

# Palliative care in Primary Care: the perspective of physicians and nurses who are tutors of Residency Programs in the Family Health Strategy

Cuidados paliativos na Atenção Primária à Saúde: perspectiva de médicos e enfermeiros preceptores em Saúde da Família

*Cuidados paliativos en Atención Primaria: la perspectiva de los médicos y enfermeras que son tutores de los Programas de Residencia Médica y de Enfermería que trabajan en la Estrategia Salud de la Familia*

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## Abstract

**Introduction:** The increase in the elderly population and the higher incidence of non-communicable chronic diseases underscore the growing demand for care at the end of life. **Objective:** This study aims to contribute to the implementation of palliative care in Primary Care based on the perspective of physicians and nurses who are tutors of Residency Programs in the Family Health Strategy in Rio de Janeiro. **Methods:** This is a qualitative study, in which semi-structured individual interviews were conducted with 5 physicians and 3 nurses, and 3 focus groups, consisting of 12 physicians; 14 physicians and 6 nurses. **Results:** The results showed that all participants experienced cases, but there was no formal learning among other main difficulties, such as: assistance pressure, lack of supplies and medicines, and not prioritizing management at the central level represented by the lack of government guidelines. However, the participants were unanimous that palliative care should be offered in primary care and pointed out that both physicians and nurses base their actions on the transfer of theoretical knowledge to practice. **Conclusions:** Among the actions discussed for the implementation, it is highlighted that its teaching must involve, in addition to a set of theories and techniques, a humanistic base, with the preceptor having a fundamental role.

**Keywords:** Palliative care; Family health strategy; Primary health care; Internship and residency; Internship, nonmedical.

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## Resumo

**Introdução:** O aumento da população idosa e a maior incidência de doenças crônicas não transmissíveis ressaltam a crescente demanda por cuidados no final da vida. **Objetivo:** O presente estudo visou contribuir para a implementação dos cuidados paliativos na Atenção Primária com base no conhecimento da perspectiva de médicos e enfermeiros preceptores de Programas de Residência que atuam na Estratégia Saúde da Família no Rio de Janeiro. **Método:** Trata-se de um estudo qualitativo, em que foram realizadas entrevistas individuais semiestruturadas com cinco médicos e três enfermeiras e três grupos focais, constituídos por 12 médicos; 14 médicos e seis enfermeiras. **Resultados:** Os resultados revelaram casos vivenciados no relato de todos os participantes, mas a inexistência de um aprendizado formal entre outras principais dificuldades: a pressão assistencial, falta de insumos e medicamentos e a não priorização da gestão em nível central representada pela falta de diretrizes governamentais. Entretanto, os participantes foram unânimes em afirmar que os cuidados paliativos devem ser oferecidos na atenção primária e ressaltaram que tanto médicos quanto enfermeiros pautam suas ações na transferência dos conhecimentos relativos para a prática. **Conclusão:** Entre ações discutidas para a implementação dos cuidados paliativos, destaca-se que seu ensino deve envolver, além de um conjunto de teorias e técnicas, uma base humanística, tendo o preceptor papel fundamental.

**Palavras-chave:** Cuidados paliativos; Estratégia saúde da família; Atenção primária à saúde; Internato e residência; Internato não médico.

## Resumen

**Introducción:** El aumento de la población anciana y la mayor incidencia de enfermedades crónicas no transmisibles subrayan la creciente demanda de atención al final de la vida. **Objetivo:** Este estudio tiene como objetivo contribuir a la implementación de los cuidados paliativos en Atención Primaria a partir de la perspectiva de los médicos y enfermeras que son tutores de los Programas de Residencia Médica y de Enfermería que trabajan en la Estrategia Salud de la Familia de la ciudad de Rio de Janeiro. **Métodos:** Se trata de una investigación cualitativa, donde fueron realizadas entrevistas individuales semiestructuradas con 5 médicos y 3 enfermeras, y 3 grupos de enfoque, dos de ellos con 12 y 14 médicos respectivamente y el tercero con 6 enfermeras. **Resultados:** Los resultados mostraron que todos los participantes experimentaron casos, pero no hubo aprendizaje formal entre otras dificultades principales, como: presión asistencial, falta de insumos y medicamentos, y no priorizar la gestión a nivel central representado por la falta de lineamientos gubernamentales. Sin embargo, los participantes fueron unánimes en que los cuidados paliativos deben ofrecerse en la atención primaria, y señalaron que tanto médicos como enfermeras basan sus acciones en la transferencia de conocimientos teóricos a la práctica. **Conclusiones:** Entre las acciones discutidas para la implementación, se destaca que su enseñanza debe involucrar, además de un conjunto de teorías y técnicas, una base humanística, teniendo el preceptor un rol fundamental.

