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Clinical Review

The importance of palliative care performed by family practice doctors in primary health care: a narrative review

A importância dos cuidados paliativos exercidos por médicos de família e comunidade na Atenção Primária à Saúde: uma revisão narrativa

La importancia de los cuidados paliativos realizados por médicos de familia y comunitario en la Atención Primaria de Salud: una revisión narrativa

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Abstract

Introduction: Terminality is a situation increasingly experienced in healthcare services due to the progression of the population's life expectancy and, consequently, the increase in patients with serious chronic diseases. In Brazil, Palliative Care services are still centralized in tertiary care services. However, in many countries, Primary Health Care has been the major provider and coordinator of Palliative Care for users, in favor of decentralizing this assistance and promoting comprehensive care. **Objective:** To carry out a narrative literature review to identify the relationship of Family Practice Doctors in the performance of Palliative Care in Primary Health Care. **Methods:** Bibliographic review through access to databases: CAPES, LILACS, SciELO, and PUBMED. Sixteen articles were selected, which were submitted to thematic analysis and subsequent discussion of the main characteristics that contribute to the greater performance of Family Practice Doctors in Palliative Care. **Results:** The importance of Family Practice Doctors in Palliative Care within the scope of Primary Health Care was observed, as well as the interconnection between the two specialties, the challenges along this path, and the benefits of this practice. **Conclusions:** The offer of Palliative Care by Family Practice Physicians in Primary Care favors the access and monitoring of patients. However, the performance of the professionals in Family Health Teams in this line of care is still insufficient due to the lack of training in the area.

Keywords: Palliative care; Primary health care; Family practice; Family health.

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Resumo

Introdução: A terminalidade é uma situação cada vez mais vivenciada nos serviços de saúde em razão da progressão da expectativa de vida da população e, consequentemente, do incremento de pacientes com doenças crônicas graves. No Brasil, os serviços de cuidados paliativos ainda se encontram centralizados nos serviços de atenção terciária. Entretanto, em diversos países, a Atenção Primária à Saúde tem sido a grande prestadora e coordenadora de cuidados paliativos dos usuários, em prol da descentralização dessa assistência e da promoção do cuidado integral. **Objetivo:** Realizar uma revisão narrativa da literatura, a fim de identificar a relação dos médicos de família e comunidade na atuação de cuidados paliativos na Atenção Primária à Saúde. **Métodos:** Revisão bibliográfica por meio do acesso às bases de dados: Portal da Coordenação de Aperfeiçoamento de Pessoal de Nível Superior (CAPES), Literatura Latino-Americana e do Caribe em Ciências da Saúde (LILACS), Scientific Electronic Library Online (SciELO) e PubMed. Foram selecionados 16 artigos, os quais foram submetidos a análise temática e posterior discussão das principais características que colaboram para a maior atuação dos médicos de família e comunidade em cuidados paliativos. **Resultados:** Observou-se a importância da atuação dos médicos de família e comunidade em cuidados paliativos no âmbito da Atenção Primária à Saúde, bem como a interligação entre as duas especialidades, os desafios existentes nesse caminho e os benefícios dessa prática. **Conclusões:** A oferta de cuidados paliativos pelos médicos de família e comunidade na atenção primária favorece o acesso e acompanhamento dos pacientes. Entretanto, a atuação dos profissionais das Equipes de Saúde da Família nessa linha de cuidado ainda é insuficiente em razão da escassa capacitação na área.

Palavras-chave: Cuidados paliativos; Atenção primária à saúde; Medicina de família e comunidade; Saúde da família.

Resumen

Introducción: La terminalidad es una situación cada vez más experimentada en los servicios de salud debido a la progresión de la esperanza de vida de la población y, en consecuencia, al aumento de pacientes con enfermedades crónicas graves. En Brasil, los servicios de Cuidados Paliativos todavía están centralizados en los servicios de atención terciaria. Sin embargo, en varios países, la Atención Primaria de Salud ha sido la principal proveedora y coordinadora de los Cuidados Paliativos para los usuarios, a favor de descentralizar esta asistencia y promover la atención integral. **Objetivo:** Realizar una revisión narrativa de la literatura, con el fin de identificar la relación de los Médicos de Familia y Comunitarios en la actuación de los Cuidados Paliativos en la Atención Primaria de Salud. **Métodos:** Revisión bibliográfica mediante acceso a bases de datos: Portal CAPES, LILACS, SciELO y PubMed. Fueron seleccionados dieciséis artículos, que fueron sometidos al análisis temático y posterior discusión de las principales características que contribuyen para una mayor actuación de los Médicos de Familia y Comunidad en Cuidados Paliativos. **Resultados:** Se constató la importancia del trabajo de los Médicos de Familia y Comunitarios en Cuidados Paliativos en el ámbito de la Atención Primaria de Salud, así como la interconexión entre las dos especialidades, los desafíos que existen en este camino y los beneficios de esta práctica. **Conclusiones:** La oferta de Cuidados Paliativos por Médicos de Familia y Comunitario en Atención Primaria favorece el acceso y seguimiento de los pacientes. Sin embargo, la actuación de los profesionales de los Equipos de Salud de la Familia en esta línea de atención aún es insuficiente debido a la falta de formación en el área.

