Psychological-affective evaluation of advanced cancer patients and caregivers

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Abstract

Objective: To establish the presence of stress, anxiety and depression in palliative care patients and caregivers and determine the relation with burden and strain of the caregiver. **Methods:** A total of 81 male and female patients who were diagnosed with cancer and 81 male and female primary caregivers were recruited in a palliative care unit of an Oncology Hospital. Clinical and sociodemographic data of participants were collected. The Perceived Stress Scale and the Beck Anxiety and Depression Inventory were used. The caregivers completed the Zarit Burden Interview and the Caregiver Strain Index. **Results:** More than 60% of the patients evaluated were women, with breast and cervical cancers being the most frequent. Among men, gastrointestinal cancer was the most frequent. The majority of patients was married, with children, without a basic education, unemployed and of low social status. A typical profile of the caregiver of the cancer patient was observed: women (79%, daughter or wife), with basic education, married, with children, with occupation at home, and of low socioeconomic level. Among both patients and caregivers, 23% reported having stress. Of the total number of patients, 54% had depressive symptoms that require greater psychiatric attention. Both caregiver burden ($p < 0.005$) and caregiver strain ($p < 0.000$) were associated with depressive symptoms. **Conclusions:** It is necessary to create multidisciplinary interventions for cancer patients in the palliative care stage and their principal caregivers, which should be carried out in order to improve their mental health.

Key words: Anxiety. Burden. Cancer. Caregivers. Depression. Strain. Stress.

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Introduction

Cancer is one of the main ailments in the world. Its origin is multi-causal; one of its causes is an autonomous and uncontrolled replication of cells, which can invade tissues (metastasis)¹. World Health Organization prospecting for Mexico reports 190,667 newly diagnosed cancer cases for the year 2018². Unfortunately, poverty and marginalization lead to late diagnosis of the disease, which increases treatment costs, reduces remission and delays palliative care implementation³.

Palliative care in cancer patients focuses on symptomatic and psychological treatment to prevent or control pain, restlessness, appetite loss, nausea, insomnia, stress, anxiety and depression, but it contemplates advice on legal, financial and labor issues as well, with these actions improving the quality of life of patients and their families. In Mexico, palliative care implementation is relatively recent and only a few hospitals provide this type of care to patients and relatives who are confronted with cancer^{3,4}.

During the progression of the disease, the patient faces physical and emotional deterioration. Patients who experience pain are more likely to develop mental disorders of anxiogenic and depressive nature⁵. Patient physiological deterioration promotes a negative psycho-emotional environment that impacts on primary caregivers' health⁶, who refer fatigue, sleep disorders and depression. The deterioration of their quality of life makes the implementation of specialized mental care relevant⁷.

In Mexico, there are only few studies on psychological evaluations in cancer patients and their caregivers. These studies were conducted in socioeconomic regions that, according to the National Institute of Statistics and Geography, have better opportunities, such as Mexico City and the State of Nuevo León, where there is more access to health services than in Veracruz, which is especially considered as one of the states that comprise the lowest socioeconomic regions of the country⁸.

Psychological investigations of cancer patients in Mexico use one or two instruments in their assessments; the Hospital Anxiety and Depression Scale (HADS) is the most widely used⁹⁻¹¹ to assess anxiety or depression in men and women with any type of cancer, and specially in women with breast cancer at different stages^{10,12}.

Studies on cancer patients' caregivers in Mexico have reported burden¹³ and others focus on measuring coping styles in caregivers of patients on treatment and at end-stage phase¹⁴. Limitations of these studies include insufficient compilation of patient and caregiver

data, as well as limited use of psychological instruments that allow the best knowledge on the Mexican population.

In view of the lack of published research on cancer patients and caregivers in Mexico, and considering the elevated incidence of this disease and the important consequences for the mental health of families, the purpose of this work is to conduct a comprehensive psychological evaluation to identify stress, anxiety and depressive symptoms in cancer patients on treatment at the Palliative Care Department and in their primary caregivers, as well as to identify the association of affective disorders with burden in primary caregivers.

