

# Palliative care and primary health care: scoping review

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## Abstract

The ageing population has increased the incidence of chronic health conditions, requiring the inclusion of different levels of palliative care (PC) in different parts of the health system, including the Primary Health Care (PHC). This new reality might interfere with the ethical issues of PHC. This research aimed to identify, from the point of view of health professionals, the ethical problems which arise from the palliative care in PHC. We carried out a systematic review in PubMed, EMBASE, LILACS, CINAHL, using the descriptors 'ethics', 'bioethics', 'Primary Health Care' and 'Palliative Care'. We found 3,915 articles of which 16 remained after analyses. The ethical problems found were: lack of resources; lack of knowledge about palliative care; lack of communication skills; difficulty in establishing limits in clinical relationship; work overload; lack of support from referral services. These problems, in general are similar to those experienced in the PHC but with differences in specific situations. The incorporation of palliative care to the Primary Health Care specific guidelines and training as well as the custom of shared and co-responsible care.

**Keywords:** Palliative Care. Chronic Disease. Primary Health Care. End-of-life. Bioethics. Ethics.

## Resumo

### Cuidados paliativos e a atenção primária à saúde: *scoping review*

O envelhecimento da população aumentou a incidência de doenças crônicas, demandando a inserção dos cuidados paliativos (CP) em diferentes níveis da rede, incluindo a atenção primária à saúde (APS). Isso poderá interferir nas questões éticas da APS. A presente pesquisa teve como objetivo identificar, na visão dos profissionais de saúde, os problemas éticos decorrentes da prática dos CP na APS. Fez-se revisão sistemática nas bases PubMed, Embase, Lilacs, CINAHL, com os descritores "ética", "bioética", "atenção primária à saúde" e "cuidados paliativos". Localizaram-se 3.915 artigos, restando 16, após a análise. Os problemas éticos detectados foram: escassez de recursos; desconhecimento sobre CP; falta de habilidades comunicacionais; dificuldade de estabelecer limites na relação clínica; sobrecarga de trabalho; falta de apoio dos serviços de referência. Na abrangência, esses problemas assemelham-se aos vividos na APS, com diferenças nas situações específicas. Para incorporar os CP na APS, são necessárias normatizações e formação específicas, além da cultura do cuidado compartilhado e corresponsável.

**Palavras-chave:** Cuidados paliativos. Doença crônica. Atenção primária à saúde. Terminalidade de vida. Bioética. Ética.

## Resumen

### Los cuidados paliativos y la atención primaria de salud: *scoping review*

El envejecimiento poblacional aumentó las enfermedades crónicas, planteando la inclusión de diferentes niveles de cuidados paliativos (CP) en la red sanitaria, incluyendo la Atención Primaria de Salud (APS). Esto puede interferir con la ética de la APS. Nuestra investigación objetivó identificar, según los profesionales, cuales son los problemas éticos de los CP en la APS. La revisión sistemática en PubMed, EMBASE, LILACS, CINAHL, con descriptores "ética", "bioética", "Atención Primaria de Salud" y "Cuidados Paliativos", identificó 3.915 artículos, restando 16, después del análisis. Los problemas éticos fueron: falta de recursos; desconocimiento en CP; falta de habilidades comunicacionales; dificultad con los límites de la relación clínica; sobrecarga de trabajo; insuficiente soporte de servicios de referencia. En general, los problemas se asemejan a los experimentados en la APS, con las peculiaridades de situaciones más específicas. La incorporación del CP en la APS requiere: directrices y formación específicas; cultura de la atención compartida y corresponsabilidad.

**Palabras-clave:** Cuidados Paliativos. Enfermedad Crónica. Atención Primaria de Salud. Fin de la vida. Bioética. Ética.

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Declararam não haver conflito de interesse.

The demographic and epidemiological transition has changed the morbidity and mortality profile of the Brazilian population. Infectious diseases were the most frequent causes of death until the first half of the twentieth century but, currently, noncommunicable chronic diseases are epidemic, in particular cardiovascular diseases, cancer and type 2 diabetes. The highest morbidity and mortality rates, due to these diseases, grow each year and account for about 70% of the health spending in the country <sup>1</sup>.

Chronic health conditions, because of their progressive and degenerative evolution, demand continuous and ongoing assistance - which includes palliative care- in various parts of the health care system (Rede de Atenção à Saúde -RAS). The continued assistance in chronic health conditions involves attention to the latent moments of the disease when it evolves without perception of the person who will suffer the deterioration of quality of life <sup>2</sup>.

It is a challenge for the Unified Health System (Abbreviated as SUS in Brazil - Sistema Único de Saúde) and the Primary Health Care (PHC) to reorganise themselves in order to meet the current health needs and demands of an ageing population with chronic diseases. Historically, the health systems were organised and focused on responding to acute conditions or episodes of worsening of chronic conditions <sup>2</sup>.

Palliative care has the objective of promoting a better quality of life, through therapeutic projects planned by a multidisciplinary team, for people with chronic degenerative diseases or are in a terminal state. The care is not restricted to specific contexts and institutions and must be performed at every level of the health system. Specialised Palliative Care is an assignment attributed to specialists in hospices, while primary health care provides the overall palliative care. All health workers should be trained for the palliative care approach, since this kind of attention needs to be established early, from the moment of the diagnosis of chronic health conditions, and aimed at a good quality of life <sup>3</sup>.

The main challenge for the palliative care at an international level is to go beyond the care of terminally ill patients with cancer. It is proposed that palliative cases should be: introduced as soon as possible in caring for diseases, not only during terminal stages; go beyond the physical dimensions of care and cover the social, psychological and existential aspects; span from hospices and specialised services to the general services in hospitals and in the community, disseminating in the community in

order to support caregivers and patient's relatives <sup>3</sup>.