Palabras clave: Cuidados paliativos; Primeros auxilios; Medicina familiar y comunitaria; Salud de la familia.

INTRODUCTION

The search for decentralization of care, the recovery of comprehensive assistance, and the valorization of the doctor-patient relationship contributed to the genesis of a specialty focused on the person.[1-3]

According to Gusso et al.,[4] "Family Practice (FP) is defined as the medical specialty that provides continuous, integral, and comprehensive health care for people, their families, and the community."

Furthermore, according to Starfield,[5] Primary Health Care (PHC) is the locus of responsibility for the health care of patients and their families over time. In addition to offering access to the health system for all of its users' needs, PHC follows their life stories, offering comprehensive attention and care, coordinating and integrating the care provided by other health services. It also shares some characteristics with other levels of assistance, such as attention to prevention, treatment, and rehabilitation, as well as teamwork.[5]

The World Health Organization (WHO)[6] defined palliative care (PC) as:

> *[…] an approach that improves the quality of life of patients and their families facing a problem associated with life-threatening illnesses, through the prevention and relief of suffering through early*

identification and impeccable assessment and treatment of pain and other physical, psychosocial, and spiritual problems. Palliative care affirms life and considers death a normal process; does not intend to hasten or delay death and uses a team approach to meet the needs of patients and their families, including bereavement and counseling if indicated. (p. 6)[6]

The need for knowledge in PC within the scope of PHC has been growing every year in Brazil and around the world.[1,2] This expansion occurs for several reasons, including the increasing prevalence of chronic illnesses and greater global life expectancy — largely due to the constant evolution of available therapies.[1,2] In the traditional care model, this situation burdens the system and often neglects many of the wishes of patients and their families.[1,2] Given this scenario, PC is gaining greater relevance, as it emphasizes comprehensive and humanized care, in line with the principles of FP.[1]

Offering PC in PHC is a means of expanding access for many patients eligible for PC, who may not be able to participate in hospital or outpatient programs.[1] The present study aimed to reaffirm the common principles that underpin patient care in both PC and FP, highlight their complementarity and significance, and advocate for increased emphasis on the training of family and community doctors to provide PC in PHC.

METHODS

This study is an exploratory, descriptive qualitative narrative review, conducted through a bibliographic review.

The databases accessed for bibliographic review included the Portal of the Coordination for the Improvement of Higher Education Personnel (*Coordenação de Aperfeiçoamento de Pessoal de Nível Superior* – CAPES), Latin American and Caribbean Literature in Health Sciences (*Literatura Latino-Americana e do Caribe em Ciências da Saúde* – LILACS), Scientific Electronic Library Online (SciELO), and PubMed.

To conduct the search, combinations of the following keywords were utilized, recognized as Health Sciences Descriptors (*Descritores em Ciências de Saúde* – DeCS) and Medical Subject Headings (MeSH): "Palliative Care" (*Cuidados Paliativos*), "Primary Care" (*Atenção Primária à Saúde*), "*Family Practice*" (Medicina de Família e Comunidade), "*Family Health Program"* (Estratégia Saúde da Família).

Out of 20 articles chosen for thorough examination, 16 were incorporated into thematic analysis and subsequent discussion. Inclusion criteria encompassed articles in Portuguese, English, or Spanish, focusing on PC and PHC, published within the last ten years. Articles falling outside this timeframe, not written in the specified languages, inaccessible in full, or not pertaining to the designated topic were excluded.

Additional sources of interest utilized for discussion included textbooks, educational materials from the Ministry of Health, and informative texts sourced from websites.

Out of the 16 articles chosen for discussion, 14 were in Portuguese, with only two in English. Despite including Spanish in the search criteria, no articles meeting the inclusion criteria were found in this language. Concerning the study type, nine were descriptive cross-sectional studies, primarily qualitative; three were systematic reviews, while the remaining articles comprised case reports, case series, and critical analyses.

The central themes discussed included eight articles focusing on the presence of PC in PHC, while three articles examined the perspectives and practices of health professionals engaged in PC within PHC settings (including physicians, nurses, and psychologists). Additionally, minor themes identified encompassed oncological PC in PHC, ethical considerations, and the development of a curriculum based on competencies for family practice doctors.

