

Perception of healthcare professionals about palliative care

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Abstract

The objective of this exploratory and qualitative study was to analyze the perceptions of professionals working in primary health care about palliative care. Semi-structured interviews were conducted, recorded, transcribed and validated individually, and the resulting data were analyzed thematically and systematized. The association between palliative care and the hospital environment was found to be very present in the discourses of participants. Moreover, it was possible to observe that the limited knowledge on the subject results in difficulty to identify early cases for which this care would be indicated. Among the fundamental points highlighted for this practice are team-based care, proximity to the territory, bonds and comprehensive care. It is suggested that this topic be included in the curricula of health courses.

Keywords: Primary health care. Palliative care. Patient care team.

Resumo

Percepções dos profissionais de saúde sobre cuidados paliativos

O objetivo deste estudo de caráter exploratório e qualitativo é analisar as percepções dos profissionais atuantes na atenção primária à saúde sobre cuidados paliativos. Realizaram-se entrevistas semiestruturadas, que foram gravadas, transcritas e validadas individualmente, e os dados resultantes foram analisados tematicamente e sistematizados. Constatou-se que a associação entre cuidados paliativos e ambiente hospitalar ainda é muito presente nos discursos dos participantes. Além disso, percebe-se que, devido ao conhecimento limitado sobre o tema, há dificuldade na identificação precoce de casos para os quais esses cuidados seriam indicados. Entre os pontos fundamentais destacados para essa prática estão o cuidado em equipe, a proximidade com o território, o vínculo e a integralidade da atenção. Sugere-se que essa temática esteja presente em grades curriculares de cursos na área da saúde.

Palavras-chave: Atenção primária à saúde. Cuidados paliativos. Equipe de assistência ao paciente.

Resumen

Percepción de los profesionales de la salud sobre cuidados paliativos

El objetivo de este estudio exploratorio y cualitativo fue analizar las percepciones de los profesionales que trabajan en la atención primaria sobre los cuidados paliativos. Se realizaron entrevistas semiestructuradas, las cuales fueron grabadas y, posteriormente, transcritas y validadas de manera individual; y los datos resultantes pasaron por un análisis temático y sistematización. Se constató que la asociación entre los cuidados paliativos y el entorno hospitalario sigue estando muy presente en los discursos de los participantes. Asimismo, debido al escaso conocimiento sobre el tema, resulta difícil identificar en una fase inicial los casos en los que estarían indicados los cuidados paliativos. Entre los puntos fundamentales en esta práctica destacan la atención en equipo, la proximidad al territorio, los vínculos y la atención integral. Se sugiere incluir a esta temática en los planes de estudio de las carreras de salud.

Palabras clave: Atención primaria de salud. Cuidados paliativos. Grupo de atención al paciente.

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The concept of palliative care (PC) was defined in 1990 and updated in 2017 by the World Health Organization (WHO). It is an approach that aims to improve the quality of life of families and people facing life-threatening illnesses, in addition to preventing and alleviating suffering through early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual. Care is provided by an interprofessional team throughout the process of diagnosis, illness, death and grieving¹.

Prominent among public policies in Brazil that include PC is the National Cancer Prevention and Control Policy², which, together with Ordinance 41/2018 of the Brazilian Ministry of Health (MS)³, offers PC at all levels of care as part of integrated continued care within the scope of the Unified Health System (SUS)⁴.

MS Resolution 41/2018 provides for on guidelines to organize PC and its main objectives include integrating PC into the healthcare network, providing patients with improved quality of life, offering permanent health education in this area for SUS workers and helping disclose information on this approach in society, among others. This resolution also provides for the offer of PC at any point in the care network: primary health care (PHC), home care, outpatient care, urgent and emergency care and hospitalization³.

MS Ordinance 825/2016, which redefines home care within the SUS, provides for the use of PC in clinical home care² with the purpose of shortening or avoiding hospitalization (Article 9)⁵. Care should be provided at least once a week to control the patient's pain and suffering. Also noteworthy is the National Primary Care Policy (MS Ordinance 2,436/2017), which includes PC as an option in individual, family and collective primary health care⁶.

