MEANINGS OF PALLIATIVE CARE IN THE VIEW OF NURSES AND MANAGERS OF PRIMARY HEALTH CARE
SIGNIFICADOS DOS CUIDADOS PALIATIVOS NA ÓTICA DE ENFERMEIROS E GESTORES DA ATENÇÃO PRIMÁRIA À SAÚDE
SIGNIFICADOS DE LOS CUIDADOS PALIATIVOS EN LA VISIÓN DE ENFERMEROS Y GESTORES DE LA ATENCIÓN PRIMARIA A LA SALUD

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ABSTRACT
Objective: to understand the meanings attributed to palliative care in the perception of nurses and managers of primary health care. Method: this is a descriptive study with a qualitative approach, based on interviews with nurses and primary health care managers. The sample was defined by saturation criterion (repetition) and data analyzed by the technique of content analysis in the Thematic Analysis modality. Results: four categories emerged: “Interface among the PCs,” “Terminality and cancer,” “Importance of preservation of quality of life in PC,” “Different meanings attributed to PC and connections between knowledge and the quality of PC.” Conclusion: it was observed from the reports that the participants had insufficient knowledge about PC, but they recognize the importance of maintaining the quality of life in these patients.

Descriptors: Palliative Care; Primary Health Care; Nursing.

RESUMO
Objetivo: compreender os significados atribuídos aos cuidados paliativos, na percepção de enfermeiros e gestores da atenção primária à saúde. Método: estudo descritivo, de abordagem qualitativa, realizado a partir de entrevistas com enfermeiros e gestores da APS. A amostra foi definida por critério de saturação (repetição) e dados analisados pela técnica de Análise de conteúdo na modalidade Análise temática. Resultados: emergiram quatro categorias << Interface entre os CP >>; << A terminalidade e o câncer >>; << Importância da preservação da qualidade de vida em CP >>; << Diferentes significados atribuídos aos CP e conexões entre o conhecimento profissional e a qualidade da assistência em CP >>. Conclusão: observou-se a partir dos relatos que os participantes tinham conhecimento insuficiente sobre os CP, mas que reconhecem a importância da manutenção da qualidade de vida nesses pacientes.

Descritores: Cuidados Paliativos; Atenção Primária à Saúde; Enfermagem.

RESUMEN
Objetivo: comprender los significados atribuidos a los cuidados paliativos, en la percepción de enfermeros y gestores de la atención primaria a la salud. Método: estudio descriptivo, de enfoque cualitativo, realizado a partir de entrevistas con enfermeros y gestores de la APS. La muestra definida por criterio de saturación (repetición) y datos analizados por la técnica de Análisis de contenido en la modalidad Análisis temática. Resultados: surgieron cuatro categorías << Interface entre los CP >>; << La terminalidad y el cáncer >>; << Importancia de la preservación de la calidad de vida en CP >>; << Diferentes significados atribuidos a los CP y conexiones entre el conocimiento profesional y la calidad de la asistencia en CP >>. Conclusión: se observó a partir de los relatos, que los participantes tenían conocimiento insuficiente sobre los CP, pero que reconocen la importancia del mantenimiento de la calidad de vida en estos pacientes.

Descripciones: Cuidados Paliativos; Atención Primaria de Salud; Enfermería.

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INTRODUCTION

There is a demographic transition with a concomitant epidemiological transition, increasing the number of elderly people and the prevalence of non-communicable chronic diseases (DCNTs), highlighting the need for policies and actions aimed at Palliative Care (PC). It is noted that this transition process has occurred through a fall in birth and death rates and an increase in the life expectancy of the population, culminating in an aging population. Thus, studies on the theme of PCs become relevant since they constitute an important public health problem today.

PCs can be conceptualized as the total care and assets for patients whose disease no longer responds to curative treatment. Therefore, they are integral care, aimed at the patient’s well-being, providing a better quality of life for patients and their families. Thus, it is a differentiated care modality that aims at the prevention and relief of suffering through early identification and detailed evaluation for the treatment of pain and other physical, psychosocial, and spiritual symptoms. They aim to increase the quality of life both of the patients and their families, trying to integrate them into the environment in which they lived before illness, and to evaluate what they lost during this process, promoting the relief of suffering.

