Palliative Care in the Pre-Hospital Service In Brazil: Experiences of Health Professionals

Jacqueline Resende Boaventura  
Universidade Federal de Mato Grosso do Sul

Juliana Dias Reis Pessalacia  ( juliana@pessalacia.com.br )  
Universidade Federal de Mato Grosso do Sul  https://orcid.org/0000-0003-0468-2283

Aridiane Alves Ribeiro  
Universidade Federal de Goias

Fabiana Bolela de Souza  
Universidade de Sao Paulo Escola de Enfermagem de Ribeirao Preto

Priscila Kelly da Silva Neto  
Universidade Federal de Mato Grosso do Sul

Maristela Rodrigues Marinho  
Universidade Federal de Mato Grosso do Sul

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Abstract

Background: An integrated care network between emergency, specialized and primary care services can prevent repeated hospitalizations and the institutionalized death of terminally ill patients in palliative care (PC). To identify the perception of professionals in a pre-hospital care (PHC) service about the outcomes of the assistance provided to patients eligible for PC.

Methods: Study with a qualitative approach, of interpretative nature, based on the perspective of Ricouer’s Dialectical Hermeneutics.

Results: Three central themes emerged out of the professionals’ speeches: (1) unpreparedness of the team, (2) decision making, and (3) dysthanasia.

Conclusions: It is necessary to invest in professional training associated with PC in the home context and its peculiarities, adopt a specific policy for PC that involves all levels of care, including PHC, and adopt a unified information system, as well as more effective procedures that favor the respect for the patients’ will, without generating dissatisfaction to the team and the family.

Background

Palliative Care (PC) is defined as an approach that improves the Quality of Life (QOL) of patients and their families who face issues associated with life-threatening chronic diseases, through the prevention and relief of suffering\(^1\). The offer of PC covers a wide variety of scenarios including hospitals, hospices, nursing homes and home care, and is classified into general or specialized care\(^2\).

Despite the observed increase in interest and knowledge about PC, there is still a difficulty in the interpretation and practical implementation of the concept. Health professionals have difficulties in electing patients who would benefit from PC, and have to deal with several obstacles, such as, little cooperation from the multidisciplinary team, communication flaws, medical paternalism and moral conflicts. All these aspects may have repercussions, causing delays in meeting the needs of patients\(^3\).

Palliative care becomes the only option during the progression of chronic diseases, but the final stage of the disease is often related to moments of agony and suffering. Thus, the death of a patient in PC may happen in services where the care for terminally ill patients does not coincide with the professionals’ usual routine of procedures. For example, in emergency services, the goal is to stabilize and preserve people's lives in acute events\(^4\).

In countries with implanted PC policies, terminally ill patients have the option of dying at home, and this has the support of research that indicates the preference for end-of-life care at home. Such decision seeks to reduce the likelihood of hospital death, decrease costs for the health service, and improve the patients’ QOL\(^5\).
The education of patients and family members regarding the progression of the disease and the definitions of PC plays an important role in making decisions that favor the maintenance of QOL, avoiding futile therapies. However, according to the World Health Organization (WHO), countries with inadequate policies and/or assistance in PC face numerous obstacles to embracing patients eligible for such care in their homes.

Care for terminally ill patients represents a barrier to be faced by teams that work in ambulances, in the emergency service. Currently, the Mobile Emergency Care Service (SAMU) is the main mobile component of the Health Care Network (HCN) in Pre-hospital Care (PHC) in Brazil and aims to reduce deaths, sequelae related to waiting time and hospital admissions.

SAMU is a public health service in Brazil linked to the Unified Health System (SUS), which serves 75% of the population by means of ambulances and aims to deal with more complex cases, such as severe trauma and cardiorespiratory arrest, where the severity of the situation exposes the patient to an increased risk of death on site. The model of PHC adopted in Brazil was shaped based on French and American examples, centralized in a communication network and based on medical regulation and emergency calls through a given phone number.