At different levels, this kind of care focuses on improving the quality of life of individuals suffering from diseases such as metastatic or inoperable cancer and chronic-degenerative pathologies, or even those in the terminal phase. There should be a team made up of healthcare providers from different areas to offer interdisciplinary care centered on the patient and the family^{7,8}.

It requires knowing how to define which patients can benefit from this care, how it is

applied in everyday practice and how it can be developed by the team in order to offer support to both patient and family, who are the main targets⁹. Therefore, the multidisciplinary team that will provide care should necessarily have knowledge about the concept of PC.

Studies relating PC to PHC in Brazil are still under development, unlike in other countries where this approach is more widespread and established. A recent study found great diversity in the extent and nature of PC offered in European countries¹⁰. In Portugal, in 2012, there were 18 community support teams, each comprising three physicians, three nurses, a psychologist and a social worker. Besides providing PC to patients and family, they also offered advice to the PHC team.

In Belgium, there are also PC networks throughout the country, with a team providing consultancy services—in Antwerp, the network is made up of nurses specialized in this line of care¹⁰. Psychologists, administrative staff and coordinators act as a support group, providing, among other services, personalized advice in complex care situations.

The authors of the study also highlighted the existence of facilitators to provide instruction/training opportunities in PC for the entire team. The training focuses on practice, continuity of care and multidisciplinary collaboration, encouragement of teamwork and creation of PC consultancy teams, among other goals¹⁰.

A study carried out in Australia analyzed the best PC practices according to the perception of general practitioners working in PHC, indicating that PC was considered proactive and responsive to a wide range of needs of patients and families. The participants also highlighted the need for a more ongoing relationship ranging from diagnosis to palliative care. In short, they perceived PC as a natural extension of primary care, mainly requiring knowledge and good communication skills between healthcare providers, patients and family members¹¹.

In Brazil, a few studies were developed with reference teams and professionals of the Expanded Family Health Center (NASF). A 2019 study explored the understanding of PC from the perspective of

13 healthcare providers of a Family Health Strategy (ESF) team. Among the professionals interviewed (all with higher education degrees) were six nurses, six physicians and one dentist.

Due to the needs imposed by clinical practice, all healthcare providers had had previous contact with the concept of PC through lectures, events or individual studies, although none of them had specific training in the area. When asked about the practice of PC, 77% of the team's members reported having provided this type of care in their professional experience, even without calling it palliative. They also highlighted that full implementation of PC required structuring PHC with more significant support from management and a focus on training those involved, including family, patients, caregivers, healthcare staff and managers¹².

Another recent study aimed to understand the perception of PC among physicians who made up the ESF¹³. In the interviews, it was noticed that these professionals had hardly any contact with the topic during their undergraduate studies and the interviewees stressed that PC was addressed together with other subjects or in lectures. The study concluded that many physicians still view such care as being aimed exclusively at terminal patients, revealing a fairly distorted outlook given the breadth of the PC concept.

A 2018 study interviewed 25 NASF healthcare staff with higher education and more than one year of experience working in PHC to investigate what meanings these professionals attributed to PC at this level of care. Based on the interviews, the authors suggested that there are barriers to providing this care—not only with regard to the concept of PC, but to “caring” itself. Disruption of the care network, fragmentation of activities and shortage of inputs in health centers stand out as reasons that hinder the continuity of various kinds of care¹⁴.

The literature that addresses the perceptions of healthcare providers regarding PC in PHC has grown recently. As part of this effort, this study aims to investigate how PHC staff perceive PC. In addition, it seeks to identify, in relation to this practice, the level of knowledge, applicability and possible facilitators and barriers.

Method

This is an exploratory study with a qualitative approach carried out in four family health centers (USF) and one municipal health center (CMS) in a medium-sized city. Fourteen healthcare providers took part in the survey, selected according to the following inclusion criteria: having secondary, vocational or higher education and being part of ESF and NASF teams, in addition to belonging to the city's CMS.

Data were collected from April to September 2021 after the approval of the research project and signing of the informed consent form. To achieve the proposed goal, the study used a clinical case, based on guidelines from the National Academy of Palliative Care (ANCP)¹ handbook, and a questionnaire with guiding questions that underwent pilot interviews.

