

Nursing Work in Palliative Care in Primary Health Care: Integrative Review

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Atuação do Enfermeiro em Cuidados Paliativos na Atenção Primária à Saúde: Revisão Integrativa

Actuación del Enfermero en Cuidados Paliativos en la Atención Primaria a la Salud: Revisión Integrativa

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ABSTRACT

Introduction: The role of nursing professionals in palliative care (PC) in Primary Health Care (PHC) aims to promote the quality of life of individuals and their families as a guarantee of comprehensive humanized and dignified care, improving the way to cope with the disease and minimizing suffering. **Objective:** To analyze and synthesize the scientific production related to the nurse's care to the individual in PC in PHC. **Method:** Integrative literature review carried out in the databases of Latin American and Caribbean Health Sciences Literature (LILACS), Medical Literature Analysis and Retrieval System Online (MEDLINE) by PubMed, Nursing Database (BDENF) and Scientific Electronic Library Online (SciELO), using the following descriptors: Palliative Care, Nursing and Primary Health Care. **Results:** 17 articles were analyzed after a systematic selection summarized in a table with their main results and grouped into three categories: training in PC: a barrier for nurses to work in PHC; perceptions, experiences, and practices of nurses regarding PC; the role of nurses in the multiprofessional PC team. **Conclusion:** It was noticed that nurses had superficial knowledge about PC in PHC, demonstrating the need for continuing education to promote their role in PC. Furthermore, thorough methodological studies targeted to the nurse as agent disseminating the practice are needed.

Key words: palliative care; nurses; patient-centered care; primary health care; home health nursing.

RESUMO

Introdução: A atuação da enfermagem ao indivíduo em cuidados paliativos (CP) na Atenção Primária à Saúde (APS) visa a promover a qualidade de vida dos indivíduos e da sua família como garantia da assistência integral, para um cuidado humanizado e digno, melhorando a maneira de enfrentar a doença e minimizando o sofrimento. **Objetivo:** Analisar e sintetizar a produção científica relacionada à assistência do enfermeiro ao indivíduo em CP na APS. **Método:** Revisão integrativa da literatura realizada nas bases de dados Literatura Latino-Americana e do Caribe em Ciências da Saúde (LILACS), *Medical Literature Analysis and Retrieval System Online* (MEDLINE) via PubMed, Base de Dados de Enfermagem (BDENF) e *Scientific Electronic Library Online* (SciELO), utilizando os descritores: *Palliative Care*, *Nursing* e *Primary Health Care*. **Resultados:** Foram analisados 17 artigos após seleção sistemática, sintetizados em um quadro com seus principais resultados e agrupados em três categorias: capacitação em CP: uma barreira para atuação do enfermeiro na APS; percepções, experiências e práticas dos enfermeiros nos CP; o papel do enfermeiro na equipe multiprofissional de CP. **Conclusão:** Notou-se que os enfermeiros possuíam conhecimento superficial acerca dos CP na APS, evidenciando a necessidade de educação continuada para promover a sua atuação em CP. Ademais, estudos com maior rigor metodológico com o foco no enfermeiro como agente disseminador da prática são necessários.

Palavras-chave: cuidados paliativos; enfermeiras e enfermeiros; assistência centrada no paciente; atenção primária à saúde; enfermagem domiciliar.

RESUMEN

Introducción: El rol de los profesionales de enfermería en los cuidados paliativos (CP) en la Atención Primaria de Salud (APS) tiene como objetivo promover la calidad de vida de las personas y sus familias como garantía de una atención integral, humanizada y digna, mejorando la forma de afrontar la enfermedad y minimizando sufrimiento. **Objetivo:** Analizar y sintetizar la producción científica relacionada con la asistencia del enfermero al individuo en CP en APS. **Método:** Revisión integradora de la literatura realizada en las bases de datos de Literatura Latinoamericana y del Caribe en Ciencias de la Salud (LILACS), *Medical Literature Analysis and Retrieval System Online* (MEDLINE) a través de PubMed, Banco de Datos de Enfermería (BDENF) y *Scientific Electronic Library Online* (SciELO), utilizando los descriptores: *Palliative Care*, *Nursing* y *Primary Health Care*. **Resultados:** Se analizaron 17 artículos después de una selección sistemática, resumidos en una tabla con sus principales resultados y agrupados en tres categorías: capacitación en CP: barrera para el trabajo de enfermería en APS; percepciones, experiencias y prácticas de enfermeros en CP; el papel de los enfermeros en el equipo multiprofesional de CP. **Conclusión:** Se observó que los enfermeros tenían conocimientos superficiales sobre CP en la APS, evidenciando la necesidad de una educación continua para promover su actuación en CP. Además, se necesitan estudios metodológicos más rigurosos, con foco en lo enfermero como agente divulgador de la práctica.

