group and 25.40% in PrC1 group), which is highly important with respect to understanding the disease and interventions during patient care.

More than half of the caregivers considered their initial health to be good (61.03% in group PrC2 and 63.49% in group PrC1), and a similar proportion reported that they had a satisfactory quality of life (63.64% in the PrC2 group and 60.31% in the PrC1 group).

The burden assessment in caregivers of cancer patients showed a statistically significant increase over the 3 months (p=0.001). There was a decrease in the burden assessment at 2 months, which can be explained by the involvement of the palliative care team at this time (Table 2).

Table 2: The mean value of the caregiver's burden from oncological group (PrC2)

	N	Mean	Std. Deviation	Std. Error	95% Confidence Interval for Mean		Minimum	Maximum	p value
					Lower Bound	Upper Bound			
BSFC (T0)	77	36.52	15.054	1.716	33.10	39.94	5	68	0.01
BSFC (T1)	26	45.58	14.111	2.767	39.88	51.28	16	69	
BSFC (T2)	17	37.65	16.105	3.906	29.37	45.93	10	58	
BSFC (T3)	13	47.08	18.866	5.232	35.68	58.48	15	70	

In the nononcological group (PrC1), an increase in the caregiver's burden was observed, but the increase was not statistically significant (Table 3).

Table 3: The mean value of the caregiver's burden in the nononcological group (PrC1)

	N	Mean	Std. Deviation	Std. Error	95% Confidence Interval for Mean		Minimum	Maximum	P value
					Lower Bound	Upper Bound			
BSFC (T0)	63	45.14	14.456	1.821	41.50	48.78	16	82	0.06
BSFC (T1)	25	47.88	11.208	2.242	43.25	52.51	14	66	
BSFC (T2)	14	47.43	13.323	3.561	39.74	55.12	13	63	
BSFC (T3)	13	56.69	15.440	4.282	47.36	66.02	14	75	

A statistically significant difference was observed between the burden of the oncological group and the nononcological group at the initial measurement (T0). Caregivers of nononcological patients experience a greater burden, especially due to the longer period of care (Table 4).

Table 4: The comparison of the caregiver's burden level between oncological and non-oncological group

| BSFC	Group	N	Mean	Std. Deviation	Std. Error Mean	p
T0	Oncologic PrC2	77	36.52	15.054	1.716	0.01
	Non-oncologic PrC1	N	45.14	14.456	1.821	
BSFC		N	Mean	Std. Deviation	Std. Error Mean	p
T1	Oncologic PrC2	26	45.58	14.111	2.767	0.52
	Non-oncologic PrC1	25	47.88	11.208	2.242	
BSFC		N	Mean	Std. Deviation	Std. Error Mean	p
T2	Oncologic PrC2	17	37.65	16.105	3.906	0.08
	Non-oncologic PrC1	14	47.43	13.323	3.561	
BSFC		N	Mean	Std. Deviation	Std. Error Mean	p
T3	Oncologic PrC2	13	47.08	18.866	5.232	0.16
	Non-oncologic PrC1	13	56.69	15.440	4.282	

The evaluation of anxiety led to obtaining several values during the care: the first value was obtained at the time of enrolment in the study (T0), and the following values were obtained at the time of T1, T2, T3. Because many patients died during the trial, the most recent value obtained throughout the three months was used. In these cases, we compared the initial anxiety of the caregiver with the value assessed at 2 months after death (Tf) (Table 5).

Table 5: Assessing caregiver anxiety in dynamics

ANXIETY	N	Mean	Std. Deviation	Std. Error	95% Confidence Interval for Mean		Minimum	Maximum	p
Caregivers for oncological patients PC2					Lower Bound	Upper Bound			
Initial values (T0)	77	11.97	4.565	.520	10.94	13.01	1	21	0.001
Last evaluated value	29	12.97	5.342	.992	10.93	15.00	0	21	
Final values (Tf)	52	8.75	4.810	.667	7.41	10.09	0	18	
Total	158	11.09	5.054	.402	10.30	11.89	0	21	
ANXIETY	N	Mean	Std. Deviation	Std. Error	95% Confidence Interval for Mean		Minimum	Maximum	p
Caregivers for non-malignant patients PC1					Lower Bound	Upper Bound			
Initial values (T0)	63	12.87	4.685	.590	11.69	14.05	2	21	0.001
Last evaluated value	25	14.32	5.210	1.042	12.17	16.47	3	21	
Final values (Tf)	35	9.34	5.734	.969	7.37	11.31	0	21	
Total	123	12.16	5.399	.487	11.20	13.13	0	21	