The following questions were asked: “Have you had any contact with the concept of PC? If so, when and where”; “Could you tell me what you understand by PC, in your own words?”; “Do you think such care only applies to terminal cases?”; “After the second reading (clinical case), do you believe that this patient would be eligible (receive an indication) for PC?”; “Do you believe you practice or have practiced PC in your work?”; “And how do you view it in your team, in the health system where you work?”; “Do you believe there is a relationship between PC and PHC, considering health promotion and disease prevention?”; “In your work, what do you believe are facilitators and barriers to the practice of PC?”

Semi-structured interviews were recorded individually with each participant and then transcribed and validated. The data were systematized with Iramuteq software, which performs statistical analyses based on the grouping of words with semantic similarity in the body of research and divides it into text segments (TS), small fragments that have a semantic relationship with each other¹⁵. After the researchers had used the software and interpreted the results, some classes were generated and the content was analyzed¹⁶. The statements will be identified by the abbreviations P1, P2 and so on.

Results and discussion

The participating healthcare providers were community health agents (ACS), nursing technicians, nurses, physicians (family and community medicine; psychiatry), occupational therapists and nutritionists, and aged between 24 and 65 years, with 42 years as the mean age.

The classification generated by Iramuteq based on some words present in the body of research enabled the researchers to define three thematic cores: 1) PC: focus on the hospital environment; 2) PC in PHC: challenges and possibilities in healthcare practice; and 3) for training with more information: identification of PC patients by interdisciplinary staff.

Palliative care: focus on the hospital environment

Healthcare providers, as well as family members of PC patients, have difficulty understanding how to cope with this care in an outpatient clinic and/or at home. This is due to the historical and cultural context, in which people spend little time with close to dying relatives and the focus is on offering complex care carried out by a specific team in a hospital environment¹⁴.

When asked about the practice of PC in their work routine, the participants almost automatically associated this kind of care with the hospital environment, making it necessary to encourage them to address the relationship with PHC to explore answers in this sense. The focus on care provided in hospital is evident in the statements:

"I do believe that I have practiced and still practice palliative care, not only as a prescription routine, hospital routine, but in humanized care with these patients, providing them with the minimum comfort they require" (P1).

"Yes... every day, I also work in a hospital. Here at the health center, not yet" (P4).

From a historical point of view, when one talks about health care, especially with terminal patients, there is a direct association with the

hospital environment. According to popular culture, only people who are very ill should go to the hospital and it is in this context that some of the main PC services in Brazil have been developed¹⁷.

According to data from a study carried out in 2019 in which 400 older adults aged 60 or over in Belo Horizonte/MG were interviewed to investigate where they preferred to die, the place of preference was their home¹⁸. However, most of the city's residents end up dying in hospital, as happens in the rest of Brazil. As a response to the growing pressure for care demands, the trend is still to focus on creating PC teams in hospitals¹⁷.

Some of the healthcare providers were not so sure about the practice of PC in PHC, as shown in the following report:

"Hmm... I think maybe yes, I may have already practiced it, that is, some of the concepts, I think so... sometime during the probation period" (P2).

A study published in 2014 in Spain aimed to evaluate the perception of knowledge about PC by interviewing PHC providers¹⁹, associating their knowledge with the applicability and practice of PC in this environment. Some issues were evaluated, such as identification of bedsores, non-pharmacological treatment of dyspnea and insomnia, use of cognitive tests and recognition of psycho-emotional problems in patients.

Sixty-five healthcare providers participated, including physicians, nurses, nursing assistants, physical therapists and occupational therapists. Practically all of them showed great interest in being trained in PC, and poor instruction to deal with symptoms through non-pharmacological practices was identified¹⁹.

A 2013 study²⁰ reports that vocational training is still based on the healing paradigm and that PHC staff, even when they consider addressing quality of life in their practice, still feel insecure in relation to PC. The study also notes the lack of knowledge and skills in providing palliative care outside the institutional hospital environments where they normally work.

In a 2015 study that addressed PC in home care from the perspective of occupational

therapists, only two of the eight interviewees reported having any practice in this type of care²¹, one of them in a hospital environment and the other in consultancy and supervision activities.

