PALLIATIVE CARE APPLIED TO THE ELDERLY AT HOME

Cuidados paliativos aplicados em idosos no domicílio
Cuidados paliativos aplicados a ancianos en el hogar

Adrielle Alves Santos¹
Arianna Oliveira Santana Lopes²
Nildeete Pereira Gomes³
Lélia Mendes Sobrinho de Oliveira⁴

ABSTRACT

Objective: to analyze scientific evidence on the use of palliative care applied to elderly at home. Methods: this is a systematic literature review, conducted in January 2020, using the descriptors: “palliative care” AND “health of the elderly” AND “home care”. Results: seven articles were selected, seven articles were selected, in which the following categories have emerged: Home care adapted to the needs of patients according to their available resources; Expansion of results through empowerment and autonomy in the participation of family care at home. Palliative care contributes to the improvement of psychological and emotional factors, positive coping and treatment acceptance. Conclusion: the literature has a general applicability without studies that specifically addresses the situation of the elderly. It also demonstrates a deliberate increase in the need for permanent assistance to these people with incurable diseases, requiring holistic support.

DESCRIPTORS: Palliative care; Health of the elderly; Home care.

¹Central de Marcação de Exames da Secretaria Municipal de Saúde, Tremedal, BA, Brasil.
²Faculdade Independente do Nordeste, Vitória da Conquista, BA, Brasil.
³Universidade Federal da Bahia, Salvador, BA, Brasil.
⁴Núcleo de Ensino e Pesquisa do Centro de Referência Estadual em Atenção à Saúde do Idoso, Salvador, BA, Brasil.

Received: 06/03/2020; Accepted: 09/24/2021; Published online: 02/03/2022

Corresponding Author: Arianna Oliveira Santana Lopes, E-mail: ariannasantana02@gmail.com

RESUMO
Objetivo: analisar evidências científicas sobre a utilização de cuidados paliativos aplicados em idosos no domicílio.
Métodos: trata-se de uma revisão sistemática de literatura, realizada em janeiro de 2020, utilizando os descriptores: “cuidados paliativos” AND “saúde do idoso” AND “assistência domiciliar”. Resultados: foram selecionados sete artigos, nos quais surgiram as seguintes categorias: Assistência domiciliar adaptada as necessidades dos pacientes de acordo com seus recursos disponíveis; Ampliação dos resultados através do empoderamento e autonomia na participação do cuidado familiar no domicílio. Os cuidados paliativos contribuem para a melhoria dos fatores psicológicos e emocionais, enfrentamento positivo e aceitação do tratamento. Conclusão: a literatura traz uma aplicabilidade geral sem estudos que tratem de forma específica a situação do idoso. Demonstra também um aumento deliberado da necessidade de assistência permanente a estas pessoas com doenças incuráveis, necessitando de apoio holístico.

DESCRITORES: Cuidados paliativos; Saúde do idoso; Assistência domiciliar.

RESUMEN
Objetivo: analizar la evidencia científica sobre el uso de cuidados paliativos aplicados a personas mayores en el hogar.
Métodos: esta es una revisión sistemática de la literatura, realizada en enero de 2020, utilizando los descriptores: “cuidados paliativos / cuidados paliativos” Y “salud de los ancianos / curar a los ancianos” Y “cuidado en el hogar / cuidado en el hogar”. Resultados: se seleccionaron siete artículos, que surgieron en las categorías: Atención domiciliaria adaptada a las necesidades de los pacientes de acuerdo con sus recursos disponibles; Expansión de resultados a través del empoderamiento y la autonomía en la participación del cuidado familiar en el hogar; Los cuidados paliativos contribuyen a la mejora de los factores psicológicos y emocionales, el afrontamiento positivo y la aceptación del tratamiento. Conclusion: la literatura tiene una aplicabilidad general sin estudios que aborden específicamente la situación de las personas mayores. También demuestra un aumento deliberado en la necesidad de asistencia permanente a estas personas con enfermedades incurables, que requieren un apoyo integral.

DESCRITORES: Cuidados paliativos; Salud de los ancianos; Atención domiciliaria.