**Palabras clave:** Cuidados paliativos; Estrategia de salud familiar; Atención primaria de salud; Internado y residencia; Internado no médico.

## INTRODUCTION

Population aging and the higher prevalence of noncommunicable chronic diseases, such as neoplasms and cardiovascular diseases, have highlighted a growing portion of the population that needs end-of-life care.<sup>1</sup>

The World Health Organization (WHO) adopted the term palliative care (PC) in 1982, when the Cancer Committee of that Organization created a working group to define policies aimed at pain relief and hospice-type care for cancer patients, stimulating the creation of support services in all countries.<sup>2</sup> It is due to the Englishwoman Cicely Saunders the new conception of specialized care for terminally ill patients developed in differentiated units, which were called hospices.<sup>3</sup>

In Brazil, PC emerged in 1980 and expanded greatly in 1997, with the creation of the Brazilian Association for Palliative Care. In 1998, the José Alencar Gomes da Silva National Cancer Institute (*Instituto Nacional do Câncer José Alencar Gomes da Silva – INCA*) inaugurated a hospital unit focused on PC. In 2005, the National Academy of Palliative Care (*Academia Nacional de Cuidados Paliativos – ANCP*) was created and the Federal Council of Medicine recognized PC as an area of expertise in 2011.<sup>4</sup>

The most current definition of PC, from 2011, by the WHO, is active and total care aimed at people whose disease does not respond to approaches that intend to cure. PC also aims to provide the best possible quality of life for patients and their families.<sup>5</sup>

Primary Health Care (PHC) professionals accompany their patients during all stages of life. No other health service manages to make itself available to patients and their families with as much ownership and knowledge of the context in which they are inserted as the PHC units.<sup>6</sup>

The Family Health Strategy (FHS) is a PHC model guided by the principles of the Brazilian Unified Health System (*Sistema Único de Saúde* – SUS). It enables the organization of activities in an assigned territory, seeking to face and solve problems in the health unit and at home and to promote integral and continuous assistance to all family members.<sup>7</sup>

As governments around the world work to improve the lives of their citizens, ways to help them die well must also be considered.<sup>8</sup> Although still a relatively new component, PC is an essential part of health systems and, due to the greater number of people living and dying with more complex conditions, the demand for such care is expected to increase.<sup>9</sup>

Financial resources for the development of PC are scarce all over the world. However, several countries display good experiences contemplating the existence of an articulation between the levels of health care. The European Association for Palliative Care (EAPC) encourages its inclusion in primary care and offers support to countries that wish to create a national policy for this purpose.<sup>9</sup> Other places, such as Canada<sup>10</sup> and Kerala,<sup>9</sup> also promote care considering the necessary integration between all levels of health care.

In Brazil, the initiatives are insufficient when taking into account its territorial extension and are still centralized in hospitals.<sup>11</sup> Although there is a Ministry of Health resolution published in 2018 that regulates the provision of PC as part of integrated continuous care within SUS, guidelines for such care have not yet been published.<sup>12</sup>

The present study aimed to analyze the knowledge about PC, as well as the facilities and difficulties for its implementation in PHC, from the perspective of preceptors of Family Health Residency Programs in the city of Rio de Janeiro.

## METHODS

This is an exploratory qualitative study developed in PHC units with FHS in the city of Rio de Janeiro, between October 2016 and June 2017. The units chosen for the research scenario have Family Practice Residency (FP) and/or Family Health Nursing Residency.