The authors also emphasized that specialized services present a higher number of PC cases compared to facilities that provide services of lower technological complexity, such as primary health centers (UBS) and general hospitals. However, the reduced number of cases treated in PHC does not mean that there is no demand for such care, but rather that the data must be further explored and documented²¹.

Challenges and possibilities in healthcare practice

In this category, the aim was to address some of the factors that facilitate or hinder the practice of PC in PHC according to the providers' experiences. The following question was asked: "In your work, what do you believe facilitates the practice of PC?"

The survey participants mentioned characteristics such as trust, empathy, bonding between staff and the patient/family, and support as factors that favor the practice of this kind of care in PHC, pointing out that having a multidisciplinary team is also a facilitator. In addition, having more knowledge and information on the subject, identifying PC referrals more clearly and knowing how to handle techniques adequately are viewed by providers as important aspects. The presence and work of community health agents, who serve as a link between patients/family and the health center, was also highlighted:

"Yes, in relation to food, which is more my area here (...). Hmm... facilitator... Within my area of knowledge, there are several techniques I can use to help these patients improve their quality of life (...), we can think of food items that afford them well-being, changing the consistency of the diet... a mild diet, for pleasure, thinking about quality of life" (P11).

"That's the facilitator, having the community health agent as a link between the center and the patient's home" (P13).

A 2018 study aimed to report the experience of resident doctors in an intervention carried out in the PHC network of a city in Brazil in order to identify the demands of healthcare staff in providing PC to cancer patients²². The study also included community health agents and the professionals showed satisfaction and responded positively to the intervention, demonstrating interest in further training in the area.

In evaluating the perception of ESF nurses on the provision of PC at home, another study stressed that bonding between healthcare staff and patients is key to this practice²³. Attention, respect and affection are necessary when caring for this kind of patient and their families, especially in cases involving terminal patients. It was emphasized that integrated action by a multidisciplinary team facilitates the provision of PC at home.

When reflecting on the barriers to the practice of PC in PHC, the participants presented some considerations:

"As a barrier, fear, not only of professionals, but especially of the people who need this care... and [of] the family, as it is new to them, it is unknown (...). I think fear is our worst barrier... I also put myself in the patient's shoes, so we are afraid to get too close, I think" (P4).

"I think that [a barrier is] communication with the family and with the nursing staff, [with] the medical staff. Because normally a palliative patient already has a pre-established illness" (P5).

"One barrier I believe is the absence of professionals, the absence of qualified professionals, which ends up obstructing, or at least hindering, the identification of these people [who need PC]. The lack of specialized professionals, as an extension, a support team. Perhaps there is lack of investment in specialized professionals to care for this type of patient" (P12).

In the reports, fear of the unknown when dealing with some PC patients, communication difficulties of staff and poor training of healthcare providers in this kind of care are mentioned as the main barriers to the development of PC.

It is important to reflect on the fear felt by healthcare providers. On the one hand, fear represents empathy and compassion for the patient, when they imagine themselves in their situation, and, on the other, it is a feeling that is also linked to the unknown²⁴, which tends to decrease with greater theoretical or practical knowledge. Therefore, the presence of fear in healthcare providers further reinforces the need for training focused on PC.

A survey carried out in 2019 to understand how ESF physicians perceived PC¹³ identified some limitations to the practice, especially their difficulty in communicating with patients and families. This is an impediment that tends to worsen in situations involving illness and death: physicians may wish to avoid facing their own finitude or even feel unprepared to address such issues with patients and family.

A 2017 study that aimed to identify common practices in specialist PC teams in Canada showed that intrateam communication and communication with the patient/family is an extremely important strategy in this sense. When communication is effective and associated with bonding, patients does not need to repeat their story countless times²⁵.

A similar conclusion was obtained in a 2018 paper: communication between the PC team and patients should be improved through the training of healthcare providers. It was also highlighted that family members need to be better instructed in relation to communicating with terminal patients²⁶.

Thus, based on reflection on the practice of PHC providers, it is observed that providing PC training and achieving greater proximity/integration of different sectors of the healthcare network may afford greater scientific knowledge and help overcome many of the barriers they mentioned.

For an education with more information

The identification of patients who are eligible for PC is directly associated with scientific knowledge and the practices that healthcare providers adopt in relation to this care. Some studies discussed in this category

suggest that such identification in PHC occurs through the use of PC-oriented scales.