INTRODUCTION

The increase of population aging in Brazil has revealed numerous challenges, both for the elderly and the caregivers. Limitations, chronic-degenerative diseases, disabilities, and complex situations resulting from functional decline are situations that require care at this stage. All of these factors consequently result in greater demand and search for health services that act more sensitively and effectively in interventions, capable of intervening and improving the quality of life (QOL) of the elderly, integrally, to meet their needs in a more efficient and holistic way, intensifying investments for a healthy old age. Some elderly can be affected by pathological conditions, such as cancer, musculoskeletal and chronic neurological diseases, causing functional dependence to perform basic activities, which, together with the decline of their health condition, require palliative care (PC).

Over the years, the prolongation of life is increasingly constant and death becomes less and less acceptable given the numerous resources that can be used to prevent it. When the possibility of extending this period is no longer possible, it is necessary to invest in PC. In this context, there is a need to discuss care for the end of life or quality in the last days of life.

The PC began in antiquity since the Middle Ages, during the Crusades as actions carried out in shelters, aimed at the orphans, the poor, the sick, the dying, the lepers, and women in labor. Sheltering not only the patients but also their families, with a view to hospitality, reception, protection, and care. In these approaches, the importance of valuing life in the front of the diseases and difficulties faced is highlighted, in a line of care and therapeutic principles, where familiar help and support are provided fully with the patient, in the performance of a multidisciplinary team.

This practice was initially linked to the care offered in nursing. The first reports of who since that time was already convinced of the importance of this practice to be dedicated to excellent care with holistic support, also recognizing its real needs in emotional, social, and spiritual practices, leaving her mark on the phrase “there is still a lot to do”.

Although PC practices are already very old and pioneered by nursing professionals, it has never been more necessary to discuss the processes of finiteness and care that involve this phase associated with the aging process in a multidisciplinary way and the most diverse spaces, including outside the hospital environment. Guaranteeing them an autonomous life, with dignity and recognition as subjects of rights.

Therefore, to investigate the types of PC offered, the professionals involved, the strengths and limitations of its application, as well as family participation in all phases and the therapeutic care of the disease, regardless of its evolution, becomes a matter of great relevance for the social, academic and health environment.
OBJECTIVE

This study aims to analyze scientific evidence on the use of palliative care applied to the elderly at home.

METHODS

This is a systematic literature review study, carried out in January 2020, with the purpose of carefully and systematically researching previous studies, putting the researcher in direct contact with everything that has already been published. Obeying the following steps:

1st PHASE – Definition of theme and guiding questions:
What does literature bring about the use of PC in the home care of the elderly? What are the used resources that allow these practices in the community?
The descriptors in health (DECS) and the Boolean operator “AND” were used to create the query: “palliative care” AND “health of the elderly” AND “home care”.

2nd PHASE – Sampling or literature search:
Data were obtained through an electronic search of articles in the Brazilian Virtual Health Library (BVS) and in the following databases: Cochrane Library, Spanish Bibliographic Index of Health Sciences (IBECS), Latin American and Caribbean Health Sciences Literature (LILACS), Medical Literature Analysis and Retrieval System (MEDLINE) and the Scientific Electronic Library Online (SCIELO).
The sample was selected through articles published in the last five years (2015 to 2019), with full texts in Portuguese, English and Spanish, related to the objective of the study, excluding theses and dissertations.

3rd PHASE – categorization of the studies:
After reading the title, abstract and keywords the articles were selected and then it was evaluated if they answered the study’s guiding questions.
The studies that met the criteria were fully read and organized in a table contemplating the following aspects: database; located articles; eligible articles; duplicate articles and selected articles (Table 1).

4th PHASE – Evaluation of the studies included in the systematic review:
For validation, a critical assessment of the impact of the selected files was performed, aiming to consider the strength of the evidence, exploring whether the observed effects are consistent across studies and investigating possible reasons for any inconsistencies.

