Chapter 51

Challenges experienced by family caregivers of patients in palliative care: an integrative literature review

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ABSTRACT

Objective: To reveal the challenges experienced by family caregivers of patients in palliative care. Method: This is an integrative literature review study carried out in four databases: BDENF, IBCS, LILACS, MEDLINE. On these bases, two descriptors identified in the DECS were crossed, such as: palliative care and caregivers. To search for the articles, a combination of descriptors was performed with the Boolean operator "AND". Results: The final sample comprised 13 articles published in national journals, with several challenges identified, among which stood out: the imposition to exercise the role of caregiver without personal choice; a change in the routine of life; the complete abdication of one's life due to the care of the loved one; living with psychosomatic symptoms; illness from depression; emotional exhaustion due to living with worsening symptoms and certainty of death; lack of knowledge to perform daily tasks. Conclusions: It become necessary to know the challenges experienced in the daily dynamics of care and to plan actions that contribute to alleviate the suffering and physical and psychological illness of caregivers. This fact requires training, personal investment and detachment from professionals to be with the other, in an ethical and empathetic way, in facing death.

Keywords: Palliative care, Caregivers, Patient Care Team, Family Caregivers.

1 INTRODUCTION

Palliative care is seen as an approach directed toward symptom control, comfort, dignity, and quality of life for patients. In addition, it involves caring for the family throughout the process of illness, death, and bereavement. This type of care is indicated from the onset of any life-threatening illness, regardless of whether it is acute, chronic with or without the possibility of reversal, or curative treatment (SILVA, 2016).

In conducting palliative care, an expanded look should be considered, involving the biopsychosocial and spiritual dimensions of the suffering person. However, it is opposed to unnecessary procedures and interventions at the end of life. For all this to be effective in practice, guaranteeing integral assistance to the patient, it is necessary that the care be offered by a qualified multiprofessional team (ESPINDOLA *et al.*, 2018).

In order to ensure that care is provided at all stages of the disease process, the interventions performed by the multiprofessional team should be started early. It is worth considering that care should be guided by bioethical principles, involving the maintenance of autonomy, human dignity and beneficence (BRASIL, 2020).

In the list of care strategies, there is the attention to the patients' relatives who, facing the threat of real loss, in an undetermined time, may become emotionally disorganized and experience countless difficulties and demands. The management of the logistics of an illness imposes challenges, changes, and the creation of different parameters of family functioning. In this perspective, the acquisition of new social roles, as a result of the rearrangement among its members, gives rise to the role of the caregiver who becomes fundamental in this whole process (ESPINDOLA *et al.*, 2018).

The family caregiver, without having technical and emotional preparation to perform the multiple activities that this position imposes, receives the role of care provider and administrator of all the patient's environment. Moreover, he also needs to account for his own suffering (SORATTO, 2013). It is understood that being the protagonist of palliative care, in this intensity, demands sacrifice of various orders, as well as, can lead to situations of stress and tension, which can culminate in a process of emotional exhaustion by the fulfillment of these tasks and the feelings that are triggered (ESPINDOLA *et al.*, 2018).

Considering that the context of suffering and deprivation experienced by family caregivers can be configured as risk factors for illness, it is necessary that the multiprofessional team, through interprofessional actions, prioritize the care to these representatives of the family (SILVA, 2016). In this continuity, it becomes important to know the challenges experienced by family caregivers in the care provided to patients in palliative care, since this routine practice may weaken the care provided to the patient, as well as result in illness to the caregiver himself. Therefore, the knowledge of these factors can contribute to the practice based on evidence and guide interventions that contribute to the assistance given and the promotion of health of these family caregivers.

2 METHODOLOGICAL PROCEDURES

This is an integrative literature review. This study enables an analysis of the literature capable of identifying gaps and summarizing information from studies on a certain topic. The following steps were taken: defining the theme and constructing the guiding question, determining the inclusion and exclusion criteria, establishing the information to be extracted from the studies, evaluating the included studies, interpreting the results and presenting the review (MENDES; SILVEIRA; GALVÃO, 2008).

To construct this study, primarily, the definition of the theme to be addressed and the construction of the guiding question were made. In this sense, the researcher sought to answer the following question: what are the challenges experienced by family caregivers of patients in palliative care?

