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Challenges and competences of nurses in palliative care in primary health care

ABSTRACT | Objective: to identify knowledge, skills and challenges faced by nurses in Family Health Strategies about palliative care. Method: qualitative exploratory study carried out in the second semester of 2018 with 24 nurses working in 24 municipalities in Rio Grande do Sul. Data collection was performed through an online questionnaire and analyzed by thematic analysis. Results: they suggest that the main challenges comprise incipient knowledge on the theme, lack of technical and scientific preparation and the absence of a multidisciplinary team in the services they operate. Regarding the necessary skills, care planning and execution, technical and scientific knowledge and establishing a comprehensive patient care plan stood out. Conclusion: It is believed that it will help municipal health managers to perceive palliative care as strategies in the feasibility, conduction and implementation of innovative care proposals based on the precepts of this practice, enabling propositional actions to users.
Keywords: Palliative care; Primary Health Care; Community health nursing.

RESUMEN | Objetivo: identificar conocimientos, habilidades y desafíos que enfrentan los enfermeros en Estrategias de Salud de la Familia sobre cuidados paliativos. Método: estudio cualitativo exploratorio realizado en el segundo semestre de 2018 con 24 enfermeras trabajando en 24 municipios de Rio Grande do Sul. La recolección de datos se realizó a través de un cuestionario en línea y se analizó mediante análisis temático. Resultados: sugieren que los principales desafíos comprenden el conocimiento incipiente sobre el tema, la falta de preparación técnica y científica y la ausencia de un equipo multidisciplinario en los servicios que operan. En cuanto a las competencias necesarias, se destacó la planificación y ejecución de la atención, contar con conocimientos técnicos y científicos y establecer un plan integral de atención al paciente. Conclusión: Se cree que ayudará a los gestores de salud municipales a percibir los cuidados paliativos como estrategias en la viabilidad, conducción e implementación de propuestas de atención innovadoras basadas en los preceptos de esta práctica, posibilitando acciones proposicionales a los usuarios.
Palabras claves: Cuidados paliativos; Primeros auxilios; Enfermería en salud.

RESUMO | Objetivo: identificar conhecimento, competências e desafios enfrentados pelos enfermeiros das Estratégias de Saúde da Família acerca dos cuidados paliativos. Método: estudo exploratório qualitativo realizado no segundo semestre de 2018 com 24 enfermeiros atuantes em 24 municípios do Rio Grande do Sul. A coleta de dados foi realizada por meio de um questionário online e analisado pela análise temática. Resultados: sugerem que os principais desafios compreendem conhecimento incipiente sobre a temática, falta de preparo técnico e científico e a ausência de uma equipe multiprofissional nos serviços que atuam. Relacionado às competências necessárias, destacaram-se o planejamento e execução do cuidado, ter conhecimento técnico e científico e estabelecer um plano de cuidado integral ao paciente. Conclusão: Acredita-se que irá auxiliar gestores municipais de saúde a perceberem os cuidados paliativos como estratégias na viabilização, condução e implementação de propostas inovadoras de cuidados alicerçadas nos preceitos desta prática, possibilitando ações propositivas aos usuários.
Palavras-chaves: Cuidados paliativos; Atenção Primária à Saúde; Enfermagem em saúde comunitária.

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INTRODUCTION

Palliative Care (PC) is an inalienable right of citizens and focuses on the control of complex functional and symptomatic issues that propose changes in the way of caring for patients with illness without therapeutic possibilities for a cure. This care model proposes to break with the traditional focus, with an emphasis on the disease, for comprehensive care based on the active participation of the patient and family in decision making.[1]

PCs involve practices that seek to increase the quality of life of patients

through the prevention and relief of suffering. This process involves the early identification of their needs, the treatment of pain, physical, psychosocial and spiritual problems detected from a sensitive and welcoming perspective. During PC, it is important to use an approach that contemplates coping with death as a natural process, especially with interprofessional actions, as recommended by the World Health Organization (WHO).[2]

PCs are most effective when started early, that is, shortly after diagnosis. In this way it is possible to minimize suffering, provide support and provide a support system capable of helping the patient to live actively for the time that remains, in addition to supporting the family in the process of illness and grief.[3]