A 2016 study explored a screening method to identify patients eligible for PC in the ESF, as well as to quantify them in an UBS area, by describing clinical and sociodemographic characteristics²⁷. To this end, the palliative care screening tool was used and a questionnaire was administered to obtain information. The Center to Advance Palliative Care recommends using this scale because it draws on a functional assessment component and also includes primary and secondary diseases and other conditions of the patient.

The work included 24 people. The frequency of patients eligible for PC, in the coverage area, was 7.3 cases per 1,000 individuals (or 0.73%). The authors concluded that there are individuals in need of PC in the ESF, especially with non-communicable diseases, such stroke sequelae, cancer and dementia syndromes, among others. The screening method also proved to be viable for identifying such patients, although the authors stress that further studies are needed to analyze how such conditions impact the demands of PHC²⁷.

The participants of this study, after reading the clinical case presented, were asked about the eligibility for PC. In other words, the need for PC was identified based on the healthcare providers' perception and reflection on the supposed clinical condition described. Some participants indicated that the patient was eligible for such care:

“Yes, yes... because his condition is very serious, he is starting to have kidney failure, his condition is deteriorating, probably leading to death” (P13).

Another provider did not consider the patient described in the clinical case eligible for receiving PC. This response may be due to the association made by some healthcare providers between PC and terminal patients:

“Look, as I see it, [given] the condition he is in and the way [in which] the family takes care of him, I don't think he would be a patient that you would refer to palliative care (...). I wouldn't recommend

it yet, I think there are things to be done... that's what I think and how I see it" (P3).

In this statement, it is clear, mainly from the excerpt *"I think there are things to be done"*, that the healthcare provider does not identify the care that can and should be offered, often early, within the context of palliative care. Other participants were uncertain when asked about the clinical case:

"Look, he hasn't improved, it's a disease that is progressing... I'm not sure, but I believe so. But I'm not sure, even though he hasn't improved" (P10).

In these statements, the healthcare providers, despite having answered in previous questions that they believe such care could be offered early, still presume that PC is only for terminal users. This is a very common understanding in the individuals' answers when the hypothetical clinical case is posed to them.

A descriptive study including 19 health centers in a city sought to identify, within PHC, patients who were eligible for PC²⁸ by administering the Karnofsky performance scale to the medical records of patients in the health sector. The tool proved to be interesting, as a large number of patients were identified as eligible for PC (2,715 people from a total of 75,524) and had their medical records analyzed. Among the pathologies found were Alzheimer's, dementia, Parkinson's, congenital anomaly, meningitis sequelae, chronic obstructive pulmonary disease, liver cirrhosis and rheumatoid arthritis.

Some curricula of higher education courses in the health area address technologies and medication aimed at curing or treating illnesses, which reinforces training aimed at defending life and fighting death, and teaching about the process of dying is still a challenge. Viewing death from an exclusively biological perspective, as an event contrary to life, limits the approach to the subject in university courses²⁹.

PC and death, especially as mandatory topics, are still poorly addressed in undergraduate courses, and are often learned in lectures, events or even in graduate courses, depending on the area. This shows the importance of addressing the topic of PC in healthcare education. The scarcity of

this approach, especially at undergraduate level, is visible in the following statement:

"There is a lack of more information, not only for the team, right?, but for the population in general. We see the gap, both in vocational and undergraduate education, the lack of this information. So, in a way, they provide the basics, but the basics are not what is needed, so there is a lack of additional content, guidance" (P4).

When evaluating the teaching of end-of-life care in 179 medical courses in Brazil, a survey showed that only 35% addressed this topic in their undergraduate curricula and that, in doing so, they discussed the topic in subjects that were not specific or in which it was not the main focus³⁰. The priority given to teaching end-of-life care was considered low, and 73% of the courses considered the time available for teaching insufficient. In addition, 65.6% of the courses cited lack of specialized faculty as one of the major barriers to teaching care of terminal patients.

In this survey, most respondents showed understanding of the concept:

"I understand that it is continuous care, in order to provide comfort, right?, in patient care... to minimize, to some extent, discomfort, pain, situations in which it is impossible for the patient to remain in a good condition. I imagine [it's] like that" (P4).