The best results in providing palliative care depend on the integrated operation of services as well as the alliance between specialists, generalists and home caregivers <sup>4</sup>. Given the demographic and epidemiological transition, the demand for palliative care in the Primary Health Care became a reality, so much so that both teams of the Family Health Strategy (abbreviated as ESF in Brazil) face situations of attention linked to the death process <sup>5</sup>.

However, this demand for palliative care at a local level is not properly evaluated or estimated. Nevertheless, it is possible to foresee the "impact" that it would bring to ethical issues experienced in the primary health care. But what would this impact be?

## Method

This is a systematic review based on the scoping study or scoping literature reviews. The strategy called scoping review (SR) consists of a systematic review, exploratory, aimed at mapping scientific production and relevant studies in a given area. The scoping review has a comprehensive approach, as the search question is extensive and the evaluation of studies' quality is less strict <sup>6</sup>.

In this review, we used the PICO strategy for the formulation of the question, "P" being for population, "I" for phenomenon of interest, "Co" for context. Adjusting the object of study to the PICO strategy, the guiding question is: What are the ethical issues, for health professionals, in palliative care in the primary health care? In order to ensure a coverage adequate to a Scoping review, the gathering of information used two search strategies. The first was held in the databases Lilacs, Embase, CINAHL and PubMed, using the descriptors "ethics," "bioethics" and "primary health care".

The second search used the descriptors "ethics," "bioethics" and "palliative care". The data bases were the same as those from the first search, with the exception of Embase, due to the the University of São Paulo (Universidade de São Paulo-USP) having discontinued its subscription to that data base. Both searches were limited to the scientific production in the period from December 31, 2002 to January 1, 2013. We included articles in Portuguese, Spanish and English. When the articles contained empirical studies, the subjects of interest were healthcare professionals of the Primary Health Care. The inclusion criteria were articles related to ethical

and operational conflicts as well as the relationships of the professionals with the users of the health system. Studies that did not meet these criteria were excluded from the review.

When the articles were not fully available in the databases, we tried to obtain them through the Portal of Magazines of the USP's libraries, the Portal of periodicals of the Coordination for the Improvement of Higher Education Personnel (abbreviated as Capes in Brazil -Coordenação de Aperfeiçoamento de Pessoal de Nível Superior) or direct contact with the author by e-mail or through Research Gate. The articles were not considered in the survey if, after these attempts, we couldn't have access to the text in its whole.

We introduced, in addition to the search in those databases and in accordance with the inclusion criteria, articles from the private collection of one of the authors, who specialises in the bioethics area in the Primary Health Care and already had works collected in previous searches.

We evaluated, for the systematisation of data, the following: periodical (title, volume, number and year); title of the article; authorship; origin of the article (thesis, dissertation or monograph); existence of funding for the research; location of the study

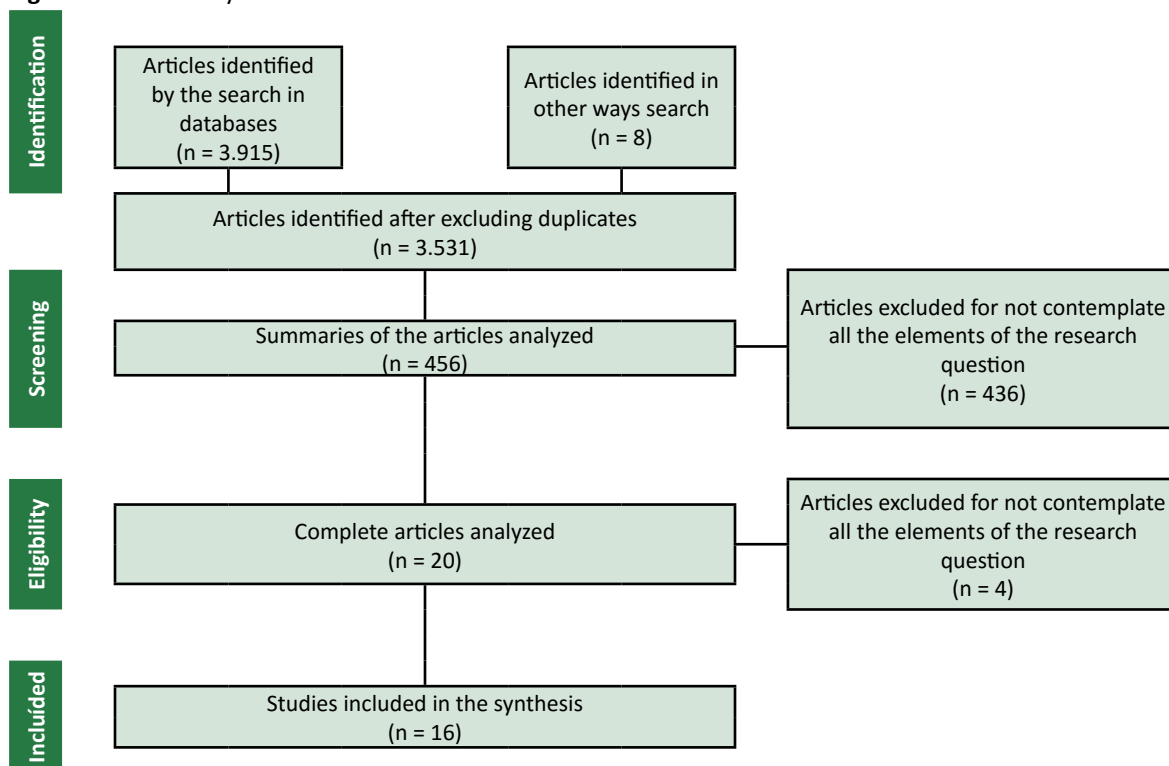
(institution, country, state and city); goals (article or research); method (type of research, sample, participants, setting, data analysis); results; reference to ethical problems concerning palliative care in the primary health care.

The articles were identified with letters and numbers, according to the database used and the sequence in which they were found. One example: P1 is the first study taken from the PubMed database, and so forth.

