

# PALLIATIVE CARE AT HOME PROVIDED BY THE PRIMARY HEALTH CARE TEAM

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## ABSTRACT

**Introduction:** Palliative care aims to alleviate human suffering with the adoption of a correct assessment and treatment of pain and other problems, whether physical, psychosocial and spiritual, based on early identification. Due to the substantial increase in the number of elderly people and the prevalence of non-communicable chronic degenerative diseases, this care has been increasingly necessary, also developed by Primary Health Care (PHC). It is known that both palliative care and PHC have teamwork as the basis of care. **Objective:** To synthesize the results of studies on the importance of palliative care at home provided by the Primary Health Care team. **Methodology:** Integrative literature review. The search for studies was performed on LILACS, SCIELO and Medline platforms. Studies in English and Portuguese, with a publication date of the last six years, were included. **Results:** Regarding the characterization of the analyzed articles, two (28.5%) were published in 2016, two (28.5%) were published in 2019, 1 in 2021 (14.5%) and two (28.5%) were published in 2022. Among the studies, none were published in specific journals for palliative care. **Final Considerations:** We know that countless patients die before receiving palliative care and of these many, before finitude, suffer from the disease without the minimum quality of life and suffering in the face of the situation. Thus, it is necessary to think and reflect on the PC, which should be available as close as possible to the patient, that is, in Primary Health Care.

**KEYWORDS: NON-COMMUNICABLE CHRONIC DISEASES; PALLIATIVE CARE; PRIMARY HEALTH CARE**

## INTRODUCTION

Palliative care (PC) aims to minimize human suffering through adequate assessment and treatment of pain and other problems, whether physical, psychosocial and/or spiritual, based on early identification. Due to the substantial increase in the number of elderly people and the prevalence of non-communicable chronic degenerative diseases, such care has been increasingly necessary<sup>1</sup>.

Cancer patients, as they experience pain and suffering on a daily basis, as well as people, elderly or not, who have chronic non-communicable diseases (CNCDs), represent a growing concern. In view of this, the World Health Organization (WHO), in 2002, defined Palliative Care as an approach that aims to improve the quality of life of patients and their families, in the face of diseases that threaten the continuity of life. This PC implies the gathering of skills by a multiprofessional team to help patients and their families to adapt to a new standard of living imposed by the disease. Due to its importance, on October 7th, the World Day of Palliative Care is celebrated<sup>2</sup>.

According to data from the World Health Organization, each year about 40 million people need PC (WHO, 2015). Among these, almost 39% are people with cardiovascular diseases, 34% with cancer, 10% with lung diseases, 6% with HIV/AIDS and 5% with diabetes, both in an advanced stage

(WHO, 2015). In this sense, Primary Health Care (PHC) guided by the principles of care coordination; of the bond and continuity; of completeness; of accountability; of humanization; equity and social participation has the potential to become one of the levels of health care with conditions to facilitate the population's access to Palliative Care<sup>1</sup>.

The principles of palliative care, according to WHO information are:

Provide relief for pain, asthenia, inappetence, dyspnea, among others; reaffirming life and death as natural processes; integrate psychological, social and spiritual aspects into the clinical aspect of patient care; not hasten or postpone death; provide a support system to help the family cope with the patient's illness in their own environment; offer a support system to help patients live as actively as possible until their death; use an interdisciplinary approach to assess the clinical and psychosocial needs of patients and their families, including grief counseling and support<sup>4</sup>.

It is known that this care is part of the scope of action of Primary Health Care (PHC) and also, both palliative care and PHC have teamwork as the basis of care by definition. Therefore, exploring this theme allows talking about symptomatic control in palliative care patients, exclusive or not<sup>5</sup>.

In view of the population aging scenario, in addition to inadequate population feeding practices, sedentary life-

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style, among other factors that corroborate the emergence of CNCDs, it is believed that a model of care that includes palliative care is essential.

It is understood that, for a long time, health professionals had well-established attitudes in a mechanistic conception of life, which is why it is currently possible to observe the numerous difficulties in recognizing the complex and multidimensional reality of health care. Regardless of the symptom, we must understand these patients in an integral way, approaching the physical, social, psychological and spiritual spheres.