Palabras clave: cuidados paliativos; enfermeras y enfermeros; atención dirigida al paciente; atención primaria de salud; cuidados de enfermería en el hogar.

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INTRODUCTION

Brazil is going through a demographic transition with the increase of the population's life expectancy in the last decades, which is currently 76.6 years according to *Instituto Brasileiro de Geografia e Estatística (IBGE)*¹. In addition to more older adults, the incidence of non-communicable chronic diseases as neoplasms, cardiovascular and neurological problems has also increased and it is necessary to incorporate new forms to deal with individuals presenting these conditions, one of them, palliative care (PC)^{1,2}.

PC are defined as a holistic approach that improves the quality of life of patients, their families and caretakers facing the problems associated with life-threatening diseases, providing relief of suffering, by means of early identification of potentially fatal pathologies from a thorough evaluation of the pain, symptoms control and other physical, social, psychological and spiritual demands³.

Until 2018, according to the National Academy of Palliative Care (ANCP)⁴, 177 PC services were in place. Although addressed since 1990, the practice started only in 2000. PC can be offered to any individual, children, adults or older adults with life-threatening or chronic diseases⁴.

Primary Health Care consists of a set of prevention, promotion, rehabilitation and maintenance actions for full care and an important tool to follow up individuals in PC⁵.

Home-based PC are government-sponsored in Belgian and France through financial incentives not only to the patient but caregivers as well, but in Germany, patients alone are financially supported. In these countries these services are cost-free with multidisciplinary teams advising and supporting health professionals and informal caregivers⁶.

Similar to these countries, the role of PHC in Brazil is not to offer homecare but support patients and their families and coaching them⁷. Nursing professionals working in PC are seen as the person who will recover the patient's health and reduce the vulnerability, in addition to controlling symptoms, applying specific techniques as hypodermoclyses, therapeutic communication, spiritual support, hygiene, liaise with the multidisciplinary team and comfort to the family⁸⁻¹¹.

Regardless of the importance and urgency to implement PC, there are political and educational barriers to overcome for its implementation. The current study has the objective of analyzing and summarizing the scientific production related to the care provided to individuals in PC by nurses of PHC and amend the educational gap to expand this practice grounded in consistent information.

METHOD

Integrative review of the literature¹² attempting to identify, review and summarize the researches and conclusions from different sources to incorporate the evidences into clinical practice.

The following steps were adopted¹²: (1) Formulation of the research question; (2) Search at the databases; (3) Critical review; (4) Selection of the articles; (5) Evaluation of the methodological quality; (6) Extraction of the data; (7) Summary of the data; (8) Evaluation of the evidences.

The research question – “What has been the action of the PHC's nurse in home-based PC?” – aims to describe the study objective and the estimated results. After a comprehensive search at the databases and critical review, the studies were identified and a team was assigned to perform the selection and acquire the data, which were analyzed and categorized through the instrument validated¹³; a list with the main results and topics discussed was prepared following the eight steps described above and adopted in the article¹³.

Data were acquired in July 2020, the databases searched were LILACS – Latin American and Caribbean Health Sciences Literature, Medical Literature Analysis and Retrieval System Online (MEDLINE) via PubMed, Nursing Database (BDENF) and Scientific Electronic Library Online (SciELO), utilizing the Descriptors of Sciences of Health (DeCS) and Medical Subject Headings (MeSH) with the Boolean operator “AND”: “Palliative Care” (AND) “Nursing” (AND) “Primary Health Care”.

