

## HOME PALLIATIVE CARE: INTEGRATIVE REVIEW

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## ABSTRACT

**Objective:** To analyze national and international scientific productions that present daily experiences of care provided by caregivers and health professionals in home palliative care. **Method:** This is an integrative review of Lilacs, CINAHL, PubMed, IBECs, BDENF and *Coleciona SUS* databases of articles published between January 2005 and March 2019. The final sample of articles analyzed was composed of 42 articles. **Results:** The studies evidenced feelings of family caregivers such as fear, anguish, overload and gratitude in the daily care of the sick person; the main difficulties experienced relate to access to support services, the buying of medicines by care providers and the use of strategies for the effectiveness of home palliative care. **Conclusion:** The analysis showed that there is a need for the construction of comprehensive care for patients and caregivers, the production of evidence about the professional practices provided to this public, better organization of the support network and access to medicines.

**Keywords:** Palliative care. Caregivers. Health personnel. Home Nursing

## INTRODUCTION

The world population is going through a process of demographic transition due to the reduction of fertility rates, reduction of infant mortality in general and the consequent increase in life expectancy. This movement occurs simultaneously with the change in the epidemiological profile of the Brazilian population, in which there is an evident increase in the prevalence of chronic non communicable diseases (CNCDs)<sup>(1)</sup>.

Population aging and increased CNCDs have required the incorporation of palliative care (PCs) into health care networks. For the World Health Organization (WHO)<sup>(2)</sup>, PC are defined as:

[...] an approach that promotes the quality of life of patients and their families facing life-threatening illnesses through the prevention and relief of suffering. It requires the early identification, evaluation, and impeccable treatment of pain and other physical, psychosocial, and spiritual problems<sup>(2:1)</sup>.

Among the modalities of services that offer PCs, we highlight home care, which has sought to optimize the use of hospital beds, strengthen

the process of humanization of care and produce new ways of care, centered on the person, on their culture and family routine<sup>(3)</sup>.

The PCs, in the context of the single health system, are dispensed at home by professionals related to basic health care (ABS) and home care services (SAD)<sup>(4)</sup>, and by caregivers. Being the last one, the person who provides care directly or continuously and most often is a relative. Providing PC at home favors quality of life, however, health professionals and those responsible for the sick may face different difficulties in providing this care<sup>(5)</sup>.

In view of this context, it is suitable to know how the health professionals and caregivers have lived with the people in palliative care at home. A look at national and international experiences may indicate strategies for the organization and operationalization of this modality of care and contribute with thoughts in this field, since in Brazil the demand for palliative care in the home environment has been increasing. Thus, the objective of this study is to analyze national and international scientific productions that present daily experiences of care provided by caregivers and health professionals in home palliative care.

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## METHODOLOGY

Integrative review is a research method that allows, through the systematic and broad character, the analysis of scientific articles, favoring the in-depth understanding of the theme and the dissemination of the knowledge produced by other writers<sup>(6)</sup>. To construct this research, the following steps were followed: identification of the theme, establishment of the guiding question, definition of sampling, literature search and selection, categorization and evaluation of studies, interpretation of results and synthesis of knowledge<sup>(7)</sup>.

In order to elaborate the guiding research question, the recommendations of the PICO format were followed; (P) participants, being this role played in the current research by caregivers and health professionals; (I) intervention, related to the daily experience of palliative care at home; (C) comparison of the types of intervention or groups, does not apply in the current study and (O) outcome and considered effects to be achieved<sup>(8)</sup>. Thus, the following guiding question was elaborated: How do health professionals and caregivers experience daily care in the context of home palliative care in Brazil and in the world?

Scientific articles published in full available for free and online, international and national, in the English, Spanish and Portuguese languages, which answered the guiding question and were published between January 2005 and March 2019 were analyzed.

The selection of articles was carried out by two researchers independently with the addition of a third one to help in moments of disagreement about the inclusion of articles.

The scientific articles were extracted from the electronic sources LILACS (Latin American and Caribbean Literature in Health Sciences); CINAHL (Cumulative Index to Nursing and Allied Health Literature); PubMed Central (PMC); IBECS (Spanish Bibliographical Index of Health Sciences); BDENF (Nursing Database) and *Coleciona SUS*. Using the descriptors: Palliative care, caregivers, health personnel and home care. In the search were found 1078 publications. By reading the titles and abstracts, it was possible to exclude repeated studies in the different databases, those that did not meet the

inclusion criteria, those that did not obey the proposed theme, those that did not have the available text in full, literature review studies, theses and dissertations. Composing the final sample of this review, 42 articles.