Based on the above, articles that address evidence-based practice were analyzed, as they improve clinical effectiveness and support health professionals in their conduct based on scientific evidence, clinical experience and client preferences <sup>6</sup>.

The general objective is to synthesize results of studies on the importance of palliative care at home provided by the Primary Health Care team.

The motivation for the theme is due to the fact that, in chronic diseases, actions and palliative care should be initiated at the time of diagnosis and developed together throughout the treatment of the disease, given that this practice brings as its main benefit a better quality of life for the patient.

## LITERATURE REVISION

Palliative care and ethical aspects

Palliative Care (PC) implies an improvement in the quality of life of patients and their families due to a disease that may compromise their quality of life, or even lead to death. Such care promotes the prevention and relief of suffering through early identification, rigorous assessment and treatment of pain <sup>1</sup>.

In this type of care, orthothanasia is promoted and dys-thanasia is avoided. In 2009, the Federal Council of Medicine (CFM) wrote for the first time the term palliative care in the Code of Medical Ethics, maintaining the wording in the current version of the Code, published in 2018 <sup>7</sup>.

Regarding health care, in 2018, Brazil had 177 Palliative Care services, expanding to 190 in 2019. Although this increase of almost 8% represents advances, it is not enough for Brazil to be among the nations with the best level of coverage of this type of care <sup>8</sup>.

Frossard <sup>9</sup> reports that palliative care denotes the reality of public health in Brazil, lacking intensive care units and expecting greater investments. For the author, it is urgent to draft laws that are actually implemented in fact. The researcher brings to light the reflection on the social assistance policy implemented at the different levels of social protection, based on the availability of social services that should incorporate demands for palliative care with reception of the difficulties of people who are dependent on this care.

## ALONG THE SAME LINES, HERE IS WHAT SANTOS, FERREIRA AND GUIRRO (2020) POINT OUT:

Unlike countries where Palliative Care is more developed,

Brazil did not have, until November 2018, any policy that specifically structured or guided the development of the area and even today there are differences when comparing the state and federal levels <sup>8</sup>.

The demand for PC is a current public health problem, especially due to the progressive aging of the world population, whose consequence is revealed by the substantial growth in the number of elderly people. This context, according to Queiroz <sup>10</sup>, highlights the importance of this care, as well as the reorganization of health services in order to ensure their supply.

This care consists of the assistance provided by a multi-professional health team, in addition to volunteers, to individuals diagnosed with a life-threatening chronic disease, with the aim of improving the quality of life of these subjects and reducing hospitalizations and unnecessary care <sup>5</sup>. In this way, PCs go through the interdisciplinarity of care, in an integral way, for people with advanced diseases in the terminal phase and their families and/or caregivers <sup>11</sup>.

In the Brazilian national territory, Primary Care is developed with capillarity and, in a decentralized way, occurs in the place closest to people's lives. There are several related governmental strategies, among them, Basic Health Units, Community Health Agents, Family Health Team and Family Health Support Nucleus, having at an intermediate level the Mobile Emergency Care Service, Emergency Care Units and Medium and High Complexity care provided in hospitals. Secondary care is composed of specialized services at an outpatient and hospital level, with a technological density between primary and secondary care. The third level of care, called tertiary or high-complexity care, is composed of highly specialized therapies and procedures, also organizing procedures that require high technology and high cost, such as oncology, cardiology, transplants, among others <sup>12,13</sup>.

According to the World Health Organization, PC can be performed at different levels of health care, especially within the PHC, bringing benefits to the health system in the reduction of hospitalizations, and can be offered by health professionals and volunteers <sup>3</sup>.

It is known that this type of care for patients with non-communicable chronic diseases can benefit them. PC is present at all levels of care, and can be adopted as an approach by qualified health professionals <sup>14</sup>.

Ethical dilemmas and insecurities from the legal point of view of professionals, in the face of palliative care, commonly arise. Therefore, one of the pillars of medical ethics is decision making. Having the ability to make the right decision, informing patients and their families and/or caregivers that they need to understand the risks and benefits of each therapeutic option, is essential so that they can make decisions according to their life history and values. However, studies show that many patients have inadequate views on their prognosis <sup>15</sup>.

