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# NURSING IN CAREGIVER ASSISTANCE IN THE HOSPITAL ENVIRONMENT IN PALLIATIVE CARE: AN INTEGRATIVE REVIEW

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Abstract: The disease is understood as acute or chronic, that associated with diseases of any type, and results in suffering that compromises physical, social, spiritual and emotional functions, and requires intervention by a specialized professional to achieve relief. Assistance in Palliative Care stands out. The proposal of this integrative bibliographic review it is to study the physical, psychological, spiritual and mental needs related to caregivers during the monitoring of their patient, as well as how the caregivers face grief. The ScienceDirect, Virtual Health Library (BVS) and Scientific Electronic Library Online (Scielo) databases were used, and 19 articles were selected from 2018 to 2022. As a result, the use of faith and spirituality in coping with death, religion in comforting the adversities of illness, the use of medication for insomnia, and the assistance of a team specialized in Palliative Care to caregivers were found. As a conclusion of this research, the assistance of the multidisciplinary team specialized in Palliative Care in caring for the caregiver and/ or family member was found. The nursing team is sensitive and adaptable, communicative and educated, and has the knowledge and skills to ensure that caregivers and/or family members receive comprehensive care, the nursing team without forgetting about their patients. When these professionals combine specialization in Palliative Care, the care provided is unique, exclusive and effective.

**Keywords:** Caregivers; Palliative Care; Nursing and Hospital Units.

# **INTRODUCTION**

The International Association for Hospice and Palliative Care - IAHPC (2019) emphasizes that palliative care is offered for primary and tertiary care, provided by a specialized multidisciplinary team in order to offer adequate support to minimize human suffering<sup>1</sup>. In this context, we can highlight Palliative Care (PC), and its detailed attributions composed of: nursing team, doctors, psychologists, dentists, nutritionists, pharmacists, occupational therapists, physiotherapists, infectious disease specialists, pediatricians, geriatricians, cardiologists, social workers, called a multidisciplinary team in the health area duly trained for this specialization<sup>2</sup>. The disease is understood as acute or chronic, a condition that causes disability leading to debility for a long period or death, suffering is related and associated with diseases of any kind. When this suffering is severe and compromises physical, social, spiritual and emotional functions, it is health related to suffering and requires intervention by a specialized professional to achieve relief<sup>1</sup>.

IAHPC1 defines PC as care offered to all ages who are experiencing intense suffering related to their health, especially those who are in their finitude, resulting from a severe illness, and its active holistic care, with the aim of improving the quality of life of patients, their families and their caregivers. According to IAHPC, they are covered by: prevention and early identification; comprehensive assessment and control of physical problems; psychosocial distress and spiritual suffering; planning in sets of specific treatments for the disease; positive influence on the progression of the disease; does not anticipate or postpone death; respects life; provides and supports the family and caregivers that death is a natural process and in mourning respects their cultural values and beliefs; active communication must prevail between multidisciplinary teams with the patient and family members/caregivers.

These concepts are applicable at primary to tertiary levels and in all health care settings; they are performed by professionals with basic training in PC; they require multidisciplinary PC specialists in their referral<sup>1</sup>.

The Brazilian Society of Pediatrics – SBP<sup>3</sup> states that PC is an inspiration to offer the best possible quality of life from the moment of diagnosis to improve life when it comes to chronic and progressive diseases with an unfavorable outcome leading to fatality. For pediatrics, the strategies and concepts differ from those for adults. Of the thirteen strategies, the first and fifth are: care needs to be directed to the child or adolescent, oriented towards the family based on partnership; and having a therapeutic proposal does not oppose the introduction of PC.

For eligibility in pediatric and adolescent PC, the vast majority are congenital and genetic diseases, followed by chronic neurological conditions, then by onco-hematological conditions. More than half have more than one diagnosis (55%) and it was shown that the end of life still occurs, for the most part, in the hospital environment. Unlike adults, where the majority of PC patients are undergoing oncological treatments and their direction is in the hospital and at home<sup>3</sup>.

The vast majority of patients assisted by the PC team are affected by situations of fragility, anguish, stress, physical, emotional and psychological exhaustion, as are their family members who assist in this care and live with fears, difficulties and doubts.