Participants and methods

Study design and tools

Cross-sectional, prospective, descriptive observational research, conducted in adherence to the Declaration of Helsinki guidelines and approved by the Centro Estatal de Cancerología Dr. Miguel Dorantes Mesa Ethics Committee (CECan, CONBIOÉTICA-30CEI01020150514), in Veracruz. This study was carried out at the CECan Palliative Care Unit from January 2016 to August 2017 (20 months).

PARTICIPANTS

Trained researchers invited patients and their caregivers to participate by explaining them the objectives, as well as the study procedure. Subsequently, they were asked to sign an informed consent. A sample of 81 patients diagnosed with cancer and 81 primary caregivers were selected by convenience sampling; this was done during their first visit to the Palliative Care Unit. This type of sampling was used due to the availability of patients, a population that owing to its characteristics is interesting for the study of mental health. This type of sampling is often used in clinical trials with volunteers because it provides operational advantages and entails low costs during the collection of information.

It is important to emphasize that this study is not intended to make general, statistically rigorous statements about the entire population; its purpose is to explore the relationships between variables that might be influencing and, this way, obtain an image of the target population to carry out future research. We consider that the bias of the study is low because the criteria for participant selection cover the variety of characteristics of the population.

The participants met the following inclusion criteria: for all of them, being Spanish-speaker, being 18-year-old or older and signing the informed consent; in addition, for patients, being first-time patients at the Palliative Care Unit, having a diagnosis of cancer at advanced stage with no chances of cure, and a value ≤ 70 on the Palliative Performance Scale (PPSv2)¹⁵; and for non-patients, being primary caregivers. Participants who did not complete the evaluations were withdrawn from the study.

MEASUREMENTS

Sociodemographic and clinical data

A sociodemographic and clinical questionnaire was used to collect information from participants about family integration, social and occupational environment and clinical data, as well as age, gender, marital status, children, level of education, occupation, income, religion and type of cancer.

Affective disorders assessment

Versions of the scales that had been validated in the Mexican population were used^{16-18,20}.

Perceived stress scale

The Perceived Stress Scale (PSS) determines the degree at which life situations are perceived as stressful. Using a Likert-type scale ranging from 0 (never) to 4 (frequently), the 14 items determine whether the individual is stressed (score ≥ 28) or not stressed (score ≤ 28)¹⁶.

Beck's anxiety inventory

Beck's Anxiety Inventory (BAI) explores the frequency of anxious symptoms and behavior. BAI is composed of 21 items, each of which is evaluated with a four-point scale (0 = not at all or a little, 3 = severely); a total score below 21 indicates low anxiety, from 22 to 35 corresponds to moderate anxiety and if it is 36 or higher it denotes severe anxiety¹⁷.

Beck's depression inventory

Beck's Depression Inventory (BDI) is composed of 21 items (with a 0-3 evaluation scale) and has the purpose to determine the presence and intensity of depressive symptoms. Total scores lower than 9 correspond to absence

of depression, 10 to 16 denote some depressive symptoms (low depression), 17 to 29 denote moderate depression and 30 or higher indicate clinically significant depressive symptoms (severe depression)¹⁸.

Zarit Burden Interview

The Zarit Burden Interview (ZBI) is a 22-question instrument used only in caregivers to gather information on burden. The ZBI assesses caregivers' perception of burden, which can affect their health and personal, social or economic well-being¹⁹. For its assessment, a five-point Likert-type scale is used, with a total score ranging from 0 to 88 being obtained; a value ≤ 46 corresponds to absence of burden and ≥ 47 indicates burden²⁰.

Caregiver Strain Index

The Spanish version of the Caregiver Strain Index (CSI) was used only in caregivers to identify strain and their ability to provide care. It comprises 13 dichotomous-answer questions (yes or no). Scores ≥ 7 indicate a high level of strain, which suggests the need for in-depth evaluation and follow-up²¹.

Statistical analysis

Descriptive statistics were used for sociodemographic and clinical data. Fisher's exact test was used to analyze the results for age, PSS, BAI, BDI, ZBI and CSI. This type of analysis allows establishing the relationship between two independent qualitative variables originating in small samples when the chi-square test cannot be used²². All the above-mentioned tests were two-sided and alpha risk was established at a value of 0.05. The analysis was carried out with the IBM SPSS Statistics® statistical program, V21.0²³.