Faced with the finitude of life, the terminal patient is granted respect for autonomy; beneficence; non-maleficence; and justice. He has the right to be treated properly until his death. Even if there is no prospect of life, he has the right to feel hope

and express, as he wants, feelings and emotions in the face of death. Another important ethical factor to consider refers to the right of this patient to participate in decisions about care, treatments and receiving medical and nursing care, even if the healing goals assume the sense of comfort goals. He must not yet die alone; be relieved of pain and discomfort and, finally, have your questions (asked or suggested) answered honestly<sup>16</sup>.

The issues related to the process of finitude faced by the patient are not always clearly explained to the health professionals involved in this care. Therefore, the qualified listening of this professional, with a view to providing more substantial information, will provide greater support for patient care. Also looking at this caregiver, respecting their limits, is essential<sup>17</sup>.

Palliative care at home provided by the Primary Health Care team

From the Declaration of Alma-ata, in 1978, a new form of organization of the health system was carried out. Primary Health Care (PHC) constitutes a primary health care model based on scientific evidence, methods and practices within the reach of individuals, families and communities.

According to the Ministry of Health, there is a configuration that does not match the care models recommended in public policies. This inconsistency is marked by the provision of services and the population's health needs. Therefore, for this discrepancy to be overcome, it is necessary to rescue the Health Care Networks, since they aim at the systemic integration of health actions and services with the increase of the system's performance in terms of access, equity, clinical and sanitary<sup>18</sup>.

As the PHC is the gateway to the health system and because it is decentralized, it should value the proximity of services to the population, whose actions are organized through the multidisciplinary team. The Family Health Strategy (FHS) is the form of action used in the Brazilian scenario<sup>1</sup>.

On the other hand, Home Care (HC) aims to reorganize the work process of teams that provide home care in PHC, in outpatient clinics, in urgent and emergency and hospital services, with the goal of reducing the permanence of hospitalized users.<sup>19</sup>

AD was adopted by Brazilian public policies as an alternative to hospitalization. In the Unified Health System (SUS), this care format was established by Law No. 10,424, of April 15, 2002, which defines this type of assistance and by Ordinance No. 2,529, of October 19, 2006, which defines the forms of action, the formation of the care team, financial resources and accreditation conditions. More recently, the forms of AD were redefined by Ordinance No. 963, of May 27, 2013, which establishes the Home Care Service (SAD) in the SUS, defining the formation of the Multiprofessional Home Care Team (Emad) and including PC and death care in its prerogatives<sup>20</sup>.

Souza et al.<sup>1</sup> and Floriani and Schramm<sup>21</sup>, refer that PC care in PHC should not be understood as home care of the home care type. Therefore, their work must be organized to assist patients suffering from advanced chronic diseases,

with high dependence, in traditional interventionist ways. In relation to PC specifically in PHC, it refers to a specific type of service that can be organized and offered at all levels of reference, without interruption.

In the Brazilian context, since the beginnings of the Community Health Agents Program (PACS) and the Family Health Program (PSF), with wide national distribution, they already provided for visits by a team of health professionals at home, so that, despite not having originally developed for palliative care actions, they were gradually structured to incorporate such a model, assuming important attributions in this care modality<sup>21</sup>.

Souza et al.<sup>1</sup> already reported the reality of patients and family members who need home care with the use of palliative care by PHC professionals. These situations they experienced generated ethical challenges, especially with regard to communication between the team, family and patient and the lack of emotional and institutional support for caregivers, due to the wear and tear resulting from the overload of care that can be clearly perceived by the team.

The integration of PC to existing health services, especially those that include home care, without requiring specialized knowledge, greatly facilitates access to this type of care for a greater number of users<sup>22</sup>.

The fact that the patient can be at home, maintaining their privacy and being able to perform daily tasks, maintaining leisure habits, are some of the numerous benefits of palliative care. You have a more varied diet at home and more flexible hours. These factors promote and/or strengthen the subject's autonomy. Another benefit is the reduction of long and costly hospital stays for the health system. Such care basically requires good communication, treatment of symptoms – such as pain and others – at the end of life, generally low cost, and great coordination of the care process<sup>3</sup>.

In addition, visits and attention from the health team that is intended for the patient and family are essential for a better quality of life for the client and there is no need to use more complex resources to control physical symptoms brings to the reflection the meaning of palliative care that is materialized through the relief of suffering, early identification, correct assessment and treatment of pain, greater autonomy of the patient in meeting their needs.