The inclusion criteria were publications available in any year until the first semester of 2020 in English, Portuguese and Spanish. Opinion pieces, reviews, theses and monographies were excluded.

The identification, selection and inclusion of primary studies followed three stages: a) 2,070 articles were identified with descriptors and filters (Figure 1); b) 75 articles selected after reading titles and abstracts and applying inclusion and exclusion criteria; c) after reading the 75 articles in full, 17 articles were selected. The study met all ethical requirements in compliance with the Copyright Law¹⁴.

The validated instrument¹⁵ was utilized for the acquisition and analysis of the data, matched to the study's objective with various information as identification of the study, host institution, methodology, methodological rigor among others. The priority items were: title, journal, year of publication, design and results¹⁵. The same variables were utilized to extract the data and describe the results. The categorization of the findings for content analysis as recommended by Bardin¹⁶ followed the stages of pre-analysis, completeness, exploration of the material and

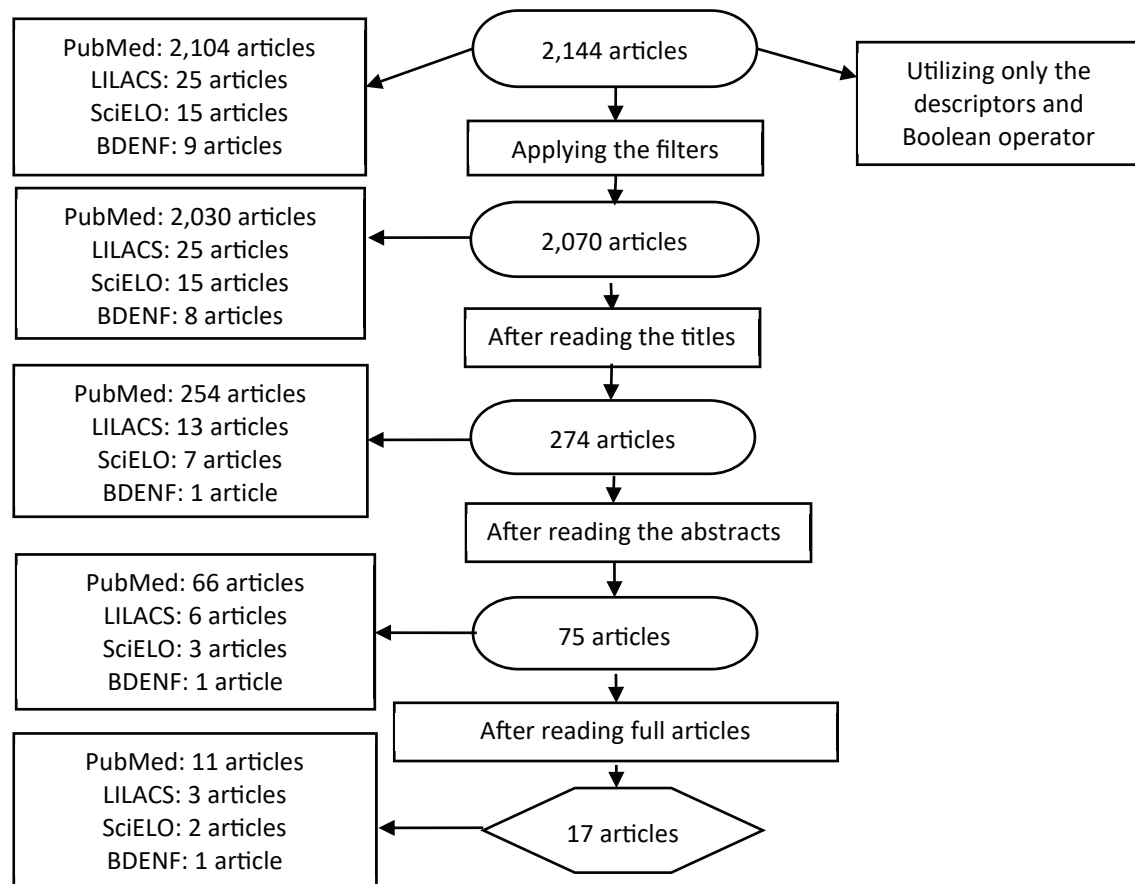


Figure 1. Search strategies to include articles

treatment of the data, inferences and interpretation. Three categories were reached at the end of the analysis: Experience in PC: a barrier for the action of the nurse in PHC; Perceptions, experiences and practice of the nurses in PC; The role of the nurse in PC multidisciplinary team.