Caregiving assistance in the hospital area of the patient in Palliative Care has a context with a theme of great emphasis in nursing, as it is a complex and multidisciplinary approach, which involves not only the patient in their treatment, but also their companions.

In this trajectory, it makes sense and is necessary for nurses to care for the caregiver who is closest to the patient undergoing treatment, interconnected in the fundamental role of promoting, restoring well-being and alleviating suffering, in addition to the outcome of not prolonging their life and respecting their finitude.

In view of the above, the following guiding question considered: What is the perspective of nursing in assisting caregivers in the hospital area in palliative care in the scientific literature? Therefore, the of this research is to demonstrate, through a literature review, the physical, psychological, spiritual and mental needs related to caregivers during the monitoring of their family members in PC, as well as how they face grief in nursing care.

# **METHOD**

This is an integrative review study of the bibliography using a qualitative research method through scoping review, which aims to map the literature that explores the main definitions of the topic in question or the area researched to identify key concepts<sup>4</sup>. The main GOAL is to analyze the dimension, scope and nature of the study, synthesize, publish the data, to point out possible gaps in existing research, recognized as a tool of great relevance in the health field, as it provides the search, critical evaluation and synthesis of evidence on an investigated topic<sup>(4,5)</sup>.

For Mendes, Silveira and Galvão<sup>26</sup>, the process of constructing an Integrative Bibliography Review can be conducted in six stages divided into:

- 1) Elaboration of the review question that will direct to the of the review and identify the keywords with a theme related to clinical practice;
- 2) Search and selection of primary studies in relevant databases to search for articles and studies published on the topic of interest, establishing inclusion and exclusion criteria;

- 3) Extraction of data from the studies to select articles that meet the criteria according to step 1, and organize and summarize the information;
- 4) Critical evaluation of the primary studies included in the review, critical analysis of the selected studies, application of statistical analyses and identification of information such as authors, year of publication, methodology, RESULTS and CONCLUSIONS;
- 5) Synthesis of the RESULTS of the review is to summarize the information from the selected studies and organize them into categories;
- 6) Presentation of the method after the information has been synthesized to identify trends and patterns in the literature and conclude the scoping review by presenting an overview of the literature and highlighting trends and gaps in the research.

# PREPARATION OF THE RESEARCH QUESTION

This research followed the PICO acronym strategy (Patient, Intervention, Comparison, Outcomes), which are the four fundamental elements of the research question and the construction of the question for the search for evidence and bibliography<sup>5</sup>.

To develop the research question, the PICO acronym strategy was used, of which the first element (P) caregiver, (I) psychological, spiritual and physical relief, (C) nursing care in the hospital environment and finally, the item (O) CP.

Resulting in the following research question formulated: What is the perspective of nursing in the assistance of the caregiver in the hospital area in palliative care in the scientific literature?

# SEARCH AND SELECTION OF PRIMARY STUDIES

The authors identified the main concepts of the theme: caregiver, palliative care, nursing and hospital. After identifying the main concepts of the theme, they gathered a list of relevant keywords by selecting the terms in the Health Science Descriptors (DeCS) and Medical Subject Headings (MeSH).

This study was carried out from secondary sources, through a bibliographic survey, seeking similarities and differences between articles collected in specialized electronic databases such as: ScienceDirect, Virtual Health Library (BVS) and Scientific Electronic Library Online (Scielo), and articles found through manual searches of gray literature.

The descriptors searched in DeSC: caregiver, palliative care, nursing and hospital. For the search in the databases, the descriptors selected in DeCS were used, connected with the Boolean operator "And" and "OR" (Nursing AND Caregiver AND Palliative Care); (Caregiver AND Hospital AND Palliative Care) and (Nursing OR Caregiver AND Hospital AND Palliative Care).

The inclusion and exclusion criteria were:

- Inclusion: published within a period of five years; availability of free text access; full-text articles and type of literature article.
- Exclusion: articles that did not fit the conceptual structure of the study, languages other than English, Portuguese and Spanish, themes involving the elderly, home-based PC and patient-centered PC.