PCs are showing an expressive growth in Brazil, since the main milestone occurred through Resolution No. 41, of October 31st, 2018, which aimed to organize continued palliative care within the scope of the Unified Health System (SUS).[4] However, there are still objections that go against the development of this care, due to the fact that health institutions are influenced by a health model aimed at curative practice, in which the main interest is to heal. Because it is a still incipient theme in our social context, PCs are neglected in many institutions, compromising the quality of patient care.[3]

The main levels of PC care are categorized as: home care, outpatient, hospital care or bed-day procedures and hospitalization.[5] Among them, home care stands out as a modality adopted within the scope of health systems, contributing to well-being, promoting self-care, providing support to patients and their families in the face of their new needs.[6]

Home care is a modality of health care complementary to the existing ones, characterized by a set of health care actions provided at home, guaranteed to patients in need of PC and attributed based on the intensity of care with restriction to the bed or the residence. This care has the advantages of performing early prevention of complications, health education, comfort, contributions to the patient's routine, and the family bond, together with dehospitalization, constituting one of the central axes of home care.

“In this context of PHC, nurses have multiple skills, such as the management of care that aims at comprehensiveness and the realization of a situational diagnosis that allows the classification of potentialities and difficulties.”

In the national scenario, this care covers Primary Health Care (PHC), which is the “gateway” of the system, the main point of attention that conceives a multidisciplinary team, built in order to reorganize health services and guarantee universal access and integral to the population.[7]

Aiming to reorganize PHC, the Family Health Strategy (FHS) was created as an PHC extension, consolidation and qualification plan, which aims to understand the health/ disease process, proposing to solve the individual and collective needs of a population. There is a direction towards the universalization of primary care, adding fundamental principles for a comprehensive PHC, respecting the principle of equity and integrality of care, with a family focus, which values welcoming, bonding, humanization and community orientation.[8]

In this context of PHC, nurses have multiple skills, such as the management of care that aims at comprehensiveness and the realization of a situational diagnosis that allows the classification of potentialities and difficulties.[9,10]

In view of an analysis of the growing number of elderly people and the increasing prevalence of chronic diseases at national and international level, it is clear that the omission of actions implicated as PCs is established as a public health problem in our country. It is estimated that in Brazil one million deaths occur annually, of which more than half, 650 thousand are caused by chronic diseases.[11] This situation results in a greater number of people who need this care, however a minority of patients still benefit from PC, especially in developing countries.[12]

In view of this problem, there is a need for a proactive insertion of PCs in the environment that the patient attends, especially in PHC, as they represent important strategies in the perspective of qualifying living and dying in the contemporary world, from a broad look at the aspects that involve the complexity of the human being.

In view of this context, the following research question emerges: what are the nurses' conceptions and difficulties regarding family health strategies on palliative care?

This study aims to identify with the nurses of Family Health Strategy units what are the conceptions, challenges and competencies for the approach to palliative care.

METHOD

This is an exploratory, qualitative study.[13] The research took place in the second semester of 2018. Participants were 24 nurses who worked in ESF in municipalities belonging to a health region composed of 24 municipalities in the State of Rio Grande do Sul. The inclusion criteria were: being graduated in nursing; work in the FHS of the municipalities that make up the health region of RS.

Data collection was carried out through a semi-structured questionnaire with open and closed questions, using the virtual tool Google Docs (online questionnaire) developed by the authors themselves. Google Docs allows the formulation of questionnaires to carry out scientific work, reducing geographical barriers, facilitating its sharing with a wide audience.

Nurses were invited to participate in the research informally, by telephone contact at all FHS, disseminating the research, when the project and its objectives were presented and asking about interest in participating in the study. Thus, that the interest was expressed by the participant, he was asked to provide an e-mail address for sending the ICF and the questionnaire. Initially, 24 nurses were invited to participate (one from each municipality), however, two refused to participate, with the need to contact two other professionals from two different municipalities. They answered the questionnaire (one from each city in the health region). After the answers, the questionnaires returned, which made up the corpus of the analysis.

The study complied with Resolution 466/12 of the National Health Council, which regulates research in human beings. The project was developed with the approval of 2.899.192 from the Ethics and Research Committee of the Integrated Regional University of Alto Uruguai and Missões - Campus Santo Ângelo/ RS and from the municipal health secretaries of the 24 municipalities of a Health Region of RS, through the signature of the Co-participant Institution Declaration. Upon receiving the questionnaires, the participant was guaranteed anonymity, which will be identified, in this study, by the abbreviation of the word nurse (NUR) and by the numerical sequence from 1 to 24.