After elaborating the guiding question, the eligibility criteria were established. Thus, the inclusion criteria were: studies that portrayed the theme, available in Portuguese, and that had been published in the last 10 years (2009-2019). Exclusion criteria were: studies published in languages other than Portuguese, literature review studies, course completion papers, and previous notes.

Four databases were consulted for data collection, these being: Latin American and Caribbean Literature in Health Sciences (LILACS), Medical Literature Analysis and Retrieval System Online (MEDLINE), Spanish Bibliographic Index of Health Sciences (IBECS) and Nursing Database (BDENF). The search process in the databases occurred with the support of the health descriptors palliative care and caregivers, found in DECS, and the use of the Boolean operator "AND". In this perspective, the crossing occurred with the descriptors in Portuguese as follows: palliative care AND caregivers.

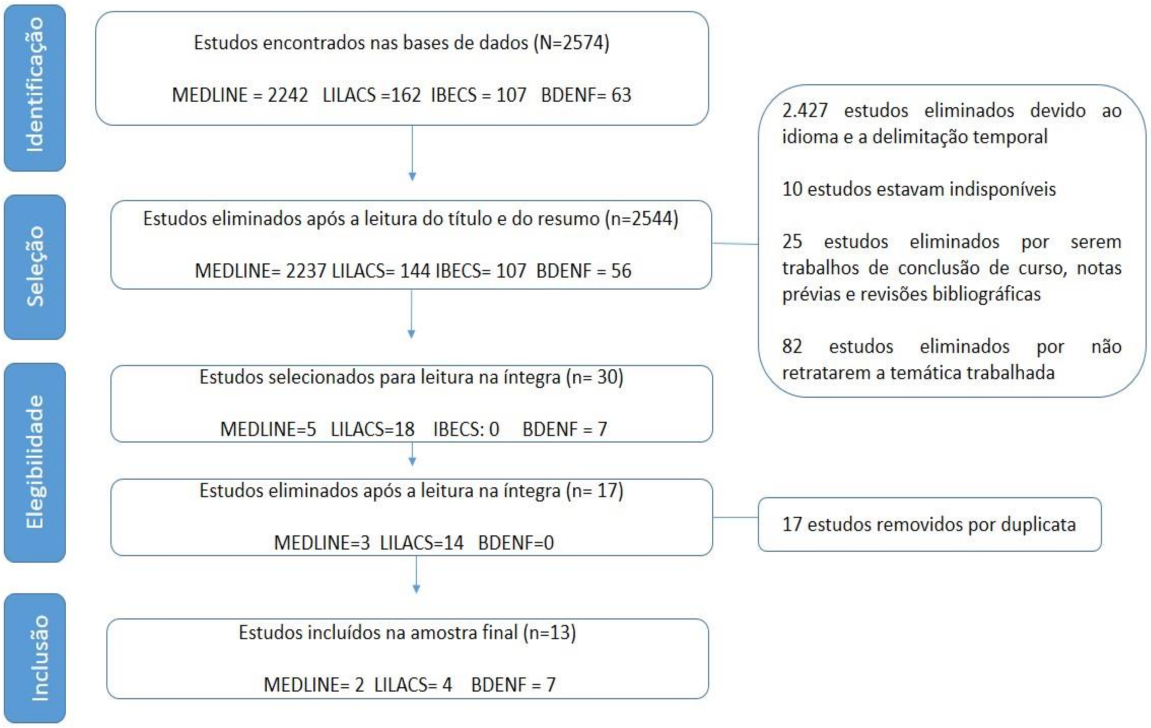
The search in the databases occurred in December 2020 via the Virtual Health Library (VHL). The elimination of studies was initially considered by reading the titles and abstracts of the articles, and then reading the articles in full. In order to optimize the understanding of the search process and elimination of scientific productions, a flowchart was built (Figure 1).

The information regarding the articles that made up the final sample of the study was organized in two charts prepared by the author. Thus, in chart 1, there was information regarding: title, author, year, database, country and objective. In chart 2, information related to: design, level of evidence, and main results was made available. Also, the articles that made up the final sample of the study were analyzed according to the levels of evidence proposed by Melnyk and Fineout-Overholt (2011 apud XAVIER *et al.*, 2020). From this perspective, the following levels were considered: I- meta-analysis of randomized clinical trials and systematic reviews, II- randomized clinical trials, III- non-randomized controlled trial, IV- cohort or case-control studies, V- systematic reviews of descriptive or qualitative studies, VI- descriptive or qualitative studies, VII- report of expert committees or opinion of authorities.