The authors adopted a time frame in the last five years (2018- 2022), of which ten articles are highlighted by the method used.

The search for articles was carried out in March, and for greater reliability, the RESULTS were exported to EndNote and duplicates were removed by the platform for greater reliability of the searched result.

### **RESULTS**

The process of searching and selecting studies for this review is presented in Figure 1, using the PRISMA methodology<sup>6</sup>.

In the construction of Prisma to highlight online searches in reliable scientific databases, we can observe the steps performed in figure (1), where we notice that the search in the first analysis in BVS N=158; Scielo N=32 and ScienceDirect N=413. Then in the second analysis, 176 studies were selected for the five-year period of the 3 descriptors, articles excluded for: Korean language; elderly; homecare; not available in full; paid; duplicates; unrelated to the theme; abstracts and PC in the patient. The articles read in full 22 and finally the eligible presentation in full 19 articles.

After selecting and reading the articles according to the inclusion and exclusion criteria, a table was constructed with the articles in order to highlight their main characteristics such as: reference number, year of publication, title, database, authors, study method, study population, description of the main results and conclusion interpretation results, presented in table 1.

### DISCUSSION

This review confirms that female caregivers are more vulnerable to mental and emotional overload<sup>(8,10-11,14,18,22,25)</sup>.

Throughout their illness, the family caregiver mediates the care offered by professionals<sup>(17)</sup>. Of which, an unpaid caregiver<sup>(25)</sup>, is an integral and essential part of PC and, given the situation, may suffer high levels of depression, anxiety<sup>(25)</sup>, stress and insomnia, mental, social, spiritual<sup>(22)</sup>, feelings of helplessness, anguish, sadness and worry<sup>(12)</sup>, psychosomatic illnesses, physical fatigue<sup>(25,23)</sup>, resulting in a decline in quality of life<sup>(8,25)</sup>.

The caregiver feels physical and psychological overload due to their absence

from work, home, leisure, and due to the strict schedules and routines of the hospital environment or even due to the suffering of their loved one<sup>(11)</sup>. The result of the emotional impact was feelings of sadness, helplessness and fear of loss  $^{(8)}$ . This helplessness is associated with the family member/caregiver since he or she is a son or daughter, wife or husband, during his or her upbringing, his or her parents took care of him or her and led him or her into adulthood with safety, guidance and care, and the opposite is now completely different, he or she, the family member and caregiver, does not have the knowledge and security to care for his or her parents(11). And the suffering in relation to understanding the severity of the clinical condition, with the chronicity of the disease(16). It was also found that the process of death generates ambivalent feelings; the desire for death to alleviate suffering and at the same time guilt, and parents hope that one day they will leave before their children and children never leave first(17).

In this process of caring, family members/ caregivers seek relief from suffering in spirituality and faith, reinforcing that through spirituality they understand the illness, the suffering of death and the strength to cope(16), confirming religion as a source of support for the family and the strategy to support and comfort the adversities of the disease. Spirituality is intrinsic, a way of coping with fears, fears and other emotions in finitude, with spiritual care being essential for the caregiver, the person who cares(16). Psychological and psychiatric monitoring as a source of support and assistance, psychotherapy assists in the process of anticipatory grief, contributes to the management of conflicts and decisions, and psychological monitoring in the reduction of psychopathological symptoms in the prevention of symptoms of imminent loss for family members and caregivers(10-12).

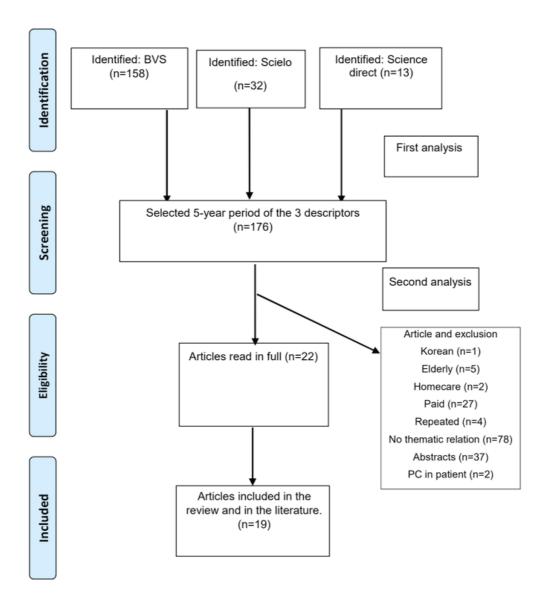


Figure 1: Prisma. Source: Adapted from Prisma-Statementlong (2009).

