Palliative Care in the Emergency Room Scenario: Perceptions of Nurses and Physicians

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ABSTRACT

Objective: To describe the perception of nurses and physicians in relation to palliative care provided to people with blood-oncologic diseases met in an emergency ward of a general hospital.

Material and Methods: This is a qualitative study, with exploratory and descriptive approach. Six nurses and six physicians were interviewed from September to November 2017. The data were treated through operative analysis of Minayo.

Results and Discussion: Three categories emerged: "end of life is only end of life, without palliative care"; "(re)thinking the palliative care with the person with cancer"; and "the urgency and emergency: challenges for the care in terminality".

Conclusion: The palliative care relates to life terminality, and the emergency room environment is considered inappropriate for this care, but nurses and physicians recognize the importance of the quality of life offered with the adequacy of assistance to palliative care.

INTRODUCTION

The palliative care (PC) originated in the 1960's, in the United Kingdom, with the pioneering of the social worker, nurse and physician Cicely Saunders. In the 1970's, Elisabeth Kbbler-Ross was responsible for disseminating it in America, a Swiss psychiatrist rooted in the United States of America, and a pioneer in the study of death and dying, the grief, thanatology and palliative care. As The Hospice Information Service of St. Christopher's Hospice in London, there are more than 7,000 PC services in 90 countries in the world and, in Latin America, there are more than 100 PC services [1]. Brazil, along with Cuba, Mexico and other 71 countries, according to the Worldwide Palliative Care Alliance, is in group 3a, which shows some initiative on PC [2].

The PC is expressly recognized in the context of the human right to health, configuring it as support system to help patients live as actively as possible until their death ^[3]. In 2018, in Brazil, the guidelines for the organization of palliative care were established, in the light of the integrated long-term care, in the framework of the Unified Health System (UHS). The Resolution describes that the PC consist of the assistance promoted by a multidisciplinary team, in favour of improving the quality of life of patients and their families, faced with a disease that threatens the life, through the prevention and relief of suffering, the early identification, impeccable assessment and treatment of pain and other physical, social, psychological and spiritual symptoms ^[4].

Among the principles for the organization of PC, there is the need for its beginning as early as possible, together with the modifying treatment of the disease, promoting the quality of life of patients with autonomy and offering support for the family. Moreover, there stands out the multidisciplinary and interdisciplinary teamwork to address the needs of the patient and their relatives, including grief counselling, if indicated, through a sensitive and empathic communication, respecting the truth and honesty in all matters involving patients, families and professionals [4].

A range of diseases may require palliative care, which include the blood-oncologic diseases [3]. The patients with an advanced clinical condition, resulting from their biography, antineoplastic therapy and/or lack of control of symptoms and suffering, may present complications and reduced performance of the treatment evolution, requiring an emergency care [5]. Thus, the goal of treatment begins to focus on controlling the progression of the disease and symptoms, implying in the beginning of the implementation of PC. The American Society of Clinical Oncology (ASCO) suggests the early involvement of PC with patients with cancer [6].

The hospitalization of patients with blood-oncologic diseases that require PC, many times, is inevitable, with need for hospital care, and can be performed in emergency room (ER) units. However, when experiencing the reality of a hospital emergency, there are difficulties faced by the multi-professional team to meet this demand, arising from various aspects, including: the questions regarding the location for permanence of these patients, the demand of time necessary to provide a quality care, and the insecurity and feelings of the team, since there is no culture to act from the principles of PC [7]. The service in PC is relatively new in Brazil, and every day, there arise new initiatives in the country [8]. Nevertheless, there are still many advances that need to be enforced and consolidated [9].

In this context, the following research question was defined: what is the perception of nurses and physicians about the PC to people with blood-oncologic diseases, assisted in the adult emergency room (ER) in a public general hospital? Therefore, the objective of this study was to describe the perception of nurses and physicians in relation to the PC provided to people with blood-oncologic diseases met in the adult ER.

MATERIAL AND METHODS

Qualitative, exploratory-descriptive study carried out in the period from September to November 2017, in the adult ER belonging to a teaching, general public, tertiary-level hospital located in south Brazil. It is the largest public hospital with the single Emergency Room operating, exclusively, for the Unified Health System (UHS), in the countryside of the state and covering a population of 1.2 million inhabitants. For more than 30 years, it has been a reference in urgency and emergency care for the population from 45 cities in the Midwest Region of Rio Grande do Sul. Currently, it offers 403 beds.