5th PHASE – Interpretation of the results:
The data were organized into specific synoptic tables and analyzed in the light of the Categorical Thematic Content Analysis Technique proposed by Bardin. Synoptic charts entitled: Chart 1: Characteristics of the articles included in the review, in terms of title, year, country, author, journal, study objective and results; Chart 2: Characteristics of the types of palliative care, professionals involved, strengths and limitations for the application of palliative care at home.

6th PHASE – Synthesis of knowledge found in the articles:
The data found were presented after the definition of each category in a descriptive way, allowing the reader to access relevant knowledge that was proposed.

RESULTS

A total of 143 studies were found in the investigated databases, of which 60 were excluded for being classified as theses and dissertations, 76 for not being related to the guiding question and objectives of the study.

After reading the titles and abstracts of the seven articles covering the proposed topic, all were fully read and selected to compose the sample of this study, that can be seen in Chart 1.

After selection, the seven articles that met the inclusion criteria were inserted in the synoptic charts (1 and 2) below.

DISCUSSION

CHARACTERISTICS OF PALLIATIVE CARE IN PRIMARY CARE

It is unanimously observed that when PC is approached at home, they appear related to general groups other than the elderly, they are carried out by a multidisciplinary team with the objective of reaching an active listening, maintenance of awareness, hope and encouragement of religiosity/spirituality/psycho emotional and environmental needs.

PC assistance prevents and alleviates the patient’s suffering, through early identification, assessment and adequate treatment of pain, as well as physical, psychosocial and spiritual problems, being essential to ensure comprehensive care. Through a set of biopsychosocial and community level activities that are carried

<table>
<thead>
<tr>
<th>Data base</th>
<th>Located articles</th>
<th>Eligible articles</th>
<th>Excluded articles</th>
<th>Selected articles</th>
</tr>
</thead>
<tbody>
<tr>
<td>SCIELO</td>
<td>10</td>
<td>5</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>PUBMED</td>
<td>15</td>
<td>10</td>
<td>5</td>
<td>0</td>
</tr>
<tr>
<td>LILACS</td>
<td>32</td>
<td>10</td>
<td>21</td>
<td>4</td>
</tr>
<tr>
<td>MEDLINE</td>
<td>85</td>
<td>30</td>
<td>49</td>
<td>3</td>
</tr>
<tr>
<td>COCHRANE</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>0</td>
</tr>
</tbody>
</table>
Palliative care applied to the elderly at home

Vitória da Conquista, BA, Brazil. 2020

Chart 1 – Characteristics of the articles included in the review, in terms of title, year, country, author, journal, study objective and results. Vitória da Conquista, BA, Brazil. 2020