Results

Sociodemographic and clinical aspects

All recruited patients ($n = 81$) and primary caregivers agreed to participate and completed the evaluations. Patients' mean age was 53.2 years (standard deviation [SD] = 14.58), 69% were women ($n = 56$) and 31% were men ($n = 25$). Regarding the caregivers, average age was 40.9 years (SD = 12.16), 79% were women ($n = 64$) and 21% were men ($n = 17$).

Table 1. Data of the sociodemographic analysis of patients with cancer (n = 81) and primary caregivers (n = 81)

Variables	Patients n (%)	Caregivers n (%)
Gender		
Female	56 (69)	64 (79)
Male	25 (31)	17 (21)
Origin		
Rural	40 (49)	37 (46)
Urban	41 (51)	44 (54)
Marital status		
Married	49 (60)	55 (68)
Single	32 (40)	26 (32)
Children		
Yes	71 (88)	62 (77)
No	10 (12)	19 (23)
Level of education		
None	37 (46)	9 (11)
Primary school	16 (20)	22 (27)
Secondary school	15 (18)	24 (30)
High school	9 (11)	20 (25)
College degree	4 (5)	6 (7)
Occupation		
Homemaker	30 (37)	29 (36)
Unemployed	41 (51)	15 (19)
Half time	8 (10)	22 (27)
Full time	1 (1)	14 (17)
Retired	1 (1)	0 (0)
Student	0 (0)	1 (1)
Social status		
Low	71 (87)	72 (88)
Middle	10 (12)	9 (11)
Religion		
Catholic	59 (73)	61 (75)
Christian	7 (9)	8 (10)
Other	15 (18)	12 (14)
None	1 (1)	2 (2)
Importance of religion		
Little	8 (10)	5 (6)
Important	32 (32)	35 (43)
Very important	40 (49)	33 (41)
Extremely important	6 (8)	6 (7)

Most caregivers (47%) included in this study are first-degree relatives (daughters or sons), followed by wives with 28%, and less frequently, parents (7%), siblings (7%) and second or third degree relatives (10%).

Table 1 shows patients and caregivers' sociodemographic data. Many of the patients come from urban areas, are married and have at least one child. Participants' level of education is low: 46% of patients are illiterate, 57% of caregivers have primary or secondary education and 87% of participants report low social status. Catholicism is the predominant religion (74%) and plays an important role in more than 90% of participants.

Table 2. Psycho-affective disorders determination in patients with cancer and primary caregivers

Instruments	Patients n (%)	Caregivers n (%)
Perceived stress scale (PSS)		
Not stressed	59 (73)	59 (73)
Stressed	22 (27)	22 (27)
Beck's anxiety inventory (BAI)		
Low	69 (85)	70 (86)
Moderate	12 (15)	9 (11)
Severe	0	2 (2)
Beck's depression inventory (BDI)		
No depression	15 (19)	32 (39)
Low	22 (27)	21 (26)
Moderate	25 (31)	21 (26)
Severe	19 (23)	7 (9)
Zarit Burden Interview (ZBI) (caregiver)		
No severe burden		71 (88)
Severe burden		10 (12)
Robinson Caregiver Strain Index (CSI)		
No extreme strain		32 (40)
Extreme strain		49 (60)

The most common type of cancer in women is breast (37%) and gynecological cancer (36%), followed by gastrointestinal (9%), hematological (5%), renal (5%), pulmonary (4%), and skin and soft tissue cancer (4%). The predominant type of cancer in men was gastrointestinal (28%), followed by prostate (16%), hematologic (12%), testicular (8%), pulmonary (8%), bone (8%), renal (4%) and head and neck cancer (4%), and in the remaining 12%, the diagnosis is not determined or primary origin is not known.

AFFECTIVE DISORDERS ASSESSMENT

Psycho-affective measurements in patients and caregivers are listed in table 2. The frequency of stress perception is low in both patients and caregivers. Of a total of 162 participants, 44 were stressed (nearly 88% were women). Of total participants, 73% reported a score < 28, which indicates they were not stressed. However, both patients and caregivers have some degree of anxiety, with mild anxiety predominating. The percentage of patients with moderate-to-severe symptoms of depression is 54% and, in the case of caregivers, 35%.