Twelve health professionals were interviewed, being six nurses and six physicians, who, after recruitment from the inclusion criteria, were willing to participate in the research after receiving information on its objectives. The selection and recruitment of participants occurred considering an intentional sample, which integrated the non-probabilistic sampling groups, comprising the researcher's participation to designate the elements of the population that composed the sample [10]. For this purpose, the inclusion criteria comprised: being a nurse or physician, professional performance in the adult ER for at least six months; being physician resident in blood-oncology working in the adult ER. The professionals on medical leave or absent from work during the period of data collection were excluded.

The semi-structured interview was conducted through guiding questions that addressed the following issues: implementation of care, professional preparation, difficulties and facilities in the care with people from the blood-oncology and PC. The interviews were audio-recorded in digital format, lasting an average of 30 minutes, carried out in the work environment in private rooms and occurred until the non-occurrence of new information, having reached the proposed objective.

The data were analysed through the Operational Analysis of Minayo, characterized by the use of two moments: the first included the determinations of the study, which were mapped in the exploratory phase of verification; the second is the interpretation, which is subdivided in two stages: initially, the ordination, in which the transcription, the rereading and the organization of materials are carried out, judging the beginning of their classification and subsequently, data classification, performed from the exhaustive and repeated reading of the collected material, aiming to resume the initial

goals of the research, enabling its reformulation $^{[11]}$. With this, the research corpus was obtained, using the classifications established by the researcher for the better analysis of the collected data.

Thus, based on these classifications, the material underwent a drying process, highlighting the most relevant themes, which will aggregate and regroup into central categories. The two previous phases allowed for an inflection on the material, from the start to the end point, in which the depth of the participants' speech was revealed [11].

The final analysis proceeded from the interpretation of the relevance sequences (central categories) with alignment to the meaning of the speech and the behaviour of the participants to the historical and social context, that is, the relationship of the final/interpretive analysis with reality [11]. After achieving the deep immersion in the empirical material and finishing the stages of data organization and classification, the researcher carried out the final analysis, which consisted of a rereading of the meaning units, in parallel with the research objectives, integrating them with the theoretical assumptions and with the context of the informants.

The participants were identified with alphanumeric codes, using the letters NUR (for nurses) and PHY (for physicians). The study followed the ethical aspects of Resolution 466/12 and was approved according to opinion n. 2.121.624 of 06/14/2017, by the Research Ethics Committee of the Federal University of Santa Maria $^{[12]}$.

RESULTS

Among the professionals participating in the research, six had nursing degree (five women and one man) and six, medical degree (two women and four men) aged between 24 years and 39 years. Regarding time since graduation, five participants reported from three to five years, three participants reported from seven to nine years, and four participants reported more than ten years. The time of experience in the urgency and emergency unit ranged from six months to fourteen years, with the exception of medical residents who work in the unit for a specific period of time, with a monthly service schedule due to the condition of in-service training in which they currently participate.

All participants had at least one specialization, being four master's degree, two with master's degrees in progress, six with medical residencies already completed and six with specializations in specific areas of expertise.

After the reliable transcription of the material collected in the interviews, it was possible to delimit them by subjects of greater relevance and significance. Therefore, the interviews resulted in three categories: "End of life is only end of life, without palliative care"; "(Re)thinking the palliative care with the person with cancer"; and "The Emergency Room: challenges for the care in terminality".

End of Life is Only End of Life, without Palliative Care

The participants perceive and understand the PC regarding an assistance that provides comfort, nutritional, water support and pain relief until the moment of death. In this process, they cite the importance of the family participation and respect for religious beliefs of people.

To take care of the individual, respecting them until the final moment; provide comfort, pain relief, nutrition if necessary, hydration; allow the family to be together; allow them to bring religious leaders, this is meaning of palliative care. (NUR4)

The palliative care is to give comfort to die and that's it. (NUR11)

The professionals recognize that the presence of people with blood-oncologic diseases in the adult ER is related to complications of the treatment, unfavourable prognosis and the process of terminality. The PC would be offered and thought in a situation of end of life.

Our reality is patient in terminal phase, there's nothing else to do. The family brings because they are in pain or cannot eat, they aren't even hospitalized and die. (NUR5)

The nurses and physicians reported disagreement that the adult ER is characterized as a unit of provision of PC. The provision of care in this perspective requires attributes related to sensitivity and time availability, unavailable characteristics due to the peculiarities of the adult ER. In the unit, the care is sometimes reduced to specific actions, such as analgesia, disregarding the biopsychosocial-spiritual dimensions of care.