"To reduce suffering as much as possible and increase quality of life, right?" (P14).

Having had prior contact with the topic in an in-depth manner leads to a better understanding of healthcare providers regarding the concept of PC. A 2011 study investigated the understanding of ESF staff about PC and its treatment options, finding from the statements collected that healthcare providers still relate PC to terminal patients only. Despite this connection, important characteristics were mentioned by interviewees such as "relief of pain and suffering", "exhaustion of the possibility of a cure", "improved quality of life" and "a physical and spiritual perspective"³¹.

Some interviewees in this study related the concept of PC with the issue of dignity, aimed at

patients at the end of their lives, as observed in the following statement:

"I understand palliative care as a therapeutic project for patients at the end of their lives, providing support for quality of life at this stage" (P8).

Although most of the healthcare providers interviewed showed some understanding of the concept, they reported having superficial training on the subject. Providing health training that includes PC helps them identify patients who should be referred to such care. It is worth mentioning a question asked to the researcher before an interview, which reveals the urgent need for training with more information about PC: *"Why did you choose to study a subject that almost no one studies?"*

Final considerations

Carried out during a pandemic (which poses many limitations and challenges), this study benefitted from the availability and dedication of the participants, who contributed to it despite being burdened with a large workload. Another major challenge faced by the study is talking about PC in the current context of health practice: NASF, previously a support team, has been practically terminated, and there are few incentives for public policies (in action) aimed at PC.

The study suggests that, in the context of PHC, the participants generally have superficial knowledge about PC, and some even have a skewed view of the topic. This has a direct influence on professional practice, as healthcare providers have difficulty identifying patients who would benefit from this care. The scant knowledge and association restricted to terminal patients, still evident in the statements, hinders the early identification of cases for which the indication would be appropriate, preventing patients and families from being relieved of their suffering at an adequate time or at all.

Some barriers and facilitators were also identified, with the establishment of personalized health care showing the greatest potential for the practice of PC in this type of service. Interprofessional team care, local ties, bonding, humanized care and comprehensive care are fundamental points. This topic should be present in the educational approaches of courses in the health area, not superficially, but as an integral part of training. Incurable diseases, relief from suffering and terminal patients are subjects that should be addressed.

The study had limitations, as it was restricted to a number of health centers in a city and was carried out during a pandemic. Therefore, further studies on this topic are suggested, with the aim of improving the quality of care for patients with indication for PC.

References

1. Carvalho RTD, Parsons HA, organizadores. Manual de cuidados paliativos ANCP [Internet]. 2ª ed. São Paulo: Academia Nacional de Cuidados Paliativos; 2012 [acesso 2 out 2023]. p. 23. Disponível: <https://bit.ly/3R9MjyO>
2. Brasil. Ministério da Saúde. Portaria nº 874, de 16 de maio de 2013. Aprova a política nacional para a prevenção e controle do câncer na rede de atenção à saúde das pessoas com doenças crônicas no âmbito do Sistema Único de Saúde (SUS). Diário Oficial da União [Internet]. Brasília, nº 94, p. 129, 17 maio 2013 [acesso 24 out 2023]. Seção 1. Disponível: <https://bit.ly/3Gq7TcG>
3. Brasil. Ministério da Saúde. Comissão Intergestores Tripartite. Portaria nº 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 (SUS). Diário Oficial da União [Internet]. Brasília, nº 225, p. 276, 23 nov 2018 [acesso 24 out 2023]. Seção 1. Disponível: <https://bit.ly/3uNfq2U>
4. Mendes EC, Vasconcellos LCF. Cuidados paliativos no câncer e os princípios doutrinários do SUS. Saúde Debate [Internet]. 2015 [acesso 24 out 2023];39(106):881-92. DOI: 10.1590/0103-1104201510600030026