After exhaustive reading of the included articles, we extracted the main information using and filling a table with the following items: author, title, year of publication, journal, objective, methodology, main results, aspects that indicate the daily experience of care in the context of palliative care in home care from the perspective of home caregivers and health professionals. This organization allowed to systematize the analysis, which favored the presentation of the results in this article from categories.

The articles were also classified according to the type of evidences presented, following the guidance of the Brazilian center for evidence-based health care, which recommends the classification of the evidence obtained according to the methodological design: Level I. Systematic review, containing only randomized controlled clinical trials. Level II. At least one randomized controlled trial. Level III 1. Controlled, well-delineated clinical trials without randomization. Level III 2. Well-designed cohort studies or case-control, analytical studies, preferably from more than one research center or group. Level III 3. Multiple time series, with or without intervention and results in uncontrolled experiments. Level IV. Opinion of respected authorities, based on clinical criteria and experience, descriptive studies or reports of expert committees<sup>(A)</sup>. The current review presents scientific articles classified in level of evidence IV.

## RESULTS AND DISCUSSION

Articles from different countries were identified: 21.42% (9) from Brazil, 19.04% (8) from the United Kingdom, 14.28% (6) Canada, 7.14% (3) Sweden, Germany, 4.76% (2) Norway, 4.76% (2) United States, 4.76% (2) New Zealand, 4.76% (2) Australia and 2.38% (1) in each country) from 6 other countries, including Chile, Indonesia, Greece, Bulgaria, Denmark and Japan.

The analysis of included studies and their

respective levels of evidence revealed that in the area of home palliative care, when we refer to the experience of family caregivers and health professionals, descriptive studies stands out (83.33%). These studies present a level of evidence IV, which allows us to infer that these are still incipient subjects in exploration, and that the development of clinical studies and meta-analyzes are necessary.

### Feelings experienced by family caregivers in the context of home palliative care

The analysis of the studies allows to affirm that in the care provided at home, the caregiver role is most often performed by a woman with a family bond<sup>(9)</sup>, whether they are wives, mothers, sisters or daughters. The caregiver takes care of the family in an unpaid way, taking responsibility spontaneously or through obligation<sup>(10)</sup>, solidarity, or a natural feeling of gratitude in retribution.

Through this review it was possible to identify feelings experienced by caregivers such as anguish, fear, overload, isolation, loneliness, gratitude, hope and frustration. These are intensified according to the worsening of the health status of the caregiver<sup>(A, B, C, D, E, F)</sup>.

The caregiver usually performs this function full-time, combining it with other daily activities<sup>(9,B,C)</sup> such as cleaning the house, preparing meals for the family, raising children, among other tasks, accumulating and playing different roles in the family context<sup>(11, B, G)</sup>. A study reveals that women who exercise these roles in full-time instead of taking care of herself, take care of others, making their life goals the goals of others<sup>(12)</sup>, generating feelings of overload and social isolation<sup>(13,C,D,E,H)</sup>.

Support from an informal caregiver network, built by family members, neighbors, friends, church members, and/or nongovernmental organizations can reduce the burden of caring for a family member in home-based palliative care, either by sharing tasks or simply for the company of someone else, thus improving their readiness and quality of life<sup>(14,B,C,D)</sup>.

While caregivers perceive their activities as "tiring" and capable of generating overload, they report a feeling of gratitude in giving care to their relatives, studies reveal<sup>(15,I)</sup>. They refer

gratitude retributing to the family member, to the social issue of caring for others, and to the sense of mission completed. It is meaningful for the caregiver to stay together with his family member, to show affection and love, a situation that is often not experienced before the need of take care, due to the routine of daily life<sup>(B,C,D,H,J)</sup>.

Studies show that caregivers do not recognize the strength they had in situations of life's adversities, such as caring for a family member in critical health situations. They sustain the strength to care for and the feeling of hope in better days, through faith, strengthened by spiritual support from various sources of beliefs, essential in palliative care<sup>(16,B,C)</sup>. Caregivers also demonstrate satisfaction and a sense of emotional balance in finding ways to get along with their family member/patient, leading them to situations close to their daily activities, such as sitting at a table for meals, visiting a park, listen to music, attend his religious temple and making the person gets dressed by him/herself<sup>(E,F)</sup>.

The caring role, exercised by family caregivers, requires training to be performed satisfactorily. When such training and follow-up by the health team do not happen, the caregiver may feel fear and insecurity to correctly perform care procedures, especially with regard to medication administration<sup>(14,15,K)</sup>. The analysis shows that there is also frustration, related to the inability to control the symptoms presented by the family member, the difficulty of referral to health support and support services<sup>(10)</sup> in situations of clinical emergencies, and especially the possibility of imminent death of this relative under his care<sup>(C,D,E,F)</sup>.

