Palliative Care for the Elderly in the Healthcare System: A Scoping Review

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Subject: Chronic care.

Contribution to the subject: The present study results highlight the relevance of discussions addressing palliative care for elderly individuals and their families in the Healthcare System. Such discussions are groundbreaking in contributing to solid national policies and guidelines that integrate and improve palliative care practices at all levels of care, especially primary healthcare and homecare. In addition, it provides an opportunity for the nursing team and other healthcare professionals to reflect on the relevance of palliative care practices for the elderly on a humanized and comprehensive basis.

Abstract

Objective: To map the scientific evidence related to the organization of palliative care practices provided for the elderly in the Healthcare System. Materials and methods: This is a scoping review following the Joanna Briggs Institute's method. The search was conducted in the PubMed, Cinahl, Web of Science, Scopus, VHL/Lilacs, Embase, and Cochrane databases, identifying 1,150 articles managed using the Endnote software. After the selection, the study sample consisted of 12 articles. The data were organized in Microsoft Excel spreadsheets, submitted to descriptive analysis, and discussed with the literature. Results: The relevance of palliative care practices for older adults to be organized in the Healthcare System was noted, focusing on primary healthcare, at home, and interdisciplinary coordination. However, there is still a fragmented offer of this care with limited considerations regarding the challenges and possibilities of its effectiveness. Conclusions: The mapping of scientific evidence on the subject shows that discussions regarding the insertion of palliative care in the Healthcare System are modest. The studies explore the role of primary care as the organizer of these practices, although in a fragmented perspective, with limited coordination between the Healthcare System services.

Keywords (Source: DeCS)

Aged; frail elderly; palliative care; primary health care; comprehensive health care.

Cuidado paliativo al anciano en la Red de Atención de Salud: una revisión de alcance

Resumen

Objetivo: mapear las evidencias científicas relacionadas con la organización de las prácticas de cuidado paliativo al anciano en la Red de Atención de Salud. Materiales y método: scoping review por el método Joanna Briggs Institute. La búsqueda se realizó en las bases de datos PubMed, Cinahl, Web of Science, Scopus, BVS/Lilacs, Embase y Cochrane, con identificación de 1150 artículos, los cuales fueron gerenciados por el software Endnote. Luego de la selección, 12 artículos compusieron la amuestra del estudio. Los datos se ordenaron en planilla del Microsoft Excel, se sometieron a análisis descriptivo y se discutieron con la literatura. Resultados: se observó que la organización de las prácticas de cuidado paliativo al adulto mayor desde la Red de Atención de Salud, con enfoque en la atención primaria de salud, en la residencia y en la articulación interdisciplinaria es importante. Sin embargo, aun hay fragmentación en la oferta de este cuidado, con limitadas consideraciones en cuanto a los retos y posibilidades de su efectuación en todos los niveles de atención. Conclusiones: el mapeo de las evidencias científicas sobre el tema demuestra que son modestas las discusiones en torno de la inserción de los cuidados paliativos en la Red. Los estudios exploran el rol de la atención primaria de salud como ordenadora de estas prácticas, aunque en una perspectiva fragmentada, con poca articulación entre los servicios de la Red.

Palabras clave (Fuente: DeCS)

Anciano; anciano frágil; cuidados paliativos; atención primaria de salud; atención integral de salud.

Cuidado paliativo à pessoa idosa na Rede de Atenção à Saúde: uma revisão de escopo

Resumo

Objetivo: mapear as evidências científicas relacionadas à organização das práticas do cuidado paliativo à pessoa idosa na Rede de Atenção à Saúde. Materiais e método: scoping review pelo método Joanna Briggs Institute. A busca foi realizada nas bases de dados PubMed, Cinahl, Web of Science, Scopus, BVS/Lilacs, Embase e Cochrane, sendo identificados 1150 artigos, os quais foram gerenciados pelo software Endnote. Após a seleção, 12 artigos compuseram a amostra do estudo. Os dados foram organizados em planilha do Microsoft Excel, submetidos à análise descritiva e discutidos com a literatura. Resultados: observou-se a importância de as práticas de cuidado paliativo à pessoa idosa serem organizadas na Rede de Atenção à Saúde, com foco na atenção primária à saúde, no domicílio e na articulação interdisciplinar. Contudo, ainda há fragmentação na oferta desse cuidado, com limitadas considerações quanto aos desafios e possibilidades da sua efetivação em todos os níveis de atenção. Conclusões: o mapeamento das evidências científicas sobre o tema mostra que são modestas as discussões em torno da inserção dos cuidados paliativos na Rede. Os estudos exploram o papel da atenção primária como ordenadora dessas práticas, ainda que em uma perspectiva fragmentada, com pouca articulação entre os serviços da Rede.

Palavras-chave (Fonte: DeCS)

Idosos; idoso fragilizado; cuidados paliativos; atenção primária à saúde; assistência integral à saúde.

Introduction

Population aging is now a phenomenon in developed and developing countries (1). The proportion of people in their 60s and older worldwide is growing faster than the other age groups. It is estimated that by 2050 there will be two billion older people, of which 80% will live in developing countries (2). Despite these estimates, the Pan American Health Organization (3) published the World Report on Aging in 2022, expressing concern over widespread age-related healthcare rationing and indicating that health research tends to exclude older adults, even though several health conditions are more prevalent in elderly individuals.

The population's longevity, associated with social and family changes, such as the increasing insertion of women in the workplace and the reduction in the size of families, raise concerns regarding the care provided to the elderly who depend on third parties (4). It stands out that the increase in life expectancy and the high morbidity rate due to chronic-degenerative diseases are some of the most significant challenges for public health today (5-7).

Although the disease affects the individual, its consequences also affect the family and the people who live and work with the patient, in a process that challenges and modifies family roles and group dynamics (8). In addition, the older adult's aging process leads to feelings that involve the perspective of life terminality, both for their families and the professional team (9-11). Thus, with an aging population that will live and die under more complex conditions, the demand for care tends to increase, along with the demand for palliative care (12-14).