In both groups, the average level of anxiety at the initial measurement was clinically significant, with scores being slightly higher in the group of those caring for nononcological patients (11.97 in the PrC2 group compared to 12.87 in the PrC1 group). During patient care, anxiety scores increased to 12.97 in the PrC2 group and 14.32 in the PrC1 group. Two months after the patient's death, anxiety decreased significantly (p = 0.001) to scores of 8.75 in the group of oncological group and 9.34 in the nononcological group but still remained above the normal value (Figure 2).
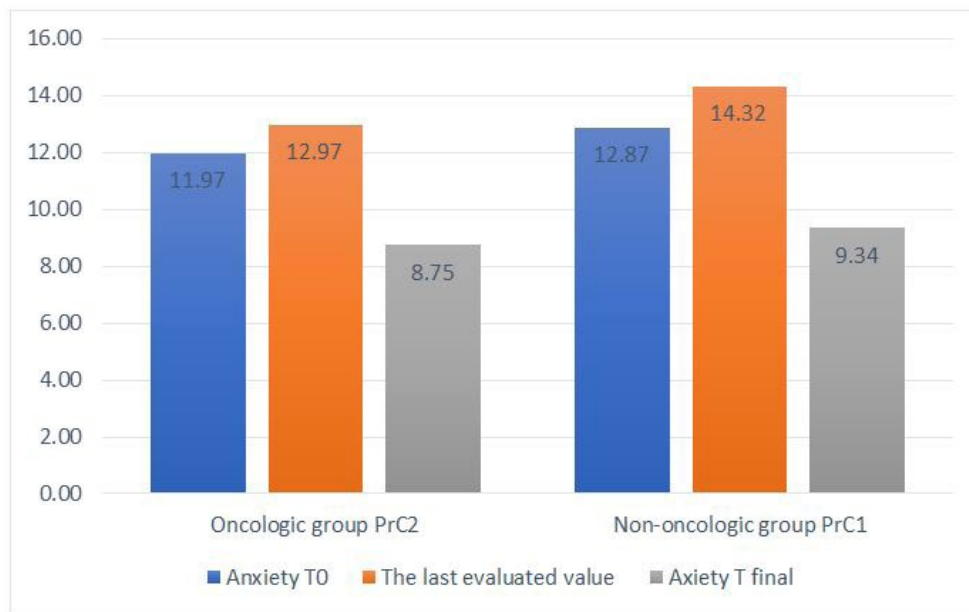
**Figure 2:** Representation of the average values of anxiety in dynamics

The baseline average values for depression in the PrC1 and PrC2 groups were 11 and 10, respectively, and remained almost the same with minor changes during care. A decrease in depression score was detected at 2 months following the patient's death, with scores of 8 in the PrC1 group (p = 0.02) and 6.5 in the PrC2 group (p = 0.004) (Table 6).

Table 6: Assessing caregiver depression in dynamics

Depression	Non-oncologic Group	Oncologic Group	p value (The Mann Whitney U Test)
Initial value	11 (8, 15)	10 (7, 13.5)	0.1
Last evaluated value	12 (10.5, 16)	12 (8, 16)	0.38
Final Value	8 (4, 13)	6.5 (4, 11.75)	0.33
p value (The Kruskal-Wallis H Test)	0.02	0.004	-

To highlight a link between the burden of palliative care and the primary caregiver's anxiety and depression, the Pearson correlation analysis was used, and a moderately strong correlation was observed in both cases (r = 0.52 for anxiety and r = 0.60 for depression). In both situations, the correlation between the caregiver's burden and anxiety (Figure 3) and depression (Figure 4) was statistically significant (p = 0.001).
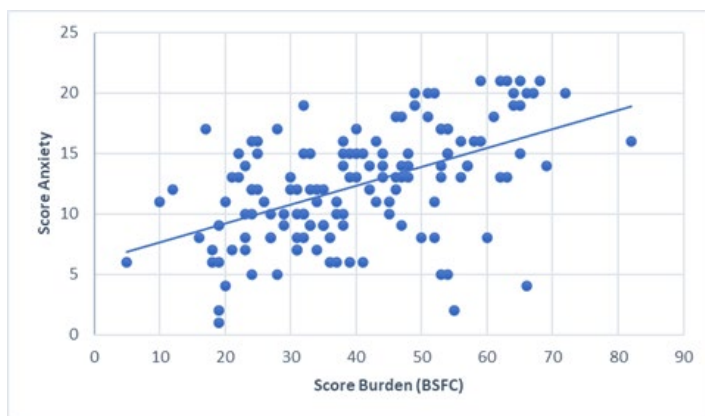
Figure 3: Assessing the link between burden and anxiety among PrCs

Figure 4: Assessing the relationship between burden and depression among PrCs

Discussion

Patients with palliative needs are most often cared for by a family member who is taken by surprise and is not prepared for the challenges of caretaking; this situation negatively affects both the caretaker and the patient [8]. In most cases examined herein, the primary caregiver was a family member (87.85%), and most commonly, the PrC was the patient's son or daughter. Possible reasons for this are the better ability to interact with teams of professionals or with the authorities, the existence of various pathologies sometimes disabling the other parent or even the lack of the other parent.