| 01  | 2022 | Experience of adult children who are caregivers of cancer patients in palliative care <sup>7</sup> ; BRAZIL. |  |   |  |
|---|------|--|--|---|--|
| METHO   | DD   |  | POPULATION   | NEWSPAPER   |  |
| Cross-sectional, descriptive and exploratory in nature, with qualitative <b>method</b> ology    |      |  | Female daughter caregivers   | ``Revista Psicologia, Saúde & Doenças``   |  |
| GOAL  |      |  | RESULTS  | CONCLUSIONS   |  |
| To understand the experience of children who are caregivers of cancer patients, Porto Alegre-RS |      |  | They highlighted the impacts on families' lives, highlighting the emotional repercussions of the illness | Lack of bibliography on verifying the impact on the caregiver's quality of life |  |
| 02  | 2018 | Palliative oncol   | ogy care: perception of caregivers <sup>8</sup> ; BRAZIL   |   |  |
| METHOD  |      |  | POPULATION   | NEWSPAPER   |  |
| Exploratory and descriptive research with a qualitative approach                                |      |  | 10 caregivers: 9 women and 1 man   | J. Health Biol Sci  |  |

| GOAL  |                                   |                          | RESULTS   | CONCLUSIONS  |
|---|-----------------------------------|--------------------------|---|--|
| To describe and analyze the perception of the primary caregiver towards a family member in PC   |                                   | primary                  | It was noted that most participants were unaware of what CP is  | To know who these subjects are and their perceptions of caring for a family member with cancer in PC   |
| 03 2  | Knowledge of h<br>PORTUGUAL       |                          | health professionals about palliative care: Analysis of a Portuguese central hospital9;   |  |
| METHOD  | )                                 |                          | POPULATION  | NEWSPAPER  |
| Quantitative, descriptive-<br>correlational, transversal  |                                   |                          | PTARGET <b>POPULATION</b> : healthcare professionals from a central university hospital   | ``Revista de Enfermagem de Referência``  |
| GOAL  |                                   |                          | RESULTS   | CONCLUSIONS  |
| TARGET I<br>healthcare<br>central uni   | profess                           | ionals at a              | Knowledge about symptom control and family support  | Most professionals demonstrate knowledge of CPS  |
| <b>04</b> 2   | 2021                              | Palliative care: l       | knowledge of cancer patients and their caregivers <sup>10</sup> ; BRAZIL  |  |
| METHOD  | )                                 |                          | POPULATION  | NEWSPAPER  |
| Descriptive quantitative  |                                   | y type with<br>ach       | 200 Participants (100 cancer patients and 100 informal caregivers)  | ``Revista Bioética``   |
| GOAL  |                                   |                          | RESULTS   | CONCLUSIONS  |
| Check the 1   | Check the perception about CP     |                          | It was possible to observe the lack of knowledge of the terminality of life   | They attest to the importance of health professionals in the perception of caregivers  |
| <b>05</b> 2   | 2020                              | Cancer Patient<br>BRAZIL | in the Final Stage of Life in Palliative Care: I  | Experience of the Family Caregiver <sup>11</sup> ;   |
| METHOD  | METHOD                            |                          | POPULATION  | NEWSPAPER  |
| Explorator qualitative  |                                   |                          | 15 Family caregivers  | ``Revista Pesq. Cuid. Fundam. Online``   |
| GOAL  |                                   |                          | RESULTS   | CONCLUSIONS  |
| To understand the experience of family caregivers of cancer patients in the final phase of life in PCs  |                                   |                          | Analysis of empirical material on:<br>Repercussions on the physical and<br>psychological health of the family<br>caregiver and II – Future perspectives | Importance of assistance that facilitates the caregiver's adaptation process, seeking to reduce physical and emotional overloads                                       |
| <b>06</b> 2   | 2018                              | Perception of fa         | amily caregivers about palliative care <sup>12</sup> ; BRAZIL   |  |
| METHOD  | )                                 |                          | POPULATION  | NEWSPAPER  |
| Descriptive qualitative   |                                   |                          | 10 Caregivers in a Reference Hospital   | ``Arq. Ciênc. Saúde``  |
| GOAL  |                                   |                          | RESULTS   | CONCLUSIONS  |
| To understand caregivers' perceptions of CP   |                                   |                          | Knowledge about palliative care, feelings aroused and needs experienced by caregivers   | Participants with poor knowledge about CP and the feelings experienced involve sadness, worry and helplessness   |
| <b>0</b> 7 2  | 7 2021 Preliminary study of SPAIN |                          | dy of the end-of-life process through data triangulation in a regional Hospital <sup>13</sup> ;   |  |
| METHOD  |                                   |                          | POPULATION  | NEWSPAPER  |
| Observational, cross- sectional. descritive   |                                   |                          | It was carried out on a sample of<br>63 subjects of which 25 were health<br>professionals, 19 family caregivers   | `` <i>Revista electronica</i> trimestral de<br>Enfermeria``  |
| GOAL  |                                   |                          | RESULTS   | CONCLUSIONS  |
| To know the characteristics<br>of the end-of-life establishing<br>convergence/divergence elements<br>in care process, decision-making,<br>information and knowledge |                                   |                          | Data triangulation shows discrepancies<br>between family members and health<br>professionals regarding care quality and<br>the information provided     | An integrated view of end-of-life care provided in a Regional Hospital, identifying priority areas of intervention in order to improve quality of life in this process |