Palliative care (PC) was defined in the 1990s and restated in 2002 by the World Health Organization (WHO) as a multidisciplinary approach that aims to improve the quality of life of patients and their families in the presence of a life-threatening illness through the prevention and relief of suffering, accurate and careful assessment, treatment of pain, and other demands (physical, psychosocial, or spiritual) (5, 8). More recently, this concept has been redefined, and PC now includes chronic conditions that are progressive from diagnosis, along with therapies that can modify or potentially cure the disease (15, 16).

PC must be regarded as a fundamental right of individuals and an essential component of comprehensive and integrated care throughout life, including at the end of life (10). Although a relatively new component of modern healthcare, it is becoming increasingly recognized as an essential part of all health systems (12). It should be available in any healthcare setting, such as hospitals, long-term care facilities, health centers, and even in patients' homes (16, 17).

In 2018, recognizing the need to improve and implement evidence-based PC policies and to support the comprehensive improvement of health systems at all levels, the Ministério da Saúde (Ministry of

Health) of Brazil published Resolution 41, which provides guidelines for the organization of PC in light of integrated continuous care within the scope of Brazil's Sistema Único de Saúde (Unified Health System) (18).

However, the implementation of comprehensive care in the Rede de Atenção à Saúde - RAS (Healthcare Network System - HNS) implies strategies that anticipate the transition of this type of care across various levels within this System. The transition of care is a strategy that involves a group of planned measures to ensure the continuity and safe coordination of the care provided, which can increase the quality of life of patients and their families (19, 20).

Therefore, conducting studies that allow a broader view of PC in the HNS is considered relevant, so patients and their families can receive comprehensive care. Given the above, this study aims to map the scientific evidence related to the organization of PC practices for older adults in the HNS.

Materials and methods

This scoping review is based on the international guidelines of the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR [21]), whose protocol was registered in the Open Science Framework (https://osf.io/83p7u/). The review was conducted according to the Joanna Briggs Institute (22) methodological guidelines, with the following steps: 1) identification of the research question; 2) identification of relevant studies; 3) study selection; 4) data analysis; 5) data grouping, synthesis, and presentation.

The review question and the inclusion and exclusion criteria were discussed and agreed upon by the researchers. The guiding question was defined using the PCC strategy, where P (population) is older adults, C (concept) is PC, and C (context) is the HNS. The question was: "How are PC practices organized for the elderly in the HNS?"

The sample was composed of studies that met the following inclusion criteria: Articles published in national and international journals from January 2010 to March 2021 in Portuguese, English, and Spanish. Articles that were not available in full-text were excluded, as well as gray literature, such as monographs, dissertations, theses, books, blogs, editorials, and guidelines. It is noteworthy that the gray literature was excluded to eliminate possible biases related to the inclusion of evidence with value judgment or opinions that failed to represent the subject matter; furthermore, due to the possibility of excessive volume of material, it would require the expansion of the inclusion criteria, possibly affecting the sample of scientific articles found. Studies that described and discussed the organization of PC practices for the elderly from the perspective of the HNS were considered eligible.

The search strategy was carried out by a librarian at the Biblioteca Baeta Vianna (Baeta Vianna Library) of the Universidade Federal de Minas Gerais (Federal University of Minas Gerais), Brazil. The articles found were managed using the Endnote software, which allowed peer review to be carried out independently. The search was conducted in April 2021 in the following databases: Medline®/National Library of Medicine (PubMed), Scopus, Cumulative Index to Nursing and Allied Health Literature (Cinahl), Web of Science (WoS), Embase, Cochrane, and Biblioteca Virtual de Saúde (BVS). The Health Sciences Descriptors (DecS) and Medical Subject Headings (MeSH) related to the elements of the research question were used, as shown in Table 1.

Table 1. Definition of database search strategies, Belo Horizonte, 2022

| Database | Search strategy | | | |
|---|--|--|--|--|
| BVS* | (idoso OR idosos OR "pessoa idosa" OR "pessoa de idade" OR "pessoas idosas" OR "pessoas de idade" OR "população idosa" OR "idoso fragilizado") AND ("cuidados paliativos" OR "assistência paliativa" OR "cuidado paliativo" OR "cuidado paliativo de apoio" OR "tratamento paliativo" OR "cuidados paliativos na terminalidade da vida" OR "cuidado paliativo a doentes terminais" OR "cuidados a doentes terminais" OR "cuidados de conforto" OR "programas de cuidados intermitentes" OR "programas de cuidados paliativos" OR "estado terminal" OR "doença terminal" OR "estado crítico") AND ("assistência integral à saúde" OR "atenção primária à saúde" OR "atenção secundária à saúde" OR "atenção terciária à saúde" OR "colaboração intersetorial" OR "serviços de saúde para idosos") | | | |
| Medline/PubMed Cochrane Cinahl Scopus WoS | (aged OR "frail elderly") AND ("palliative care" OR "hospice care" OR "critical illness") AND ("comprehensive health care" OR "primary health care" OR "secondary care" OR "tertiary healthcare" OR "intersectoral collaboration" OR "health services for the aged") | | | |
| Embase | (aged OR "frail elderly") AND ("palliative therapy") AND ("primary health care" OR "secondary health care" OR "tertiary care center" OR "intersectoral collaboration" OR "elderly care") | | | |

Source: Elaborated by the authors.

The first step involved searching the databases and extracting the identified articles into the EndNote® software. The articles then had their titles and abstracts read and analyzed by six reviewers, who worked in pairs in a double-blind format to select the potential eligible articles. In cases of doubts regarding inclusion, the researchers performed the inclusion analysis jointly.