However, communication failure between the different levels of health care stands out as a barrier. An integrated care network between emergency, specialized and primary care services can prevent repeated hospitalizations and the institutionalized death of terminally ill patients in PC.

In view of the Brazilian context of discussion of a policy for PC integrated with the SUS health care network and the experiences of researchers working in the professional and research field on themes related to PHC and PC, the present study sought to identify the perception of health professionals of a PHC service in Brazil about the outcomes of the care provided to patients eligible for PC.

**Methods**

Study with a qualitative approach, of interpretative nature, based on the perspective of Ricouer's Dialectical Hermeneutics.

Data collection took place at the SAMU base in the period between August and September of the year 2017. A semi-structured interview was used, composed of questions related to the professionals' experience of working with patients eligible for PC, during cases assisted by the SAMU. The elaboration of the questions of the script considered the professional experience, the theoretical framework of the research, and the information that the researchers compiled about the social phenomenon.

It is understood that the curative paradigm is intertwined in the actions of PHC professionals in Brazil, who do not have an understanding of the phenomenon of death and PC. A search for information about the phenomenon showed that in the year 2017, the PHC service that constitutes the scenario of this
research assisted a total of 354 occurrences involving patients eligible for PC, of whom 265 were referred to the hospital as a result of these assistances, and 66 patients were assisted more than once.

Thus, the interview conducted considered the following guiding questions: (1) What do you understand about Palliative Care? What are the limitations and possibilities that you find when providing this type of assistance in the emergency service? (2) In emergency services, professionals seek to save lives. Do you think you are prepared to 'deal' with the death of a terminally ill patient during a call in which the SAMU is requested to promote comfort and/or pain relief at that moment? Why? (3) What is your perception about the outcome of the care provided by SAMU that impacts on the quality of life of the palliative patient?

The study universe comprised the 25 health professionals working in the SAMU intervention in a municipality in the state of Mato Grosso do Sul, central region of Brazil. The professional categories included were: medicine, nursing at technical level (medium level qualification with the objective of training students with theoretical and practical knowledge in the referred area) and higher education level, drivers/rescuers. The following aspects were considered for inclusion of participants: experience of two years or more in PHC and age over 18 years. Professionals who were on sick leave and/or vacation during the interviews were excluded.

Data collection started after approval by the Research Ethics Committee of the Federal University of Mato Grosso do Sul (UFMS), CAAE 98491218.2.0000.0021, under opinion nº 2,921,437. Consent was obtained in a two-stage process, according to Resolution 466/2012 of the National Health Council/Ministry of Health (NHC/MOH). Before starting each interview, the participants were verbally informed about the objectives, risks and benefits, and methods to be employed in the study.

The number of participants was defined at the moment when the data answered the study questions. When new interviews did not add further data and the existing data provided sufficiently clarifying information for the research, no more participants were included.

Data collection and analysis were guided by Ricouer's Dialectical Hermeneutics. As each interview was carried out, the team proceeded to an exhaustive reading of its transcript. All interviews were thoroughly read in order to carry out the hermeneutic movement of the whole to the parts and vice versa. During this process, the questions were improved in order to deepen the understanding of the object of study.

The data analysis followed the steps: I) Reading of the material (records of observations, transcribed interviews, and institutional documents); II) Extraction of information related to the study; III) Definition of pre-categories according to the research objectives and theoretical framework; IV) Inference, and after identification of the main meanings, transformation of the pre-categories into thematic categories.

Results

Twenty-five interventionist professionals who work in PHC ambulances responded to the interview. The studied social group comprised physicians, nurses, nursing technicians and drivers/rescuers.
The consideration of all the speeches showed a transversal understanding of PC and of the assistance provided by the PHC team. Therefore, central and interdependent themes were obtained from the analysis of the data corpus, from the perspective of the dialectical hermeneutic movement\textsuperscript{12}, namely: unpreparedness of the team, decision making and dysthanasia. These themes converge into challenges for the care to PC patients.