To constitute the sample of participants in this study, physicians and nurses who had been acting as tutors in the aforementioned residences for at least one year at the time of their participation in the research were invited. The sample of participants also sought to contemplate the different sociodemographic and occupational characteristics of the preceptors, including gender, age group and time of work in preceptorship.

It is known that the preceptor of residency programs, in addition to teaching theory and clinical practice, must advise, inspire, and influence the development of their residents.<sup>13</sup> The example set by a preceptor is considered the most powerful influence on standards of conduct and practice of each student, whether they are undergraduates or graduates.<sup>14</sup>

The study had two qualitative procedures: semi-structured individual interviews (IIT) and focus groups (FG). In the first phase, data collection was performed through IIT. The interview is a way of obtaining objective and subjective data, the latter related to the values, attitudes, and opinions of the interviewees. The semi-structured interview is characterized by the articulation of the use of previously prepared questions, while allowing participants to speak freely about the topic.<sup>15</sup>

Individual interviews were conducted with five medical preceptors and three nurse preceptors, aged between 27 and 37 years old, three men and five women, whose experience of professional practice and preceptorship took place in three different public institutions — two universities and the municipal health network. Doctor preceptors (D) were identified by numbers 1 to 5 and nurse preceptors (E) by numbers 1 to 3, followed by the identification of the interview procedure (IIT).

To complete the first phase of individual interviews, the concept of “information power” by Malterud et al.<sup>16</sup> was used. For the authors, in the development of a given study, the greater the information power obtained from some participants, the fewer participants would be necessary for the construction of an adequate sample. The “information power” of a sample depends on the purpose of the study, the specific characteristics of the potential participants, the theoretical framework chosen, the quality of the dialogue during the interview, and the analysis strategy.

In the second phase, focus groups were carried out and, for this purpose, three guiding questions were configured based on the thematic analysis of the individual interviews. Three focus groups were carried out, consisted of 12 physicians, 14 physicians, and six nurses, respectively. Only two physicians among the eight participants in the individual interviews were present in the focus groups. The three groups took place at the time and place of regular technical meetings. Participants in the focus groups constituted a convenience sample with the agreement of the coordination of the residency programs. In the present study, units of individuals’ contexts were valued, as well as consensuses and disagreements arising from the interaction between participants in the focus groups.<sup>17</sup> Doctor preceptors (D) were identified by numbers from 1 to 26 and nurse preceptors (N) by numbers from 1 to 6, followed by the identification of the focus group (FG).

The definition of the FG questions sought to deepen or reveal issues that were not reached in the individual interviews. The analysis of the individual interviews revealed that the subjective dimension involved in the experience of carrying out PC by the interviewees was mentioned superficially, despite the case reports. Therefore, this topic was taken to the FG. Spirituality was not spontaneously mentioned in any individual interview and, taking into account the paradigm shift suggested by the WHO in 1986 for the care of patients in PC, which includes an approach to the spiritual dimension, it was introduced as a question to the groups. The objective of the third question was to discuss actions and initiatives that, in the opinion of the participants, could contribute to the implementation of PC in PHC.

Thematic analysis of the speeches was carried out following Bardin’s precepts.<sup>18</sup> Initially, a pre-analysis was carried out with skimming of theoretical references, with the formulation of hypotheses and prior elaboration of categories of analysis, in correlation with the research objectives. The transcribed material from the interviews was coded, aggregated and categorized. The categorization promoted the emergence of new categories of analysis, which had not been raised by the previous study of the theme. After exploring the material, results were treated, with the inference and interpretation of the units of analysis.

The research was approved by the Research Ethics Committee of the Clementino Fraga Filho University Hospital of Universidade Federal do Rio de Janeiro and by the Research Ethics Committee of the Municipal Health Secretariat of Rio de Janeiro. All participants signed the Informed Consent.

## RESULTS AND DISCUSSION

### Discovering and understanding palliative care

#### *Palliative care in training*

Palliative care is still little prioritized in the undergraduate curriculum of physicians and nurses.<sup>19</sup> The few successful initiatives are rather specific.<sup>2</sup> Only one nurse reports having had formal contact with the subject during her undergraduate studies.