<table>
<thead>
<tr>
<th>Title</th>
<th>Year and code</th>
<th>Author/journal</th>
<th>Studies’ objective</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Oncological palliative care in a public home care service</td>
<td>2017 (01)</td>
<td>Patrícia Pilattia et al. Rev Bras Med Fam Comunidade</td>
<td>To identify the profile of patients with cancer and palliative care and their demands regarding the multidisciplinary care existing in a Home Care Service.</td>
<td>In the practice of this service, it is observed that most patients needed complex care, but possible to be performed at home by the health team and/or trained caregiver.</td>
</tr>
<tr>
<td>Corporeality of oncological patients in palliative home care: the experience of family caregivers</td>
<td>2018 (02)</td>
<td>Raisa Silva Martins’ et al. J. res.: fundam. Care</td>
<td>To describe the experience of caregivers with regard to care for the dimensions of the body of patients in palliative home care.</td>
<td>Their experiences manifest the knowledge that the cure will not be achieved and that the aggravated physical condition can only be postpone, however, they often manifest as an (in)perceivable desire the aspiration of a probable physical recovery.</td>
</tr>
<tr>
<td>Factors predicting a home death among home palliative care recipients</td>
<td>2017 (03)</td>
<td>Ming-Chung Ko, et al. Medicine</td>
<td>To evaluate the factors that predict home death among patients in palliative care.</td>
<td>The overall rate of death at home for patients on PC was 43.6%. Doctors’ home visits increased the likelihood of death at home. The greater the number of consultations, the greater the probability of death at home. Compared with hospitalized individuals, the greater the number of hospitalizations, the lower the probability of death at home.</td>
</tr>
<tr>
<td>Family Caregiver Participation in Palliative Care Research: Challenging the Myth</td>
<td>2017 (04)</td>
<td>Samar Aoun, PhD, et al. J Pain Symptom Manage.</td>
<td>To analyze the experiences and impact of research involvement in family caregivers (FCs) of terminally ill people, focusing on home PC.</td>
<td>97% of the control and intervention groups perceived positive and beneficial aspects, while almost all of them did not report any negative aspects of being present in this research.</td>
</tr>
<tr>
<td>Identification and characteristics of patients with palliative care needs in Brazilian primary care</td>
<td>2016 (05)</td>
<td>Marcucci, et al. BMC Palliative Care</td>
<td>To provide information about patients with PC needs in Brazilian primary care services.</td>
<td>Patients with PC needs are accessing the ESF program, regardless of the lack of specific PC support. Of the 238 patients identified, 73 (43 women, 30 men) were identified as needing PC, and their mean age was 77.18 years, with non-malignant neurological conditions such as dementia and cerebrovascular diseases being the most common (33% of all patients). Chronic conditions (2 years or more) were found in 70% of these patients, with 71% scoring 50 or fewer KPS points.</td>
</tr>
<tr>
<td>Prevalence and typology of patients susceptible to palliative care who died at home</td>
<td>2018 (06)</td>
<td>Martínez Ríos, et al. An. Sist. Sanit. Navar</td>
<td>To compare, globally and by sex, the type of disease of patients with PC and those identified as histories.</td>
<td>As a result of death at home, only 66.4% of the histories were identified. Cancer, usually in men, was the most frequent and frequently identified, although 80% of the dementia population, frequent in women, was not identified as palliative.</td>
</tr>
<tr>
<td>The interfaces between social support, quality of life and depression in patients eligible for palliative care</td>
<td>2017 (07)</td>
<td>Cissa Azevedo al. Rev. esc. enfer. USP</td>
<td>To analyze the relationship between social support, QOL and depression in patients eligible for PC treated in Primary Care in an interior city of Minas Gerais, Brazil.</td>
<td>The greater the social support, the better overall quality and functional QOL; the highest level of physical symptoms, the lowest level of social support and the highest level of depression; such as symptoms of major depression, lower general and functional QOL and lower levels of social support.</td>
</tr>
</tbody>
</table>

Chart 2 – Characteristics of the types of palliative care, professionals involved, positive points and limitations for the application of palliative care at home. Vitória da Conquista, BA, Brazil. 2020