Figure 1 summarizes the themes and their respective nuclei of meaning emerging from the conclusion of the hermeneutical movement of analysis of the interviews, considering the experiences of professionals and the care provided to patients eligible for PC.

**Figure 1.** Central themes and their respective nuclei of meaning about the professionals’ experiences and the care provided in cases of patients eligible for PC. Três Lagoas (MS), Brazil, 2020.

**Theme: Unpreparedness of the team**

The theme ‘unpreparedness’ represents the perceptions of PHC professionals regarding the unpreparedness of health professionals to deal with death and to provide care for patients in PC. The core meanings of this theme are: Death as a taboo and Professional training.

**Subtopic: Death as a taboo**

The workers interviewed understand the maintenance of life as the very intention of pre-hospital care.

“It is because, within our routine, the issue of maintaining the patient's life is very strong. In the case of palliative care that you are there just to give comfort, you are out of your routine, this causes you an emotional shock right away, because you will only give comfort, you will not fight for his life” (25)

Therefore, for the participants, death represents a taboo, a dilemma in their work in the PHC. It is possible to interpret in the testimonies a certain fear of health professionals and the Western society as a whole towards the theme of death.

“It is because here in Brazil we have a very short view of death and to accept this fatality, which is something that we will all experience, right?... and the family that does not accept the disease, the state that the person is in, and they don't even accept death, right?” (3)

**Subtopic: Professional training**

This nucleus discusses the speeches of professionals who indicated the flaws in professional training regarding PC or even the lack of emotional preparation to deal with death. They also reflected about the curative education paradigm, in which professionals are trained to save lives at all costs.

“No, I don’t feel prepared, my team doesn’t feel prepared for that either. It is an issue that must be developed, right? new studies, new protocols; because unfortunately we arrive, right? and we are used to arrive and do something to make a difference, doing what must be done.” (10)
“No, I don’t think so, by now. I was not prepared for this yet, we were prepared for, as you said yourself, right? to try to reestablish life, and not give this kind of news... this kind of news, no, right?! This kind of comfort.” (16)

Theme: Decision making and ethical conflicts

This theme reflects the ethical conflicts reported by PHC professionals in decision making involving PC patients and their families during calls, as illustrated in the following report:

“If this patient is really a terminal patient, this patient is not to progress any further, the family is aware of palliative care, but they cannot take the situation, the person’s suffering. So many times they tell us, please do it, I’m aware of it, they already explained it to me, but I want you to do something, I want you to invest, the family changes their opinion out of nothing... and then, what are we supposed to do? As long as I have a palliative care letter explaining everything correctly, indicated by the responsible doctor... “ (15)

The participants believed that the main conflicting aspects in their work was the family's lack of knowledge regarding the patient's will and the lack of access to the patient's history (for PHC professionals). The existence of an advanced health care directive or living will could be of help in conflicts regarding decision making about invasive therapies that can prolong the patient's suffering. Thus, this theme is composed of two nuclei of meaning: family and information and communication.

Subtopic: Family

The PHC professionals said that lack of prior clarification of family members about the clinical picture of palliative care and about the patient's will is one of the greatest difficulties they face.

“What happens is that, many times, no matter how much the family is informed, the family is not prepared, and they see that patient there in agony, unable to breathe and they end up calling us, and we have to be willing to help” (14)

“And today, as an emergency worker and rescuer, I think that we can alleviate the suffering as long as we know the history beforehand and that the family knows the history beforehand. Avoiding heroic measures to try to revive the patient in case of an eventual CRP, there would be no need for resuscitation if the family member were aware, if we knew that this patient is a palliative patient” (23)

“I doesn't matter if I know that maybe that patient is in a terminal stage, but that the family does not accept that, I have to act as if the patient was not, because I don't have any documents in the pre-hospital service that support me, telling me that I have to call the family and talk to them, no, let it be, this is the end of the person's life, so that's the biggest problem.” (12)

Subtopic: Information and Communication

The PHC professionals in this study attributed to the communication failures between health services and professionals the meaning of difficulties in decision making. They reported that information
regarding the history, clinical condition, and reference services in PC for the referral of the patient is absent/limited.