It should be emphasized that there are different concepts around the eligibility criteria for PCs. One of the most commonly used criteria is patients who present one or more of the following conditions: Alzheimer’s disease and other dementias, cancer, cardiovascular disease (excluding sudden death), cirrhosis of the liver, congenital anomalies, meningitis, hematological and immunological conditions, neonatal conditions, chronic obstructive pulmonary disease (COPD), diabetes, acquired human immunodeficiency syndrome (HIV/AIDS), renal insufficiency, multiple sclerosis, Parkinson’s disease, rheumatoid arthritis and resistant tuberculosis. Another widely used criterion is the patient’s survival time, as adopted by the American Medicare (health insurance system). The Medicare criteria can be summarized as life expectancy assessed less or equal to six months; The option of the patient for exclusive PCs and to give up life-prolonging treatments, and being beneficiaries of the plan. In general, eligibility shows for people with evolutive and progressive chronic diseases, with a prognosis of life supposedly shortened, beyond therapeutic possibilities of healing.

PCs are still a neglected issue in a significant part of the countries, and social and political actions are required to promote as well as possible the well-being and quality of life of patients who need these care.

Currently, there is a significant increase in PC in Brazil. However, there is still no national policy in this regard. The country has been consolidating this modality of care within the health system, through ordinances and documents, such as the ordinance that establishes the National Pain Relief Program and PC and as the main legal instrument, the ordinance that includes PCs in the National Cancer Care Policy. However, this excludes the other diseases and patients who also need these care, in a line that includes all levels of care.

In the context of Primary Health Care (APS), PCs stand out because this is the reference scenario of the great majority of patients with CNCD out of the therapeutic possibility of a cure. Also, APS plays an important role in the humanization of care, favoring not only the improvement of the quality of life but also the quality and continuity of the care provided to patients in PCs inside and outside the home. However, the inclusion of PCs in APS has been presented as one of the main difficulties for PC work in Brazil.

In this scenario, the nurse is the professional who deals directly with the person in PC, providing a range of care that aims at the relief of physical, emotional and spiritual symptoms, and, for that, have enough knowledge to assist this patient adequately. It is considered that the practice of nursing in APS favors the identification of the needs of care referred by patients and relatives, since it is a scenario in which the practice is centered on the person and not only on the task. Thus, the nursing professional is fundamental for the implementation of the CPs, and their adequate training is also extremely important.

In this context, the nurse, as well as all the multi-professional team that works in the APS, needs to involve the health service manager in patient care since the patient’s demands must be the basis for the elaboration and planning of the actions developed in the APS, impacting positively on improving the quality of life of the population.

Considering the importance of the role of nurses and the manager of APS in PC care, relevant studies are becoming relevant to understand the meanings attributed to this modality of care by these professionals, with
the purpose of implementing actions geared towards training and continuing education of these professionals. Thus, this study aims to:

- Understand the meanings attributed to palliative care in the perception of nurses and managers of primary health care.

**METHOD**

This is a descriptive study with a qualitative approach carried out with nurses and managers of 22 primary health care units (UAPS), from the Family Health Strategy (ESF) model, from the city of Divinópolis, Minas Gerais, Brazil. In these units, there are 335 professionals working, of which 42 are nurses, and three are managers of the health sectors where the units are inserted. Therefore, the universe of the study comprised the 42 nurses and the three managers of the ESF of the municipality.

The nurses who participated in the research were selected through a raffle, and the inclusion criteria were to work in the ESF, for at least 6 months and to be in activities during the period of data collection. The saturation criterion was used for the definition of the participant population, and data collection was completed when systematic repetition of the speech was identified. All three managers of the municipality’s ESF units were included.

The technique of interview with the semi-structured script was used. The interviews were recorded on the MP4 device and later transcribed in full. Participants were identified by acronyms and numbers to maintain secrecy. Thus, the acronym “E” and the numbers 001, 002, and 003, and so on were successively used for nursing professionals and the abbreviation “G” and the numbers 001, g 002, g 003 for the managers.