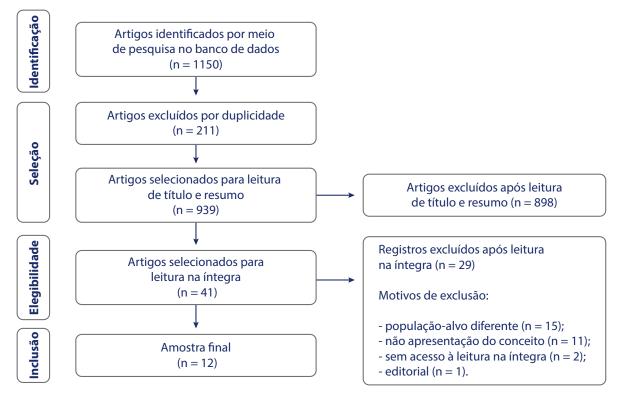
The articles that composed the final sample were read in full by all reviewers independently, aiming to answer the review question and extract the data of interest. It should be noted that the reference lists of the article sample included in the review were examined for additional sources. However, no articles were added. Subsequently, the data were organized in a spreadsheet created in Microsoft Excel 2016, whose structure contemplated essential elements of

the studies: Publication year, country of origin, objectives, study type, population, study site, and main results. The data synthesis is descriptively presented in this article and discussed with the relevant literature.

Results

A total of 1,150 articles were identified in the database search, and the final sample consisted of 12 articles, as shown in Figure 1.

Figure 1. Study selection flowchart, adapted from PRISMA-ScR, Belo Horizonte, Minas Gerais, Brazil, 2022



Source: Elaborated by the authors.

The 12 articles included in this review were organized into a bibliographic framework presented in Table 2, containing the article title, country of origin, publication year, type of study, and result synthesis.

Table 2. Articles included in the scoping review, Belo Horizonte, Minas Gerais, Brazil, 2022

| Author(s) | Title | Location, year | Type of study | Article result synthesis |
|---|--|-----------------|----------------------|--|
| Albers G, Froggatt K, Van den Block L, Gambassi G, Vanden Berghe P, Pautex S, et al. (23) | A qualitative exploration of the collaborative working between palliative care and geriatric medicine: Barriers and facilitators from a European perspective | Europe, 2016 | Qualitative study | States that the care system for the elderly in PC should be based on the premise of interdisciplinary coordination Points to the fragmentation of care for the elderly in PC and the frailty of communication between disciplines Stresses the relevance of interdisciplinary teamwork as an opportunity for mutual and collaborative learning |

Author(s)

Ankuda CK,

Petterson SM,

Wingrove P,

Bazemore AW

(24)

Title

Regional variation in

primary care involvement

at the end of life

Providing optimal

palliative care for persons

Location, year

The United

States of

America,

2017

The

Netherlands

Type of study

Cross-

sectional study

Article result synthesis • Discusses how the participation of primary

care medical professionals in PC for the elderly

reduces health system costs, the length of stay

in hospital institutions, and invasive procedures

• Indicates that care at the primary level reduces

the fragmentation of care for the elderly in

• States that the main obstacles faced by the

healthcare system in managing older adults

with dementia in PC are professionals' limited

end-of-life care

| | Brasil K, Galway K, Carter G, Van der Steen JT (25) | living with dementia: A comparison of physician perceptions in the Netherlands and the United Kingdom | Netherlands and The United Kingdom, 2017 | Cross- sectional study | with dementia in PC are professionals' limited education and limited access to specialized ca • Suggests that care for older people with dementia in PC should be person-centered, with family involvement and staff training on effective communication |
|--|---|---|--|---------------------------|--|
| | Ahia C, Blais CM (26) | Primary palliative care for the general internist: Integrating goals of care discussions into the outpatient setting | The United States of America, 2014 | Case study | Discusses that accompanying the elderly in PC at the primary level contributes to their trajectory in the healthcare system and effect communication and assists in decision making Reports that general practitioners and family physicians at the primary level are crucial to discussing the treatment objective and achiev better outcomes |
| | Lanza CC, O'Shea CJC, Herrera JL, Pena CG (27) | Cuidados paliativos: la opción para el adulto en edad avanzada | Mexico, 2015 | Review study | States the need for PC for the elderly to be coordinated and integrated into the health system Cites primary care as the organizer of care and highlights its proximity to the patient's home PC Highlights that, in the primary care context, it is necessary to guide caregivers and family members in collaborative interdisciplinary cal with the health team |
| | Toye C, Blackwell S, Maher S, Currow DC, Holloway K, Tieman J, et al. (28) | Guidelines for a palliative approach for aged care in the community setting: A suite of resources | Australia, 2012 | Systematic review | Highlights primary care in the center of care in the health system and the importance of considering the home for PC practice Stresses that the home is a preferred PC locus for the elderly, as it integrates family and relational elements that already exist and reduces expenses and avoidable procedures Contextualizes that many older people spend their end of life in hospital institutions against their wishes and notes that there are unnecessary transfers |
| | Tuckett A, Parker D, Clifton K, Walker H, Reymond E, Prior T, et al. (29) | What General Practitioners said about the palliative care case conference in residential aged care: An Australian perspective. Part 2 | Australia, 2015 | Qualitative study | States the importance of the multi-profession primary care team in the care provided to the elderly in PC Highlights the role of nurses as powerful age for reducing the frailty of PC supply Emphasizes the home as the preferred locus PC for the elderly, emphasizing the need for a formalized care plan, effective communication teamwork with the family, and prioritization the bond with the team instead of a profession. |
| | Van der Steen JT, Dekker NL, Gijsberts MJHE, Vermeulen LH, Mahler MM, The BAM (30) | Palliative care for people with dementia in the terminal phase: A mixed- methods qualitative study to inform service development | Australia, 2017 | Qualitative study | Discusses the relevance of primary care as settings for PC practices for the elderly Highlights the importance of providing PC to elderly at home, especially in the terminal ph States that the elderly spend the end of life in hospital institutions against their will and justifies that this is due to the health system's frailty, as it fails to focus on chronic diseases the long wait for consultations, and the lack of dedicated PC professionals Suggests specialized mobile teams that accompany the elderly in PC and their familie instead of unnecessary transfers to hospitals. |