3 RESULTS

In this study, after crossing the descriptors and the Boolean marker in the four databases, a total of 2574 scientific productions were found. Of this total, 2242 belong to MEDLINE, 162 to LILACS, 107 to IBECS, and 63 to BDENF. After their analysis in each database, considering the reading of the title and abstract, as well as the exclusion criteria, 30 scientific articles were left for reading in full, as shown in figure 1. After reading the full text, some studies were eliminated and the sample was composed of a total of 13 scientific articles.

Figure 1. Flowchart of the selection of articles, according to PRISMA. Recife-PE, Brazil, 2020.



The main information of the articles included in the study was synthesized in two tables. As revealed in table 1, all articles were Brazilian (n=13). Among these, it was observed that most studies were published in the year 2018 (n=4), followed by the year 2016 (n=2), 2019 (n=2), 2011 (n=2), 2009 (n=1), 2012 (n=1), and 2014 (n=1). Most of the selected studies were in BDENF (n=7), followed by LILACS (n=4) and MEDLINE (n=2). In chart 2, regarding the design, there was a predominance of studies with a qualitative approach (n=11). Regarding the level of evidence, all studies (n=13) were classified as belonging to level VI, which encompasses descriptive or qualitative studies.

Table 1. Characterization of the articles included in the final sample according to title, author, year, country and objective. Recife-PE, Brazil, 2020

TITLE	AUTHOR/YEAR/DATABASE/COUNTRY	OBJECTIVE
Primary caregiver of cancer patient beyond the possibility of cure, repercussions of this burden.	Araújo LZS, Serpa CZ, Souto AKBA, Oliveira MS. 2009. BDENF. Brasil.	To identify the profile of caregivers of cancer patients; to ascertain the activities performed, changes and difficulties.
Family caregiver of the elderly in palliative care: the dying process at home.	Frazeti FR, Gutierrez BAO. 2011. MEDLINE. Brazil	To identify and analyze the meaning of the dying process for family caregivers of elderly patients in palliative care.
A look at the caregiver of cancer patients receiving palliative care	Guimarães CA, Lipp MEN. 2011. LILACS. Brazil.	To ascertain how the primary caregiver experiences the act of caring and how the impending loss of the patient affects his or her stress level.

Understanding the experience of the caregiver of a family member with cancer beyond the possibility of cure.	Cruzeiro NF, Pinto MH, Cesarino CB, Pereira APS. 2012. BDEF. Brazil.	Understanding the experience of caring for a family member with cancer beyond the possibility of cure.
Children and adolescents with cancer in palliative care: experiences of family members	Sanches MVP, Nascimento LC, Lima RAG. 2014. BDENF. Brazil.	To investigate the experience of family members in caring for children and adolescents with cancer in palliative care.
Difficulties of caregivers of palliative care patients in the family health strategy.	Meneguin S, Ribeiro R. 2016. BDENF. Brazil.	To unveil the caregivers' difficulties and their perception of the support offered by the Family Health Strategy
Palliative care and its influence on family relationships	Gutierrez BAO, Cambraia TC, Fratezi FR. 2016. LILACS. Brazil.	Know the influence of palliative care on family relationships.
Experiences of caregivers in palliative care and support networks	Pessalacia JDR, Silva AE, Araújo DHQ, Lacerda MA, Santos KC. 2018. BDENF. Brazil.	To understand the lived experiences of family caregivers of patients in palliative care.
Circumstances and consequences of caring: characterization of the family caregiver in palliative care (*)	Delalibera M, Barbosa A, Leal I. 2018. MEDLINE Brazil.	Characterize the family caregiver by assessing the circumstances and consequences of caregiving.
Palliative oncology care: perception of caregivers.	Cunha AS, Pitombeira JS, Panzetti TMN. 2018.LILACS. Brazil.	To describe and analyze the primary caregiver's perception of a family member in palliative care
Primary Caregivers Facing the Experience of Death: Their Meanings and Meanings.	Lima CPL, Machado MA. 2018. LILACS. Brazil	To understand the senses and meanings attributed by primary caregivers to the experience of accompanying cancer patients in End of Life Care.
Together we endure, apart we fall: experiences of family caregivers of cancer patients in palliative care.	Lima LES, Santana ME, Correa Junior AJS, Vasconcelos EV. 2019. BDENF. Brazil.	To describe the experience of family caregivers of cancer patients in palliative care.
Experiences and feelings of the family caregiver of cancer patients in palliative care.	Inocenti A, Rodrigues IG, Miasso AI. 2019. BDENF. Brazil.	To know the experience and feelings of the family caregiver of cancer patients in palliative care.