<table>
<thead>
<tr>
<th>Code</th>
<th>Types of palliative care</th>
<th>Professionals involved</th>
<th>Positive points</th>
<th>Difficult and limitations for its application</th>
</tr>
</thead>
<tbody>
<tr>
<td>01</td>
<td>- Pain control;</td>
<td>HC multidisciplinary teams and also the multidisciplinary support teams.</td>
<td>Identification of the main demands of patients in cancer PC assisted by an HC service.</td>
<td>There are challenges with regard to care with a view to comprehensive care, both in relation to the support of services and the preparation of health professionals to promote care with families.</td>
</tr>
<tr>
<td></td>
<td>- Dressings in oncological surgical wounds or pressure injuries;</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Glycemic control;</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Administration of medications;</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Food through the most diverse ways</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Oxygen management, tracheostomy and aspiration;</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Management of ostomies;</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Catheter management</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Code</td>
<td>Types of palliative care</td>
<td>Professionals involved</td>
<td>Positive points</td>
<td>Difficult and limitations for its application</td>
</tr>
<tr>
<td>------</td>
<td>----------------------------------------------------------------------------------------</td>
<td>----------------------------------------------------------------------------------------</td>
<td>------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>02</td>
<td>Procedures related to care such as food, medication, evacuations and dressings; * Faculties reflected in corporeality, such as: Love, affection, active listening, awareness, hope and encouragement of religiosity/spirituality/psycho-emotional and environmental needs.</td>
<td>Oncology team with 17 other medical specialties.</td>
<td>The smoothing of unexpected transitions and the glimpse of progress in quality of life in nursing coordination was also described in a service that offered a palliative approach to chronic diseases through innovative solutions, sources of support, training and education throughout life.</td>
<td>Nursing behaviors need to provide the means that start effective treatment of the disease, encouraging them not to neglect aspects inherent to the subjective faculties of being sick. During the visits, the team must invest in the biopsychosocial area and emotional support in a uniform way, preparing everyone for the outcome.</td>
</tr>
<tr>
<td>03</td>
<td>Nasogastric tube insertion procedure, indwelling urinary catheter and endotracheal tube insertion being used to identify its use.</td>
<td>Doctors, nurses or other health professionals.</td>
<td>Awareness of the factors that predict a death at home among patients who receive CP at home can improve communication between healthcare professionals and patients and their families about the patient’s preferences and the feasibility of dying in the preferred location.</td>
<td>Important characteristics, including socioeconomic status, preference of PC recipients at home, as well as the preference of caregivers at the place of death, and status and roles of family caregivers must be considered. Characterization and profile of patients in PC at home.</td>
</tr>
<tr>
<td>04</td>
<td>Investment in qualified listening and caregiver support</td>
<td>Nursing Consultants at Silver Chain Hospice Care Service Clinic in Perth, Western Australia.</td>
<td>It provided them with the opportunity to share their experiences, stimulating reflection, heightened awareness of emotional concerns and a sense of validation in their role as caregivers.</td>
<td>The caregiver’s involvement in PC actions can be influenced by the nurse’s workload on the day and with the pressure of time that she adapts to the various patients who needed to be visited.</td>
</tr>
<tr>
<td>05</td>
<td>Supply of medication, technical guidance from both professionals, supply of material for dressings or PPE and professional care.</td>
<td>Community health agents, doctors, nurses, physiotherapists and nutritionists</td>
<td>The screening method used proved to be feasible for identifying patients with indication to receive PC, but further studies are needed to investigate how these conditions impacted the demands of the PHC and to identify more offered ways of care to patients with advanced stage diseases or with no possibility of cure, as well as integrating the PC in the health service network.</td>
<td>Lack of research on this topic to understand this reality and provide adequate support for these patients; It is necessary to develop public policies that encourage the inclusion of actions in the PC in a planned way to meet the complexities of these conditions and encourage the training of health professionals in this area, including a dissemination of the theme in academic training.</td>
</tr>
<tr>
<td>06</td>
<td>Set of biopsychosocial and community-level activities that are carried out in the person’s home, in order to detect, assess, support and monitor the social and health problems of the individual and their family, to increase autonomy and improve their quality of life.</td>
<td>Health history of the Andalusian Public Health System (SSPA).</td>
<td>The identification of those patients who die at home who are susceptible to PC and their subsequent inclusion in the PAI-PC, presents a remarkable opportunity rate of improvement, especially in patients with non-oncologic diseases, if there are differences by sex in said fictional identity.</td>
<td>Obtain central medical assistance and experience in resolving symptomatic problems, providing the comfort and help to achieve a peaceful death, for which it is essential to identify.</td>
</tr>
<tr>
<td>07</td>
<td>PC prevents and alleviates the suffering of the patient, through early identification, assessment and adequate treatment of pain, as well as physical, psychosocial and spiritual problems, being essential to ensure complete care.</td>
<td>APS Units (UAPS) of an interior city of Minas Gerais, Brazil.</td>
<td>The availability of social support positively influences biological systems, the general health status and the psychological well-being of patients.</td>
<td>It is necessary to prepare the health units to deal with this new care scenario. An important challenge for the implementation of PC in PHC is an adequate assessment of the patient, including the identification of parameters to support the diagnosis, with the incorporation of means and the preparation of the team to increase the UAPS’ resolving capacity.</td>
</tr>
</tbody>
</table>
out in the person's home, in order to detect, assess, support and monitor the social and health problems of the individual and their family, to increase autonomy and improve their QOL.