## Results

The first search strategy identified 2,366 studies; the second search identified 1,549 studies, besides 8 articles taken from the private collection of one of the authors. The Prisma (preferred reporting items for systematic reviews and meta-analyses) is in Figure 1. The screening covered the analysis steps according to their titles and abstracts. Based on the title, 3,075 articles were excluded, remaining then 456 for analysis of the abstracts. The 16 articles included in the review refer to 15 studies, since the A11 and A12 have results which are different aspects of the same research.

**Figure 1.** Prism study



Source: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009) <sup>7</sup>.

The table 1, annexed to the end of this paper, shows the included articles and their respective authors as well as original locations of the study. The Table 2, also presented as an annex, exposes the ethical problems found in each article included in the review.

Different scenarios in which palliative care are provided affect significantly, the manifestation and the kind of ethical question, being necessary to emphasise that such problems are inextricably linked to the peculiarities of each service. Article E1, the aim of which was to analyse ethical problems experienced by paediatricians whilst associating them to their workplace, found that the 16 UBS doctors (UBS stands for Unidade Basica de Saude - Health system Basic Unit) had no ethical problems relating to end-of-life care<sup>8</sup>. Despite these peculiarities, the ethical issues are focused on decision making, the futility of therapy, the patient's autonomy and nursing work<sup>9</sup>.

The non-resuscitation orders and the choice made by patients not to be treated, with consideration of their quality of life, stand out in the decision making. The usefulness of treatments is determined by the expectation of benefits. Decisions to prolong life are avoided. As for the autonomy, patients must be well informed about their situation because many euthanasia requests result from the loss of control about the care. In their work, the nurses feel responsible for defending the rights of patients and stand firm in their defence, to the point of even confronting the medical team. Nevertheless, these professionals complain about "difficult patients" who are never satisfied with the nursing work. In these situations, they need to make an effort to feel sympathy for those patients, besides remaining motivated to watch them and talk to them about death<sup>9</sup>.

Primary health care professionals feel the duty to accompany patients in their last days of life<sup>10</sup>. Doctors justify such an obligation as a way to compensate for the powerlessness they feel because of the impossibility to provide to patients in palliative care a treatment as effective as the one for patients with normal life expectancy. Therefore they devote more time and attention to patients in the palliative care<sup>11</sup>.

When it comes to terminally ill patients with cardio-respiratory diseases, the feeling of impotence of physicians increases. Because they were insufficiently trained to offer palliative care in the terminal stage of this class of diseases, doctors recognise that their help is lower in these cases than in the final stages of cancer. Therefore, in these situations, professionals no longer inform patients that

they are in the final stage of their illness<sup>12</sup>. If a doctor from the Primary Health Care did not follow the curative treatment phase, then the communication about the transfer to palliative care is more complicated<sup>11</sup>. Physicians find it difficult to determine whether the person is terminally ill in the absence of a diagnosis of underlying malignant disease<sup>12</sup>.

Doctors believe that to discuss palliative care is time consuming and therefore it is unlikely that they will have this kind of conversation with patients. They consider that this discussion is not beneficial to the patient, as it is exhausting and uncomfortable<sup>13</sup>. In turn, nurses recognise the importance of talking about death with patients who have no chance of a cure, although they only have this kind of conversation when they are willing to or when there is an opportunity<sup>14</sup>. The lack of truthfulness whilst talking to patients and their families about their actual health situation is another ethical problem identified in the relationship and communication of primary health care professionals working in palliative care<sup>15</sup>. Besides the lack of information, professionals report breach of confidentiality in the treatment and prognosis of patients<sup>16</sup>.

This deficiency in the communication and relationship between professionals and patients as well as their families may explain why most of Primary Health Care doctors were unaware of the final wishes of their patients, even when they had already expressed those wishes in anticipated directives in another health service. Another example of the consequence of ineffective communication happens when patients say that they had not expressed any anticipated directive whilst doctors claim otherwise. Although the review leaves unclear the reason of this disagreement, at least it is indicative of communication problems<sup>17</sup>. Nurses attribute the inadequate communication with patients and families to their poor training in this requirement<sup>15</sup>. In the United States, anticipated directives are legal documents, not clinical documents; that is, they are a particular initiative of the patient or anyone else, regardless of their health status<sup>17</sup>.

Communication also fails between doctors and nurses, among members of the Primary Health care team<sup>18,19</sup> and teams of different services<sup>12,16,20</sup>. Primary Health Care doctors complain that the specialists do not share information<sup>20</sup>. In cases of cardiorespiratory diseases, Primary Health Care physicians feel frustrated for failing to take full care of the patients as, during the worsening crisis of underlying diseases, the specialists of the hospital are the ones who manage the palliative care.

Primary health care doctors say that medical specialists fail in the transmission of information, since they do not inform the decisions taken at the hospital about the patients' treatment regimens who are under their care. As a result, they lose confidence in the hospital which, in addition to failing to communicate about treatments and interventions, often gets in to conflict with the prescriptions already given by primary health care doctors. Conflicts arising from inadequate communication between services are worse in cases of cancer patients who participate in clinical trials because the team of researchers prohibits that the primary health care and the hospital modify or introduce any conduct without their consent<sup>12</sup>.

Nurses from the primary health care see in doctors a reluctance to accept new initiatives and to respond to the needs of patients and requests from the nurses. Nurses get an idea about the "good" or "bad" doctor based on the willingness of that professional to receive and respond to requests from patients or the nursing staff and also on the respect with which doctors treat other professionals. Thus, in the assessing of the nurses, technical expertise and medical knowledge are less important than interpersonal relationships<sup>21,22</sup>.