| <b>08</b> 2019   | About how to take care of people under palliative care <sup>14</sup> ; BRAZIL  |  |  |  |
|--|--|--|--|--|
| METHOD   |  | POPULATION   | NEWSPAPER  |  |
| Qualitative appro  | ach research   | 20 family caregivers   | Cad. Bras. Ter. Ocup., São Carlos  |  |
| GOAL   |  | RESULTS  | CONCLUSIONS  |  |
| To understand the patterns of prima people in oncolog  | ry caregivers of   | The changes in the organization of the routine and the dedication to taking care of the loved one in CP stand out  | The condition of being a caregiver in PC so that health professionals also direct their attention to caregivers                                    |  |
| <b>09</b> 2020   | Nursing care fo  | or patients in palliative care from the caregiver's perspective <sup>15</sup> ; BRAZIL   |  |  |
| METHOD   |  | POPULATION   | NEWSPAPER  |  |
| Descriptive, cross quantitative study  |  | 19 caregivers of patients in palliative care   | Braz. J. Hea. Rev., Curitiba   |  |
| GOAL   |  | RESULTS  | CONCLUSIONS  |  |
| To describe the operation of pating regarding the care the nursing team                              | ents in PC   | The sample consisted mostly of women, satisfied with the care provided by the nursing team   | The survey revealed that family members/caregivers of patients in CP are always satisfied with the nursing staff                                   |  |
| <b>10</b> 2018   | The family as a  | member of palliative care assistance <sup>16</sup> ; BRAZ  | ZIL  |  |
| METHOD   |  | POPULATION   | NEWSPAPER  |  |
| Qualitative, explo descriptive study   |  | 10 nurses  | ``Revista de Enfermagem UFPE``   |  |
| GOAL   |  | RESULTS  | CONCLUSIONS  |  |
| To analyze nurses' perceptions regarding family participation in PC care                             |  | The importance of welcoming the family and including them in the care process  | The family is one of the pillars of patient care   |  |
| <b>11</b> 2019   | A phenomenolo  | ogical look at family caregivers and palliative  | e care for cancer patients <sup>17</sup> ; BRAZIL  |  |
| METHOD   |  | POPULATION:  | NEWSPAPER:   |  |
| Qualitative appro<br>the perspective o<br>phenomenologic   | f the  | Family caregivers  | ``Revista Arquivos Científicos (IMMES)<br>Macapá``   |  |
| GOAL   |  | RESULTS  | CONCLUSIONS  |  |
| To understand he caregiver felt whe responsibility of a the patient who w                            | n faced with the accompanying  | It was noted that, given the changes in<br>the caregivers' lives, they feel as if they<br>had done everything for their family<br>member, in the best way possible | It is understood that there are differences<br>in the experiences of each family<br>caregiver, and some factors are similar,<br>the function       |  |
| <b>12</b> 2021   | Psychological I  | Distress in Bereaved Caregivers of Patients wi   | ith Advanced Cancer <sup>18</sup> ; U.S.A  |  |
| METHOD   |  | POPULATION:  | NEWSPAPER:   |  |
| Secondary analys<br>caregivers enrolle<br>supportive care s  | ed in a  | 168 bereaved caregivers  | J Pain Symptom Manage  |  |
| GOAL   |  | RESULTS  | CONCLUSIONS  |  |
| To describe the rates of<br>depression and anxiety<br>symptoms in bereaved caregivers<br>of patients |  | Of the 168 bereaved caregivers, 30.4% (n=51) and 43.4% (n=73) reported clinically significant depression and anxiety symptoms, respectively                        | Many bereaved caregivers of cancer patients experience symptoms of depression and anxiety, which are associated with their perceptions of distress |  |
| <b>13</b> 2019   | Parental experiences and coping strategies when caring for a child receiving paediatric palliative car a qualitative study <sup>19</sup> ; U.S.A |  | a child receiving paediatric palliative care:  |  |
| METHOD   |  | POPULATION   | NEWSPAPER:   |  |
| An interpretative study using them performed   |  | with 42 parents of 24 children with<br>malignant or non-malignant diseases<br>receiving palliative care  | European Journal of Pediatrics   |  |
| GOAL   |  | RESULTS  | CONCLUSIONS  |  |