RESULTS

The final sample consisted of 17 articles, six of them published in 2018 and the others, in 2012 (1), 2015 (3), 2016 (2), 2017 (2), 2019 (2), 2020 (1). 12 articles were published in English, 3 in Portuguese and 2 in Spanish (Chart 1).

It is recent the increase of the number of articles about care to PC patients in PHC, mostly from 2015 to 2018; in addition, the number of studies on the theme increases annually because of the significant raise of the mortality rates¹⁷.

DISCUSSION

TRAINING IN PC: OBSTACLES FOR THE NURSE ACTION IN PHC

A study²³ described the utilization of the following tools to evaluate knowledge and difficulties of PC from

2008 to 2015, in Japan: Palliative Care Knowledge (PCKT), Palliative Care Difficulty Scale (PCDS) and Palliative Care Self-Reported Practices Scale (PCPS). Improvements in knowledge and less difficulties were identified in PC because of the continuous nursing education programs as well as the necessity of expert nurses in the PC team and inclusion of PC in the regular health professionals formation²³.

During the nursing undergraduate program there is no discussion about PC or the theme is addressed superficially as the studies^{20,21,28} identified. A research with PHC managers concluded that the Family Health Strategy teams are unaware of what PC means and it is barely discussed²¹, confirming ANCP's conclusion: most of the teams have no formal education and is based in self-taught initiatives⁸. To amend these gaps and feelings of impotence, fear and insecurity in coping with finitude, continuous education is the solution²⁸. According to Dahlin et al.²⁰, knowledge and self-confidence of the professionals improved after continuous education.

The nursing formation at the universities does not enable the professionals to act in different settings³⁵. The reality is the generalist formation, which is one of the difficulties for a proper work of the nursing team

Chart 1. Distribution of the references according to the journal, title, design, year of publication and results

Author/year	Journal	Title	Design	Outcomes
Sousa e Alves, 2015 ¹⁸	Acta Paul Enferm	Nursing competencies for palliative care in home care	Descriptive, exploratory, quantitative	Nurses reached a consensus about general and specific competences to develop home-based PC through multidisciplinary and transdisciplinary care
Pesut et al., 2015 ¹⁹	Rural Remote Health	Feasibility of a rural palliative supportive service	Not informed	The nursing team divulged the service, enrolled and visited the patients biweekly to implement PC in rural community
Dahlin et al., 2016 ²⁰	J Palliat Med	The advanced practice registered nurses palliative care externship: a model for primary palliative care education	Cohort, descriptive	Initially, the nurses affirmed having poor or no knowledge of PC. After continuous education, they showed more confidence in developing PC
Pereira et al., 2017 ²¹	Rev Enferm UFPE on line	<i>Significados dos cuidados paliativos na ótica de enfermeiros e gestores da Atenção Primária à Saúde</i>	Description of palliative care	Nurses understand the importance of PC, however, they report there is an educational gap which impacts care
Gálvez Ramírez et al., 2017 ²²	Rev Eugenio Espejo	<i>Caso relacionado con el proceso asistencial integrado cuidados paliativos en atención primaria de salud</i>	Case report	Describes the applicability of the systematization of the nursing care in PC
Nakazawa et al., 2018 ²³	J Pain Symptom Manage	Changes in nurses' knowledge, difficulties, and self-reported practices toward palliative care for cancer patients in Japan: an analysis of two nationwide representative surveys in 2008 and 2015	Cohort study	After the application of knowledge tests, it was possible to detect significant improvements in the practice of PC by the nurses with more training
Johansen e Ervik, 2018 ²⁴	BMC Health Serv Res	Teamwork in primary palliative care: general practitioners' and specialised oncology nurses' complementary competencies	Descriptive, qualitative	Based in the competences of a skilled primary PC nurse, the study indicated their ability to describe and notice signs and symptoms based in the experience and updated knowledge of PC in PHC
Seow et al., 2018 ²⁵	BMC Palliat Care	Benchmarking time to initiation of end-of-life homecare nursing: a population-based cancer cohort study in regions across Canada	Cohort, retrospective	Time to initiate home care varies, however, PC nursing was the option of choice, ensuring more days of life for the patient
Mkwinda e Lekalakala-Mokgele, 2016 ²⁶	Curationis	Palliative care needs in Malawi: care received by people living with HIV	Descriptive, qualitative approach, exploratory	The results showed the necessity for nurses to know the main demands to care for the persons living with HIV