These needs range from adaptations in the environment to spiritual, emotional and religious demands; they must be adapted to the available resources that allow these practices in the community with the professional help of doctors, nurses and other health professionals such as psychologists, nutritionists and physiotherapists before multidisciplinary teams of HC for continuous integral care, promoting health and well-being in QOL respecting their own particularities and personal references.

**CATEGORY 1: HOME CARE ADAPTED TO THE PATIENTS’ NEEDS ACCORDING TO THEIR AVAILABLE RESOURCES**

Articles A1, A2, A3 and A6 highlight the importance of developing PC in home care adapted to the needs of individuals with available resources.

With regard to the health care of individuals in PC, this requires a multidisciplinary approach that precedes and prepares for the mourning phase and involves issues of health, physical, spiritual and emotional well-being. In this sense, the multidisciplinary approach is dimensioned on a practical level, recognized in the planning and coordination of efficient actions to fully meet the needs of patients and families in conjunction with the services that make up the Health Care Network (HCN).

David Le Breton, when describing the situation of death and dying, considers the existence of connections characterized as bodily and brings the individual's aversion and resistance to an expected and feared physiological process. When there is a crisis in the identity of legitimacy of bodily actions, its correspondence with the world is shaken, affected by these oscillations, the subject hesitates to confirm the physical imprisonment of which he is the object. The body should not be a prominent place, but an inclusion that surpasses individual existence yet simultaneously connects the subject to others.

Late-stage demands are distinct and some places of death may be more suitable for certain patients than others. Place of death, and particularly death at home, is sometimes seen as an important indicator of the quality of care at the end of life, however, certain factors of the place of death may be more modifiable than others. Understanding the factors that affect the place of death can not only improve communications between healthcare providers and patients and their families regarding patients’ preferences and the feasibility of dying at the preferred place, but also inform policy decisions that aim to improve the likelihood of patients dying.

Within the different organizational models of terminal care, there is home care, defined as the set of biopsychosocial and community activities carried out in the person's home, in order to detect, assess, support and monitor the social and health problems of the individual and their family, to increase autonomy and improve their QOL. This model of care is very important, as most terminal patients want to be cared for and die at home, as long as they have adequate care and are well informed. In this same sense, the challenge of caring for the terminal patient at home is to obtain health care aimed at solving symptomatic problems, providing comfort and helping to reach death in peace, for which it is essential to correctly identify this population.

It is observed in the selected articles that the practice of PC in primary care is limited to HC in the home care format. But little is discussed about PC at home.

Home care is one of the key factors to achieve a high degree of humanization, fully involving the family in their proper care, the necessary support and care, effecting benefits, decreasing complications and long hospital stays, technological costs are reduced, materials and all possible expenses that are required.

But this home care requires adaptations in the health services that will be offered at home. It is observed that as there is a rapid transformation of population aging, health practices are also affected, it is necessary to adapt care to new technologies, thus meeting the demands.

It appears that some conditions are necessary for patient care to be effective, such as the previously established therapeutic plan, obeying all imposed factors; having continuous and adequate monitoring of the PC team; living in a home that offers the minimum necessary conditions for hygiene and food; having one or more responsible caregivers, in order not only to understand, but to perform all the proposed interventions in a succinct and objective manner, following the appropriate guidelines, in the patient's desire and permission to remain at home.

Through these concepts, it is observed that the dedication of zeal and attention between the caregiver and the person being cared for are dedications imposed together, where physical, financial, emotional, social and existential factors need to be taken into account. In a multidisciplinary team, imposing comprehensive health, and daily monitoring.

**CATEGORY 2: EMPOWERMENT AND AUTONOMY IN THE PARTICIPATION OF FAMILY CARE AT HOME**

Empowerment and autonomy were aspects identified as relevant in the application of PC at home. Giving an opinion on the treatment to be followed and deciding on the finiteness process were the factors highlighted in articles A1, A2 and A7. In articles A1, A4, A5, A6, A7, the expansion of results and adherence to treatment were associated with possible and appropriate interventions through PC at home.