After critically reviewing the selected articles, four points of discussion were identified: 1. The significance of the role played by family practice doctors in providing PC within PHC settings; 2. The alignment between the guiding principles of PC and FP; 3. Anticipated advantages associated with offering PC through PHS; and 4. Persistent barriers hindering the improved implementation of PC decentralization.

RESULTS

This review highlighted a significant connection between FP and PC, demonstrating that they are not only intertwined in their principles and attributes but also complement each other.

The provision of PC by FP in PHC emerges as crucial, particularly considering that such care remains unequally accessible to all individuals in Brazil.

Moreover, numerous challenges hinder the enhancement of PC performance by FP, including professional unpreparedness stemming from the inadequate curriculum within the field, conflicts of personal values, the concentration of specialized services in tertiary care, insufficient incentives from local health management, and the existing burden on FP.

DISCUSSION

The literature reviewed unanimously acknowledges the significant aging of the population as a prevalent global demographic trend. This demographic shift entails various changes in the national socio-sanitary landscape, notably the rise in non-communicable chronic degenerative diseases (NCDs).[7-12] Such conditions require ongoing and comprehensive care — encompassing PC, which aims to enhance patients' quality of life by alleviating the pain and suffering inherent in the illness process.[1,8-12]

Recently, discussions surrounding the decentralization of this form of care have intensified — as PC can be provided across various settings and are not limited to a specific institution.[7,9] Illness and death, akin to birth, necessitate ongoing monitoring and care — which are primary features of PHC.[2]

To optimize the assistance provided to eligible PC patients in Brazil, the Ministry of Health (MoH) issued new guidelines, in 2018, aimed to organize the provision of PC within the Brazilian Unified Health System (*Sistema Único de Saúde* – SUS) and stipulated that "PC should be offered at any point in the Health Care Network (HCN), including primary care."[13]

The importance of the role of family practice doctors in palliative care in Primary Health Care

The rising longevity of the population underscores the necessity to bolster PC within health services, particularly in primary care — the main entry point for users.[1,2,7-14] Globally, the distribution of PC services is already quite varied, but in Brazil, most are centralized in hospitals and specialized clinics, often making access difficult for many eligible patients.[1,11,12,15]

The expansion of PHC activities in PC is aimed at reducing this barrier and improving access for many patients to these services.[2,7-9,16,17] According to Saito et al.,[9] family practice doctors often encounter situations of therapeutic terminality within the Family Health Strategy (FHS) context — emphasizing the need to integrate the principles of PC into PHC at an increasingly early stage.[9,10,14,17]

Furthermore, managing patients in PC is a competence of FP, as outlined since 2017 by the Competence Matrix of the National Council of Medical Residency (*Conselho Nacional de Residência Médica* – CNRM) and included in the Competency-Based Curriculum of the Brazilian Society of Family Practice (*Sociedade Brasileira de Medicina de Família e Comunidade* – SBMFC). The National Primary Care Ordinance (*Portaria Nacional de Atenção Básica* – PNAB) also mandates the provision of PC in PHC,[1,18] supported by various laws aimed at standardizing PC practices in PHC, such as the National Assistance Program for Pain and Palliative Care (2002)[13,19] and the more recent *Programa Melhor em Casa* (2011).[2,18-22]

Proximity to home, comprehensive care, and familiarity with the territory, social, and family context are among the many attributes of family doctors that align with the guiding principles of PC.[11,13,16] As Silva states,[16] "No other health service can stand side by side with these families with such skill and face the path of palliation with constant presence, guidance, and support." Similarly, Combinato and Martins[8] highlight the excellence of PHC (in supporting PC), particularly when hospital curative treatment is not possible, by allowing the patient to return home — thereby enhancing comfort and support.

Connection of guiding principles of palliative care and Family Practice

FP is characterized by providing comprehensive, continuous health care that encompasses the territorial, cultural, and spiritual aspects of the user and extends to their family members at any stage of life. Additionally, FP has intrinsic characteristics, including the ability for self-reflection in response to the patient's needs and sociocultural context — allowing practitioners to derive the true meaning of their encounter with the person seeking help.[23-25]

Therefore, PC can be characterized as a form of care focused on patient comfort, regardless of the pathological stage they are in. Its objective is to alleviate suffering through comprehensive, longitudinal, multidisciplinary medicine that equally addresses cultural, spiritual, and territorial aspects — while also integrating the health and well-being of family members and caregivers.[1,9,10]

According to Freeman and McWhinney,[24] "family practice can be described as a set of knowledge about the problems encountered by family practice doctors." Similarly, PC can be seen as a set of practices and knowledge focused on addressing the problems faced by doctors caring for suffering patients.