Another factor to be pointed out as an aid tool used by professionals who work at home is qualified listening and guidance to family members and caregivers about unexpected situations with the patient. This listening can help to reduce anguish, moreover, these people need to be prepared, as much as possible, for some events, such as clinical complications<sup>17</sup>.

There is no ready-made recipe about PC for patients and their families and/or caregivers. However, the approach is of great importance as, in this phase of life, of great vulnerability, with the proximity of the finitude of life, people almost always cling to their beliefs and values as an inner resource to relieve their anguish. Therefore, understanding death as a natural

process of life, although not an easy task, may be the only way to relieve the suffering of definitive disconnection from life as we know it<sup>19</sup>.

Highlights as fundamental the adequate relief of symptoms, which can restore the confidence of the patient and their families, making them safer and more comfortable to enjoy care, according to their needs, in the comfort of their homes, living every moment that is rightfully theirs<sup>4</sup>.

**METHODOLOGY**

The integrative review was adopted as a method for grouping the data collected on the proposed theme. It is a broad methodological approach that allows the inclusion of experimental and non-experimental studies, data from the theoretical and empirical literature on what is to be analyzed<sup>23</sup>.

Unlike the systematic review that constitutes experimental studies of recovery of critical analysis of the literature, the integrative review appears with the objective of reviewing and combining studies with different methodologies, integrating the results<sup>24</sup>.

Like other review methods, integrative review is linked to Evidence-Based Practice (EBP). Data were sought in order to answer the guiding question: What is the importance of palliative care at home provided by the Primary Health Care team, consisting of a doctor, nurse, community health agent and nursing technician, based on the characteristics of each municipality, as established by the guidelines of the National Primary Care Policy (PNAB) and the essential attributes of PHC?

For data analysis, a search for articles from the last six years was carried out, seeking the most up-to-date publications on the subject, being searched in a database in the Latin American and Caribbean Literature on Health Sciences (LILACS), Scientific Electronic Library Online (SCIELO) and MEDLINE. The search was carried out in November 2021, with an update in January 2022 in the same databases. The following descriptors were used: non-communicable chronic diseases; palliative care and primary health care. For the operationalization of the study, the descriptors were crossed in the referred database associated with the Boolean operator and.

As inclusion criteria in the results, articles published between 2016 and 2022 were used, with full text, described in Portuguese and English, free of charge. Articles that were not in accordance with the objectives proposed in this study were excluded.

The process of identification, selection and inclusion of primary publications took place in the following steps: step 1 - identification of studies through descriptors and application of filters, totaling 568 articles; 2 - reading the titles and abstracts of the articles, applying the inclusion and exclusion criteria, being selected 34 articles. After reading these in full, 7 articles were chosen that met the objective of this study. It should be noted that the ethical aspects and the Copyright Law were met.

**RESULTS AND DISCUSSION**

Regarding the characterization of the analyzed articles, two (28.5%) were published in 2016, two (28.5%) were published in 2019, one (14.5%) in 2021 and two (28.5%) were published in 2022. Among the studies, none were published in a specific journal for palliative care, 2 were published in public health journals, 1 in a cancerology journal, 2 in nursing journals, 1 in a PHC journal and 1 in a psychology journal. In this study, in order to facilitate the visualization of the results found, a synoptic table was built containing the author, journal, article title, method and conclusion.