Another major challenge to be faced when caring for PC patients at home concerns the professional preparation to deal with and address grief with the family. It is understood that this is a topic that needs to be worked on in spaces for discussion and support for the teams themselves. Authors like Pereira, highlight the importance of training professionals involved in PC and relate work as "experiencing pain, suffering, disputes and tensions between users and family members together, the
desires of each one, negotiating in the face of conflicts, so that defense is guaranteed of life on the verge of death."

Thus, nursing care at home should integrate the family as an effective care strategy, however, this framework should not be a tool of unrealistic optimism about the cure, but a strategy so that care is shared and difficulties minimized and adapted.

Although there are already several specialized services in PC, patients with non-cancerous chronic diseases are assisted in parallel in the Primary Health Care (PHC) environment. Therefore, considering the fact that most people prefer to die at home rather than in hospitals, the role of PHC in PC becomes increasingly important and significant.16

The selected studies demonstrated that PC are provided by a multidisciplinary team, with the aim of optimizing the QOL of patients and their families, in the face of a serious disease, regardless of the prognosis. PC can then be started at any stage of a chronic illness, and in conjunction with curative or life-extending treatments.16

For PC to be effectively applied in PHA, it is necessary to invest in prior guidance and knowledge for those involved, including among users and in groups.

In view of the epidemiological and demographic transition processes that indicate an aging population, around 40 million people need this care, 78% live in a low- and middle-income country and only 14% have access to care. Considering these alarming numbers, it is necessary to obtain full attention, given this evidence, with changes for these reported cases.17

Brazil offers universal health coverage at all levels of care through a decentralized network of health services, which includes community health units, clinics and hospital care, free of charge at the point of delivery for the entire population. However, limited resources can affect the quality of health services and, although chronic non-communicable diseases (CNCDs) have a high impact on the Brazilian population and account for the majority of deaths, there are few specific policies to support PC in the public system of health. As a result, Brazil has a low rate of deaths at home or in nursing homes, and high occurrences in hospital environments, when compared to other countries.18

Functional incapacity, vulnerability and limitation caused by CNCDs require interdisciplinary looks at new practices in public health, since the need for prevention, care and rehabilitation can directly reflect on public spending19. In the current Brazilian health model, the objective is to achieve an increasingly early de-hospitalization, reducing the risk of infections in stable elderly and hospital costs. In this way, home care reduces periodic consultations, allowing for complete and individual-centered care.17

The identification of patients susceptible to PC at home is essential for its clinical management, since in the terminal situation there is physical deterioration, increased weakness, decreased alertness and even difficulties in administering oral medications can cause additional suffering to the patient and the family. Therefore, it is necessary to know the characteristics and type of disease of the population susceptible to PC who die at home, according to gender, to reinforce their acceptance and improve their care.12

Faced the conditions with proximity to death or that limits patient survival, PC present an approach that seeks to guide actions to favor the increase in the QOL of the elderly, reducing the symptoms and afflictions of this moment, in addition to favoring autonomy and expanding support for family members and caregivers. However, its insertion in health services is still limited in Brazil, so it is necessary to spread its potential to health professionals and structure policies to expand its application.20

On account of this, it is observed that the process of professional training is still in its infancy regarding the PC theme, with the biggest problem among professionals being the lack of information. The theme is little discussed in nursing graduation and among health professionals, who are poorly trained to deal with the elderly in coping with terminal illness through PC, and it is rare in some educational institutions to approach the topic itself. the situation of death is frequent even at home and therefore it becomes a duty of every professional to know how to deal with it.21

Then comes the proposal of higher QOL through PC, in the process of death and dying, recovering its principles that were interrupted in the face of the current diagnosis, through a therapeutic plan, in the ideals of bioethics, having autonomy and discernment necessary to establish and/or keep its essence.4

Nursing, therefore, even in primary care, has a fundamental role in this type of care, its main attribution is to establish a care plan, expanding its discussion in relation to themes inherent to human life and the process of death and dying, understanding that they are moments of adaptation and change, in which the individual is faced with finitude, where non-acceptance occurs, and where family and professional support is necessary, from everyone around them.4

Once the minimum requirements are met, comprehensive care will be achieved, ensuring the autonomy and participation of the user in the care process, in a continuing education, associated with safety and comfort at home, according to the necessary support from the family and others.15

**CATEGORY 3: PALLIATIVE CARE AND IMPROVEMENT OF PSYCHOLOGICAL AND EMOTIONAL FACTORS, POSITIVE COPING AND ACCEPTANCE OF TREATMENT**

Articles A1, A4, A5 and A7 point to improvement in the psychological and emotional factors of those involved, which consequently contributes to positive coping with the diagnosis and acceptance of treatment.