| To align healthcare professionals'support with the needs of parents   |                   |   | Four closely related coping strategies were identified: suppressing emotions by keeping the loss of their child at bay, seeking support,  | Parents need health professionals who understand and carefully deal with their concerns, losses, parent-child relationships and coping strategies  |
|---|-------------------|---|---|--|
|   |                   |   | on of the caregiver of the patient in oncology POPULATION   | NEWSPAPER:   |
| Quantitative, cross- sectional research   |                   |   | 30 Caregivers are mostly female   | ``Revista de Enfermagem de UFPI``  |
| GOAL  |                   |   | RESULTS   | CONCLUSIONS  |
| To investigate the socioeconomic and health profile of the caregiver of a patient in palliative care  |                   |   | The most prevalent diseases were hypertension and polycystic ovary syndrome   | Most caregivers have no source of income   |
| 15  | Satisfaction with |   | Caregiving Burden of Family Caregivers of Advanced Cancer Patients and Their h the Dedicated Inpatient Palliative Care Provided to Their Patients: A Crossform a Tertiary Care Centre in South Asia <sup>21</sup> ; INDIA |  |
| METHO   | OD                |   | POPULATION:   | NEWSPAPER:   |
| Cross-se  | ectional st       | udy assessed  | 211 Family Carigive   | Asian Pacific Journal of Cancer<br>Prevention  |
| GOAL  |                   |   | RESULTS   | CONCLUSIONS  |
| In this study, caregiving burden<br>of FCs and their satisfaction with<br>dedicate Inpatient palliative care<br>(IPC) services provided to their<br>patients were studied |                   |   | FCs who were male, unmarried, unemployed, and residing in rural experienced higher caregiving burden  | FCs from lower-income groups experienced higher caregiving burden  |
| 16  | 2018              | Caregiver burd  | en for oncology patients in palliative care <sup>22</sup> ;   | BRAZIL   |
| METHO   | OD                |   | POPULATION  | NEWSPAPER  |
| quantitative, descriptive,<br>observational, cross- sectional<br>study  |                   |   | 50 Caregivers and 50 patients   | ``Revista de Enfermagem UFPE online``  |
| GOAL  |                   |   | RESULTS   | CONCLUSIONS  |
| Correlate the impact of caregiver burden on the quality of life of cancer patients in palliative care   |                   |   | Caregiver burdens were fatigue, lack of appetite, constipation and overall impact.  | Increased caregiver burden reduces the quality of life of cancer patients in palliative care   |
| 17  | 2021              | Quality of life of  | family caregivers of people with cancer who receive palliative care attention <sup>23</sup> ; Colombia  |  |
| METHO   | OD                |   | POPULATION  | NEWSPAPER  |
| Cross-sectional, correlational, quantitative descriptive study  |                   |   | 208 Family caregivers of people with cancer in outpatient PCs in Medellín-Colombia  | Rev. esc. enferm. USP 55   |
| GOAL  |                   |   | RESULTS   | CONCLUSIONS  |
| To describe the quality of life<br>and related factors in Colombian<br>caregivers of people with cancer<br>in palliative care   |                   |   | Quality of life was scored between 116.36 and 122.35 (95% CI)   | It is necessary to develop interventions to improve the quality of life of caregivers  |
| 18  | 2022              | Perception of speech therapists about their work in the area of palliative care in a public hospital in Santa Catarina <sup>24</sup> ; Brazil |   |  |
| METHOD  |                   |   | POPULATION  | NEWSPAPER  |
| Qualitative, descriptive study  |                   |   | 5 speech therapists from Santa Catarina<br>hospital   | Audiol Commun Res.   |
| GOAL  |                   |   | RESULTS   | CONCLUSIONS  |
| To identify the perception of<br>speech therapists about their<br>own performance in palliative<br>care in a public hospital in Santa<br>Catarina                         |                   | about their<br>in palliative  | After analyzing the content of the speech of the participating speech therapists, concept and understanding of palliative care  | The perception of speech therapists reveals the concept that palliative care is provided to patients who no longer have the possibility of a cure. |