With regard to caregivers (n = 81), average time engaged in the caregiver function is 20 months and without any help to look after their patient in 35% of cases. Suffering from any disease was reported by 44% of caregivers; however, they perceive their health

Table 3. Fisher's exact test results for associations between caregivers' variables

	Age	Stress (PSS)	Anxiety (BAI)	Depression (BDI)	Burden (ZBI)	Strain (CSI)
Age	-	0.46	0.75	0.04*	0.51	0.26
Stress (PSS)	0.46	-	0.01*	0.02*	0.12	0.80
Anxiety (BAI)	0.75	0.01*	-	0.18	1.00	0.51
Depression (BDI)	0.04*	0.02*	0.18	-	0.01*	0.00*
Burden (ZBI)	0.51	0.12	1.00	0.01*	-	0.08
Strain (CSI)	0.26	0.80	0.51	0.00*	0.08	-

*Fisher's exact test two-sided significance: $p < 0.05$.

BAI: Beck's Anxiety Inventory; CSI: Caregiver Strain Index; BDI: Beck's Depression Inventory; PSS: Perceived Stress Scale; ZBI: Zarit Burden Interview (for the caregiver).

as regular (59%) or good (37%). About the caregiver-patient relationship, 60% of caregivers refer it to be pleasant, 18% regular and 22%, complicated. On the other hand, in ZBI and CSI, high levels of burden and strain were observed in 12 and 60% of caregivers, respectively (Table 2).

In the Zarit burden interview (ZBI) for the caregiver, high scores were identified in terms of low economic solvency, high level of patient dependence on the caregiver and reference of exhaustion due to prolonged periods of care. Regarding the CSI, the three items with the highest scores were: a) presence of adjustments at work, b) changes in personal plans and c) feelings of financial strain.

Fisher's exact test revealed that in patients there is a significant association between the stress and anxiety ($p < 0.00$, 32%), and stress and depression variables ($p < 0.00$, 27.26%). In the group of primary caregivers younger than 40 years, a positive association was observed with the presence of depression in 37% ($p < 0.04$). On the other hand, stress showed an association with anxiety ($p < 0.01$, 8.6%) and depression ($p < 0.02$, 22.2%). In addition, in the case of depression, there is a relationship with the burden ($p < 0.01$, 12.3%) and strain variables ($p < 0.00$, 46.9%). Table 3 shows the rest of statistical analysis results.

Discussion

Sociodemographic factors

During this investigation, sociodemographic data of participants were collected prior to psycho-affective assessment. The characteristics of the group of patients indicated that more than 50% of the evaluated population are women; on the other hand, married marital status, having children and basic level of education, being

unemployed and belonging to the lower social class predominated. This information shares similarity with data reported for the Mexican population with cancer²⁴. In addition, the incidence of breast (women) and gastrointestinal cancer (men) is consistent with reports from Latin American countries². Therefore, this study reveals socio-demographic data similar to those of others, at least for Latin American populations affected by cancer.

On the other hand, caregivers were generally women (daughters or wives), with complete basic education, married, with children, homemakers and of low socioeconomic level. These characteristics are consistent with the typical profiles of cancer patients' caregivers observed in other studies^{14,25}.

Stress, anxiety and depression

Patients and caregivers were observed to have the same levels of stress, with a higher prevalence in the female gender. The stress level reported by both patients and caregivers in the PSS was only 23%. Although perceived stress can sometimes negatively influence on coping strategies, there are also cognitive adaptation processes, such as problem solving, perceived emotions and management of stressful situations²⁶.

People with end-stage cancer experience a great deal of unpleasant symptoms during their last months of life. Anxiety and depression are the most common emotional problems, with prevalence ranging from 16 to 40% in the case of anxiety and from 7 to 48% for depression, with intensities ranging from moderate to severe^{27,28}. The present study showed that the prevalence of anxiety in patients with end-stage cancer is similar, but that depression is higher than that observed in previous studies. Regarding caregivers, the prevalence of anxiety was twice as high as that reported in a study of

caregivers of patients on palliative care in Spain²⁹, but one-third part when compared with studies in other countries³⁰. In this study's population, we found similar figures for depression in caregivers, who generally reach scores within the limits of severe depression.