In a study whose objective was to investigate whether mood influenced measures of social support and QOL in elderly patients, it was found that those who have better levels of social support have fewer depressive symptoms, and therefore, that social support is an important factor capable of protecting or predisposing a person to depressive mood, consequently affecting their QOL.
Results like this suggest the importance of further research on the benefits of psychosocial assessment of patients in PC, in order to ensure the expansion of care and thus improve their QOL.4

The integration of PC in the health system is considered an important aspect for quality care at the end of life. According to the Global Atlas of PC at the End of Life, countries with a high standard of PC support are characterized by the development of social activism; broad offering by multiple service providers; broad awareness of PC by health professionals and society in general; unrestricted access to opioids and strong pain relievers; specific policies in this area, in particular in public health; educational and academic structure associated with the development of PC; and the existence of a related national association.18

According to Mendes and Vasconcellos,22 an effective change is needed from the fragmented model of PC care, in which the principles of the Unified Health System (SUS) are guaranteed and there is social and psychological support for patients and families at this very delicate moment in which they find themselves, as well as, interlocution between these various areas of care. HC can enhance new forms of care production and performance linked to Health Care Networks (HCN), focusing on the health needs of patients and the applicability to PC, as they are not exclusive practices for chronic or degenerative diseases, but expands in various aspects and behaviors.23

These emotional aspects also affect the caregiver. It is of supreme importance to provide support to caregivers as well, as they often remain fragile in the face of all the challenges faced, thus emerging the need for emotional and physical support, so that they can develop their assistance subsequently to be cared for.24

This is, therefore, a great challenge to be overlook in PC, the preparation of professionals, to deal and approach individuals correctly, as it involves mourning in the family, requiring correct and firm information to maintain, designate and intervene with caution, providing appropriate spaces and discussions, preparing them. Therefore, there is a need to empower them, living together, guaranteeing the defense of life in the face of death.9

Providing assistance to family members and people close to the patient is essential, allows family participation in all phases and therapeutic care in the bond and including them in their experience, making them realize their reality and face it in harmony, of safe and responsible way, taking an active role, to pre-establish and make free choices in all its proposed decisions in a clear and transparent manner.4

CONCLUSIONS

It is concluded that on the use of PC for home care for the elderly, the literature has a general applicability without studies that specifically address the situation of the elderly. It demonstrates a deliberate increase in the need for permanent assistance to these people with incurable diseases in need of holistic support.

Home PC are performed by a multidisciplinary team and must be tailored to the needs and reality of individuals. Aspects such as autonomy and participation in care processes and valued in palliative behaviors are pointed out as amplifying the results and acceptance of treatments and diagnoses. Positive influences on the patient’s psychological and emotional aspects were also identified as benefits and need to be intensified with the family members involved.

The study points out as limitations and difficulties in the applicability of PC at home, the lack of preparation of professionals, inadequate environments and the need for guidance and care for caregivers as well.

Clearly and succinctly, the studies state the importance of providing this care, encouraging their adaptation through therapeutic and multidisciplinary advances, in the achievement of an improvement in QOL, acting indispensably in the prevention and relief of suffering, in resources that are used allowing practices in the community where community members can also be involved, in controlling basic symptoms, communication skills, valuing and recovering ethical, social, environmental, spiritual and psycho-emotional principles, determining their autonomous decisions and respecting their due spaces as subjects of rights.

In view of this set of tools to be used, it appears that there is a need to raise awareness among the population, which is essential for the Brazilian health system to change its approach to patients who are threatening the continuity of their lives. Being a public health need, a humanitarian need.

REFERENCES