AUTORIA	PERIÓDICO	TÍTULO	MÉTODO	CONCLUSÃO
Marucci et al. (2016)	Cadernos de Saúde Coletiva	Identificação de pacientes com indicação de Cuidados Paliativos na Estratégia Saúde da Família: estudo exploratório	Estudo exploratório transversal, realizado a partir da seleção de uma UBS do município que possuía uma equipe da ESF.	Os CP ainda não estão incluídos nas diretrizes de atuação da ESF, apesar de DCNT's estarem presentes no cotidiano dos profissionais inseridos na atenção primária e demandarem cuidados frequentes por parte das equipes e de seus cuidadores.
Possalacia, Zoboli e Ribeiro (2016)	Revista de Enfermagem do Centro Oeste Mineiro	Equidade no acesso aos cuidados paliativos na atenção primária à saúde: uma reflexão teórica	Estudo de reflexão teórica	Identificou-se como determinantes e condicionantes: financiamento em saúde, responsabilidade dos profissionais, quantitativo de profissionais necessário, estrutura dos serviços, acesso a medicamentos; organização dos serviços para a tomada de decisão justa mediante recursos limitados; políticas voltadas para correção das disparidades; estratégias de priorização e racionalização do acesso aos serviços.
Oliveira, Bombarda e Moriguchi (2019)	Cadernos de Saúde Coletiva	Fisioterapia em cuidados paliativos no contexto da atenção primária à saúde: ensaio teórico	Revisão da Literatura	Para atuação qualificada, há necessidade de integração das perspectivas e da filosofia dos CP em sua totalidade e em consonância com as diretrizes de atuação na APS durante a formação profissional do fisioterapeuta, com a necessidade também de investimentos no desenvolvimento de pesquisas nesse cenário.
Cóbo et al. (2019)	Boletim Academia Paulista de Psicologia	Cuidados paliativos na atenção primária à saúde: perspectiva dos profissionais de saúde	Estudo descritivo e exploratório	A APS é feita por profissionais identificados com seus princípios e diretrizes, direcionada por sua demanda, sendo que há uma cultura que impõe uma visão imediatista sobre a saúde.
Oliveira et al. (2021)	Revista de APS	Cuidados paliativos na Atenção Primária à Saúde: atribuições de enfermeiros e enfermeiras	Revisão Integrativa da Literatura	Percebe-se a necessidade de mais estudos que demonstrem as atribuições da equipe de enfermagem na APS, haja vista a mudança do perfil epidemiológico, o aumento da prevalência das doenças crônicas não transmissíveis (DCNT's), causas externas e câncer.
Silva, Nietzsche e Cogo (2022)	Revista Brasileira de Enfermagem	Cuidados paliativos na Atenção Primária à Saúde: revisão integrativa de literatura	Revisão Integrativa da Literatura	Evidências encontradas relacionando cuidados paliativos na Atenção Primária à Saúde apontam para a possibilidade desse cuidado; equipes de saúde atuam de maneira próxima a família e seu domicílio, porém ainda se percebe a necessidade de ampliação deste tema
Fonseca et al. (2022)	Revista Brasileira de Cancerologia	Atuação do Enfermeiro em Cuidados Paliativos na Atenção Primária à Saúde: Revisão Integrativa	Revisão Integrativa da Literatura	Os enfermeiros possuem 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.

Chart 1 - Synoptic table with distribution of references according to authorship, journal, article title, method and conclusion, 2016 - 2022.



The increase in chronic non-communicable diseases (CNCDs) has represented one of the main causes of death of individuals, implying a great challenge for the health system. These CNCDs are associated with physical and social limitations with aging, causing comorbidities. Thus, there is a need for continuous care <sup>25,29</sup>.

These non-communicable pathologies, such as cancer, diabetes, hypertension and others, cause the subject to gradually lose their functional independence, greatly impacting their quality of life, compromising their autonomy. In addition, deaths from these diseases are preceded by a decline in physical and nutritional conditions, trauma, physical and psychological symptoms, requiring a comprehensive approach to NCD patients <sup>27</sup>.

The fact is that people with no possibility of curing certain diseases, in the terminal phase, are, for the most part, kept in hospitals, sometimes receiving inadequate care since the focus is on keeping them alive. Therefore, invasive methods and technologies are applied that do not consider the suffering of the patient and their families, who stay in their homes apprehensive, not really knowing how the loved one is, or how their feelings are in the face of the cold environment of the hospital. It is important to consider the home as a place where the patient can be at the end of life and, in this perspective, PHC is the closest level of care to the community, being thus the most appropriate for providing palliative care of the terminal patient, also giving full support to the family <sup>29</sup>.

It should be noted that palliative care in PHC, at home, aims to assist the subjects in their terminality, as well as their family members, allowing the individual to live their last days with dignity, minimal suffering, intensity and better quality of life, since they will be next to their loved ones. In order to guarantee this right, the Ministry of Health launched the Better at Home Program in 2011, which allows the health team to get to know the patient's reality more deeply, helping to improve the quality of life of the subject and their families <sup>29</sup>.