It is also worth mentioning the feeling of distress, associated mainly with the lack of knowledge of the prognosis, the lack of clarity in the communication of health professionals<sup>(17)</sup>, and the impossibility of reversion of the disease state of the family member, when it evolves to terminality. The feelings of fear and anxiety cause apprehension and may cause changes in the health status of this caregiver. Hence the importance of meetings, aiming at the "listening" of the user and the familiar caregiver, the training of skills and the revision of the care plans in the home, so that these feelings are minimized<sup>(C,E,F)</sup>.

### Main difficulties faced by caregivers in the context of home palliative care

Regarding the caregiver, the analysis identified the following difficulties related to palliative care at home: laborious access to PCs support services, financing of home care, sleep of the caregiver, and the logistics of medication administration.

The need to improve the access of caregivers with their relatives to palliative care services such as emergency care, home care or continued care is of great relevance to the quality of life of both the users and their caregivers<sup>(C,L)</sup>.

By reporting how difficult access to care services to PCs is, caregivers express that this inaccessibility generates material losses, that is, supplies that will favor care and reduce costs for the family, as well as physical and emotional harm. Studies show that the financing of care generates care support that can minimize the burden cited by caregivers, as it alleviates the feeling of anxiety generated by the fear of not being able to afford the necessary care to their families. The use of follow-up strategies for people with home PCs and their family context is essential so that the quality of care through the reduction of overload is established<sup>(18,B,C,D,M,N)</sup>.

Studies have revealed that the costs of a PC patient are a challenge for families' daily lives. This situation is due to the high cost of materials and medicines to meet the basic needs of the person at home, the lack of resources to subsidize more caregivers in order to alternate the care with the family caregiver when the main income of that household originates of the person under care and have no other source of income or government subsidies for survival<sup>(15,B,F,G,I,O,L,M,N,P,Q)</sup>.

The financial difficulty in home care generates limitations in sustaining the efficacy of PC, a fact that generates a feeling of impotence on the part of caregivers when they cannot perform the desired care functions. Continued care, government funded, or private care plans are a tactic to subsidize palliative care<sup>(G,H,K)</sup>.

Sleep deprivation emerged as a difficulty in the caregiver's experience<sup>(9)</sup>. Since most of them perform this full-time function, they need being alert most of the time to accompany their relative while taking care of them. They report

that the more dependent the user becomes and the closer to terminality, the greater the need to watch for signs and symptoms that require care<sup>(19,D,G)</sup>.

Sleep deprivation contributes vigorously to the caregiver's state of physical and mental exhaustion, making the quality of life of the caregiver and the care of the family member weakened and this contributes to the feeling of exhaustion<sup>(9,C,H,P)</sup>.

The logistics of medication administration was another significant experience expressed in article. The practice of administering medication is one of the most performed activities in patients with PC at home, since a primary principle of this type of care is the reduction or minimization of the patient's signs and symptoms, which can be attenuated through drug interventions or non-use of medicines<sup>(D,P)</sup>.

Managing and executing the administration of medication in patients in home PC by non-health care providers is becoming a more usual practice in this type of care. When the same activity is performed successfully, it generates pride and tranquility to the caregiver, because it can control symptoms<sup>(20,C)</sup>, but there is a bureaucracy in obtaining medical prescriptions to keep symptom control<sup>(15,I,M,K)</sup>, the lack of written and verbal information that clarifies the function, the way of use, the allowed dosages, the conservation and the stability of the medication<sup>(F)</sup>, makes the caregiver experience difficulty in managing this duty at home.

Health professionals play key roles in palliative care. They encourage family members in the decision-making process by providing information, offering support, mediating difficult situations, acting on the person's illness, death and dying in palliative care, and meeting both the needs of the sick and family members in order to minimize suffering in the bio-psycho-socio-spiritual aspects, enabling a better quality of life<sup>(21)</sup>.

From the review articles we can verify the complexity of the communication between the different professionals and health services of palliative care<sup>(L,M,R,S)</sup>. Poor communication and networking information may prevent professionals from getting to know the users of health services in a way that allows personalized assistance that enforces the principle of focusing

on the needs of the person in PC and their families.

The professionals who work in PCs face obstacles in the service environment as difficulties in accessing drugs that act on pain (opioids), due to the control over this medication, this being related to professional disability and disinformation in the treatment of the symptom<sup>(22)</sup>. There are also barriers related to the transportation of the staff to the home, to confront with complex states of patient's health and different socioeconomic situations.

The analysis of the studies included in this review indicates the lack of research that reveals the professional experience in the PC at home. In addition to a careful look at the training of professionals and caregivers involved in this care modality, it is opportune to develop research that reveals how health professionals are experiencing home PCs.