| Author(s) | Title | Location, year | Type of study | Article result synthesis |
|--|--|--------------------------------|----------------------------|---|
| Ayyar A, Varman S, De Bhaldraithe S, Singh I (31) | The journey of care for the frail older person | The United Kingdom, 2010 | Review study | Recognizes that the healthcare of the elderly in PC needs to be provided in an expanded format in the different devices of the health system Stresses the importance of the interface between primary and secondary care of the elderly based on information exchange and reliable and quality care. Suggests an integrated care model for the frail elderly, composed of a multi-professional team in the different healthcare devices, which should be prepared to promote bonding and perform safe transfers |
| Jadhav AV (32) | Rural elderly and access to palliative care: A public health perspective | India, 2020 | Review study | Identifies frailty in the organization of PC in the public health system Highlights that PC for the elderly is neglected in the health system context, especially regarding the patients' access and the investment allocated to oncologic hospitals States the importance of primary care as the organizer of care |
| Deborah R, Waterworth S, Merryn G (33) | The role of practice nurses in providing palliative and end-of-life care to older patients with long-term conditions | Australia, 2014 | Qualitative study | Highlights the role of primary care nurses in PC and end-of-life in the elderly States the professionals' need to develop PC skills and knowledge Criticizes the nurses' limited autonomy in PC participation, conditioned to the referring physician Recognizes the importance of nurses and multiprofessional performance in PC for the elderly |
| Hermans S, Sevenants A, Declercq A, Broeck NV, Deliens L, Cohen J, Audenhove CV (34) | Inter-organisational collaboration in palliative care trajectories for nursing home residents: A nation-wide mixed methods study among key persons | Belgium, 2019 | Sequential mixed method | Discusses the relationship between the PC system devices such as nursing homes, hospitals, and home Reflects on the limited production of research in this field States that the collaboration process in PC for the elderly at the inter-organizational level is fragile Reports that the frailties of the interorganizational relationship are the divergence of routines, poor communication, lack of a unified information system between services, and the professionals' wrong perception of PC |

Source: Elaborated by the authors.

The results, in general, demonstrated the importance of PC practices for the elderly to be organized in the HNS, with primary healthcare, home care, and interdisciplinary coordination with the geriatrics specialty as key to the comprehensiveness and continuity of care.

Discussion

Although the articles analyzed mention the importance of inserting and discussing PC in an integrated health system, in practice, there is still fragmentation in the provision of this care, with limited considerations regarding the challenges and possibilities of the effectiveness of PC at all levels of care. We noticed that most of them choose to emphasize one of the levels of health-care, prioritizing primary healthcare and home care. From this perspective, they understand that primary care explores the light care technologies, which include communication, welcom-

ing, bonding, listening (35), establishing trust, and allowing more significant interaction with the elderly and their families/caregivers in the development and implementation of the care plan.

The increase in life expectancy and population aging leads the elderly to die primarily due to chronic diseases (36). With aging and the progression of these diseases, older adults tend to be subjected to unnecessary suffering, resulting in a compromised quality of life at the end of life (37, 38). This happens because public health has failed to manage and follow up on the burden of noncommunicable diseases in the aging population, such as chronic diseases, whose challenge is the loss of functional health (36).

From this perspective, the WHO suggests integrating and providing PC throughout the lifespan (27, 39). In this review, we inferred that the insertion of PC throughout the entire HNS is a powerful strategy to promote the integration of PC practices for the elderly. In this sense, it was possible to identify in the sample initiatives and reflections that propose PC to the elderly from the perspective of an integrated healthcare system.

It is highlighted that care is a continuous process, where an individual may, at any given time, need to access more than one health system service, especially in aging populations that face the challenges of chronic diseases (40). Moreover, the continuity of care is more than only the connection between the different levels, but it also depends on the information flow regarding the assistance provided between the different services (40). In this regard, the authors (31) point out that the care provided in the different scenarios should be coordinated and easily transferable, constituting a safe and seamless care journey for the elderly and ensuring the patient's holistic experience. The successful joint operation of this system depends on an active interface between the various parts of the system (31).

A study (34) conducted in Belgium suggests that the organization of a care system is essential for the provision of integrated PC. This description is like the proposed care model of the Brazilian health system organized from the perspective of care integration through the HNS (18). However, it is noteworthy that PC integration in a system requires administrative, organizational, clinical, and service aspects that enable the continuity of care throughout all agents involved (34). Moreover, formalizing the system structure through government policies is insufficient to ensure successful inter-organizational collaboration. In practice, the collaboration process is complex. It entails overcoming challenges such as leadership, coordination, lack of critical organizational members to drive the cooperation, power imbalances, agents' varying expectations, cultural diversity, corporate governance, means of communication, and opportunities for interaction (34).

Given these challenges mentioned by the authors, it is understandable why primary healthcare has been indicated in several of the

studies analyzed as the care organizer in the care system (24, 26-28, 31, 32). Primary healthcare was recognized in such studies for its relevance in developing PC measures for the elderly. The articles explored primary healthcare considering its role as a care organizer in the system, its properties of integrating different services and prioritizing light care technologies, and its proximity and relationship with the region and home setting.

Primary healthcare engagement and participation in the coordination and continuity of care are factors that operate to maximize general health outcomes (24). Patient-centered care and continuity of care improve discussions, resulting in the unity of patient and health provider objectives for future care and improved end-of-life outcomes (26). Regarding PC at the primary level, a study carried out in the United States (24) indicated that primary care physicians are vital to providing competent PC at this level of care, with preliminary evidence that the engagement of these professionals is a source of regional variation in the standard of care offered at the end of life. The study results (24) indicate that patients who received greater engagement in primary care provided by physicians experienced fewer hospitalizations and intensive care procedures in the last six months of life and, consequently, lower healthcare costs.