Women made up two-thirds of the caregivers in the study, likely due to their availability and capacities to participate in everyday domestic tasks (cooking, home hygiene, and housekeeping), as well as the efficacy of nursing interventions (hygiene, patient nutrition).

The literature indicates that women are more vulnerable to psycho-emotional decompensation than men [9-11]. Almost half of the caregivers examined herein were employed, and a similar percentage were retired. There was a higher proportion of caregivers who were retired because they had the time available to care for loved ones. On the other hand, they are vulnerable due to their age or various diseases. The number of unemployed caregivers was small in our study (9.29%). Employed persons are at higher risk for burnout because, in addition to the time spent at work, additional hours will be spent performing caregiver responsibilities. However, the percentage of caregivers who had to give up employment was limited (6.43%) because the PrCs often had help from an additional person. The percentage of caregivers who were retired was 47.86%, with both old-age and disabled pensioners included in this category. These individuals often care for a sick family member, but the caregiving process may exacerbate existing conditions or cause new ones due to overwork [9].

Other significant aspects of the caregiving process include the amount of time provided to the patient and the PrC's residence. A non-significantly higher proportion of primary caregivers in the non-oncological group reported allocating more than 10 hours a day for patient care and in the oncological group. This is explained by the more intense and numerous cares needs in the group of non-oncological patients due to the increased dependence on another person and due to the longer period of survival. The large number of hours allocated to care is directly proportional to the intensity of care. These factors lead to the physical and emotional exhaustion of the caregiver [12,13]. The PrC needs to live in the same place as the patient or only a short distance away to ensure high-quality care. The prevalence of anxiety and depression among caregivers has been identified in many studies; the average intensity varies from mild to moderate and even severe, and the relationship be-

tween these conditions and the burden of care has been proven [4-7,14-16].

Anxiety has different aspects: fear of the patient's future, financial difficulties, changing patient behaviour, the multitude of responsibilities, and feelings of guilt [17,18]. The intensity of anxiety depends greatly on previous experience) and positive aspects of care, such as the feeling of usefulness for the patient and the satisfaction of a well-done job [19]. A high level of spirituality is an important positive factor that has a protective role against psycho-emotional stress [20].

PrCs had moderate anxiety at the start of the study, with an average value of 11.97 in the oncology group and 12.87 in the nononcological group. This level of anxiety can be explained by late access to a palliative care service after a period of disease progression, a period during which the burden can affect a PrC's psycho-emotional state.

An increase in anxiety was observed in the dynamics, and this increase was nonsignificantly larger in the nononcological group. Anxiety among caregivers decreased two months after the patient died, but it remained at a subclinical level. This issue must be considered in two ways: early assessment of the emotional status of caregivers to intervene properly to decrease anxiety and depression, and follow-up in the bereavement period. The anxiety score decreased two months after the patient's death, but the risk for mental health issues remained.

Depression among PrCs was present at a moderate value at the time of initiating palliative care, and a return to normal is observed 2 months after the patient's death.

This study shows that the burden impacts the caregiver's psycho-emotional state. As the patient's needs increase, the responsibilities become greater, and the PrC becomes increasingly anxious. High levels of anxiety among PrCs will have a negative impact on fulfilling the responsibilities [21].

The ways in which pharmaceuticals are administered, the side effects of the treatment, the progression of the sickness, the approaching of death, the lack of support, and so on are all facets of anxiety. The onset of depression occurs as a result of learning the diagnosis and prognosis, which is exacerbated by the disease's unfavourable progression. The burden and emotional state will lead, on the one hand, to physical and mental exhaustion among caregivers who want to escape from this situation and, on the other hand, will influence the quality of care provided to the loved one.

Anxiety and depression are two important factors associated with a decrease in the quality of life of caregivers [22]. These are aspects that negatively influence the quality of medical and nursing interventions and decrease the quality of care. It is important to start palliative care early for both patients and caregivers.

Study Limitations
The results of this research confirm the literature data that the caregiver burden increases during patient care and the caregiver anxiety and depression scores are high. These findings suggest the importance of early interventions to decrease the emotional impact of the caregiver's burden for good case management. The limitation of this study is the small sample size at the one- and two-month follow-ups. This is a major impediment due to the importance of timely access to palliative care.

Conclusion
The burden of care is an individual "symptom" that each person perceives differently. It is proportional to the number and severity of care requirements. The perceived level of burden is influenced by a number of individual-level factors. The load has a direct and statistically significant impact on the PrC's psycho-emotional state, and there is a strong link between it and the caregiver's anxiety and sadness when caring for a palliative patient. From a practical point of view, it is important to identify early the burden of care and to know how the PrC perceives the burden, as well as to assess his or her psycho-emotional state to implement appropriate and individualized interventions.

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