For nurses, the quality of interpersonal relationships and the perception that each professional has about the performance of other professionals are factors that influence teamwork and the referral of users to another services. The team cohesion depends more on the relationships among its members than in the care to be provided to the user. For doctors, the negotiating issues and interpersonal relationships count less on the assessment made of the professionals. This could be due to the difference of authority between doctors and nurses. The question of the leadership of doctors became clear in the focus groups of articles: nurses did not give their opinions, and the groups were to be represented, formally or informally, by a doctor, who chooses the day of the meeting and would eventually lead it, directing the discussion<sup>21,22</sup>.

The excessive importance attached to inter-professional relationships is evident when Primary health care professionals assess the benefits of introducing a program to improve the quality of care solely on the basis of those relations, without taking into account the interactions with patients and the impact on the direct care. When professionals from the primary health care need to refer the patient to specialists, and make that decision considering only the relationship with these professionals, it is pos-

sible that they will be successful. In such cases, it would indicate the possibility of obtaining facilities now and in the future, which ultimately influence the judgment that the primary health care team makes of the professionals from the specialised services<sup>21,22</sup>.

Nurses don't have availability for palliative care interventions<sup>15</sup>. Insecurity, lack of access to emergency drugs, the lack of interpreters to attend the aboriginal population, the high cost of overtime and the limited cell phone coverage are aspects that justify the non-availability of these professionals to work at night. They claim that an amendment of the legislation in order to allow nurses to make the assessment of death could increase the participation of these professionals in the palliative care, especially in shifts after opening hours of the primary health care<sup>18</sup>.

Doctors of primary health care, in turn, also mention some obstacles to their involvement with palliative care: lack of time; home visits; personal or family commitments; lack of interest; unavailability for work after hours; lack of knowledge of palliative care; emotional reasons, and lack of support of specialists<sup>20</sup>. The nurses agree that the limited availability of doctors to work after hours is one of the limiting factors for palliative care in the primary health care system. In turn, doctors claim that the unavailability of nurses for work after hours is also a limiting factor<sup>18</sup>.

Doctors and nurses have proposed some strategies for improvement of work in home-based palliative care: regular multidisciplinary meetings; easiness of referral to specialised services of palliative care; more nurses for home visits; nursing training in telephone service after the opening hours of the primary health care and, especially, the development and adoption of standardised protocols for the plan of treatment concerning each patient<sup>18</sup>.

Professionals in the primary health care involved in palliative care wish to continue in the program, but the scarcity of resources, lack of organisation and management of services cause overload<sup>10,16</sup>. The lack of resources and referral services, the work overload and lack of space to discuss the experiences in the care of dying patients are factors that make nurses more prone to psychological illnesses, besides creating frustration among them, because they can not provide care of good quality<sup>23</sup>. The difficulty of access to referral services, mainly the ones specialised in palliative care, is higher for patients with cardiorespiratory disease and lower for patients with cancer, as reported by nurses and doctors in one of the studies<sup>12</sup>.



Nurses and doctors find it difficult to set limits to the relationship with terminally ill patients and their families<sup>15,23</sup>. The close proximity of professionals to users of the primary health care creates intense bonds, which causes distress to nurses<sup>11,23</sup>. Primary health care professionals go to the point of giving the number of their personal phones to family members of patients in palliative care so they can get in touch if necessary. Those professionals also do voluntary home visits after working hours<sup>10</sup>. This attachment is also present when families and caregivers require actions outside the scope of the competence of the primary health care when the family requests, for example, constant visits to the patient<sup>23</sup>.

The proximity between primary health care professionals and patients in palliative care interferes with communication of the truth about the patient's health condition. Some PHC doctors do not report poor prognosis to patients for fear that if they do, patients and/or family will nurture resentment towards them, leaving this task to the specialists who will have to watch the patients until the end<sup>9</sup>.

Doctors report that fatalistic thoughts, insecurity and helplessness of caregivers tend to compromise the autonomy of patients, making them dependent and susceptible to emotional suffering<sup>11</sup>. Therefore, while recognising the importance of family support, nurses believe that such support sometimes hinders the care<sup>14</sup>. They also mention suspicion of physical, psychological and economical abuse practiced by the patient's family towards the patient.<sup>16</sup> When faced with abuse, carelessness and neglect by family members, nurses change their behaviour in the attention to the patient, restricting their care to an exclusively technical scope.

As for the family members who mistreat patients, nurses do not assess that they also need care<sup>23</sup>. Doctors feel lack of support for dealing with ethical issues related to palliative care<sup>11</sup> and assurance of the continuity of home care to patients, especially after the opening hours of the primary health care services<sup>18,19</sup>. They suggest courses on standards and ethical values, including how to discuss and confront problematic situations from an ethical point of view in the sphere of operation of the primary health care staff<sup>11</sup>.

Doctors' lack of information about available services and resources in the community and in the primary health care after opening hours contributes to the discontinuity of care for patients in palliative care at home<sup>18</sup>. Another factor is the poor cooper-

ation between teams and between professionals<sup>19</sup>, such as the absence of reports from nurses about interventions in multidisciplinary teams<sup>15</sup>.

Doctors report that informal caregivers are the main collaborators in the provision of palliative care at home<sup>19</sup>. The relationship between professionals of the PHC and the family and informal caregivers is of poor quality, according to those professionals<sup>16</sup>. The nurses claim lack of conditions, time and preparation to accompany the mourning family and informal caregivers<sup>15</sup>, while recognising their emotional suffering<sup>11</sup>.

The PHC professionals consider that the lack of their knowledge about palliative care limits their activities<sup>11</sup>, especially in the management of symptoms<sup>9,11,15,20</sup> and complex clinical situations<sup>10,20</sup>. In such cases, they base themselves on their accumulated clinical experience through professional practice, but do not feel safe on the best approach to be adopted<sup>10</sup>. Doctors mention the lack of time to devote to studies as an obstacle to their continued training in palliative care<sup>18</sup>.

Doctors think that the most important aspect of palliative care is more in the somatic domain than in psychosocial and spiritual grounds, which is why they rarely cooperate with religious ministers or discuss spiritual issues with patients<sup>19</sup>. Nurses also feel unprepared to address spiritual or religious matters with patients, although they recognise the importance of these talks at the final stage of life<sup>14</sup>.