For the data treatment, the content analysis technique was used, firstly the floating reading of all the transcribed material, followed by the pre-analysis to identify the profile of the participants. Subsequently, the clipping, aggregation, and enumeration of the data were performed, enabling to clarify the indications of categories. Then, the categorization was started, where the information contained in the participants’ statements formed the corpus of analysis that led to the elaboration of indicators that were submitted to analytical procedures and subsequent inference, comparing with the literature data.

**RESULTS**

The population consisted of 15 nurses and 3 managers. After reliable transcription of the collected material, the material was read and re-read, approximating them dialectically from the theoretical references, and later delimited them by subjects of greater relevance and significance, grouping them into four categories: “Interface among palliative care, terminality and cancer”; “Importance of quality of life preservation in palliative care”; “Different meanings attributed to palliative care” and “Connections between professional knowledge and quality of care in palliative care”. The discourses for each of these categories are presented below.

- **Category 1. Interface among palliative care, terminality, and cancer.**
  
  This category represents the reports of 7 nurses and 1 manager, which refer to the conception that PCs are intended for “terminal” and “cancer” patients.
  
  *Now we are not having, but we have had a patient [...] with a terminal stage of cancer [...] who received this care at home. (E 001)*
  
  *They are those patients [...] in a critical state; [...] even terminally ill, cancer patients. [...] Patients with advanced CA right?! (E 003)*
  
  *Palliative care in my understanding is when the person, [...] let’s say, terminal right?! Moreover, the prognosis is not good, so we [...] will not let the person [...] go to death like that without any care. (E 004)*
  
  It is observed that the participants of the research associate the PCs with the terminal or end-of-life status of the patient, especially when it comes to cancer patients. Participants are also associated the PC concept with “patient survival time.”

- **Category 2. Importance of quality of life preservation in palliative care.**
  
  This category refers to the statements of 4 nurses and 1 manager demonstrating their understanding of the importance of maintaining the quality of life of patients in PC. In this category, the participants relate...
the concept of palliative care to the quality of life, according to the following sections.

[…] for him to have a better quality of life so that he dies worthily […]. (E 015);

[…] you try to offer a quality of life, a better quality of life for that patient […] (E 010)

[…] They are care to offer a better quality of life for the person before the illness that she experiences; A disease most often chronic, right? Serious and palliative care comes to ease the suffering, or give more quality of life to these people. (G 003)

♦ Category 3. Different meanings attributed to palliative care.

In this category, the reports of 2 nurses and 2 managers, who demonstrate different meanings about PCs, are presented. It was found from the reports that these professionals do not recognize the eligibility criteria for PCs, referring to them based on mistaken and unsubstantiated concepts.

For me, palliative care is that care provided to the patient from the moment we evaluate and see the need, for example, a surgical post, or some illness that he has, or some wound; it is all that care that we are going to give the patient from the moment he needs it. (E 002)

[…] Palliative care is the primary care with the patient, from the consultation (…) up to a pressure measurement. It would be the dressing, or the delivery of medicine in the units […]. They are, I believe, the preventive care of the primary health care to the patient. All patients. [… ] he must receive […] from the moment that in the unit he already should receive some care. […] It may be that he will come with several complaints. […] If it is a serious pathology, then it will be referred […] to polyclinics, serious for the UPA. (G 001)

It is observed in these reports that the professionals do not understand the meaning of PCs, relating them to “any” modality of care provided by APS health professionals.

There is care that is not medicated, right, the medicated ones that now exist are like homeopathy, acupuncture, and other forms of treatment that exist today. Alternative measures. Sometimes when only the drug is not working, or you do not want to do the drug or want to do something else before you start to see if you can help. (E 005)

The reports above are about PCs as “alternative” or “non-drug” care but with no consistent reasoning. The report, below, refers to PCs to inadequate therapies, that is, in the absence of appropriate therapies, PCs would be a “second option.”