Burden and strain in primary caregivers

The status of caregiver of a person with a long-term illness such as cancer has been considered a challenging, chronic stress situation³¹ that can induce detrimental effects on physical and psychosocial health³².

The caregiver role variables indicate that this population has risk factors for experiencing caregiver burden because: a) 35% are single caregivers, b) average time of care is 20 months and c) at least 44% have some disease. These are issues that are related to the occurrence of burden, as reported by other studies^{33,34}. However, despite the factors that can generate burden, there are also conditions that, if well managed, can promote the acquisition of adequate skills for providing the care³⁴.

Regarding the caregiver burden assessment, 88% of interviewees do not experience it. However, it is important emphasizing that ZBI focuses on measuring subjective burden³⁵, and it is assumed that there is no burden because caregivers do not give up their duty until the patient's death. Conversely, the high frequency (60%) of objective strain detected with the CSI could be related to concrete effects on domestic life and disturbances in patients' lives³⁵. The most common burden-related problems were insufficient economic income (highest score on ZBI) and the perception of the disease as a financial strain (highest score on CSI).

Association between affective variables and burden

The results showed that there is a significant relationship between both variables in the group of patients, where acute stress factors that are limited in time were found, such as referral to the Palliative Care Area, and chronic stressors such as pain or cancer side effects. The findings of emotional disorders in end-stage cancer patients and primary caregivers suggest the need for specialized psychological and psychiatric care³⁶.

With regard to caregivers, chronic stressors include lack of support for care activities, average time being a caregiver, financial burden, forced work adjustments, and loss of social roles, in addition to acting as caregivers for two populations (children and sick patient) in the case of caregivers younger 40 years. The significant

associations between depression, age, stress, severe burden and extreme strain in the present study are consistent with other reports where stress and high levels of depressive symptoms³⁷, gender³⁸ and age³⁹ appear to increase subjective burden.

Stress is a neurobiological response that originates from internal and external demands and requirements that affect the balance of cellular homeostasis. The frequency and intensity of stressful stimuli can promote health deterioration and cause serious emotional damage⁴⁰. The results shown in [table 3](#) might be related to the allostatic load (AL) experienced by primary caregivers. We interpret these findings based on the hypothesis that recurrent exposure to environmental demands generates a progressive alteration in the regulation of multiple physiological systems that are necessary in the adaptation process (homeostasis). Therefore, the patterns of physiological response associated with stress, burden and strain during the entire period of patient care exceed the caregiver metabolic tolerance threshold, thus affecting the brain, the cardiovascular system and the immune system, which could contribute to a high AL that results in depressive symptoms and in that 44% of caregivers report suffering from some disease³¹.

Study limitations

Since this is cross-sectional study, patient monitoring is complicated. Aspects such as withdrawal from treatment or death significantly reduce the number of individuals in the sample. This study cannot determine whether the symptoms of stress, anxiety and depression change over time in patients and caregivers. Future studies might explore changes in the intensity of affective disorders and burden from the beginning to the end of the care received during palliative care.

Despite these limitations, this study provides relevant information on a population of patients with cancer and caregivers referred to the medical area of palliative care. Unfortunately, in Mexico there are still few professionals dedicated to working with risk factors associated with the mental health of cancer patients referred to the medical section of palliative care⁴. Therefore, this study stands out for the identification and integration of socio-affective variables that affect cancer patients and caregivers in a region with limited resources for health promotion^{9,11,12,14}.

Conclusion

This research determines both the sociodemographic factors and the relationships between variables that

can predict the risks associated with mental health. The information presented by this study can be used to identify the population at risk and, in addition, it could suggest the need for simultaneous intervention for patients and caregivers. The creation and implementation of care strategies within the Mexican health system focusing on the population attended to in the palliative care setting is necessary. The possible areas of intervention that are proposed are: psychoeducation, mindfulness, thanatological guidance and stress inoculation training.

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Conflict of interests

The authors declare not having any conflicts of interest.

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