*“I had a teacher who was in the field of chemotherapy, then there was this one class about palliative care.” N6 FG3*

Despite not being in the curriculum, nor being an objective of teaching, colleges provided situations that led to contact with the PC:

*“The first time I found out about this was when I was still in medical school and I came across a patient in the ward, who made a big impression on me. But it was a scenario that I didn’t know what to say, what to do, I didn’t have that type of training in college.” D1 IIT*

PC are included in the Competency-Based Curriculum of the Brazilian Society of FP.<sup>20</sup> And it was during this residency that some physicians were able to review their understanding of PC:

*“I believed, When I left college, that palliative care was [sic] a cancer thing only. During residency, I realized that palliation goes beyond cancer.” D1 IIT*

Some of the reports referred to the experience in PC during specialization, showing that, through practice, there may be some learning about this area, even without in-depth theoretical aspects. Often, the form of learning after the initial contact was self-taught.

*“I like to be always learning, so even if we have difficulties, we have to make an effort to learn, like maybe studying more about therapies.” N3 IIT*

#### *The “taboo” of spirituality*

Returning to the WHO definition of PC, in addition to the biopsychosocial aspects, the spirituality of patients, family members, and caregivers must also be addressed. This was an aspect absent from the individual interviews. According to Bardin,<sup>18</sup> the absence of an element can be an important variable. This absence can manifest blockages or repressions on the part of the interviewees. In order to better understand this aspect, the theme of spirituality was thought of as a motivating issue for the FGs.

In the first of them (FG1), consisted of 12 physicians, spirituality was raised spontaneously by one of the participants as a relevant and necessary topic for professionals as a care tool. This professional uses

terms such as “*relationship with the divine, with the sacred*”, demonstrating knowledge of the difference between spirituality and religiosity.

Spirituality is a broader term than religion. According to Sulmasy,<sup>21</sup> spirituality refers to the relationship of an individual or group with the transcendent. Many people express their spirituality through religious practices, others express their spirituality in relation to nature, music, art or philosophical beliefs. Religion, on the other hand, is a set of beliefs, practices, and languages characteristic of a community that seeks a transcendent meaning in a particular way, usually based on the belief in a deity.<sup>21</sup>

Returning to the group, a doctor said that it is common for doctors to intentionally choose not to address spirituality: “*ah, you’re already going to church, good for you*” (D3 FG1). This speech corroborates the inference made by the absence of the theme among the speeches of the participants interviewed individually and described above, in which professionals can avoid the theme or run away from it.

The Patient-Centered Medicine (PCM) method is remembered in this group, about how Family Practice breaks with the mind-body duality. This approach is widespread in FP<sup>22</sup> and has four elements, the second being the understanding of the person as a whole, through the integration of the concepts of health, illness and illness experience, including the life cycle and context. This includes the role of spirituality in the patients’ life as well as in their experience with the disease.<sup>23</sup>

In the second group (FG2), consisted of 14 physicians, there was a long silence after the question from the group coordinator about the approach to the patients’ spirituality. This silence can be interpreted as the result of a topic that makes participants uncomfortable.

The first physician to enter the topic recognizes difficulty in the subject, but reports that, when able to talk about this dimension with her patient, she observed positive responses both in the biological expression of the disease and in the interpersonal relationship between professional and patient. Grant et al.<sup>24</sup> reinforce the relationship between spiritual issues and physical aspects by saying that, when not met, patients’ spiritual needs can turn into physical symptoms.

Contrasting what was exposed in the literature above and the speech of the first doctor, another doctor said she believed that patients do not expect health professionals to address this issue. She also said that possibly this approach would not be needed by the patient. It was a dissent that appeared right at the beginning of the group.