“Yes... as a doctor I have the obligation to take a quick action. If I am not aware that the patient is in palliative care, the family does not know that he is in palliative care, from that moment on this is a patient with prognosis. So, if he is a patient with a prognosis, then he is a patient with whom I will act as in an emergency, I will intubate, I will resuscitate, I will take all these measures” (12)

“For sure, for sure, and I bring again the issue of lack of information, so many times we make so many mistakes, the patient is many times in palliative care or not, and ends up going through invasive procedures, what it was maybe against the patient's or the family's desire, but we don't have this information, there is nothing written” (2)

“And if we don't have this history, if we don't know or if we want to apply our protocol, which may go eventually against palliative care, it can certainly worsen or even influence the diagnosis or the survival of this palliative patient” (10)

**Theme: Dysthanasia**

Despite treating the subject of death as a taboo, the health professionals responding the study recognized that the professional performance in PHC contributes to an approach based on futile therapies that sometimes prolong the suffering of patients and family members.

The participants attributed to hospitalization and futile procedures the meaning of outcomes of this type of action at PHC.

**Subtopic: Hospitalization**

This sub-theme represents the professionals' perceptions of the need to refer the patient to the hospital, even though they are aware of the implications in terms of prolonged suffering for the patient and family that hospitalization will cause.

“But obviously if I arrive at a situation where the patient has respiratory failure and I take the attitude of intubating him or adopt an invasive action, I certainly prevent him from having a natural and good process of dying, what is actually expected for the process. Then he arrives at another service, intubated, then this becomes a snowball right?! Because he is intubated, then he needs to go to the ICU... so... the people who would die today, we have the means to keep the person alive and some cases for good and some other cases unfortunately for suffering... it increases the suffering, it prolongs the suffering... dysthanasia.” (22)

“If the patient is giving his last breaths, I think he needs an access, oxygen, we need to take him to the hospital... he hasn't died yet” (19)

**Subtopic: Futile procedures**
The professionals recognized futile procedures in PC patients during PHC, aspects that prolong suffering and lead to dysthanasia.

“... unfortunately what we can do is get there, do some procedure and tell the family, unfortunately we cannot stay there at the patient’s residence, that we have to go away, and at the moment the patient stops breathing they will have to call us again to come and confirm, but I’ve already seen that some professionals are not prepared, they think that SAMU is only for Ahhhh it is an arrest, we have to resuscitate, let’s go... Oh no, we are going to do anything, so we’re not going to do anything. I don’t think that’s right.” (14)

“...Then the relative comes there, please do something.... Obviously, if all of this is on record, documented, that he is a palliative that he has, okay, we will not do anything; if there is nothing written, and we do not have knowledge, it is our obligation to do the procedures... this is my opinion. Well, preparedness, when we talk about preparedness, we’re kind of.. well,.. like that, right?! I don’t know, I don’t know, I think I’m prepared to save lives.” (15)

**Discussion**

The pre-hospital emergency service deals directly with saving lives and, therefore, faces ethical conflicts in decision making involving patients at risk of death. The distance from places with more resources, the provision of care at the patient’s residence, the realization of procedures on public roads, and a low number of team members contribute to make the work stressful and challenging. The work of these professionals with PC patients is even more challenging and conflicting because it involves conflicts related to futile therapies that prolong suffering.

The nuclei of meaning Death as taboo and Professional training emerging from the theme 'unpreparedness' represent the perceptions of the PHC professionals regarding the team’s inability to deal with death and care in the case of PC patients, which is reflected in the outcomes of care.