5. Brasil. Ministério da Saúde. Portaria nº 825, de 25 de abril de 2016. Redefine a atenção domiciliar no âmbito do Sistema Único de Saúde (SUS) e atualiza as equipes habilitadas. Diário Oficial da União [Internet]. Brasília, nº 78, p. 33, 26 abr 2016 [acesso 24 out 2023]. Seção 1. Disponível: <https://bit.ly/3T9Vp0l>
6. Brasil. Ministério da Saúde. Portaria nº 2.436, de 21 de setembro de 2017. Aprova a política nacional de atenção básica, estabelecendo a revisão de diretrizes para a organização da atenção básica, no âmbito do Sistema Único de Saúde (SUS). Diário Oficial da União [Internet]. Brasília, nº 183, p. 68, 22 set 2017 [acesso 24 out 2023]. Seção 1. Disponível: <https://bit.ly/46MBVC6>
7. Arantes ACLQ. Indicações de cuidados paliativos. In: Carvalho RT, Parsons HA, organizadores. Manual de cuidados paliativos ANCP [Internet]. 2ª ed. São Paulo: Academia Nacional de Cuidados Paliativos; 2012 [acesso 24 out 2023]. p. 56-74. Disponível: <https://bit.ly/3R9Mjy0>
8. Saito DYT, Zoboli ELCP. Cuidados paliativos e a atenção primária à saúde: scoping review. Rev. bioét. (Impr.) [Internet]. 2015 [acesso 24 out 2023];23(3):593-607. DOI: 10.1590/1983-80422015233096
9. Paz CRP, Pessalacia JDR, Zoboli ELCP, Souza HL, Granja GF, Schweitzer MC. New demands for primary health care in Brazil: palliative care. Invest Educ Enferm [Internet]. 2016 [acesso 24 out 2023];34(1):46-57. DOI: 10.17533/udea.iee.v34n1a06
10. Rotar Pavlič D, Aarendonk D, Wens J, Rodrigues Simões JA, Lynch M, Murray S. Palliative care in primary care: European Forum for Primary Care position paper. Prim Health Care Res Dev [Internet]. 2019 [acesso 24 out 2023];20:e133. DOI: 10.1017/S1463423619000641
11. Herrmann A, Carey M, Zucca A, Boyd L, Roberts B. General practitioners' perceptions of best practice care at the end of life: a qualitative study. BJGP Open [Internet]. 2019 [acesso 24 out 2023];3(3). DOI: 10.3399/bjgpopen19X101660
12. Côbo VA, Dal Fabbro AL, Parreira ACSP, Pardi F. Cuidados paliativos na atenção primária à saúde: perspectiva dos profissionais de saúde. Bol Acad Paul Psicol [Internet]. 2019 [acesso 24 out 2023];39(97):225-35. Disponível: <https://bit.ly/46QmMQw>
13. Ribeiro JR, Poles K. Cuidados paliativos: prática dos médicos da estratégia saúde da família. Rev Bras Educ Méd [Internet]. 2019 [acesso 24 out 2023];43(3):62-72. DOI: 10.1590/1981-52712015v43n3RB20180172
14. Carvalho GAFL, Menezes RMP, Enders BC, Teixeira GA, Dantas DNA, Oliveira DRC. Significados atribuídos por profissionais de saúde aos cuidados paliativos no contexto da atenção primária. Texto Contexto Enferm [Internet]. 2018 [acesso 24 out 2023];27(2):e5740016. DOI: 10.1590/0104-070720180005740016
15. Tomicic A, Berardi F. Between past and present: the sociopsychological constructs of colonialism, coloniality and postcolonialism. Integr Psychol Behav Sci [Internet]. 2018 [acesso 24 out 2023];52(1):152-75. DOI: 10.1007/s12124-017-9407-5
16. Bardin L. Análise de conteúdo. Lisboa: Edições 70; 2011.
17. Rodrigues LF. Modalidades de atuação e modelos de assistência em cuidados paliativos. In: Carvalho RT, Parsons HA, organizadores. Manual de cuidados paliativos ANCP [Internet]. 2ª ed. São Paulo: Academia Nacional de Cuidados Paliativos; 2012 [acesso 24 out 2023]. p. 86-93. Disponível: <https://bit.ly/3R9Mjy0>
18. Jorge R, Calanzani N, Freitas A, Nunes R, Sousa L. Preference for death at home and associated factors among older people in the city of Belo Horizonte, Brazil. Ciênc Saúde Colet [Internet]. 2019 [acesso 24 out 2023];24(8):3001-12. DOI: 10.1590/1413-81232018248.24102017
19. Sánchez-Holgado J, Gonzalez-Gonzalez J, Torijano-Casalengua ML. Percepción sobre conocimientos en cuidados paliativos de los trabajadores de los centros sociosanitarios de personas mayores de una zona básica de salud. Soc Esp Med Rural Gen [Internet]. 2016 [acesso 24 out 2023];42(1):19-24. DOI: 10.1016/j.semrg.2014.10.013
20. Queiroz AHAB, Pontes RJS, Souza AMA, Rodrigues TB. Percepção de familiares e profissionais de saúde sobre os cuidados no final da vida no âmbito da atenção primária à saúde. Ciênc Saúde Colet [Internet]. 2013 [acesso 24 out 2023];18(9):2615-23. DOI: 10.1590/S1413-81232013000900016
21. Portela SG, Galheigo SM. Cuidados paliativos na atenção domiciliar: a perspectiva de terapeutas ocupacionais. Cad Bras Ter Ocup [Internet]. 2015 [acesso 24 out 2023];23(1):15-29. DOI: 10.4322/0104-4931.ctoAO472