to be continued

Chart 1. continuation

Author/year	Journal	Title	Design	Outcomes
Mancilla et al., 2018 ²⁷	Anales del Sis San Navarra	<i>Percepciones de los profesionales sobre la atención prestada, obstáculos y dilemas éticos relacionados con el final de la vida en hospitales, centros de Atención Primaria y residencias de ancianos</i>	Descriptive, cross-sectional and multicenter	PHC professionals do not find obstacles to provide care, however, in the hospices, there were ethical dilemmas which became issues
Silva et al., 2018 ²⁸	Rev APS	<i>Construindo a linha de cuidado do paciente oncológico paliativo em um município do sul do Brasil: relato de experiência</i>	Descriptive report	Based in an intervention, it has been shown that gaps in the education of the professionals exist and they reported difficulties with oncologic patients in PC. It was concluded that continuous education to construct full health care is mandatory
Klop et al., 2020 ²⁹	BMC Palliat Care	Strengthening the spiritual domain in palliative care through a listening consultation service by spiritual caregivers in Dutch PaTz-groups: an evaluation study	Qualitative descriptive	Address non-fulfillment of spirituality, one of the health dimensions in the caring process
Sijabat et al., 2019 ³⁰	Enf Clinica	Experiences of palliative care nurses in providing home-based care for patient with advanced cancer	Descriptive phenomenologic	Nurses adopted biomedical approach for symptoms relief as pain, shortness of breath and vomits and waived holistic care
Chong e Abdullah, 2017 ³¹	Am J Hosp Palliat Med	Community palliative care nurses' challenges and coping strategies on delivering home-based pediatric palliative care: a qualitative study	Qualitative	Illustrates the collaborative interdisciplinary approach for pediatric PC practice
Danielsen et al., 2018 ³²	BMC Palliat Care	Experiences and challenges of home care nurses and general practitioners in home-based palliative care - a qualitative study	Qualitative, phenomenological dimension	Nurses emphasized the importance of a reliable relation created from empathy and time to listen patients and their families. In addition, they reinforced the necessity of planning home-based PC
Gágyor et al., 2019 ³³	Fam Pract	Ethical challenges in primary care: a focus group study with general practitioners, nurses and informal caregivers	Qualitative	For nurses, the bureaucratic requirements, conflict of financial interests among family members and patients and the uncertainty about what to do with the users were barriers to provide high quality PC
Yamagishi et al., 2012 ³⁴	J Pain and Symptom Manage	Providing palliative care for cancer patients: the views and exposure of community general practitioners and district nurses in Japan	Cross-sectional	The study indicated that 93% of the district nursing services were opened for PC consultation and had domain over the use of opioids

Captions: PC = Palliative Care; PHA = Primary Health Attention; HIV = Human immunodeficiency virus.

in PC, requiring additional education to improve this scenario³⁵. Active practice with realistic simulation is an important method to guide the focus in PC and prepare the resident, student or professional to live the reality and help to develop skills as active listening, empathy and communication³⁶.

PERCEPTIONS, EXPERIENCES AND PRACTICE OF NURSES IN PC

The nurse working with the general population is at the first level of access to health services and able to meet the patients needs³⁷. A study of Gálvez Ramírez et al.²² discusses the relevant role the nurse plays in PHC to patients in PC, in addition to the family and community while promoting quality of life. Care must be individualized and continuous with good communication with the patient and the family and able to support the family caretaker²².