The data analysis process, together with their discussion and interpretation, was guided by the content analysis technique of the speeches, in the thematic mode.[14] Two thematic categories emerged from the analysis: Palliative Care: conceptions of nurses in the FHS and Challenges, skills and contributions of nurses in relation to palliative care in the FHS.

RESULTS

Characterization of participants

Participants were identified as to sex, age, length of experience. There was a predominance of females with 87,5% (n= 21). The average age was 36,1 years and the average length of experience in the nursing field was 10,5 years.

Palliative Care: conceptions of nurses in the FHS

All participants replied that they knew the concept of PC, however, the definitions presented were incomplete or mistaken. Only two respondents described the correct definition of PC, which covers the physical, social, psychological and spiritual dimensions, assessment and treatment for pain relief. Three understood PCs in fragmented dimensions with a focus on care and symptom control, as defined below:

> (NUR 01) They are care for patients for symptom relief, with some incurable disease.
> (NUR 11) By palliative care, I understand the care practices used in terminally ill patients.
> (NUR 17) Palliative care promotes assistance to terminally ill patients, at that moment about their need to be at the place of care.

And 19 of the participants did not know or chose not to define the PC, demonstrating conceptual gaps in the knowledge of these workers about palliative care.

Another relevant aspect from the responses is the association with terminality. There is a tendency for professionals to associate PC only with terminally ill patients, which can be seen in the previous quotes and according to this answer:

> (NUR 24) I mean by palliative care the care practices used in terminally ill patients.

Some professionals who are largely unaware of the CP assume that in the terminality process there is no more to do, according to the statements:

> (NUR 2) [...] Often the professional is faced with patients who are already in the terminal phase, making it impossible to develop strategies that would enable a better quality of life [...]
> (NUR 15) Challenge is a word that we encounter every day. But the big challenge that we face since we received the patient, is the response to the tre-

atment decreasing according to the days, and you see that you can not do anything else, besides waiting.

As for the pathologies applicable to PC, six demonstrated to know the diseases and seven participants mentioned that they are the care for cancer patients only.

(NUR 1) Cancer, Stroke.
(NUR 3) Cancer.
(NUR 5) Cancer patients.
(NUR 6) Oncological,
(NUR 24) Bedridden and cancer patients

The others brought both applicable and inapplicable diseases, configuring a still incipient knowledge about the diseases that fall within this care.

Challenges, skills and contributions of nurses regarding palliative care in the FHS

The nurses described some challenges, skills and contributions related to PC in FHS, but which can also be attributed in general to all areas of PHC.

Initially, the professionals were asked about their contact with patients in PC and whether these patients were cared for. The vast majority answered that they have already cared for or take care of these patients, pointing to the great demand of patients who need this care in PHC.

Regarding the challenges faced by nurses, ignorance and insecurity in relation to PCs was indicated as the main factor.

(NUR 1) The challenges are in knowing the disease and what care to apply.
(NUR 6) Lack of knowledge.
(NUR 7) More needs to be discussed on this topic.
(NUR 9) The lack of qualification in certain practices and even the understanding of palliative care hinder the process.

Interestingly, this result was obtained after the majority of participants mentioned knowledge about PC. In this sense, most of the nurses answered that they received information about PC during graduation. Regarding the question of technical and theoretical preparation for control of common symptoms such as pain, dyspnea and fatigue, three quarters of the participants answered that they had this preparation during graduation, a situation that signals progress in academic training.

The process of understanding the finitude of life is also seen as a challenge because it is a complex phenomenon for everyone involved. In addition, there is a difficulty in helping the family understand the PC, as mentioned in the statements:

(NUR 8) The biggest challenge is to understand the end of life [...].
(NUR 9) Make the family understand and help in the palliative care process.
(NUR 10) Dealing with death and dying. Family and patient fragility.
(NUR 23) The biggest challenges would be the patient's resistance to accepting the disease, as well as the other family members.

Another challenge is related to the absence of a complete multidisciplinary team; only the minimum staff of an FHS is often unable to work with all the demands that the patient in PC requires.

(NUR 17) Palliative care goes beyond the minimum ESF team, we need the understanding of all professionals who are part of Primary Care such as: Manager, Psychologist, Nutritionist, Physiotherapist, Social Worker, Pharmacist [...]
(NUR 17) having help from a multidisciplinary team in this kind of care.
(NUR 20) We need support from more health professionals not only from nursing, but from other areas.