Table 2. Characterization of the articles included in the final sample, according to design, level of evidence and main results. Recife-PE, Brazil, 2020.

DELINEATION	**LEVEL OF EVIDENCE**	**MAIN RESULTS**
Descriptive, quantitative study.	**VI**	Family caregivers exercise multiple functions and the reflection in their lives is given through physical, psychological and social signs and symptoms. There is a strong tendency to mental illness due to the rupture of bonds and social isolation, contributing to the feeling of loneliness, depression, sleep disorders, etc. The feeling of fear and heavy use of psychotropic drugs was significant. The financial decline affected the emotional balance contributing negatively to the family caregiver's life.
Qualitative study.	**VI**	Feelings presented by the family caregivers: impotence, difficulty to dedicate to other activities, sadness followed by depression, physical exhaustion and financial difficulties. The absence of technical knowledge and of adequate support for the caregiving functions, capable of causing psychological alterations, was highlighted. Emotional difficulties were also due to the difficulty in dealing with the patient's suffering and the prospect of death. Negative change was associated with job loss and decreased social life.

Quantitative and qualitative study.	**VI**	Overburdening of caregivers, difficulties in meeting the patients' needs due to lack of information and guidance. Abdication of self-care in favor of caring for others, causing social distancing. Feelings of isolation, sadness and loneliness and, consequently, the emergence of stress. Caregivers are unaware of the concept of palliative care and showed difficulties in facing death. The lack of clear communication generates in the caregiver a feeling of helplessness, impotence and despair leading them to a phase of near exhaustion.
Descriptive study with a qualitative approach.	**VI**	The family caregiver experiences changes in the routine of life, priorities, personal values. Performance of tasks that lead to physical and psychological symptoms: fatigue, rupture of social bonds, irritability, difficulty in sleeping, feeling of loneliness, sadness, uselessness. Expectations and difficulties to face death. Religiosity as a strategy to face suffering. Support network with friends, neighbors and religion. Need for welcoming and instrumentalization by the health team, orientation about palliative care.
A descriptive and exploratory study, with a qualitative approach.	**VI**	Feeling of pain and fear as death approaches. Loneliness, giving up one's life for the sake of the patient, physical and emotional overload due to daily demands. Life changes leading to psychosocial and financial imbalance. Faith/religiosity as a way of accepting suffering. Need for support, support and information, allied with adequate, clear and objective communication. Lack of knowledge about what palliative care is, contributing to the difficulties of accepting death and mourning. Need for training and planning of the health team.
Exploratory, descriptive study with a qualitative approach.	**VI**	Numerous difficulties were observed in family caregivers: physical and emotional overload, unpreparedness to deal with suffering and death, financial difficulties to provide materials and supplies, lack of support from the formal support network of the municipality, unpreparedness to deal with the patient's demands. Giving up one's own life. Need for psychosocial support, guidance, support actions by the ESF. Training of the ESF including evaluation of the profile of its members.
Qualitative study.	**VI**	Overload of work, absence of support, and feeling of helplessness. Rearrangement of roles within the family, due to the crisis, triggers emotional imbalance for the caregiver. Present feelings: fear and insecurity in the face of death indicating stress and psychological suffering. Interruption of life for the sake of caregiving and annulment of one's own individuality. Intense suffering with caregiving contributes to psychiatric disorders such as depression and anxiety. Spirituality appears as a resource of comfort and support for negative feelings.
Qualitative, descriptive and exploratory study.	**VI**	Family caregivers experience changes in daily routines and perform multiple activities without training to perform them, causing physical and emotional overload. There is a need for a formal and informal support network to provide support, guidance, and training to avoid burnout.
Quantitative, prospective, longitudinal study.	**VI**	Overload related to the amount of hours that caregiving is performed and triggers anxiety, depression and somatization. Caregivers have no time for themselves or for other activities of their interest. The lack of social support appeared associated with greater psychopathological symptoms in the caregiver and also with worse family functioning. The more functional the family, the more support the caregiver will have and the less burdensome the task of caregiving.
Exploratory and descriptive study with a qualitative approach.	**VI**	Caregivers presented lack of knowledge of palliative care. Observed feelings of sadness, discomfort, loneliness, helplessness, fear of the future. Abdication of life for the sake of the patient. Anxiety due to lack of information to conduct daily situations. Physical and emotional overload. Precariousness of support sources, mainly formal, for orientation and care of the caregivers.
Exploratory qualitative research.	**VI**	Need for training of the multiprofessional team. Physical and emotional exhaustion due to the intensity of care. Feeling of anxiety, insecurity and powerlessness in the face of approaching death Need for information, orientation and good communication with the professional team. Feeling of loss of identity for having abdicated his life and distanced himself from himself.