When dying patients in home care ask PHC professionals about issues related to the search for the meaning of life, the professionals, though unprepared, feel the duty to talk about it with patients and their family. Due to the prolonged coexistence of PHC professionals with the people in their care, many of them visit homes of friends and relatives of hospital's patients. It is a peculiarity of the palliative care in the PHC that is not as common in other areas of the Health System<sup>9</sup>.

Doctors do not accept that ethical issues such as euthanasia can be solved by just good provision of palliative care<sup>11</sup>. In Sweden for example, even if rarely and despite counting with an excellent palliative care service, doctors feel obliged to offer euthanasia as a last resort due to unfavourable social conditions of some patients<sup>9</sup>. This finding drew attention of the authors of this article, as it is difficult to guess what would be the unfavourable social conditions in Sweden, when we live in a country much poorer and socially uneven; however, the article included in the review does not specify those situations.

## Discussion

Attitudes and skills necessary to provide high quality palliative care overlap with those needed for optimal PHC: communication skills; understanding of reality and the peculiarities of the way of life of the patient; commitment to comprehensive and integrated care of the patient and family; attention to the psychosocial and spiritual issues; emphasis on quality of life and independence of the patient; respect for the values, objectives and priorities of patients in managing their own health condition; provision of care in the community, depending on its cultural diversity; collaboration with other professionals, including specialists. This way, it appears that the palliative care and the PHC can, and should, be strengthened and also strengthen each other<sup>24</sup>.

With regard to collaboration among professionals, we need to face several challenges: conflict, ambiguity and overlapping of the roles of the professionals; inadequate communication, and leadership problems. The introduction of multidisciplinary teams is a necessity for the provision of health services in order to increase the efficiency of care, especially the palliative care. The team represents a workspace focused on creative problem solving, especially when the contribution of all its professionals is based on respect and when there is a sense of responsibility towards the patient's well-being<sup>25</sup>.

This review found out that the type of ethical problem faced by professionals is closely related to the place where the palliative care is provided, which reinforces the fact that such conflicts are inextricably linked to the peculiarities of each health service. Ethics in health care implies the acting of moral subjects in situations of life and in the process of health-disease<sup>26</sup>. As the situations and processes are peculiar to each subject, ethical issues deriving from them will also be specific. Problems arise with their own characteristics in the various spheres of social life. Therefore, it is necessary to grasp, in each one of these contexts, the logic and modulation of ethical principles which are peculiar to them<sup>27</sup>.

At the prospect of introducing palliative care in the PHC, especially through the ESF (Abbreviation, in Portuguese, of *Estrategia Saude da Familia - Family Health Strategy*), two aspects are fundamental: that the informal caregiver can rely on the provision of educational activities aimed at the comprehensive care of the patient<sup>5</sup> and the presence of a professional in the team<sup>28</sup>.

In the professional practice of palliative care at home, the informal caregivers consider important the knowledge, behaviour, communication skills and relationship quality of the professionals with their patients and their family members<sup>28</sup>. In general, the ethical problems found by this review are close to the ethical issues experienced by PHC professionals and identified in other studies<sup>26</sup>:

- Closer and more intense bond of PHC professionals with patients and families, which ends up creating difficulties for the maintenance of impartiality in clinical relations
- Request of unnecessary or improper procedures, which in the case of the palliative care, are considered extraordinary or outside the scope or the potential of the PHC
- Lack of collaboration between teams, creating difficulties in interprofessional work
- Lack of interprofessional respect, bad relationship between members of the multidisciplinary team
- Lack of institutional support for the management of ethical problems
- Work overload
- Disregard, by the reference and specialised services, of medical prescriptions made by PHC doctors
- Lack of resources to carry out home visits

Considering the axes on which the ethical problems of PHC are placed, the ethical issues of the palliative care, according to this review, focus on the practice of the teams and their professional profile. The first aspect presents ethical problems arising from the fragmentation of the work of teams and difficulties in interdisciplinary practice. The professional profile covers the ethical issues related to the behaviour of the PHC Professionals<sup>26</sup>.

These two axes are focused on ethical problems related to the following aspects: bad relationship between the teams and difficult interprofessional communication, which interferes negatively with the quality of the care provided; training and preparation insufficient to act in the PHC and palliative care; lack of communication skills of professionals for conversations in the scope of the clinical relationship, the interprofessional relationship and other points of attention of the RAS (Abbreviation of 'Redes de Atencao a Saude' in Brazil - Health System Network); lack of shared information.

Apparently, the introduction of the palliative care in the PHC will not interfere in the axes of ethi-

cal problems in this area of care, even if the specifics and peculiarities of palliative care reveal themselves in new situations.

In their practice, the ESF teams face the demand for palliative care at the end of life stage and, earlier, in the diagnosis of chronic degenerative diseases<sup>5</sup>. As a result, the systematisation of guidelines for palliative care actions in the PHC is essential, considering especially those aimed at addressing the ethical issues involved in this type of care.

Dying with dignity is a result of living with dignity; before the right to a dignified death, there is a right to a dignified life, with conditions to blossom fully - that means right to health<sup>29</sup>. Thus, ethical palliative care are the result of an ethical PHC.

### Final considerations

This research aimed to discuss the ethical dilemmas relating to palliative care in the PHC. For this, we developed a systematic literature review to identify, from the point of view of health professionals, what are the ethical issues that arise from the practice of the services. The review also served to detect the difficulties in the professional profile, in the practice of the teams, management of services and health care systems in different parts of the world that offer palliative care in the PHC. Such difficulties are indicative that the lack of organisation of services and the lack of specific qualifications of professionals to deal with demands and needs of chronic health conditions is present also in countries which have had an ageing population for longer than Brazil.