#### Use of strategies for the effectiveness of home palliative care

Properly caring for people who need palliative care requires specific skills and knowledge from professionals and caregivers who perform this role. In the studies analyzed, caregivers express the need for training so that they can provide these care adequately<sup>(P,T,U)</sup>, as they show insecurity and difficulties when the instructions, especially care practices do not happen<sup>(E,R)</sup>. One research<sup>(B)</sup> states that the control of signs and symptoms are the situations that generate anxiety in home palliative care.

Periodic meetings and support groups between health professionals and caregivers/family members are suggested in some studies<sup>(B,P,T,V)</sup>, so that doubts are remedied and exchanges of experiences are provided, thus reducing caregiver anxiety.

Since health professionals will not be full time in the home of the sick person, caregivers must carry out certain activities and procedures

related to preventive and/or control of health problems at home<sup>(23)</sup>. And for these activities and procedures to be performed it is necessary for health professionals to train caregivers. Thereby, these professionals must have training and experience to instruct the caregivers to practice, in addition to providing means to operationalize such action, in a responsible, judicious, ethical and legal manner, always using judgment.

The training of health professionals who provide palliative care in home care is the central cornerstone for the successful implementation of this modality of care in the practice of health services. Thus, the planning, design and development of continuing education will have positive impacts on the care of persons eligible for palliative care.

#### FINAL CONSIDERATIONS

It was evident that the family caregivers of patients undergoing palliative care at home experienced feelings that were mostly negative. With this, it is necessary to provide care to the caregiver, offering a care that includes the bio-psycho-socio-spiritual aspects, conditions that allow safety and comfort in the follow-up of the person in PC and family.

Health professionals are essential in palliative care. They face barriers that interfere with care such as poor communication and network information, obstacles to access to pain relief medications (opioids), transportation, professional inability, among others.

It was also possible to verify in the review the lack of studies that presents the experience of health professionals who work in the PCs at home, so that there is an urgent need for research that points the practice of the professionals involved in the CP, with quality, better organization of the support network and access to medicines for relief of symptoms.

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## CUIDADOS PALIATIVOS DOMICILIARES: REVISÃO INTEGRATIVA

### RESUMO

**Objetivo:** Analisar produções científicas nacionais e internacionais que apresentam vivências do cotidiano de cuidados prestados pelos cuidadores e profissionais de saúde nos cuidados paliativos domiciliares. **Método:** Trata-se de uma revisão integrativa nas bases de dados Lilacs, CINAHL, PubMed, IBECS, BDENF e Coleção SUS de artigos publicados entre janeiro de 2005 a março de 2019. A amostra final de artigos analisados foi composta de 42 artigos. **Resultados:** Os estudos evidenciaram sentimentos dos cuidadores de familiares como o medo, angústia, sobrecarga e

gratidão no cotidiano de cuidados ao ente adoecido; as principais dificuldades vivenciadas referem-se ao acesso a serviços de apoio, à aquisição de medicamentos pelos prestadores de assistência bem como ao uso de estratégias para a eficácia dos cuidados paliativos domiciliares. **Conclusão:** A análise evidenciou que há necessidade de construção de cuidado integral a pacientes e cuidadores, produção de evidências sobre as práticas profissionais dispensadas a este público, melhor organização da rede de apoio e acesso a medicamentos.

**Palavras-chave:** Cuidados paliativos. Cuidadores. Pessoal de saúde. Assistência domiciliar.

## CUIDADOS PALIATIVOS DOMICILIARIOS: REVISIÓN INTEGRADORA

### RESUMEN

**Objetivo:** analizar las producciones científicas nacionales e internacionales que presentan vivencias del cotidiano de cuidados prestados por los cuidadores y profesionales de salud en los cuidados paliativos domiciliares. **Método:** se trata de una revisión integradora en las bases de datos *Lilacs*, *CINAHL*, *PubMed*, *IBECs*, *BDEFN* y *Colección SUS* de artículos publicados entre enero de 2005 a marzo de 2019. La muestra final de artículos analizados fue compuesta de 42 artículos. **Resultados:** los estudios evidenciaron sentimientos de los cuidadores de familiares como miedo, angustia, sobrecarga y gratitud en el cotidiano de cuidados al ente enfermo; las principales dificultades vividas se refieren al acceso a servicios de apoyo, a la adquisición de medicamentos por los prestadores de atención así como al uso de estrategias para la eficacia de los cuidados paliativos domiciliares. **Conclusión:** el análisis evidenció que hay necesidad de construcción de cuidado integral a pacientes y cuidadores, producción de evidencias sobre las prácticas profesionales ofrecidas a este público, mejor organización de la red de apoyo y acceso a medicamentos.

**Palabras clave:** Cuidados paliativos. Cuidadores. Personal de salud. Atención domiciliar de salud.

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