Descriptive and qualitative study.	**VI**	Family caregivers face changes in their daily lives, experiences of social isolation, leisure deprivation, disconnection from work activities. There is a need for information, clarification, and translation of the medical language. It is necessary to empathize, listen, and welcome the family caregiver as well as to take actions focused on their needs.
Descriptive research with a qualitative approach.	**VI**	Feelings of the family caregivers: anxiety, anguish, impotence in the face of death, causing family imbalance. Changes in daily life due to the demands, allowing them to give up their own lives. Overload of care, fatigue, stress. Need for psychological support in facing the situations. Need for welcoming, orientation, and family meetings as an intervention to minimize the anguish. Training of health professionals for orientation and listening.

4 DISCUSSION

Palliative Care represents a new form of assistance in health care and stands out for focusing on integral care, seeking to respond to the needs of the patient and family through a broad and transdisciplinary vision in the prevention and control of symptoms that are assessed and cared for involving the physical, psychological, social and spiritual dimensions (NATIONAL ACADEMY OF PALLIATIVE CARE, 2012).

Through this study, several challenges experienced by family caregivers were verified, such as: changes in the routine of life, execution of the unwanted function, social exclusion, disruption of affective bonds, living with feelings of loneliness, sadness, helplessness, loss of perspective of life and, in many cases, the falling ill due to depression. These findings reinforce the importance of continuous and integral attention to the caregivers, because, just like the patient, they must be the target of the care provided by the multiprofessional team.

Although the family caregiver receives the function of offering conditions of well-being and quality of life to the loved one, he/she faces countless difficulties and does not always choose to occupy this place. Some studies demonstrate this reality by showing that the choice of caregiver is usually made by the family, based on their own criteria, without being related to the chosen person's desire (ARAÚJO *et al.*, 2009; CRUZEIRO et al., 2012; FRATEZI; GUTIERREZ, 2011; GUIMARÃES; LIPP, 2011; LIMA *et al.*, 2019; MENEGUIN; RIBEIRO, 2016). This often happens because there are no other options available. Thus, the decision ends up being the family's regardless of the desire of the chosen family member (SILVA; ACKER, 2007).

Most of the time, to contemplate all the activities directed to the patient in palliative care, the caregiver needs to abandon his work and give up his life. In this sense, some articles highlight the occurrence of the abnegation of life (ARAÚJO *et al.*, 2009; CRUZEIRO *et al.*, 2012; CUNHA; PITOMBEIRA; PANZETTI, 2018; DELALIBERA; BARBOSA; LEAL, 2018; GUIMARÃES; LIPP, 2011; GUTIERREZ; CAMBRAIA; FRATEZI, 2016; MENEGUIN; RIBEIRO, 2016). This factor can cause the disruption of affective bonds and social interaction for these caregivers (SILVA, 2016). In this sense, feelings of loneliness, helplessness and lack of support become present in the experiences of caregivers (DELALIBERA; BARBOSA; LEAL, 2018; GUIMARÃES; LIPP, 2011; GUTIERREZ;

CAMBRAIA; FRATEZI, 2016; INOCENTI; RODRIGUES; MIASSO, 2009; SANCHES; NASCIMENTO; LIMA, 2014). This, in turn, ends up making them vulnerable to psychological illness (PEREZ; SILVA; COUTO, 2009).