There is a shortage of knowledge from professionals about palliative care, which contributes to the emergence of ethical problems in situations more traditionally associated with this kind of care such as the accompaniment of the death and grieving process, the communication of bad news, management of complex symptoms and clinical conditions. In the SUS (abbreviation of "Sistema Unico de Saude" in Brazil - Unified Health System), one must take into account that the ESF (abbreviation of "Estrategias Saude da Family" in Brazil- Family

Health Strategies) teams already face the demands of terminal patients and users with chronic health conditions. And in this aspect, perhaps the biggest ethical challenge for incorporation of palliative care in the PHC is: to change the view of the professionals about the palliative care in order to introduce them earlier in the services, starting from the diagnosis of chronic health conditions.

Palliative care is not only suitable for people with cancer or people who are close to death. It is an extremely beneficial care and its early intervention, well before the final stage of the disease, may become essential to the excellence of the PHC before the demographic- epidemiological transition and its impact on the population's morbidity and mortality profiles. The palliative care must be offered according to the health needs of the population, so that the Primary Health Care and the RAS (Abbreviation of "Redes de Atencao a Saude" in Brazil - Health System Network) can realize their social function.

Communication difficulties also affect the internal work of the team and of the team with the RAS. Political definitions and guidelines for the effectiveness of the health care network in the SUS are not enough; It is necessary to invest in interpersonal and inter professional communication as well as between the different levels of services, creating a collaborative culture based on the co-responsibility for the health of the population.

The survey results highlighted the work overload of the PHC teams, which is an obstacle to the implementation of palliative care. The ESF teams, in addition to caring for the health of the population in their area of work, have to contribute for the UBS to be able to deal with the many spontaneous demands that are required from them. Moreover, chronic health conditions require constant monitoring, including periods when the disease is latent, because this condition implies the need for early palliative care, that is, general palliative care aimed at maintaining good quality of life in the present and during the disease progression. For the introduction of palliative care under the SUS's Primary Health Care, it is essential to review the number of ascribed families in the ESF teams and reorganise the work process and the primary health care services.

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#### Participation of the authors

Danielle Yuri Saito Takauti developed the master's study in which this article is based, participated as the first reviewer in the scoping review and drafted the original article. Elma Lourdes Campos Pavone Zoboli directed the master's study from which this article has been originated. She also participated as secondary reviewer of the scoping review and revised the original article.

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## Annex

Table 1. List of Studies included in the revision

Artigo	Título	Autores	Local
E1 <sup>8</sup>	Ethical problems in paediatrics: What does the setting of care and education show us?	Guedert JM, Grosseman S	Brasil
E2 <sup>17</sup>	The personal and social context of planning for end-of-life care	Kahana B, Dan A, Kahana E, Kercher K	EUA
E3 <sup>13</sup>	Primary care physician knowledge, utilization, and attitude regarding advance care planning, hospice, and palliative care: Much work remains	Snyder S, Allen K, Hezelett S, Raswany S	EUA
P4 <sup>10</sup>	Understanding the provision of palliative care in the context of primary health care: Qualitative research findings from a pilot study in a community setting in Chile	Cameron BL, Santos Sala A	Canadá
C5 <sup>11</sup>	Education needs of general practitioners in palliative care: Outcome of a focus group study	Meijler WJ, Van Heest F, Ottor R, Sleijfer DTH	EUA
P6 <sup>14</sup>	Identifying care actions to conserve dignity in end-of-life care	Brown H, Johnston B, Ostlund U	Reino Unido
A7 <sup>15</sup>	Os cuidados paliativos no âmbito dos cuidados de saúde primários: as intervenções dos enfermeiros	Carvalho SCC, Botelho MAR	Portugal
A8 <sup>16</sup>	Identificación de los conflictos éticos en la atención sociosanitaria. Un estudio exploratorio	Ribas S, Aguado H, Tella M, Márquez I, Viñas P, Himénez J, Asens G	Espanha
A9 <sup>20</sup>	Attitudes and barriers to involvement in palliative care by Australian urban general practitioners	Rhee JJO, Zwar N, Vagholkar S, Dennis S, Broadbent AM, Mitchell G	Austrália
A10 <sup>18</sup>	GP and nurses' perceptions of how after hours care for people receiving palliative care at home could be improved: A mixed methods study	Tan HM, O'Connor MM, Miles G, Klein B, Schattner P	Austrália
A11 <sup>21</sup>	Judgements about fellow professional and the management of patients receiving palliative care in primary care: A qualitative study	Walshe C, Todd C, Caress AL, Chew-Graham C	Inglaterra
A12 <sup>22</sup>	Implementation and impact of the Gold Standards Framework in community palliative care: A qualitative study of three primary care trusts	Walshe C, Todd C, Caress AL, Chew-Graham C	Inglaterra
A13 <sup>23</sup>	Estudo fenomenológico sobre a visita domiciliária do enfermeiro à família no processo de terminalidade	Valente SH, Teixeira MB	Brasil
A14 <sup>19</sup>	Interdisciplinary cooperation of GPs in palliative care at home: A nationwide survey in the Netherlands	Borgsteede SD, Deliens L, van der Wal G, Francke AL, Stalman WAB, van Eijk JTM	Holanda
A15 <sup>12</sup>	Palliative care in the community for cancer and end-stage cardiorespiratory disease: The views of patients, lay-carers and health care professional	Exley C, Field D, Jones L, Stokes T	Reino Unido
P16 <sup>9</sup>	Moral problems in palliative care practice: A qualitative study	Hermesen MA, ten Have HA	Holanda