Palliative care does not match with ER because it needs time, sensitivity, which we don't have. We have this life thing here, if we have a trauma, we resuscitate. No one stays by the patient's side to give a hand, chat, and provide some comfort. (NUR11)

PC in the ER is limited to morphine in the pump to sedate the patient; it is not a psychologist, chatting with the family. (PHY6)

The assistance is reduced; the patient remains symptomatic for a long time. (PHY9)

The professionals reported that they perceive lack of care in the adult ER and that people with blood-oncologic diseases have their process of terminality without having their needs and expectations met.

The ER has no care, so end of life is only end of life in the ER. (PHY7)

We could do more for the patient of the blood-onco, because he will evolve to death or to the PC. (NUR1)

Patients with blood-oncologic diseases admitted to the adult ER and who are at the end of life, lack relief of suffering and the presence of PC. As noted in the reports, this process is considered incompatible, due to the demand of care traditionally met in the adult ER, added to the characteristics that professionals do not have, which include sensitivity and attention necessary for the proper care with these patients.

(Re) Thinking the Care with the Person with Cancer

Concerning the manifestation of dissatisfaction with the assistance and absence of PC, the participants demonstrate the movement of (re)thinking their practices on the PC, however permeated by conflicts and differences of opinions and actions. Some professionals indicate that the knowledge in PC is not fruitful in the adult ER, because, in general, the assistance focuses on healing and therapeutic obstinacy.

People have little knowledge or do not engage, they believe that palliative care is not doing anything else. Medicine is based on cure, which often does not work, generates higher costs, unnecessary invasive measures. (PHY9)

There is a conflict surrounding the expectation of people for treatments and surgical interventions aiming at the cure. The professionals understand that this form of assistance, many times, expected by family members, results in futile actions for the care with regard to the palliative philosophy. The professionals realize that, while some families do not understand the evolution of the disease, sometimes, others manifest the desire of not performing futile measures. This perception seems to be honed by the desire to cease or not exacerbate the suffering of the person at the end of life, in relation to unnecessary technical procedures in family view.

Families do not understand the evolution of the disease, do not know that the disease has no expectation, they think it's negligence, we don't want to take care, which is not, the patient is on unnecessary treatment. (PHY9)

The family says "don't let suffer, don't intubate". A patient with no venous access and the family said "don't do anything", and I said, "but he will stay in pain". (NUR1)

The dialog on the progression of the disease, therapeutic decisions and PC is restricted to the healthcare team, and sometimes to family members, excluding the ill person from the decision-making, an inadequate behavior. Nonetheless, concerning the need for quick decision-making and short time to work the mobilization of feelings generated to the person, the dialog with the family is prioritized.

The ideal would be to see the patient's understanding to see what they would decide, knowing they have an incurable disease. The discussion is with the family and the patient remains aside. (PHY12)

The professionals reported difficulties with the team in the care routine with people in PC, such as the use of acronyms related to the management of patients at the end of life, facing situations of cardiorespiratory arrest, which imply in ethical dilemma and conflict.

In measures of comfort, there will be no resuscitation. (NUR5)

The team inserted the central access, but the patient eligible for PC stopped, the doctor said: "bring me the emergency car", "no, don't bring", then I said "Should I bring it or not? Did he stop or not?", "no, don't bring". (NUR1)

Among the experiences listed as positive and facilitators for the care with blood-oncological patients in the unit, there stands out the presence of a consulting team in PC that was recently created within the institution where the study took place.

I've had experiences when I called the PC personnel to help me, and it was much better than doing on my own, we understand what's happening. (PHY9)

Conflicts and dilemmas involving professionals, family members and the multiprofessional team are present in the assistance provided in the adult ER unit. These differences may intensify as triggers for (re)thinking the care with people with blood-oncologic diseases, enabling discussions on and the improvement of the PC practice. The dialog has proved indispensable tool in providing care with the person and families, as well as for the teamwork.

The Emergency Room: Challenges for the Care in Terminality

The process of limited work in the management of care with people in terminal stage in the adult ER results from the inadequacy of structure available for its implementation. The professionals reveal the difficulty of accommodation of admitted people due to the overcrowding of the service, resulting in the lack of available beds and demanding the use of stretchers in the corridors. This situation prevents the inclusion of family members in the process of end-of-life care.

They are at the end of the hallway, the family cannot stay together. The emergency room lost its essence, its goal is not to leave people in terminality. (NUR4)

The adult ER is a limited and inadequate scenario to meet the needs of the people in process of terminality. This reality is also recognized as a limiting factor for the difficult communication and news approach.