22. Silva KF, Pucci VR, Flores TG, Giaretton DWL, Weiller TH, Concatto MEP, Damaceno AN. Construindo a linha de cuidado do paciente oncológico paliativo em um município do sul do Brasil: relato de experiência. *Rev APS [Internet]*. 2018 [acesso 24 out 2023];21(3):470-7. DOI: 10.34019/1809-8363.2018.v21.15944
23. Baliza MF, Bousso RS, Spineli VMCD, Silva L, Poles K. Cuidados paliativos no domicílio: percepção de enfermeiras da Estratégia Saúde da Família. *Acta Paul Enferm [Internet]*. 2012 [acesso 24 out 2023];25(esp 2):13-8. DOI: 10.1590/S0103-21002012000900003
24. Ciceri MR. O medo. Curitiba: Loyola; 2004.
25. Seow H, Bainbridge D, Brouwers M, Bryant D, Toyofuku ST, Kelley ML. Common care practices among effective community-based specialist palliative care teams: a qualitative study. *BMJ Support Palliat Care [Internet]*. 2020 [acesso 24 out 2023];10(1):e3. DOI: 10.1136/bmjspcare-2016-001221
26. Landers A, Dawson D, Doolan-Noble F. Evaluating a model of delivering specialist palliative care services in rural New Zealand. *J Prim Health Care [Internet]*. 2018 [acesso 24 out 2023];10(2):125-31. DOI: 10.1071/HC18004
27. Marcucci FCI, Perilla AB, Brun MM, Cabrera MAS. Identificação de pacientes com indicação de Cuidados Paliativos na Estratégia Saúde da Família: estudo exploratório. *Cad Saúde Colet (Rio J.) [Internet]*. 2016 [acesso 24 out 2023];24(2):145-52. DOI: 10.1590/1414-462X201600020012
28. Azevedo C, Rates CMP, Pessalacia JDR, Mata LRF. Perspectivas para os cuidados paliativos na atenção primária à saúde: estudo descritivo. *Online Braz J Nurs [Internet]*. 2016 [acesso 24 out 2023];15(4):683-93. DOI: 10.17665/1676-4285.20165370
29. Correia DS, Taveira MGMM, Marques AMVFA, Chagas RRS, Castro CF, Cavalcanti SL. Percepção e vivência da morte de estudante de medicina durante a graduação. *Rev Bras Educ Méd [Internet]*. 2020 [acesso 24 out 2023];44(1):13. DOI: 10.1590/1981-5271v44.1-20190200
30. Toledo AP, Priolli DG. Cuidados no fim da vida: o ensino médico no Brasil. *Rev Bras Educ Méd [Internet]*. 2012 [acesso 6 nov 2023];36(1):109-17. DOI: 10.1590/S0100-55022012000100015
31. Costa ICP. Cuidados paliativos na atenção básica: depoimentos de profissionais da saúde [dissertação] [Internet]. João Pessoa: Universidade Federal da Paraíba; 2011 [acesso 24 out 2023]. Disponível: <https://bit.ly/413k1dj>

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