Also of note is that the care provided to the frail elderly at this level of care improves patient satisfaction and reduces the transfer of the elderly to long-stay institutions and inadequate hospital admissions (31). The present study results corroborate a literature review (41) conducted on the role of primary health-care in PC for the elderly, which indicates as benefits of PC at this level of care factors such as the improvement of symptoms manifested by patients, their satisfaction, and the reduction of hospitalizations at the tertiary level and expenses with specialized services.

However, challenges remain in the organization of the health system in primary healthcare to be overcome for incorporating PC in its scope of action, especially regarding the lack of professional training and educational activities aimed at the patients and their families (42). The importance of nurses and managers at this level of care to recognize PC opportunities that offer families and patients adequate and quality care is highlighted. Therefore, they suggest two fronts of action in this scenario: The training and discussion forum on the topic and community awareness regarding the importance of PC (42).

Still, on the importance of primary healthcare in PC, the study analyzed (27) in this review indicates that PC for the elderly should include the promotion, prevention, and rehabilitation measures, with guidelines for training volunteers and caregivers for the elderly at the primary level and considering the participation of family and society in the interdisciplinary work with the

health team (27). In this sense, it is essential to emphasize that primary healthcare in PC needs a healthcare network system that offers specialized services in PC, among the other services, whose criteria for referral are the patients' needs and not only their limiting characteristics (43, 44).

It was highlighted in the studies as the basic level of care for the continuity of healthcare between the different levels of care, considering the role of primary healthcare in the health system (26). It can be attributed to the fact that primary healthcare is the closest to patients, their families, and homes, the favored care location for the elderly in PC, with the possibility of better bonding and resolution (43).

Regarding the continuity of care, a study (26) analyzed in this review states the importance of every care transition of the older adults in PC (specialized consultation, hospital discharge, performance of procedures, or referral to long-term care facilities) as an opportunity for monitoring, adjustment, and definition of care goals. The authors emphasize that this is a potential developed by primary healthcare professionals, as it implies the availability of the physician's time for consultation and contact with specialists who provide care to the patient. This process is assisted by professionals at the primary level, as it is perceived that they have the time, ability, and willingness to discuss PC with patients and their families, in addition to a dynamic health team (26). Primary healthcare, in addition to centering patient care, also improves the emotional support provided to patients and their families since the professionals engage in empathic communication, promoting the discussion of the objectives of PC (26, 30).

However, it should be considered that the continuity of care for the elderly in PC is still fragile due to the professionals' lack of knowledge concerning this type of care, the health system's lack of planning for the epidemiological transition with population aging, and the lack of integration between health services (41, 44, 45), especially when patients are transferred to hospital care and in the processes related to discharge from this service (45). Continuity of care happens effectively when the dimensions of time/environment, patient-professional relationship, communication, and management are aligned (44, 45). In addition, planning, information exchange (face-to-face, telecommunication, or electronic medical records), ongoing interaction and coordination, and clear roles between services, whether for home or another level of care, are essential for the transition of care (44, 45).

It is also noteworthy the emphasis of studies (29, 33) on the role of primary healthcare nurses in promoting PC to the elderly. Although the multi-professional team is considered relevant, the nurses are recognized as critical agents in overcoming the limitation of PC availability in different contexts (46). Several aspects were mentioned regarding the nurses' attributes that favor their participation in end-of-life care: Their greater availability of time than physicians

to be with patients; the promotion for patients to receive the best PC possible; the centrality of patients in holistic care; the competence to manage pain and other symptoms; the ability to share care with other professionals and services, focusing on the continuity of care and not only on transfer (29, 33). However, the nurses' autonomy in PC is still limited, primarily associated with the referring physician, and their participation in care depends on them (33). Other studies (47-49) corroborate the present review, as they recognize the importance of nurses in PC for the elderly, especially considering their relational and technical skills. However, they emphasize the limitations of nursing work due to the lack of specialized qualifications and limited recognition by the health team.

That said, considering the epidemiological and demographic overview of the population, it is increasingly necessary to focus on healthy aging, with the comfort and well-being of patients in line with a sustainable health system, which has the home as the primary location for care (27-30). These authors indicate the importance of the home being part of the care network for the elderly in PC. In addition to being a strategy to reduce avoidable expenses for the system, society, and family, it is an environment defined by the patients and their families capable of meeting the patients' demands, which encompass more than the physical aspect, including existing relationships.

An analysis of the operational viability of PC intervention at home offered to elderly returning from intensive care units showed improvements in physical functioning, quality of life, and symptom management, leading to patient satisfaction (50). In this regard, studies (28, 30) indicate that most elderly eligible for PC currently spends their end of life in hospital institutions, often against their will, due to unnecessary transfers. The health system's frailties include the absence of a health system designed for the care of chronic diseases, the impaired relationship between professionals and patients due to the short consultation time, the long wait for appointments, and the limited number of professionals dedicated to PC (27). Overcoming these frailties implies forming a system in a network, with the primary level of healthcare as the structuring line of care, with improved range, home, and families (27).

For good practices to be established at home, the authors (28-31) mention the importance of a formalized care plan with supporting information for the elderly, caregiver, and family; the need for communication, teamwork, and the availability of time and interaction with the family; the integration of a multi-professional approach rather than a physician-centered approach; the monitoring of the quality of care, requiring robust clinical governance, research, and adequate professional training; the prioritization of the bond with a team rather than several professionals and single specialists in the treatment (28-31 PC at home increases

patients' and caregivers' sense of security as they must deal with life-threatening diseases in this environment (51).