**Table 2.** Ethical problems concerning palliative care in the primary health care

Article	Ethical issues
E1 <sup>8</sup>	<ul style="list-style-type: none"> <li>• None of the 16 doctors from the UBS (UBS stands for Unidade Basica de Saude - Health system Basic Unit) had a problem with end-of-life care</li> </ul>
E2 <sup>17</sup>	<ul style="list-style-type: none"> <li>• 75% of PHC doctors were unaware of their patients final wishes of life, even if these patients had already stated them in anticipated directives (AD) in another service</li> <li>• 11% of doctors did the anticipated directives without the patient's consent</li> </ul>
E3 <sup>13</sup>	<ul style="list-style-type: none"> <li>• Most doctors believe that to discuss palliative care is time consuming, so it is unlikely that they will have that discussion with patients</li> <li>• To discuss palliative care with the patient is stressful and uncomfortable for most doctors</li> <li>• Most doctors do not believe that this discussion is beneficial to the patient</li> </ul>
P4 <sup>10</sup>	<ul style="list-style-type: none"> <li>• Primary health care staff professionals feel obliged to accompany patients in their last days of life; therefore, they give their personal phone numbers so they can be contacted by the family of the patient. They even visit the patient's home after working hours</li> <li>• The professionals involved in palliative care show enthusiasm to stay in the program, but the scarcity of resources causes overload</li> <li>• The biggest concern of the professionals was related to the inadequacy of their expertise in palliative care. They see this as a limitation when faced with complex clinical situations because, although they work based on clinical work learned through practice, many times they have doubts about the best course of action</li> </ul>
C5 <sup>11</sup>	<p>Doctors feel powerless in the palliative care as to what they can do for terminally ill patients, compared to what they can do for those patients whose life expectancy is normal. To compensate for this impotence, they feel compelled to pay more attention to patients in palliative care, staying next to them for a longer time.</p> <ul style="list-style-type: none"> <li>• Doctors report emotional distress of patients, families and professionals</li> <li>• Doctors mention that fatalistic thoughts, insecurity and helplessness of informal caregivers tend to compromise the autonomy of patients, creating dependency and suffering</li> <li>• One doctor reports a crisis of confidence between the patient and the doctor of the PHC who was not involved in curative care because the specialist was in charge of it.</li> <li>• According to doctors of the PHC, the poor quality of communication in the moving of a patient from the second to the first level of attention disturbs the application of the palliative care at home.</li> <li>• Doctors feel lack of support for dealing with ethical issues in palliative care and suggest the need for a course on the subject, including notions of norms and values, as well as ways to discuss and share these problems within the work team</li> <li>• Doctors report a lack of knowledge and training of professionals in the management of symptoms (pain, nausea, dysphagia, delirium, depression etc.) of patients in palliative care</li> <li>• Doctors refuse to accept that ethical issues such as euthanasia can be solved only with the good performance of palliative care</li> </ul>
P6 <sup>14</sup>	<ul style="list-style-type: none"> <li>• Nurses recognise the importance of talking about death with patients; however, they only do so when they are willing to or when the opportunity arises</li> <li>• Nurses report that they do not feel prepared to talk to users about spirituality or religiosity, even knowing that this subject is essential in the final stage of life</li> <li>• Nurses recognise the importance of family support, but they say that sometimes that support hinders care</li> </ul>
A7 <sup>15</sup>	<ul style="list-style-type: none"> <li>• Nurses don't have availability for interventions in palliative care</li> <li>• Three nurses mention the lack of veracity whilst talking to the patient and the family about the patient's actual health situation</li> <li>• Nurses recognise that they lack knowledge in the management of symptoms of patients in palliative care</li> <li>• The communication with patients, according to nurses, is not appropriate because of the deficient training of the professionals</li> <li>• Nurses report lack of conditions, time and training to accompany the mourning</li> <li>• None of the nurses reported interventions in multidisciplinary teams</li> </ul>

Article	Ethical issues
A8 <sup>16</sup>	<ul style="list-style-type: none"> <li>• Professionals mention the lack of information and breach of confidentiality about the treatment and the prognosis</li> <li>• Professionals report suspicion that patients suffer physical, psychological, economic or other types of abuse by family members</li> <li>• Professionals report poor relationship with the team and of the team with the different levels of the health care network</li> <li>• Professionals report poor relationship with family members of patients and / or informal caregivers</li> <li>• Professionals mention the lack of social and financial resources of the services</li> </ul>
A9 <sup>20</sup>	<ul style="list-style-type: none"> <li>• Between 20% and 30% of 269 PHC doctors who provide palliative care report that the specialists do not share information with them</li> <li>• 25.2% of 269 doctors from the PHC mention, as obstacles for their involvement with palliative care: lack of time; home visits; personal and family commitments; lack of interest; unavailability for work after hours; lack of knowledge; emotional reasons and a lack of support of specialists</li> <li>• 25.2% of 269 doctors of the PHC do not feel safe to deal with issues related to palliative care, such as terminal restlessness, psychosocial aspects, agitation and neuropathic pain</li> </ul>
A10 <sup>18</sup>	<ul style="list-style-type: none"> <li>• 82% of 114 doctors and 85% of 52 nurses report that the communication between professionals is flawed</li> <li>• 59% of 114 doctors and 62% of 52 nurses mention that patients are reluctant to call in the professionals who are available after work hours</li> <li>• 58% of 114 doctors and 87% of 52 nurses claim that the amendment of legislation to allow the nurse to review the death could increase the offer of after hours palliative care services.</li> <li>• The professionals report a lack of continuity in the care for people receiving palliative care at home, after the closing time of Primary Health care services</li> <li>• 54% of 114 doctors and 67% of 52 nurses mention the high cost of overtime on the provision of palliative care</li> <li>• 41% of 114 doctors and 63% of 52 nurses claim that the insecurity in services leads them to give up night shifts</li> <li>• 40% of 114 doctors and 44% of 52 nurses reported that the limited coverage of mobile telephony has a negative impact on the provision of palliative care</li> <li>• 76% of 114 doctors and 90% of 52 nurses consider that the limited availability of doctors to work after hours is a limiting factor of palliative care in the PHC</li> <li>• 79% of 114 doctors and 83% of 52 nurses estimate that the limited availability of nurses to work after hours is a limiting factor of palliative care in the Primary Health Care</li> <li>• 49% of 114 doctors and 54% of 52 nurses report the lack of interpreters, after opening hours, to attend the needs of aboriginal populations</li> <li>• 69% of 114 doctors and 71% of 52 nurses mention that the access to emergency medications is limited after hours</li> <li>• Doctors reported lack of training to provide palliative care as they don't have time to devote to a continuous training in this specialty</li> <li>• Doctors are unaware of which services and resources, available in the community and in the primary health care (PHC), are able to ensure continuity of care after hours or are adequate to plan the support to attend the needs of patients in palliative care</li> </ul>
A11 <sup>21</sup> /A12 <sup>22</sup>	<ul style="list-style-type: none"> <li>• 14 nurses from PHC consider that doctors are resistant to new initiatives and are reluctant to meet the needs of patients and the requests of the nursing staff</li> <li>• The concepts of "good" or "bad" doctor, in the view of nurses, do not necessarily relate to technical expertise or knowledge, but to the availability of the professional to receive and respond to requests, be them from the nurse or the patient</li> <li>• Nurses recognise that interpersonal relationships and perceptions of each other about their respective performances influence the work of the staff and the referrals of users to other services. The team cohesion stems more from interpersonal relationships than from the patient care</li> <li>• Doctors enjoy friendly working relationships with nurses; however, trading issues and interpersonal relationships do not weigh much on the assessment made of these professionals, probably by the difference in authority between the two categories</li> <li>• Professionals describe the positive impact of the introduction of a program to improve the quality of care in the PHC based only on the professional relationship, ignoring interactions with patients and the influence on their care</li> </ul>