The Kaiser Family Foundation conducted a survey of people’s views and experiences of end-of-life care in four different countries. When asked about the importance of several factors suggested in the survey, when thinking about their own death, Brazilians listed “being spiritually at peace” as the most important. “Being comfortable and pain free” took second place.<sup>25</sup>

Still in the second group with physicians (FG2), one professional reported that the approach to spirituality occurs too late, already at the end of life, but recognizes that it should be done before, even to know the patient more comprehensively. Another physician associates the idea of integrality with PCM, as in FG1, which was also carried out with physicians. However, although FP is described in the literature as having a greater focus on patients, in general, spirituality is neglected in consultations.<sup>22</sup>

In the third group (FG3), consisted of six nurses, when asked about the approach to spirituality, one of them stated that she not only asks about the patients’ religion, but also encourages them to practice spiritual rituals, already disconnecting the concept of religion and spirituality. Another nurse corroborated the encouragement of individual beliefs, also differentiating religiosity and spirituality. A third participant said that this approach is carried out routinely, which was reaffirmed by the other participants.



## Performing or not palliative care in primary care

### *Facilities and advantages in palliative care*

According to Starfield,<sup>26</sup> PHC should be the gateway, the point of easiest user access to the health service system:

*“The thing is that PHC is a gateway, there will always be these cases, so we have to incorporate this care into our practice.” D1 IIT*

Donabedian<sup>27</sup> classifies access as socio-organizational or geographic. The former refers to the facilitators for the citizen to reach the service, and the latter relates to the characteristics involved in the displacement to reach the services.

*“PHC is the main focus since we are the doctors who are close to patients all the time, we who are there in the continuity of care, we who have a bond, who are closer to their home.” D5 IIT*

This last sentence emphasizes another essential attribute of PHC: longitudinality. This principle promotes a long-term relationship between health professionals and users, allowing the monitoring of individual or group changes over the years.<sup>26</sup> Longitudinality is mentioned by both nurses and physicians.

In addition to first contact access, longitudinality and comprehensiveness, the last essential attribute of PHC was also mentioned: care coordination. Essentially, care coordination is the management of information regarding health problems and services provided to an individual.<sup>26</sup>

*“Patients are in our area, they are our responsibility. So even when accompanying other specialists, we are the care coordinators.” D3 IIT*

Responsibility, coordination of care, as well as comprehensiveness, require cooperation between professionals, both in the PHC teamwork and with other workers at other levels of the health system.<sup>28</sup>

*“The NASF [Núcleo de Apoio à Saúde da Família/Family Health Support Center] is very powerful in helping; both physiotherapy and nutrition, sometimes social assistance can get some support, get some benefits for the patient, the physical educator can help, the psychologist.” D3 IIT*

The multidisciplinary approach is one of the principles of PC, focusing on the needs of patients and their families, including grief monitoring.<sup>4</sup> Only two nurses mentioned the grief approach.

### *Difficulties and disadvantages in providing palliative care*

According to the WHO,<sup>5</sup> all patients with serious illnesses, threatening the continuity of life, should receive the PC approach from their diagnosis. Some doctors reported the difficulty in identifying which patients should receive this care:

*“There is also a fear exactly about this division, this line, this milestone of when palliative care begins.” D1 FG2*

The difficulty of understanding by family members, especially if death is being experienced as a relatively close threat, is brought up by both doctors and nurses:

*“Discussing with the family in a context that death left home to happen in an institution like the hospital. The community’s perception is that this [hospital] is the best care that can be given to that grandmother who is in a terminal phase.” D13 FG1*

The professionals’ opinion is corroborated by the ranking prepared by the Economist Intelligence Unit,<sup>8</sup> which rates the Brazilian population with low knowledge and awareness of what PC is.

Physicians and nurses alike commented on prioritizing management for other illnesses. In Brazil, the Ministry of Health<sup>12</sup> published guidelines for the organization of PC in SUS, but guidelines for care have not yet been created.

Shipman et al.<sup>29</sup> report that excessive demand and bureaucratic work can limit PC patients’ access to health services. The same was said by several professionals:

*“Because the number of users we serve does not allow for the higher frequency that palliative care deserves.” N2 FG3*

Another difficulty reported several times was access to medicines and supplies. The WHO<sup>5</sup> advocates some minimum needs for palliative care, namely: adequate national policies; education and training; availability of medications, especially opioids; implementation at all levels of care.