[…] the term of the word palliative, would be one, something that should have a correct methodology, but not having the correct methodology you would use a second, another form of care, is, using the term palliative, right? I could not tell if this is correct, but it is what I understand by the term palliative. (G 003)

The APS professionals’ lack of understanding of CPs is again perceived.

♦ Category 4. Connections between professional knowledge and the quality of care in palliative care.

This category refers to the speeches (10 nurses and 1 manager) that reflect the importance of the knowledge about PCs for the implementation of quality care.

When the professional knows what he is doing, he knows how to recognize that the patient is in palliative care, that he needs that kind of care, that he/she improves well the type of care, the assistance. (E 001)

[…] totally influences the quality of care, it is, in my view, the same today, we do not have the training, we study more or less at the undergraduate level, which is palliative care, right? It always comes to doubt what will be even palliative care? It is just the same, treat the disease, treat the pain, but we know it is not, so it influences a lot, so the more knowledge, the more training, the more training the professional has, the better it will be the result of care. (E 002)

Knowledge is essential, I think that from the moment you know of any subject, you have how to intervene better, more effective, so if we know in our unit who are the patients who need this care, according to these eligibility criteria, We will be able to program how we will be able to provide this assistance, both to enable ourselves to be trained if the case and the question even of material also [… ] (E 006)

[…] I think it opens a knowledge of palliative care, it opens a door for professionals to have another way of caring for these patients and not just pure biomedical care, let’s talk like that. Because palliative care is performed not only by the doctor and the nurse, it is a multi-professional team, so it makes the professionals, is, have that work more in a team taking care of one patient in the various, is, theories, right? Psychology, social service, nutrition, physiotherapy, so I think he (the phone rang again) comes, it comes to increase the effectiveness of the team to be able to take better care of his patient, who is in a case of a terminal illness. (G 002)

The statements of the professionals refer to the importance of knowledge of the PC theme since such knowledge influences care planning and the quality of care provided. The professionals report that there is a lack of
knowledge of the team about this care and that the issue is not discussed in the graduation in an effective way and that this has negative consequences for the quality of care.

**DISCUSSION**

It was observed from the reports that the participants presented an understanding about PCs, still very focused on the initial concept of this care, that is, when the care emerged, they were limited to cancer patients with reduced survival time.12

Participants are associated the PC concept with the “patient survival time,” referring to the term “terminal patient.” Currently, this criterion is still considered one of the most used for the eligibility of patients to PCs, such as in American Medicare, which establishes the expected survival time of six months as a condition for this assistance.7 The survival time should not be considered as the sole criterion for eligibility, but rather the absence of therapeutic possibilities for a cure. It is important to emphasize the importance of early identification and assistance to these patients, reducing the associated complications.

It is also observed, from the reports, that the participants did not approach care for their relatives when talking about PCs. However, PCs are conceived as integral care aimed at the patient’s well-being, to provide quality of life not only to these but to their families.4,13

Regarding the association between PC and cancer, it is worth mentioning that such care aims to benefit the patient when he or she no longer responds to the so-called curative treatments and has a function of relieving pain and suffering14, being applied not only to cancer but to other CNCDs.7 This perception can be related to the fact that PCs in Brazil has the National Cancer Care Policy as the main legal instrument.

Even through the current context of increasing NCDS and PC demands, this type of care is still a neglected subject in many countries. Therefore, it is important to carry out social and political actions to promote knowledge about PCs, for early identification and assistance.8

Nurses and managers also related the concept of quality of life in their statements. However, once again, the reports did not refer to the quality of life of family members and caregivers, only to patients, which demonstrates an understanding of this modality of care. A study15 shows the importance of PCs for the maintenance of quality of life and emphasizes that the team should work actively and effectively with patients and their families to encourage positive attitudes and clarify doubts, as well as support the family reducing the overload and strengthening it.