As it's an emergency, we aren't able to provide comfort. We have no good conditions to promote a care at the end of life. (NUR10)

The place where the patient is in the corridor is difficult to address these things (communication of bad news). (PHY12)

Regarding the structure of the adult ER, professionals suggest the possibility of the process of terminality occur with quality at home or in a specific location to perform the care. The professionals' view is characterized by the implementation of procedures and actions that save lives and, in this context, professionals reported the lack of professional ability to work in philosophy and logic of PC and end of life.

The patient is in a situation of terminality, comes to the hospital seeking quality and would be better at home. (PHY9)

There should be a specific place for palliative care. (PHY8)

I had no training. In the emergency, we precisely think of saving lives, we are not prepared to provide support to the end of life. (NUR5)

The adult ER is characterized by the excessive number of hospitalizations of patients at different levels of severity, which reflects in an inadequate structure for the care, associated with the lack of professional ability to act in PC and in the end-of-life care. The adult ER is seen as a challenge for the work of nurses and physicians in a quality assistance and consistent with the needs of each person, especially those at the end of life.

DISCUSSION

When treating people with blood-oncologic disease and performing the end-of-life PC, the participants realize that the assistance should offer comfort to patients. Thus, the care centered on patients with life-threatening diseases suggests the search to ensure dignity and comfort until the last minute of the patient's life. For this reason, the care scenario must have a supportive and welcoming atmosphere, which supports the patient and the family, minimizing pain, relieving anguish and reducing avoidable damage, arising from a body in progressive decline [13].

The actions of the teams, in the scenario of the adult ER, are permeated by many challenges, in relation to the PC, especially when it comes to providing the comfort and relief to the patient and their family. Nonetheless, this finding is an inconsistency, once the emergency medicine is a skill that operates mainly in the intervention of acute conditions and traditionally focuses less on alleviating chronic symptoms ^[14]. Furthermore, according to the national guidelines for the organization of PC, the Urgency and Emergency services should assist patients by directing the care for the relief of acute symptoms, focused on comfort and on the dignity of the person, from best practices, and available evidence ^[4].

One of the PC principles is the integration of psychological and spiritual aspects in patient care. The care should be promoted for the relief of pain and other physical symptoms, including the psychosocial, spiritual and existential suffering, not only for the patient but also for families and caregivers ^[4]. Thus, when the patient requires PC, they should be perceived in an integral and humanized way, discussing with the multiprofessional team the best approach to promote their quality of life in the process previous to their death. In this way, the interdisciplinary practice makes the work concise, ensuring a dignified survival, benefiting the patient and family ^[15].

The interdisciplinary teams of PC can assess and subsidize the treatment of symptoms, help the decision-making process, in the spiritual well-being, align treatments to achieve the goals of the patient and the family, approaching other resources to enable support for patients and their caregivers ^[14]. The appropriate preparation of the entire multidisciplinary team is essential, since the security transmitted by them can directly affect the treatment outcome ^[8]. To this end, there stands out the need to offer continuing education in palliative care for health workers in the UHS ^[4].

Teamwork is advantageous, since it assists in making difficult decisions, allows for the improvement of skills, as well as the support, recognition and the sharing of experiences, benefiting the patient and family [15]. However, a study performed with a nursing team from an adult emergency unit on PC, in south Brazil, revealed the lack of ability of the

nursing team professionals to act with patients on PC, in addition to the lack of infrastructure to maintain these patients in the unit. The same study suggests institutional measures, such as the consolidation of the PC team, standardizing actions for these patients in the hospital space [7].

A previous study, performed in Australia, explored the experience of health professionals who work in the emergency department and that provide PC to patients with dementia and with terminal diseases like cancer. The findings indicate that many nurses do not believe they have the knowledge, skills or resources necessary to provide an effective PC in the emergency [16]. Another research conducted with Australian physicians in an emergency service to assess barriers and facilitators in the PC provision showed that most physicians admitted that care with terminal patients was part of their role. Nevertheless, these professionals also believed that the adult ER was not the ideal place to die. The results of this research also show that physicians reported that an effective PC was not always possible due to the limitations of the emergency environment [17].

The findings of this research highlight the challenges and needs to explore strategies to integrate the PC in the routine of the adult ER, which has multiple and competing demands that affect the service of nurses and physicians. A study conducted in Hong Kong showed that the nurses and physicians usually have a stressful workload, making the engagement in complex and time-consuming interactions with patients and families incompatible with other important clinical and organizational tasks [18].