It is also pointed out as a difficulty the late start of palliative care, the lack of return from the other levels of care, as this level of care does not cover high-level care, with the need often for care to be scaled to another level of care.

(NUR 9) In my practice in Primary Care, I think that the lack of communication and counter reference of this patient in the Care Network, make the care, the coordination of care very difficult;
(NUR 13) Reference records and counter-reference to cancer patients.

As nurses' skills, the ability to promote care, have technical and scientific knowledge, establish a comprehensive care plan for the patient, analyzing social and spiritual needs, but also physical needs, aiming to assist in the management of pain in a broad way, providing guidance and actions that promote quality of life. Some of the skills presented:

(NUR 2) The nursing professional has a relevant role in the palliative care team, considering their privileged position to remain most of the time with the sick person and to be able to provide the largest share of care, in addition to being able to position themselves as an intermediary between the person/family and other team members.
(NUR 4) Among the skills the nurse must have knowledge to

systematically assess the patient's clinic, establishing priorities. In addition to the clinic, you should know the biopsychosocial conditions of the patient and their family. The technical knowledge for carrying out the procedures must incorporate a holistic and integral view. Communication, whether verbal or non-verbal, is essential for establishing a bond and identifying the needs of the patient and his family [...].

(NUR 16) In the multidisciplinary palliative care team, nursing professionals are at the forefront of providing care, comfort and counseling for families and patients. In this interaction, the success in providing care comes from the relationship established between patient-nursing and their interest and willingness to exercise care at the end of life.

It is also described by one of the professionals as the competence of nurses linked to PC:

(NUR 19) Be a professional specialist in the area, have a profile for palliative care.

(NUR 20) Have knowledge on the subject to develop it correctly.

Another competence cited was care in home care.

(NUR 5) [...] together with the multiprofessional team, plan the care that the patient needs, improving their quality of life, involving the family and using home care as a tool.

Therefore, from the challenges and competencies linked to PC, it is observed that nursing seeks to contribute to the realization of this care through guidance and home visits. It was found that the contributions described by the research participants were similar to the skills of the professional nurse in ESF, according to reports:

(NUR 4) Programming the home visits of the team to patients in need of palliative care, guiding and having the ability to dialogue with team members regarding pain, suffering and death. Explain that the role of the health team is to provide comfort, safety, meet the basic needs of patients, expanding the look to the holistic and integral. Dialog with empathy with the patient and his family to form the bond.

(NUR 10) First, to know all your enrolled population and its problems, in order to be able to elaborate the care plans. Remembering that the entire team is responsible for patient care.

(NUR 22) [...] Patients at home need a lot of guidance and support from the FHS.

(NUR 24) It is important to teach caregivers and family so that they can assist this patient with all their needs.

Finally, when the participants were asked about their interest in the continuing education activity on PC linked to the FHS, almost all of the nurses replied that they consider such an activity relevant to their practice. It is understood that education for these professionals is an extremely relevant factor, which will add great contributions to this care and, therefore, more purposeful, dynamic interventions are needed that impact the health needs of the user, within the PHC scope.

DISCUSSION

The attributions related to the PC show the incipience of the meaning referred to this care. Even though most professionals reported knowing and having received information during graduation, it was possible to realize, through conceptualization on the theme, that professionals have incomplete and/ or deficient knowledge about PC. One of the factors that contribute to this situation is the gaps in the teaching and learning process regarding the socialization of knowledge about PC in the curricular components, during graduation, consequently, the professionals when leaving the academic formation are unprepared in face of this reality.[15]

Fragmented associations, such as the relation of PCs only to the terminality process, reinforce the deficiencies in the knowledge of professionals, especially when considering that this care must be present throughout the course of the disease, not exclusively in the end-of-life process, as the earlier they start, the greater the chances of providing quality of life during the course of the disease.[16] In addition, the association of PC only with cancer patients also suggests the fragmentation of knowledge, since PCs encompass several other diseases.[17]

If we start from the assumption that only professionals in the field, that is, specialists should take care of these patients, the majority of the population that needs PC will remain unattended. Consequently, the professionals involved in this context must be able to take care of this. Even though you are not a specialist, you must have a wide knowledge on the subject, to apply the PC correctly, following the principles of the same.