Participants also conceptualized PCs in different ways, and in some cases without any theoretical basis, such as the reports that referred PCs to “alternative therapies.” The so-called “alternative” or “holistic” therapy focuses on the relationship between body and spirit and is based on a global conception of well-being, associating it with physical, psychic, emotional, spiritual and environmental aspects. The practices included in the holistic health area belong to several areas: medicine (conventional and alternative), food and spirituality.16 Such therapies can be used in PC, however, do not represent the concept of such care. The participant did not mention any of the eligibility criteria accepted by the literature, to conceptualize PCs.

One of the reports associated the PCs with inadequate therapies that is, in the absence of appropriate therapies, which shows a great lack of knowledge about this care. This leads to a conception that PCs are practices that neglect care, that is when the health institution or the professionals do not have the structural and technical conditions to offer the appropriate treatment. According to some authors9,15-16, the lack of knowledge about PCs is due to the lack of qualification of the professionals during their academic formation, due to the small presence of courses suggestive to PC, which suggests the lack of theoretical and technical preparation of them.

One study17 pointed out that it is only with the change in knowledge management and the undergraduate curriculum of health professionals that PCs can be done in Brazil since the training courses in the area are scarce and there is still resistance in the debate on the subject.

It is observed that, among the reports, there were two managers who showed a total lack of knowledge about the concept. In this regard, it should be noted that many of the APS managers are not health professionals, which does not justify the lack of knowledge about the subject, as they are the main responsible for planning health actions. Thus, it is important to emphasize that the managers’ knowledge is essential to obtain continuity of care so that the patient can have...
a quality not only in the care but also in the materials offered. The professionals reported that there is a shortage of knowledge of the APS team about PCs and that the issue is not discussed in the undergraduate course in an effective way, leading to negative consequences for the quality of care. Such insufficiency in professional training may be related to the biomedical paradigm that professionals are trained to heal, and when this does not occur, they say that “there is nothing more that can be done,” hindering the patient to receive dignified care in PC. Such concern was mentioned in a manager’s report. In the same speech, the manager also stresses the importance of integrating professional knowledge for quality and integral care, that is, not only based on the biomedical model, which considers the disease and its treatment, but focused on the biopsychosocial aspects of the care.

Given this, it is of paramount importance the knowledge and preparation of the health professionals regarding the PC, for an integral and quality assistance. Broadening the view of these, which previously was only linked to the underlying problem, would be the disease, making care more holistic, involving all those who have a contact in some way and need to understand such care. The incorporation of programs that integrate PCs in the APS in a coordinated manner into the health network will contribute to the humanization and integrality of care since it can help reducing the abandonment and suffering of patients and their families.

CONCLUSION

Based on the analysis of the data from the participants’ discourses, it was possible to identify the understanding and meanings attributed by nurses and managers of APS on PCs. Some challenges were also identified for the training of these professionals and their role in PCs in APS.

The reports show that nurses and managers of APS have insufficient knowledge about these care, as well as their characteristics, often associating them with terminality and cancer. Participants also did not include patients’ relatives when discussing PC.

From the speeches of the professionals, it was identified that they understand the importance of maintaining the quality of life of the patients they attend and who recognize that, one way of preserving this quality of life, is through the implementation of the PC as a philosophy of outpatient care of therapeutic possibilities.

It should be noted from the reports, the lack of knowledge of the managers of the APS regarding the issue since such ignorance can compromise the planning of care and the quality of care.

The reports also demonstrate the insufficiencies of undergraduate nursing curricula on the subject, and that such inadequacies directly affect the quality of care provided by these professionals, who are not adequately trained. Thus, greater discussions about PCs in the practice of nurses and the planning of undergraduate curricula of these professionals become more relevant, which should address specific contents on the subject and have trained and experienced teachers to minister to them.

Although the results of this study do not present generalizations about the meanings attributed by the participants, they may contribute to the discussions about the importance of professional training in PC, both for health professionals and for APS managers. Also, it can give subsidies for the process of construction of curricula of undergraduate courses in nursing and health.

CPs are experienced by APS professionals, and it is essential to provide care to patients and families based on technical and scientific knowledge. Therefore, it is necessary for nurses and managers to know more than to recognize the patients who need PC, but also to offer a quality assistance aiming the well-being of the patient and his family.

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