Article	Ethical issues
A13 <sup>23</sup>	<ul style="list-style-type: none"> <li>• Nurses claim that the work overload and the lack of space in everyday life to discuss the feelings experienced in the care of dying patients, causes the professionals to be more susceptible to emotional distress</li> <li>• Nurses feel frustrated because they can not provide quality care because of the lack of resources in the PHC and reference services as well</li> <li>• Nurses can not establish limits for their relationship with terminally ill patients and their families</li> <li>• Nurses create intense links with terminal patients in their care, which leads to suffering at work</li> <li>• Nurses, given their close proximity to users, go beyond technical limitations in their work in the ESF (abbreviation of “Estrategias Saude da Family” in Brazil- Family Health Strategies) staff.</li> <li>• When faced with abuse, lack of care and neglect of the patient by the family, nurses change their behaviour: they start to offer merely technical care to the patient, and do not consider the possibility of family members also being part of the care</li> <li>• Nurses report that families and informal caregivers request care or actions that are beyond the means of Primary Health Care, such as constant visits to the patient</li> </ul>
A14 <sup>19</sup>	<ul style="list-style-type: none"> <li>• Doctors consider the somatic domain as the most important in palliative care, followed by psychosocial and spiritual care</li> <li>• 63% of doctors report that informal caregivers are the main collaborators in palliative care</li> <li>• Few doctors cooperate with religious ministers, which may indicate that they alone deal with such problems, or that few patients have spiritual problems, or that few doctors recognise the spiritual problems</li> <li>• In 71% of cases, doctors describe that cooperation with colleagues was present. This number could be considered low and provoke questions about the quality of communication and continuity of care, considering that an efficient exchange of information about patients is expected so 24 hours healthcare services can provide proper care after the end of working hours in the primary health care</li> </ul>
A15 <sup>12</sup>	<ul style="list-style-type: none"> <li>• In cases of patients with cardiorespiratory disease, PHC doctors report frustration because they can not take full care, as specialists from hospitals are the ones who manage these patients palliative care when the underlying disease gets worse.</li> <li>• According to doctors from the PHC, hospitals’ specialists fail to give them information, not making them aware of decisions taken in the hospital about the treatment regimen of patients under their care</li> <li>• PHC doctors lose confidence in the hospital because communication about treatments and interventions is flawed, and conflict with the requirements of PHC, especially in cases of cancer patients enrolled in clinical trials prohibiting the PHC and the hospital to change or introduce treatment without the consent of the research team</li> <li>• Doctors and nurses from the PHC say it is easier to get specialised services for palliative care patients with cancer than for those in the final stage of cardiorespiratory diseases</li> <li>• PHC doctors recognise that they provide less help when it comes to patients with end-stage cardiorespiratory diseases, than in the case of cancer patients at the same stage as they were not sufficiently trained to deal with the first situation</li> <li>• For doctors of PHC, it is more difficult to reach the conclusion that the person is dying when the person does not have a malignancy. This makes professionals less willing to communicate to these people that they are in a state of terminal illness</li> </ul>

Article	Ethical issues
P16 <sup>9</sup>	<ul style="list-style-type: none"> <li>• PHC professionals face moral problems when, in respect for the principle of the patient autonomy, must decide on the resuscitation or not, or the performance or nonperformance of futile medical actions for the patient who has no chance of cure</li> <li>• PHC Professionals face moral problems when the treatment chosen by the patient is considered futile by doctors but improves their quality of life</li> <li>• PHC professionals struggle to create a bond and motivate themselves to look and talk about death when the patient is considered "difficult," such as the one who is never satisfied with the work of nursing. This compromises the quality of care</li> <li>• PHC doctors offer the option of euthanasia to the patient when there is no possible treatment to relieve their symptoms, although this procedure is not carried out under the PHC and even terminal patients in home care raise questions regarding the search for the meaning of life, often appealing to the PHC professionals. These, unprepared, try to answer the patient and family members, who are also their patients</li> <li>• PHC Doctors prefer that the specialist inform the patient about the poor prognosis because they believe that if they do, it can generate conflict in their relationship with the patient and the family, and they fear it may interfere with keeping a care of quality</li> <li>• The PHC professionals face moral problems in the management of symptoms such as terminal sedation, principle of the double effect and use of opioids</li> </ul>