| 19  | 2019 | Social determinants of health, family burden and quality of life of family caregivers of cancer patients in palliative care <sup>25</sup> ; Chile |   |  |
|---|------|---|---|--|
| METHOD  |      |   | POPULATION  | NEWSPAPER  |
| Analytical, cross-sectional study with non-porpoise sample  |      |   | 212 Family caregivers   | Rev. Salud Pública   |
| GOAL  |      |   | RESULTS   | CONCLUSIONS  |
| To determine which structural, intermediate and family burden factors explain the quality of life of family caregivers of cancer patients in PC |      |   | The best health levels corresponded to physical function with Average | It was mainly identified that female gender and overload interfere in the quality of life and health of caregivers |

TABLE 1: Selection of included articles

Source: The authors (2023)

The caregiver who is the parent of a child with life-limiting/life- threatening cancer, this pediatric caregiver has a routine of stressful emotional tasks, with routine child care, rigorous, extensive and complex nursing techniques. In addition to the anxiety of losing the child, coping with denial and grief, the lack of information about the child's real condition generates tension among the professionals involved<sup>(19)</sup>.

Nursing stands out in PC, due to its competence, maintaining and negotiating goals agreed with the patient/family and team, acting in favor of effective, open and adaptive communication to the therapeutic context aiming at family interaction, its assistance is sensitive and educational care, demanding actions of physical and affective proximity that are effective in practice<sup>(25)</sup>.

Furthermore, in a study from Portugal<sup>(9)</sup>, it is stated that symptom control and support for family members/caregivers are precarious in the professional's practice. They highlight that the longer the professional has been practicing the profession, the less knowledge there is in PC at a Central University Hospital. Due to their pre-graduate training in 2018 and only in the curriculum of medicine, nursing, psychology, nutrition, social work, gerontology and occupational therapy and physiotherapy. In another study<sup>(10)</sup>, reports that among health professionals, patients and

family caregivers, there is a lack of knowledge about living wills and do-not-resuscitate orders due to lack of communication skills, inability to deal with the suffering of others related to the confrontation of finitude<sup>(13)</sup>, the language used by health professionals, lack of clarification about prognosis and exclusion of the patient in decision- making, which in turn generates anguish and helplessness in both the patient and their family members/caregivers. And as the Spanish authors<sup>(13-18)</sup> established in their research, it establishes the conspiracy of silence and the concealment of reality from family members.