In some countries, there are initiatives to integrate the PC into emergency services, including the adherence of a specialized team, resembling with the positive report of the study participants, who rely on a consulting team, enabling greater security to professionals from the adult ER $^{[14]}$. The creation of an interdisciplinary team should, in a first moment, facilitate the planning and directing the efforts, led and formed by engaged people; the second step involves the assessment of needs and resources to improve the PC in the emergency room, which includes a review of the literature and of the existing sources of information; the third step includes the identification of local resources of PC; and the fourth and last step is the development of an action plan to foresee work responsibilities and establish a timeline $^{[14]}$.

The PC, in many moments, can be confused with the practice of euthanasia, resulting in erroneous decisions regarding the implementation of unnecessary interventions and the enormous difficulty concerning the tenuous and delicate line of to do and not to do ^[9]. These decisions should be shared with the family and, if feasible, count on the participation of the patient, who decides on the measures of constraints and investment in advanced life support. The curative medicine has made patients live longer, but fails to provide quality of life to its terminality ^[19]. In this sense, the PC is important as it approaches assistance to human values and dignity.

The PC rescues the possibility of death as a natural and expected event in the presence of a life-threatening disease, placing emphasis on the life that can still be lived. Among the principles of PC, offering support system to assist the family during the patient's illness and to cope with the grief is necessary, since these people also suffer and require embrace [9]. Some guiding principles for the organization of PC include the affirmation of life and acceptance of death as a natural process and the multidisciplinary and interdisciplinary teamwork, which should address the needs of the patient and their family, including grief counselling, if indicated ^[4]. The participants identified this support as deficient, mainly due to the physical structure of the adult ER.

A study conducted with nursing and medical students found that the lack of theoretical subjects creates difficulties in learning the PC, suggesting that the theoretical and practical teaching of PC should be encouraged in the syllabus of graduate courses in the health area ^[20]. In this sense, some goals of PC include encouraging the establishment of subjects and programmatic contents of palliative care in graduation and specialization of health professionals ^[4]. The palliative care should be part of the skills necessary for all health professionals who work in emergency services ^[21].

Another study conducted with nurses pointed out that the uncertainty in the provision of PC in the adult ER environment also encompassed knowledge and skills, with many participants feeling educationally unprepared to provide quality care. The emergency nurses in that study emphasized the need for better training directed to the safe and effective provision of PC, especially in the following aspects: having difficult conversations, determining the desires of the patient and the family, recognizing terminality, determining appropriate levels of treatment and improving the management of pain and symptoms ^[17]. However, only the specialized education will not be effective if the systemic barriers remain without solution. Therefore, there should be a complete system approach to develop a standardized and sustainable provision of PC in the ER, supported by appropriate policies and guidelines.

The PC is little discussed between nurses and physicians, although there are significant advances in Brazil. In the adult ER, the challenge to accomplishing the PC refers to the available structure, requiring time-consuming adaptations, but, listening to the team and formulating guidelines based on the need of those who provide the care and knowing the reality of the institution is an initial guiding step for the changes. In this sense, the present study is relevant, because it considers the need to (re)think health professionals' look to palliative care from the perspective that the assistance in this working area in frank ascension in Brazil.

CONCLUSION AND FUTURE CONSIDERATIONS

Concerning the detection of difficulties, dilemmas and conflicts faced by the research participants about the PC provided to people with blood-oncologic diseases met in the adult ER of a general hospital, in fact, this healthcare philosophy is recent in Brazil. In this sense, the theme is still insufficiently addressed and discussed in the professional training of nurses and physicians. The PC with people with blood-oncologic diseases treated in the scenario of adult ER is ineffectively applied, reflecting on deductive and superficial perceptions about the theme, often limiting to end-of-life care. There is understanding about the importance of maintaining the quality of life of patients through the implementation of the PC philosophy.

In this way, the theme remains being emerging, especially with people affected by a blood-oncologic disease who require care in the scenario of an adult ER, since this unit focuses on a care practice centered on healing and reversal of the disease. Such situations raise the need for discussions, inserting the theme during the process of training and continuing education of professionals about the PC in the adult ER. Thus, providing a personalized and individualized assistance to patients and families, based on technical and scientific knowledge, enables not only the recognition of patients who need PC, but also the provision of a qualified assistance, aiming at relief of suffering, promoting the quality of life and well-being of the patient and their family. Therefore, this study contributes to the possibility of discussing the implementation of care in ER services, taking into account the local and regional characteristics of each service.

The limitations of the study lie on the restricted number of participants and the delimitation of the study site, i.e., it was carried out in a hospital unit in the central region of Rio Grande do Sul, whose health professionals' experiences may differ from other hospital sites and environments.

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