*“If patients can’t buy it or when they start increasing the dose, it becomes very expensive, so they end up dying in pain.” D5 IIT*

The difficulty of network interaction impairs the provision of comprehensive care to patients. Several points in the network were cited as difficult to access, including contact with secondary and tertiary care or the Home Care Program (*Programa de Atendimento Domiciliar – PADI*).

Still regarding difficulties, talking about death was brought up by the two professional categories. Death continues to be seen by many professionals as a failure, which can be justified by academic training focused on curative obstinacy, always fighting death,<sup>30</sup> but also referring to terminality itself.<sup>31</sup>

*“We don’t accept death. We are not taught that. We work for the cure.” N6 FG3*

*The professional’s suffering is not necessarily placed as a negative aspect. The speech below, from a doctor, shows resignation when dealing with suffering:*

*“There’s no way, the family doctor suffers along, we suffer every day, not only with PC, but also with a history of violence, abortion, with real life.” D2 IIT*



Still in the field of feelings, two nurses had stories of family members in PC. They brought their experiences to the interviews. The fact that they experienced the proximity of the death of a loved one generated positive feelings such as empathy and compassion toward people in the same situation. The personal experience of mourning and sadness related to the death of a close person is of great value for the way professionals deal with the loss of a patient and also helps professionals to aid their patients and families in dealing with their own grief.<sup>32</sup>

## Implementing palliative care in primary care

Physicians and nurses suggested the creation of a line of care for performing PC:

*“I think we need to go further along this line of care. So we need to have a greater proposal, training professionals, discussing cases.” N3 IIT*

Starting from individual care, doctors point to the need for dialogue between those who are working at the front and managers, who are more distant:

*“Fighting over morphine prescriptions, fighting to have access to death certificates, to do some things that would normally only be done in the hospital, but that are moving toward primary care, to people’s homes, and to show the resident that this is possible, that you can fight for it, to make it happen.” D1 FG2*

In this last speech, the doctor also brings responsibility to the preceptor’s role. Participants pointed out different ways of how they can act based on the discussion of the individual case in the preceptorship for the execution of PC in PHC. Ensuring the space for PC in practice was suggested:

*“I think the first thing is to guarantee the palliative care space. Because, sometimes, these vertical management demands do not allow much space. So we have to show the resident that that is important.” N2 FG3*

The idea of presenting and discussing PC cases in the residency theoretical channels was proposed by both categories.

And, finally, the speech of two physicians exemplifies how the preceptor’s “doing” can influence the residents’ practice, underlining the preceptor’s role as a model, as cited by Crosby.<sup>14</sup>

*“I think the most important thing is for us to do it and not turn our backs on these people who are perhaps the ones who need our attention and time the most. [...] The cases we had there at the clinic, which the residents lived with a preceptor, especially the terminally ill patients who died at home, it is certainly an experience that marks them for a lifetime.” D10 FG2*

## CONCLUSION

The research reveals difficulty in approaching spirituality by physicians, while this is routine among nurses. The difference in this approach between the two categories needs to be deepened in future research.

Tensioning the management is important so that the PC does not continue to be neglected by demands based only on disease indicators, as well as for the acquisition of necessary inputs for good care to be offered. As well as dialogue with other levels of care, it is recommended that preceptors seek professionals from other categories and specialties, in order to offer more comprehensive care to those in need.

The guarantee of space in theoretical channels in residency programs allows filling the gap left by graduation on the subject, as well as raising awareness of these future specialists for carrying out PC on a daily basis. The preceptor's practice, by showing that it is possible to offer this care in PHC by actively performing it, added to the direct and frequent contact between preceptor and resident, makes it possible to develop a professional capable of understanding that death is a stage of life, and that he can also provide direct and frequent care for PC patients and their families.

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## CONFLICT OF INTEREST

Nothing to declare.

## AUTHORS' CONTRIBUTIONS

MCLS: Project administration, Conceptualization, Writing – original draft, Writing – review & editing, Investigation, Methodology. ARNDS: Conceptualization, Writing – review & editing, Methodology, Supervision. MIPA: Conceptualization, Writing – review & editing, Methodology, Supervision.

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