Another vital aspect mentioned in studies (23, 31) regarding the health network for elderly care in PC is the importance of services having interdisciplinary coordination with the geriatrics specialty as a connection to best practices, providing an integrated care approach. Regarding this coordination, a study that sought to identify barriers and enablers of integration in the European context (23) indicated that the form of organization and fragmentation of healthcare, along with the participation of several health professionals in care, seem to hinder this process. In contrast, strong leadership was identified as an enabler at both the clinical practice and the strategic and political levels. Strong leadership locally and nationally can support ongoing communication between organization members and the development of new initiatives in the integration of PC and geriatrics (23).

In a prospective controlled study (52) that compared elderly patients in home PC, followed up by primary healthcare and elderly patients who, in addition to this follow-up, received a geriatric home intervention and the availability of 24-hour geriatric service, the rate of hospitalizations and emergency care, as well as unnecessary hospitalizations after the first year of intervention, were reduced. There was an increase in the proportion of patients who died at home. The authors emphasize that although death at home was considered a favorable outcome, an integrated care model in the service network is essential so that patients who prefer or need to be hospitalized have easy access to this resource.

Also worth highlighting is the care provided to older people with dementia. In an aging society, dementia, a chronic, progressive, and terminal disease leading to complex care needs, is increasingly present. The cognitive decline caused by this disease weakens the patients' leading role in their care process, requiring intense family participation (30). Authors (25) indicate that dementia is still neglected mainly from the perspective of PC for the elderly since it is considered a natural aging condition. Person-centered care, with family participation for optimal communication and decision making, as well as training in communication skills and orientation for professionals, are still barriers to the consolidation of PC for the elderly with dementia (25). From this perspective, the ideal PC for the elderly with dementia includes discussing the prognosis and care plan with patients and caregivers, patient access to services, and standardized guidelines, as these can contribute to the first approach but may lead to the loss of patient-centered care (53).

As a study limitation, it is worth mentioning that the theme is still nascent in the literature, and only 12 articles were selected from the researched databases. In addition, the option to use DeCS and MeSH may have limited the search scope and resulted in the loss of essential documents that discussed the theme in question.

Conclusions

When mapping the scientific evidence related to the organization of PC practices for the elderly in the HNS, it is noted that, given the impact of aging on society, discussions around PC for the elderly and their families are still modest. Although the studies indicate the importance of the insertion of PC within a care network, having primary healthcare as the organizer of these practices, the concept of a network effectively established is still developing, which indicates fragmented assistance. However, the coordination between more than one level of care is eventually addressed. They also address the importance of PC being provided in the home/residence of the elderly, which favors the interface with primary care. At this level, it has the location and people's homes as the object of care.

One of the gaps identified in this review was the low number of studies published by countries that have been facing the challenges of aging, highlighting the limited discussion around solid national policies and guidelines that direct these practices. It is believed that this study can contribute to shedding light on the theme, broadening discussions that reach society, multi-professional teams, and health system managers in the search for an HNS that integrates PC at all levels of care.

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References

- World Health Organization (WHO). World report on Ageing and Health [Internet]. Switzerland: WHO; 2015. Available from: https://apps.who.int/iris/bitstream/handle/10665/186463/9789240694811_eng.pdf;jsessionid=C-8B86A8F09F4CEF86F6A6EADB0A03C7D?sequence=1
- World Health Organization (WHO). National Institute on Aging. National Institutes of Health. U.S. Department of Health and Human Services. The Global Health and Aging [Internet]. Switzerland: WHO; 2011. Available from: https://www.who.int/ageing/publications/global_health.pdf
- 3. Oliveira JM, Rozendo CA. Instituição de Longa Permanência para Idosos: um Lugar de Cuidado para quem não tem

- opção? Rev Bras Enferm 2014;67(5):773-9. DOI: https://doi. org/10.1590/0034-7167.2014670515
- Organização Pan-Americana da Saúde (OPAS). Relatório mundial sobre o idadismo. Washington, DC: Organização Pan-Americana da Saúde; 2022. DOI: https://doi. org/10.37774/9789275724453
- World Health Organization (WHO). Alzheimer's disease international. Dementia: A public health priority [Internet]. Switzerland: WHO; 2012. Available from: https://www.who.int/publications/i/item/dementia-a-public-health-priority
- 6. Araujo MT, Velloso IC, Ceci C, Purkis ME. Caregiving for the elderly person: Discourses embedded in the Brazilian practi-