This connection between the principles of the two specialties has led the FHS to acquire a fundamental role in the provision of PC by PHC — due to the ability to offer close, longitudinal care to patients and families, address the caregiver's health, and establish bonds of trust with patients and their families —, ensuring the humanization of the illness and death process.[13,15]

Expected benefits from offering palliative care through Primary Health Care

A greater incorporation of PC into FP practices enhances access to this type of care and ensures continuity of care based on territorial allocation, comprehensiveness, and the possibility of home visits, allowing for close contact with patients and their families.[1,14]

Integrating PC into the PHC setting enables the provision of such measures early in the treatment process — from the initial diagnosis and at various stages throughout the natural progression of the disease —, which is a fundamental concept of the specialty.[9] Moreover, PHC, facilitated by family practice doctors within the FHS, plays a crucial role in care coordination — monitoring each stage of patients' journeys and referring them to specialized services as needed.

One of the key positive aspects of this integration highlighted in the literature is the ability to ensure greater comfort for PC patients through longitudinal home care — facilitating increased contact with family, community, and spiritual support—, which are essential factors for comprehensive care.[1,10-12]

Furthermore, maintaining these patients at home with the assurance of primary and secondary care provided by PHS in conjunction with HCN helps promote the dehospitalization of numerous patients. This contributes not only to the satisfaction of these patients and their families but also to the reduction of clinical determinants such as hospital infections, hospitalizations, and invasive procedures.[16,18,23]

These qualities are already inherent in the natural profile of family practice doctors — and it is precisely this alignment of values that further enhances the provision of PC by these professionals. However, despite the inherent compatibility of these specialties, there are still numerous obstacles to overcome.[7]

Barriers still existing for the better implementation of decentralized palliative care in Brazil

Despite the similarities, contributions, and legal frameworks supporting the work of PC in PHC, this reality is still not widespread across much of the Brazilian territory — particularly within the public health sector.

PC centers are predominantly situated in hospitals or tertiary health care outpatient clinics, meaning they are often distant from the user's home and therefore inaccessible. This is partly attributable to the absence of public policies that effectively coordinate levels of care, relying on referral and counter-referral models.[7-9]

In addition to this, there is deficient medical training within the scope of PC.[16]

The vast majority of Brazilian universities lack a robust PC teaching structure in their curriculum — this subject often relegated to extracurricular courses or, in the worst-case scenario, overlooked entirely. This situation contributes to the proliferation of a mechanistic approach to medicine focused solely on cure and disease. Consequently, family doctors, when confronted with terminally ill patients, often feel vulnerable and unsupported.[18,19] According to Marcucci et al.,[7] more than half of FHS professionals have worked with patients in the PC process and have identified shortcomings in providing comprehensive care during the illness and terminality process.

This challenge is partly attributed not only to the technical shortcomings of PHC professionals regarding end-of-life care but also to the difficulty they face in reconciling their own values. As noted by Combinato and Martins,[8] "promoting quality of life during the dying process necessitates professionals to detach themselves from their own convictions and values to align with the values and desires of patients and families."

Furthermore, the absence of public policies ensuring end-of-life care by the FHS also exacerbates this sense of care void — affecting both patients and families, as well as professionals who find themselves without the necessary tools and support to manage the quality of life of these users.[7,18,19]

Despite the need and importance of better integrating the management of PC patients into PHC, it is important to recognize that professionals working in FHS already face immense pressure to provide care, balancing acute care with scheduled consultations for longitudinal care of the enrolled population. At present, they are often overloaded and struggle to fulfill basic service requirements for the population. Much of this strain is also due to the lack of organization in access methods, scheduling, and deficiencies in team training. Therefore, the implementation of another line of care in PHC must be well-coordinated with existing programs and discussed as a team to determine feasibility within current operations.[18,19,23]

FINAL CONSIDERATIONS

The present study underscored the necessity of increasingly integrating PC into the practice of family and community doctors working in PHC. Such assistance ensures access, comprehensiveness, and comfort for patients while also aligning with the competencies outlined by regulatory institutions.

Despite the limitations identified in this review, and acknowledging the scarcity of studies that comprehensively evaluate the utilization of PC in PHC (not necessarily confined to cancer-related cases), it is evident that this field is experiencing significant expansion.

It is anticipated that with the strengthening of FP medical residencies and undergraduate curricula focusing on PC, there will be improved performance by doctors in terminal cases. Furthermore, it is recommended not only to implement continuing education programs for professionals within FHS teams but also to initiate new studies aimed at fostering the ongoing advancement of PC practiced by family and community doctors within the realm of PHC.

AUTHORS' CONTRIBUTION

MFD: Conceptualization, Data Curation, Formal Analysis, Funding Acquisition, Investigation, Methodology, Project Administration, Resources, Software, Supervision, Validation, Visualization, Writing – Original Draft, Writing – Review & Editing. MMSC: Conceptualization, Formal Analysis, Supervision, Validation, Visualization. NCC: Formal Analysis, Visualization.

CONFLICT OF INTERESTS

Nothing to declare.

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