Analyzing the principles established by the Unified Health System (SUS) within the scope of PHC, there is comprehensive care, that is, considering the patient as a whole. The National Primary Care Policy points out this principle as follows:

Set of services performed by the health team that meet the needs of the population enrolled in the fields of care, health promotion and maintenance, prevention of diseases and injuries, healing, rehabilitation, harm reduction and palliative care. It includes accountability for the provision of services at other health care points and the adequate recognition of the biological, psychological, environmental and social needs that cause diseases, and management of the various care and management technologies necessary for these purposes, in addition to expanding the autonomy of people and collectivity (PNAB, 2017, s/n).

Therefore, palliative care, according to the aforemen-

tioned Law, includes one of the approaches used by PHC professionals with a view to guaranteeing the integrality of health actions. Assistance is provided by a multidisciplinary team, including diagnosis, illness process, end of life and mourning, and the team needs to recognize the subject in all its dimensions <sup>31</sup>.

Among the few norms that mention Palliative Care are Ordinance No. 741, of December 19, 2005, its update, Ordinance No. 140, of February 27, 2014, and Ordinance No. 483, of April 1, 2014. Ordinance No. 741 defines and Ordinance No. 140 updates the criteria for the performance of the High Complexity Assistance Units in Oncology (UNACON), the High Complexity Assistance Centers in Oncology (CACON) and the High Complexity Reference Centers in Oncology. Ordinance No. 483 redefines the Health Care Network for People with Chronic Diseases within the SUS, establishing guidelines for the organization of its lines of care <sup>8</sup>.

For Pessalacia, Zoboli and Ribeiro (2016), the health system in Brazil is not prepared to meet the demands arising from a new population profile that needs PC, still being linked to curative and hospital-centric practices. In this way, there is a great overload of the secondary care sector, which has resulted in an increase in the costs of financing health actions. <sup>26</sup>

However, for Azevedo et al. (2016), although there is a lot of evidence on the positive impacts of early palliative care, this type of care has been given to patients who are in advanced stages of the disease. Many are referred late, which minimizes the chances of having a better quality of life in their finitude <sup>5</sup>.

It is known that PHC constitutes the first level of the Health Care Network, being its gateway and whose characteristics encompass both individual and collective health actions, including promotion, health protection, disease prevention, diagnosis, treatment, rehabilitation and maintenance of health, being developed with participatory management and health practices, through a multidisciplinary team focused on populations in well-defined territories <sup>28</sup>.

Studies by Silva, Nietzsche and Cogo (2022) aimed to analyze scientific evidence on the implementation and performance of palliative care in Primary Health Care. For the authors, palliative care is part of the work of PHC professionals, clearly contemplating the assessment of symptoms through the multidisciplinary team in its holistic approach <sup>30</sup>.

Like Silva, Nietzsche and Cogo <sup>30</sup>, studies by Fonseca et al. <sup>31</sup>, address the holistic issue in patient care. Fonseca and collaborators analyzed the role of nurses, who are an integral part of the PHC team, in palliative care in primary health care. According to this study, this type of care is defined as holistic, that is, it aims to assist the patient in their physical, mental and spiritual dimensions, seeking to assist the subject with life-threatening illnesses, through the relief of symptoms and consequent quality

of life improvement, both for him and for his family and caregivers. Thus, palliative care is based on careful pain assessment, symptom control and other physical manifestations.

It is concluded by stating that, with the emergence of non-communicable chronic diseases, a model of care that includes palliative care is essential. It is necessary to attend to the patient in an integral way, adopting a holistic approach, considering that the terminality of some health problems go beyond the proximity of death, they are a background for other needs that may involve family, social, cultural and economic problems.

### FINAL CONSIDERATIONS

Palliative care at home aims at quality of life for the patient through assistance based on humanization and compassion towards those who are at the end of their life and who are inserted in a sociocultural context. Through these care established with a professional-patient-family bond, maintaining continuity of care, the terminal patient lives more comfortably and safely with their families.

We know that countless patients die before receiving palliative care and suffer from the disease, often without the minimum quality of life and with a lot of suffering in the face of the situation. Thus, it is necessary to think and reflect on Palliative Care, which should be available as close as possible to the patient, that is, in Primary Health Care.

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