- cal guide for the caregiver. Journal of aging and social policy. 2017;29(5):444-60. DOI: https://doi.org/10.1080/08959420.2017.1342526
- Araujo MT, Velloso IC, Ceci C. Purkis ME. The significance of overlooked objects: Materiality and care at home for people with dementia. Nurs Inq. 2019;27(1):1-8. DOI: https://doi. org/10.1111/nin.12306
- 8. Sociedade Brasileira de Geriatria e Gerontologia (SBGG). Vamos falar de cuidados paliativos [Internet]. Brazil: SBGG; 2015. Available from: https://sbgg.org.br/wp-content/uploads/2014/11/vamos-falar-de-cuidados-paliativos-vers--o-online.pdf
- Faria SS, Figuereido JS. Aspectos emocionais do luto e da morte em profissionais da equipe de saúde no contexto hospitalar. Psicol. hosp. (São Paulo). 2017;15(1):44-66. Available from: http:// pepsic.bvsalud.org/pdf/ph/v15n1/15n1ao5.pdf
- Fringer A, Hechinger M, Schnepp W. Transitions as experienced by persons in palliative care circumstances and their families: A qualitative meta-synthesis. BMC Palliat Care 2018;22(17):1-15. DOI: https://doi.org/10.1186/s12904-018-0275-7
- 11. Rosa DSS, Couto SA. O enfrentamento emocional do profissional de enfermagem na assistência ao paciente no processo da terminalidade da vida. Rev Enf Contemp. 2015;4(1):92-104. DOI: https://doi.org/10.17267/2317-3378rec.v4i1.467
- 12. Worldwide Palliative Care Alliance (WPCA). Global Atlas of palliative care at the end of life. 2nd Ed. London: WPCA; 2020. Available from: http://www.thewhpca.org/resources/global-at-las-on-end-of-life-care
- Lupu D, Quigley L, Mehfoud N, Salsberg ES. The Growing Demand for Hospice and Palliative Medicine Physicians: Will the Supply Keep Up? J Pain Symptom Manage. 2018;55(4):1216-23. DOI: https://doi.org/10.1016/j.jpainsymman.2018.01.011
- Etkind, SN, Bone, AE, Gomes, B, Lovell N, Evans CJ, Higginson IJ, et al. How many people will need palliative care in 2040? Past trends, future projections and implications for services. BMC Med 2017;15(102):1-10. DOI: https://doi.org/10.1186/s12916-017-0860-2
- Souza HL, Zoboli ELMP, Paz CRP, Schveitzer MC, Hohl KG, Pessalacia JDR. Cuidados paliativos na atenção primária à saúde: considerações éticas. Rev. Bioét. 2015;23(2):349-59. DOI: https://doi.org/10.1590/1983-80422015232074
- 16. Gómez-Batiste X, Connor S, eds. Building Integrated Palliative Care Programs and Services. Espanha: Collaborating Centre Public Health Palliative Care Programmes; 2017. Available from: https://www.thewhpca.org/resources/category/building-integrated-palliative-care-programs-and-services
- 17. Sekse RJT, Hunskår I, Ellingsen S. The nurse's role in palliative care: A qualitative meta-synthesis. J Clin Nurs. 2018;(1-2):21-38. DOI: https://doi.org/10.1111/jocn.13912
- 18. Brasil. Resolução n. 41, de 31 de outubro de 2018. Dispõe sobre as diretrizes para a organização dos cuidados paliativos, à luz dos cuidados continuados integrados, no âmbito Sistema Único de Saúde. Diário Oficial da União 31 out. 2018.
- Lima DWC, Vieira AN, Gomes AM, Silveira LC. Historicidade, conceitos e procedimentos da análise do discurso. Rev enferm UERJ. 2017;25(e12913):1-4. DOI: https://doi.org/10.12957/reuerj.2017.12913
- Weber LAF, Lima MADS, Acosta AM, Marques GQ. Transição do cuidado do hospital para o domicílio: revisão integrativa. Cogitare Enf 2017;22(3):1-11. DOI: https://doi.org/10.5380/ ce.v22i3.47615
- Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for scoping reviews (PRISMA-ScR): checklist and explanation. Ann Intern Med 2018;169(7):467-73. DOI: https://doi.org/10.7326/M18-0850

- 22. Peters MDJ, Godfrey C, McInerney P, Munn Z, Tricco AC, Khalil H. Chapter 11: Scoping Reviews (2020 version). In: Aromataris E, Munn Z, eds. JBI Manual for Evidence Synthesis, JBI; 2020. DOI: https://doi.org/10.46658/JBIMES-20-12
- 23. Albers G, Froggatt K, Van den Block L, Gambassi G, Vanden BP, Pautex S, et al. A qualitative exploration of the collaborative working between palliative care and geriatric medicine: Barriers and facilitators from a European perspective. BMC Palliat Care. 2016;15(47):1-10. DOI: https://doi.org/10.1186/s12904-016-0118-3
- 24. Ankuda CK, Petterson SM, Wingrove, BSP, Bazemore WA. Regional variation in primary care involvement at the end of life. Ann Fam Med. 2017;15(1):63-7. DOI: https://doi.org/10.1370/afm.2002
- Brazil K, Galway K, Carter G, Steen JT. Providing optimal palliative care for persons living with dementia: A comparison of physician perceptions in the Netherlands and the United Kingdom. J Palliat Med. 2017;20(5):473-7. DOI: https://doi.org/10.1089/jpm.2015.0274
- 26. Ahia CL, Blais CM. Primary palliative care for the general internist: Integrating goals of care discussions into the outpatient setting. Ochsner J. 2014;14(4):704-11. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4295749/
- 27. Lanza CC, O'Shea GJC, Herrera JL, Peña GL. Cuidados paliativos: la opción para el adulto en edad Avanzada. Gaceta Mexicana de Oncología. 2015;14(3):176-80. DOI: https://doi.org/10.1016/j.gamo.2015.07.005
- 28. Toye C, Blackwell S, Maher S, Currow DC, Holloway K, Tieman J, et al. Guidelines for a palliative approach for aged care in the community setting: A suite of resources. Australas Med J. 2012;5(11):569-74. DOI: https://doi.org/10.4066/AMJ.2012.1400
- 29. Tuckett A, Parker D, Clifton K, Walker H, Reymond E, Prior T, et al. What General Practitioners said about the palliative care case conference in residential aged care: An Australian perspective. Part 2. Prog Palliat Care. 2015;23(1):9-17. DOI: https://doi.org/10.1179/1743291X13Y.000000069
- 30. Van der Steen JT, Dekker NL, Gijsberts MJHE, Vermeulen LH, Mahler MM, The BAM. Palliative care for people with dementia in the terminal phase: A mixed-methods qualitative study to inform service development. BMC Palliat Care. 2017;16(1):16-28. DOI: https://doi.org/10.1186/s12904-017-0201-4
- 31. Ayyar A, Varman S, De Bhaldraithe S, Singh I. The journey of care for the frail older person. Br J Hosp Med. 2010;71(2):92-6. DOI: https://doi.org/10.12968/hmed.2010.71.2.46487
- 32. Jadhav AV. Rural elderly and access to palliative care: A public health perspective. Indian J Palliat Care. 2020;26(1):116-9. DOI: https://doi.org/10.4103/IJPC_IJPC_162_19
- 33. Deborah R, Waterworth S, Merryn G. The role of practice nurses in providing palliative and end-of-life care to older patients with long-term conditions. Int J Palliat Nurs. 2014;20(8):373-9. DOI: https://doi.org/10.12968/ijpn.2014.20.8.373
- 34. Hermans S, Sevenants A, Declercq A, Broeck NV, Deliens L, Cohen J, et al. Inter-organisational collaboration in palliative care trajectories for nursing home residents: A nation-wide mixed methods study among key persons. Int J Care Coord. 2019;22(2):69-80. DOI: https://doi.org/10.1177/2053434519857352
- 35. Merhy EE, Onocko R, editors. Agir em saúde: um desafio para o público. 3ª ed. São Paulo: Hucitec; 2007.
- Murray CJL, Lopez AD, Vos T, Lim SS. Five insights from the Global Burden of Disease Study 2019. Lancet. 2020;396(10258):1135-59. DOI: https://doi.org/10.1016/S0140-6736(20)31404-5
- 37. Cardona-Morrell M, Kim JCH, Turner RM, Anstey M, Mitchell IA, Hillman K. Non-beneficial treatments in hospital at the end