Another study confirmed that caregivers who receive PC experience anticipatory grief and the intervention of the multidisciplinary team is important to minimize the damage caused in this process of finitude and support for grief. Without this mediation, they suffer from symptoms of depression and anxiety after death within three to six months, increasing psychological suffering, according to these same authors. For caregivers/family members, they do not know the difference between palliative care and care<sup>(11,18)</sup>.

In their research<sup>(11,12,15,21)</sup> confirms that quality individual care for the patient and caregiver generates trust. And they point out the importance of clear and effective communication to strengthen the bond of trust and friendship in this triad (patient-

caregiver, family member-nursing team). In their research<sup>(24)</sup>, reports that speech-language pathologists are important for the integration of the multidisciplinary team, to maintain a good communication and nurturing relationship between the patient and caregiver.

From this review, it was possible to list and identify three themes, as follows:

# THE QUALITIES OF A CAREGIVER

The family member/caregiver plays the role of mediator of the care offered by professionals and an unpaid caregiver<sup>(25)</sup>.

# CAREGIVERS' ILLNESSES AND HOW THEY DEAL WITH THEM

High levels of depression, anxiety<sup>(7,10,25)</sup>, stress<sup>(7)</sup> and insomnia, mental, social, spiritual suffering<sup>(21)</sup>, anguish, sadness and psychosomatic illnesses, physical fatigue resulting in a decline in quality of life<sup>(12)</sup>.

In the results of the authors<sup>(11)</sup>, concluded that the caregiver feels physical and psychological overload due to their absence from work, home, leisure, the strict schedules and routines of the hospital environment and the suffering of their loved one. And the suffering in relation to understanding the severity of the clinical condition, with the chronicity of the disease, and the process of death generates ambivalent feelings; the desire for death to alleviate suffering and, at the same time, guilt<sup>(17)</sup>.

To alleviate suffering<sup>(18)</sup> in their research found spirituality and faith, and concluded that through spirituality they understand the illness, the suffering of death and the strength to cope. They advise psychological monitoring to reduce psychopathological symptoms in the prevention of symptoms of imminent loss, psychiatric and psychotherapy assists in the process of anticipatory mourning, which contributes to the management of conflicts

and decisions. And finally<sup>(8)</sup>, in their research, state that, as a source of support for the family and a strategy for support and comfort in the adversities of the disease, they confirm the search for religion. And some family members/caregivers use medication such as antidepressants and sedatives for insomnia.

# HOW THE FAMILY MEMBER/ CAREGIVER ATTACKS THE FINITUDE PROCESS

With PC support, they experience anticipatory mourning, minimizing the damage caused in the finitude process<sup>(25)</sup>.

As limitations of the study, I highlight the absence of articles referring to the caregiver of the adolescent patient in palliative care, approach of other chronic diseases in palliative care because it found extensive research focused on the oncology, elderly and pediatric patient. And the contributions to the area, is that they have the courage to publish the article, many times it does not need to be an article with a PHD, but rather with foundations, without plagiarism, paying attention to what is being sought so as not to leave a gap in the search databases.

# CONCLUSION

Through the development of this work, it was possible to identify the diseases affecting the caregiver, the most commonly used type of therapy, as well as the importance of good care from a multidisciplinary team specialized in PC, which guarantees protection, support, and trust to improve the quality of life of the caregiver or family member and their patient. This research showed that nursing teams are sensitive and adaptive, communicative and educated, have scientific knowledge and the ability to provide complete care to the caregiver or family member, without forgetting the patient in their care. When this

professional adds specialization in PC, the care is highly exclusive, unique, and effective. It is noteworthy that the physical, spiritual, and psychological support in this literature review highlighted religion and faith as support for these overloads, the use of antidepressants

and sedatives for insomnia, and the support of psychotherapy for imminent loss and mourning. Therefore, we recommend that future research be carried out by the nursing team, emphasizing care for the caregiver.

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