The following instruments were used in this same study to evaluate the family, caretaker and patient: Zarit's scale (burden of the caretaker), family Apgar (identification of family support) and Virginia Henderson's 14 basic needs²². Later, for implementation and development of the care plan, the North American Nursing Diagnosis Association (NANDA), Nursing Outcomes Classification (NOC) and Nursing Interventions Classification (NIC)²² were utilized to define potential priority diagnoses, goals and interventions. The following diagnoses were reached: Anxiety prior to death and risk of fatigue of the caretaker; Goals: maximum score always demonstrated in the indicators expression of the will to live and motives for living, maximum score (none) for indicators fear and frustration; Interventions: emotional support to the patient through the following activities (hug or touch the patient to offer support; encourage the patient to express feelings of anxiety, anger and sadness; provide support during bereavement and help for decision taking) and support to the main caretaker (determine the level of knowledge of the caretaker; support decision taking and difficulties the caretaker lives etc.)²².

In a study with adolescents with neoplasm in PC, taxonomies NANDA, NIC and NOC were implemented based in Callista Roy's Adaptation Model of Nursing to ensure evidence-based full and humanized care³⁸.

In a study with oncologic nurses and paliativists, the latter showed competency and skills while dealing with the patients as observing and describing accurately signs and symptoms based in their knowledge and prior PC experience; due to their knowledge²⁴ they also suggested possible therapeutic conduct for analgesia.

In another analysis, the capacity of nurses in anticipating and meeting human needs in PC and understand their own limitations while looking for help

with complex practices¹⁸ was investigated. They reported issues related to lack of confidence, financial conflicts among families, knowledge and autonomy in providing care and disputes among the multidisciplinary team, mainly the family doctor and other professionals³³.

It was possible to detect that great challenges in implementing PC in PHC exist yet as there are gaps in professionals' knowledge. In another study, nurses associated PC with survivorship and concluded that the family was neglected. In addition, nurses related PC with an alternative or inappropriate therapeutic in addition to considering only oncologic patients eligible for care²⁵. WHO's PC principles as a thorough evaluation provided by skilled professionals, offer of support system and integrate psychological and spiritual aspects into care can help to enable PC⁸.

THE ROLE OF THE NURSE IN PC MULTIPROFESSIONAL TEAM

Social workers, nurses, physicians and psychologists are the base of the interdisciplinary team with possible inclusion of educators, physiotherapists, licensed practical nurses, speech therapists, music therapists, nutritionists, psychiatrists, occupational therapists and spiritual advisers or chaplains to offer full care. The number of experts depends on the resources available^{39,40}.

Two studies addressed the composition of the PC team, one team included a physician, nurse, physiotherapist and occupational therapist and the other, only nurses and physicians^{19,24}. As a result, the patient needing multi specialties-based care may not have all the symptoms minimized, further to unmet social and spiritual issues or properly followed-up because of the team profile³⁹.

It is quite relevant that each professional performs its role but in the most diverse settings of PC, the nurses reported "moral suffering" and felt ignored because of hierarchy; even with large experience and having more contact with the patients, their inputs and suggestions for the choice of the therapeutic conduct were neglected⁴¹. Communication is a key tool to integrate care and resolution of potential conflicts among the teams^{20,42,43}.

These conducts have direct impact in the quality of the care provided by the multiprofessional team and blocked the practice recommended for PC⁸. Health managers must be aware of the professionals' vulnerabilities, so they are able to intervene to improve the quality of the service based in evidences, offer humanized care and improve the relations among professionals to achieve the integrality of health services^{11,39}.

The lack of standardization in PC described in the studies hampered the synthesis of the results after categorical analysis, however, it permitted a broad visualization of the nurse work in PHC. It is recommended

that new studies are developed to allow more involvement of nurses with PC in PHC as the knowledge is scarce and patients need full care.

CONCLUSION

In PHC, nurses help caring for patients with general skills like observing and describing signs and symptoms accurately, establishing good communication with the family and the patient and detecting gaps as poor expertise to offer PC. As concluded in the present study, the main obstacles that need to be resolved are scarce specific knowledge about PC and lack of expertise.

CONTRIBUTIONS

All the authors contributed substantially for the study conception/design, collection, analysis and/or interpretation of the data, drafting, critical review and approved the final version to be published.

DECLARATION OF CONFLICT OF INTERESTS

There is no conflict of interests to declare.

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