- of life: a systematic review on extent of the problem. Int J Qual Health Care. 2016;28(4):456-69. DOI: https://doi.org/10.1093/intqhc/mzwo60
- 38. Baal KV, Schrader S, Schneider, N. Wiese B, Stahmeyer JT, Eberhard S, et al. Quality indicators for the evaluation of end-of-life care in Germany: A retrospective cross-sectional analysis of statutory health insurance data. BMC Palliat Care. 2020;19(187):1-10. DOI: https://doi.org/10.1186/s12904-020-00679-x
- 39. World Health Organization (WHO). Institutional Repository for Information Sharing. Strengthening of palliative care as a component of integrated treatment throughout the life course: Report by the Secretariat [Internet]. Switzerland: WHO; 2014. Available from: https://apps.who.int/iris/handle/10665/158962
- 40. Jackson C, Ball L. Continuity of care: Vital, but how do we measure and promote it? Aust J Gen Pract. 2018;47(10):662-4. DOI: https://doi.org/10.31128/AJGP-05-18-4568
- Queiroga VM, Menezes LV, Lima JMR, Andrade DDBC. Cuidados paliativos de idosos no contexto da atenção primária à saúde: uma revisão da literatura. Braz J Develop. 2020;6(6):38821-32. DOI: https://doi.org/10.34117/bjdv6n6-429
- 42. Silva TC, Nietsche EAC, Bastos S. Palliative care in primary health care: An integrative literature review. Rev Bras Enferm. 2022;75(1):1-9. DOI: https://doi.org/10.1590/0034-7167-2020-1335
- 43. Nooijer K, Penders YW, Pivodic L, Van Den Noortgate NJ, Pype P, Van den Block L. Specialist palliative care services for older people in primary care: A systematic review using narrative synthesis. Palliat Med. 2020;34(1):32-48. DOI: https://doi.org/10.1177/0269216319874978
- 44. Dudley N, Ritchie CS, Rehm RS, Chapman SA, Wallhagen MI. Facilitators and barriers to interdisciplinary communication between providers in primary care and palliative care. J Palliat Med. 2019;22(3):243-9. DOI: https://doi.org/10.1089/ jpm.2018.0231
- 45. Bahr SJ, Weiss ME. Clarifying model for continuity of care: A concept analysis. Int J Nurs Pract. 2019;25(2):e12704. DOI: https://doi.org/10.1111/ijn.12704

- 46. Paice JA, Battista V, Drick CA, Schreiner E. Palliative nursing summit: Nurses leading change and transforming primary palliative care: Nursing's role in providing pain and symptom management. J Hosp Palliat Nurs. 2018;20(1):30-5. DOI: https://doi.org/10.1097/NJH.00000000000000405
- 47. Fonseca LS, Carvalho BC, Santos HO, Silva JM, Santos JCO, Ferreira LLL, et al. Atuação do enfermeiro em cuidados paliativos na atenção primária à saúde: revisão integrativa. Rev. Bras. Cancerol. [Internet]. 2022;68(1):e-071383. DOI: https://doi. org/10.32635/2176-9745.RBC.2022v68n1.1383
- Pavlic RD, Aarendonk D, Wens J, Simões JAR, Lynch M, Murray S. Palliative care in primary care: European Forum for Primary Care position paper. Prim Health Care Res Dev. 2019;20(e133):1-6. DOI: https://doi.org/10.1017/S1463423619000641
- 49. Karam M, Chouinard MC, Poitras ME, Couturier Y, Vedel I, Grgurevic N, et al. Nursing Care Coordination for Patients with Complex Needs in Primary Healthcare: A Scoping Review. Int J Integr Care.2021;21(1):1-21. DOI: https://doi.org/10.5334/ijic.5518
- Mayr FB, Plowman JL, Blakowski S, Sell-Shemansky K, Young JM, Yende S. Feasibility of a Home-Based Palliative Care Intervention for Elderly Multimorbid Survivors of Critical Illness. Am J Crit Care. 2021;30(1):12-31. DOI: https://doi.org/10.4037/ajcc2021117
- Sarmento VP, Gysels M, Higginson IJ, Gomes B. Home palliative care works: but how? A meta-ethnography of the experiences of patients and family caregivers. BMJ Support Palliat Care. 2017;7(4):390-403. DOI: https://doi.org/10.1136/bmjspcare-2016-001141
- 52. Pollina L, Guessous I, Petoud V, Combescure C, Buchs B, Schaller P, et al. Integrated care at home reduces unnecessary hospitalizations of community-dwelling frail older adults: A prospective controlled trial. BMC Geriatr. 2017;17(1):53. DOI: https://doi.org/10.1186/s12877-017-0449-9
- 53. Stewart JT, Schultz SK. Palliative Care for Dementia. Psychiatr Clin North Am. 2018;41(1):141-51. DOI: https://doi.org/10.1016/j.psc.2017.10.011