As understood by the participants in this study, professional training and continuing education need to address the issue of death, as observed in a study conducted in Canada. A research\(^\text{16}\) analyzed the barriers for the implementation of PC in Canada in relation to four countries (United Kingdom, Ireland, New Zealand and Australia) and the results emphasized that significant investments in undergraduate and graduate courses in medicine and nursing are necessary to train professionals in PC, with knowledge and skills to meet the fundamental needs of this profile of patient. However, professionals who are already in the work market need continuing education to meet such demands.

According to another study\(^\text{17}\), members of the emergency team chose biomedical studies as more important when compared to the psychological and social approach. That said, the offer of additional training and continuing education aimed at death has an impact, favoring more reliable and assertive decisions, especially when associated with complex issues which are not part of the routine of professionals who deal with acute events.
The theme 'Decision making' reflects ethical conflicts and their impact on care outcomes related to limited or even nonexistent information on the patient's current health condition and the family approach at the moment of the occurrence.

The results of a qualitative research\(^{18}\) revealed that professionals working in the pre-hospital service were concerned with the patient's manifestations of will, but there was a possibility of contradicting the objectives of the service they perform. They also expressed a feeling of helplessness regarding the will of the family in relation to the Non-Resuscitation Order (NRO), and confessed that there was distrust in accepting the manifestations contained in the document even seeing the signature of the patient's physician.

In order to assess the care provided to terminally ill patients in their homes, researchers\(^{7}\) conducted a qualitative investigation in an English hospital and the results demonstrated that a set of factors impaired the ability of respondents to keep patients at their homes when they were close to the end of life. Such factors were: poor availability of support in the community, limited information about the patient and his health condition, and tendency towards invasive procedures in PHC.

The results found in the present study are consistent with the findings presented in that research. There is a need for quick decision making in PHC and the limitation of information about the patients' history and care preferences often interferes with their permanence in their residence, leading to successive hospitalizations and the performance of futile procedures\(^{7}\).

A systematic literature review\(^{2}\) showed that in countries such as Australia, New Zealand, Canada and countries of Europe, where medical records of patients are shared by the health systems, the choice of actions and care measures in during emergency calls are facilitated. The study also emphasized that when the information is integrated between primary care and specialized PC services, positive factors are observed in terms of less repeated admissions and shortest hospital stay, besides relevant improvements in pain control and other symptoms and, consequently, improved QOL for patients.

The theme 'dysthanasia', which addressed the issue of carrying out futile procedures and referrals to hospital admissions, demonstrated the concern of professionals working in the emergency service with the actions adopted in the pre-hospital service in the country side of Brazil.

Despite this, the results of a study\(^{19}\) demonstrated that it was more acceptable for the emergency team to start treatment and then leave it if the expected benefit was not obtained than "doing absolutely nothing" (p. 41). Death can be seen as a failure in the care provided and many professionals do not notice the value of choices and end-of-life desires, such as dying at home and in the presence of relatives\(^{20}\).

It was observed in this study that, although the professionals understand that PC should be taken into account in cases assisted by the PHC, the lack of knowledge of family members and lack of integration between health services result in the implementation of futile therapies, which will only prolong the suffering of patients and families.
In this context, the curative medical model contributes considerably to disease-centered approaches, leading to the adoption of futile procedures for prolonging life, and a discouraging understanding about communication in terminal care between members of the multidisciplinary team, patients and family members. However, this culture can be modified directly through education and training, and can be also influenced by the success of previous cases, because positive experiences and results drive the team's reasoning and encourage the continuous practice of actions\textsuperscript{20}.

Decisions involving whether or not to transport the patient to specialized services also generate conflicts within the PHC team, because keeping the patient at home involves decisions that go beyond clinical knowledge, and the rate of future calls for the emergency service is high when the patient remains at home\textsuperscript{21}.

In this context, Home Care (HC) is a type of assistance favorable to PC, since the philosophy and principles that guide PC and HC are similar. However, it is known that the curative, technical and biological aspects of care present in the health system offered in Brazil do not favor the implementation of these principles in the context of HC\textsuperscript{22}.