Therefore, there is a need for permanent education of these teams in PHC, and from broad reflections on conceptual, diagnostic and therapeutic discussions on this subject, develop care strategies in accordance with the principles of PC.[17] In this sense, it is essential to instigate the training of

professionals in both undergraduate and graduate education, in addition to permanent education.[4]

As for the nurse's competencies, according to Ordinance No. 2.436 of September 21st, 2017, of the National Primary Care Policy, he highlights that among the duties of the professional nurse in PHC, there is the elaboration of a care plan for people who have chronic diseases, together with the multidisciplinary team, qualified listening and risk classification, planning, managing and evaluating activities.[8]

The professional nurse contributes significantly to the PC, however he does not develop care alone, for this account a multidisciplinary team. However, the minimum FHS team consists of at least one doctor, a nurse, an auxiliary and/ or nursing technician, a community health agent (CHA), and may have a dental surgeon and an assistant or technician in oral health, 8 characterizing a great challenge, since there is a need for comprehensive care, since these are interconnected and are of great importance for quality care provided to the patient.

Although the FHS does not have the complete team for PC, it is necessary to ensure this care with the current conditions and to seek other strategies to provide quality of care, whether articulating with other levels of care, or other care networks.[18,19] It is from the problems, demands and health needs of people and social groups in their territories, as well as professional difficulties and that of all types of staff working in PHC that the work process is established. For this, intersectoral practices, management, knowledge sharing, network care and permanent education in territories for which the team is responsible are necessary.[8]

The development of communication is also presented as a challenge, since it is an element of great importance for quality PCs, as it allows the clarification of doubts, contributing to the care directed to ideals, as well as the formation of bonds with the patient, family members, and engaging care.[20,21] Thus, there is a need to assist in the construction of knowledge aimed at PCs, to support health professionals so that they feel more confident in providing care to these patients.[10]

The professional nurse contributes significantly to the PC, however he does not develop care alone, for this account a multidisciplinary team.

Understanding PC and recognizing a disease without a cure is extremely difficult for the patient and for the people around him, especially when considering that the reflection on death is still seen as a feeling of defeat, being little discussed and understood in our society. Death is commonly considered synonymous with fear and sadness in the face of an unfavorable prognosis, requiring the provision of psychological, social and spiritual support.[5]

The unpreparedness of professionals, patient and family members, makes understanding and acceptance difficult, so there is a need for therapeutic relationships between them, in order to build partnerships in order to guarantee the quality of care provided. For this, clear communication is necessary in the entire trajectory of the disease, emphasizing previous care plans, goals, based on a careful, compassionate assessment, aiming at the profile of each patient, are premises for excellent care.[22,23]

In this scope, a reference about health education to family members is valid, as a social practice, whose process "contributes to the awareness and formation of critical awareness of people regarding their health problems, to discuss their reality, discussing collectively, in search of solutions" (p.89), together with trained professionals and managers. They involve actions on the formation of emancipatory attitudes for health promotion, which occurs through active listening and open dialogue, building horizontal, facilitating relationships that motivate people to collaborate in solving their needs and demand from their leaders, empowering health actions,[24, 25] attentive to health promotion and the prevention of diseases that expose vulnerable groups.

CONCLUSIONS

In this sense, it is up to these professionals to understand the PC in its broad dimension, considering the importance in PHC to carry out assistance, bureaucratic and educational actions, creating strategies for the effective implementation of the PC, always aiming for quality patient care with the multidisciplinary team and training the team in this process.

Based on this reflection, so that professionals can understand PC and consequently apply it in their practice,

it is believed that there must be actions aimed at building the knowledge of these professionals on the topic, since it was configured as one of the great challenges found in this study.

The teaching and learning process in undergraduate courses must offer empowering tools, active methodologies and mainstreaming of knowledge to strengthen knowledge about PC. For professionals already graduated, permanent education actions on the theme should be part of the planning of the health system, in all its instances, encouraging intersectoral and network actions, in order to favor not only access, but the resolution of the health needs of users who need this care.

Although the findings of this research are promising, some limitations are highlighted, such as the regional character of the research. In this context, it is emphasized the importance that other studies are explored on this theme, such as PC in the view of users of the health system, offering new contributions to the development of this area of knowledge.

It is believed that the study can help municipal health managers to perceive PCs as strategies in the feasibility, conduction and implementation of innovative care proposals based on the protocol's precepts of the theme. The qualification of attention to users of health services requires the implementation and effectiveness of the actions implemented, and must involve workers, managers, users, family members.

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