Emotional suffering is characterized by feelings of anguish, anxiety, helplessness, and fear with the worsening of clinical symptoms and the approach of the patient's death (CRUZEIRO *et al*, 2012; CUNHA; PITOMBEIRA; PANZETTI, 2018; FRATEZI; GUTIERREZ, 2011; GUTIERREZ; CAMBRAIA; FRATEZI, 2016; INOCENTI; RODRIGUES; MIASSO, 2009; LIMA; MACHADO, 2018; LIMA *et al.*, 2019). Three studies made mention of depressive states of family caregivers who faced with difficulties needed to use medications (anxiolytics and antidepressants) to be able to cope with the monitoring of their patients (ARAÚJO *et al.*, 2009; CRUZEIRO *et al.*, 2012; DELALIBERA; BARBOSA; LEAL, 2018). Sometimes, the feelings triggered at this moment cannot be expressed because there is no space to talk about the impact that this process brings (BROTTO; GUIMARÃES, 2017).

Some scientific publications have emphasized the need for the support network of family, friends, neighbors and the religious communities themselves as an important tool for family caregivers (CUNHA; PITOMBEIRA; PANZETTI, 2018; FRATEZI; GUTIERREZ, 2011; GUIMARÃES; LIPP, 2011; GUTIERREZ; CAMBRAIA; FRATEZI, 2016; PESSALACIA *et al.*, 2018). This support network has the function of contributing to the satisfaction of needs and, especially, with the emotional support to the caregiver, even after the loss of his patient (REIGADA *et al.*, 2014).

In this same sense, it was observed in some studies the lack of embracement felt by caregivers by the health team, triggering feelings of abandonment, loneliness and fear of facing the death of the family member (CRUZEIRO *et al.*, 2012; INOCENTI; RODRIGUES; MIASSO, 2009; MENEGUIN; RIBEIRO, 2016; PESSALACIA *et al.*, 2018). In this context, it is important to emphasize the need for adequate support from professionals to the caregiver, aiming to ensure the feeling of support and security to better cope with the stress caused by the end-of-life process, ensuring the well-being and dignity to the patient (ESPINDOLA *et al.*, 2018).

In this context of communication, a study advocates the need for monthly family meetings, also aiming at the provision of information, guidance and support as a strategy to minimize the caregivers' suffering (INOCENTI; RODRIGUES; MIASSO, 2009). Such fact reinforces the need for care with the mental health of caregivers who live with a chronically ill patient in order to avoid Burnout syndrome, among other aggravations (ALVES *et al.*, 2019).

Research draws attention to the unpreparedness of the multiprofessional team and shows how much the family caregiver is penalized and their actions have repercussions on the patient. Thus, these studies suggest the realization of training including the evaluation of the profile of each professional who will compose the palliative care team (GUTIERREZ; CAMBRAIA; FRATEZI, 2016; INOCENTI; RODRIGUES; MIASSO, 2009; PESSALACIA *et al.*, 2018). This context reinforces the reality that many professionals are still unaware of the palliative care approach contributing to many patients dying with unnecessary suffering (PESSINI; BERTACHINI, 2004).

At any rate, it is observed that the vast majority of family caregivers do not present responses that show resilience to the difficulties encountered in their daily practices and refer to suffering in various areas as described in some studies (CUNHA; PITOMBEIRA; PANZETTI, 2018; GUTIERREZ; CAMBRAIA; FRATEZI, 2016; SANCHES; NASCIMENTO; LIMA, 2014). For this reason, there is a need for the health team to invest in their training aiming at the prevention of injuries to the physical and mental health of these caregivers. The more they are supported, oriented and informed, the better caregivers will adapt to the function and will be able to manage safely and autonomously the issues around them (ESPINDOLA *et al.*, 2018).

5 FINAL CONSIDERATIONS

Through this study it was possible to conclude that there are several challenges experienced by family caregivers of patients in palliative care. Among them, the ones that stood out the most were: the imposition to exercise the role of caregiver without any personal choice, change in the routine of life, social exclusion, rupture of affective bonds, living with feelings of loneliness, sadness, helplessness, loss of perspective of life and, in many cases, the falling ill due to depression. Besides these, the lack of knowledge and guidance to perform daily tasks was also observed. In view of this, it was observed that the caregiver often felt distressed, worn out, and apprehensive. This directly reflected on his relationship with the patient, giving him more suffering.

As limitations, this study presented the fact that only four databases were used and the delimitation of the language considering the Portuguese language. This fact occurred due to the short period of time for the execution and the limitation facing the comprehension of other studies in other languages. However, the study showed important aspects related to the challenges experienced by family caregivers of patients in palliative care that can be used to understand this reality and to conduct future interventions and planning of the multiprofessional team to work more effectively in this context. It is also suggested the construction of new studies with the expansion of languages and databases used.

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