Research by Patterson et al.\textsuperscript{23}; Sharp and Thompson\textsuperscript{24} and Pentaris and Mehmet\textsuperscript{25}, indicate that, sometimes, the feeling of uncertainty and the fear of lawsuits come from limited and unreliable information regarding end-of-life patients. Thus, even when the team knows that transportation to the hospital will not benefit the patient's current health condition, the professionals think that the stay in the home is not safe and end up making a decision that is often inappropriate or even contrary to the patient's will.

Thus, if PHC professionals had information and established effective communication with other services, there would be discussions for better decisions about transportation, actions performed, and acceptance of the patient's desires. In this context, the role of nurses in PHC stands out because they constitute the main link among professionals of the team and they have the ability to communicate effectively with patients and their families.

**Conclusion**

The perception of PHC professionals regarding the outcomes of the care provided to patients eligible for PC showed that the team felt unprepared when it comes to decision making involving PC patients. Such unpreparedness has to do with the view of death as a taboo and lack of training and continuing education on death and PC.

In the meantime, it is observed, based on the reports, that the professionals experienced ethical conflicts and barriers in decision making on a daily basis during PHC service. Such conflicts and barriers are due to the fact that despite the fact that there have been more discussions about PC and its guidelines in Brazil, the absence of a specific policy and lack of integration and communication between health services constitute obstacles for teams working in this kind of service.
Thus, it is concluded that there is a need for professional training that includes end-of-life issues associated with PC and its peculiarities and the development and implementation of a specific policy for PC that involves all levels of care and that establishes the place of PHC service in the holistic perspective of patient care. In addition, it is necessary to adopt a unified information system that allows for more effective actions and that favors the patients’ wills without generating discontent among health care team workers and family members.

Moreover, nurses are components of the PHC teams who due to their greater contact with patients and families have a broad view of the patients' social life and needs. They are essential to manage conflicts and act in the training of the team and to provide assistance when it comes to the spiritual and psychological suffering of patients and their families.

The limitations of this study include the low number of participants and the realization in the context of a single municipality. However, it is understood that the results of this research reflect the reality of PHC in Brazil.

**Abbreviations**

**CRP:** C-reactive protein  
**HC:** Home Care  
**HCN:** Health Care Network  
**ICU:** Intensive Care Unit  
**MOH:** Ministry of Health  
**NHC:** National Health Council  
**NRO:** Non-Resuscitation Order  
**PC:** Palliative Care  
**PHC:** Pre-hospital Care  
**QOL:** Quality of Life  
**SAMU:** Mobile Emergency Care Service  
**SUS:** Unified Health System  
**UFMS:** Federal University of Mato Grosso do Sul  
**WHO:** World Health Organization
Declarations

Ethics approval and consent to participate

The project was approved by the Research Ethics Committee of the Federal University of Mato Grosso do Sul (UFMS) opinion n° 2.921.437, registered with CAA under number 98491318.4.0000.0021 and was conducted according to ethical rules of research involving humans established by Resolution 196/96 of the National Health Council. Written informed consent was obtained from all individual participants included in the study.

Consent for publication

No individual persons’ data is included within the manuscript, except in the form of anonymous quotes from the reported case. The participant signed and completed a consent form stating, "your name and that of your family member will not be identified in no time of the research, and the results of the study will be disclosed at scientific events or in a publishable journal".

Availability of data and material

Data sharing not applicable to this article as no datasets were generated or analysed during the current study.

Competing interests

The authors declare that they have no competing interests.

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Authors’ contributions

JRB and JDRP conceived and designed the study. JRB and JDRP, wrote the first draft of the manuscript. JRB, JDRP, AAR, FBS, PKSN and MRM, critically reviewed the manuscript. All authors read and approved the final manuscript.

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Figures
Figure 1

Central themes and their respective nuclei of meaning about the professionals’ experiences and the care provided in cases of patients eligible for PC. Três Lagoas (MS), Brazil, 2020.