



RESEARCH ARTICLE

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## MULTIPROFESSIONAL ASSISTANCE AND FRAGMENTED PERCEPTION OF THE PRINCIPLES OF PALLIATIVE CARE

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### ABSTRACT

**Objective:** to describe and analyze the perception of the multidisciplinary team about the principles that guide palliative care. **Method:** ethnographic study with qualitative analysis performed with 36 professionals who work in palliative care. Data collection consisted of recorded interviews, guided by a semistructured script and with the help of a field diary. The interviews were analyzed according to the technique of collective subject discourse where the statements present a group idea. **Results:** from the analysis of the data emerged categories that refer to the daily life of the palliative practice and show a care that is often centralized in the physical-biological dimension of the patient, subduing other important dimensions such as social, psychological, family and spiritual. **Conclusion:** the need for a preparation regarding the domain of technical knowledge and the understanding of the meaning of palliative care was verified, as well as a preparation focused on the emotional aspects of the professionals.

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### INTRODUCTION

The technological improvement applied to health has enabled an improvement in the quality of life of patients, acting notably in the processes of beginning and ending life. As technological progress has taken place, the problems that arise in dealing with end-of-life care have also advanced, thus contributing to a process of institutionalizing death, and it is necessary to critically debate human existence (Coelho, 2017; Gulini, 2017 and Kelly, 2018).

Palliative care is defined as an approach that aims to improve the quality of life of patients and their families while facing the problems associated with the disease that compromise the continuity of life through prevention and relief of suffering through early identification and assessment. treatment and treatment of pain and other possible physical, psychosocial and spiritual problems (WHO, 2016). The concept of palliative care was introduced with the aim of creating a new philosophy for the care of patients with serious diseases. This philosophy is centered on two major areas of attention, namely, effective

control of pain and symptoms of the disease and treatments, and care for the patient and family in the physical, psychological, social and spiritual dimensions (Almeida, 2014). In recent years, the interest in palliative care has grown considerably, especially regarding the technologies used to prolong life and the improvement of care offered during the life terminality process (Gulini, 2017). Systematizing care and organizing care for a clientele in their last days of life is still a great challenge for the multiprofessional team. Therefore, it is necessary that professionals are qualified to provide care in a systematic way, thus maximizing the implementation of the actions implemented (Lima, 2015). However, it is known that the process of training of professionals favors the naturalization culture of a technical assistance considered as the only form of care. This creates a mismatch between the needs of family members and professional practice, because while family members seek compassionate and loving care, professionals often appropriate an eminently technical, cold and impersonal practice, evading closer interactions. that palliative care often requires on the grounds of avoiding countertransference processes (Lima, 2015). Based on this problem, this study aims to analyze the perception of the multiprofessional team about the principles that guide palliative care.

## MATERIALS AND METHODS

This is an ethnographic study with a qualitative approach to data. The ethnographic study is developed in three distinct moments, but linked to each other: the look, the hearing and the writing. Looking and listening are presented in data collection, while writing is part of the analysis and interpretation of field data (Olsen, 2015). The participants of this study correspond to 36 professionals who are part of the multiprofessional care team and who provide care to patients and families in palliative care at the University Hospital of Brasilia - HUB, specifically in the Medical Clinic sector. The final sample was determined by convenience (Olsen, 2015). Inclusion criteria were the performance in the sector of the Medical Clinic of the University Hospital of Brasilia, and as exclusion criteria professionals who were on vacation or leave during the data collection period, and / or professionals who did not perform care activities. Data collection took place in two stages: the first consisted of a process of environment where the researcher, with the help of a field diary, experienced the work process with the care team in order to build a relationship of trust. The second stage of data collection consisted of conducting interviews guided by a semi-structured script and recorded using an MP3 player. The interviews were transcribed in order to achieve greater reliability in the data.

The interviews collected in this study were analyzed according to the technique of collective subject discourse (CSD) whose method resumes social representations, linking individual and collective interpretations, that is, grouping particular ideas with similar logic to build a discourse that expresses the concept from the collective, group point of view (Olsen, 2015). Dessa forma, não há uma análise individual dos participantes da pesquisa, uma vez que as falas apresentam uma ideia coletiva. This study was approved by the Research Ethics Committee of the Faculty of Ceilândia - FCE of the University of Brasilia - UnB under opinion No. 2,642,997.

## RESULTS

**Sample Characterization:** The sample consisted of 27 nurses, 2 doctors, 2 physiotherapists, 1 social worker, 2 nutritionists and 2 psychologists. Of these, 31 (86%) were female, with training time of more than 5 years 18 (50%). This data has direct repercussions when we analyze the length of professional practice in palliative care assistance where 32 participants (88%) had less than 5 years of experience. All 36 participants (100%) had specialization, training and / or improvement courses to work in the area of palliative care and life terminality, thus constituting a qualified sample and professionals. From the analysis of qualitative data emerged 3 categories. Observing the method used for the analysis, all the information presented that corresponded to an individualized perception of the participants and that would represent a possible specificity of the professional area were not presented in the results, since the collective subject discourse seeks to present a collective interpretation.

### Fragmented perception of palliative care principles

In this category, through the participants' discourse, we can infer that there is a fragmented perception about the meaning of palliative care, which is often centered on assistance in the patient's physical-biological dimension, subterfuge other important dimensions, such as social, psychological, familiar and spiritual.

*CSD 1 - We apply palliative care to patients with no prognosis, like this. Without a good prognosis. they are just pain containment measures; of relief, right? That's basically it, right? Promote pain relief? Yeah, administer the medications that are prescribed, right? providing comfort to the patient. All patients with palliative care usually go more in for pain control, morphine administration, to actually have a follow-up and to control that pain.*

We realize that there is a clear gap regarding scientific knowledge about palliative care. It was found that knowledge regarding palliative care is superficial, since most participants emphasized the improvement of quality of life by restricting it to the control of pain and physical comfort.

*CSD 2 - Palliative care is that of terminal patient care, when the patient does not have a favorable prognosis and ends up being more a comfort to the patient, a comfort conduct. With the therapeutic use of medicines, painkillers and prioritizing comfort, and pain relief, because the patient is already in a critical situation, so pain relief, in a way, is a comfort for him. Because, like that, the person is already dying, so, I think the least we can do for her is to make her pain free, to make her more comfortable, to try.*

It is possible to observe that some participants have a superficial discourse about the meaning of palliative care in which there are discrepancies in the definitions used and restriction to the physical aspects of the patient, not contemplating the principles of palliative care, as we can see in the following discourses.

*CSD 3 - Palliative care means offering comfort to the patient who no longer has a therapeutic proposal. It is to offer what he needs in that moment of pain, without*

*thinking exactly about healing; without thinking about specific treatment; but, you think more about relieving the symptoms, relieving the pain, alleviating the problem of patients and family too.*

It is important to clarify that there is no appreciation of a certain dimension of care over others. In this sense, the care of physical symptoms is not seen as more important than the symptoms resulting from spiritual, psychological and social suffering. However, it is imperative to point out that if physical symptoms are not controlled, it is very difficult to cope with the other aspects of the patient's life. Thus, we can see that there is an order of action.

*CSD 4 - Of course you have the full notion that you will not cure him, but neither will you abandon him. Palliative care is to try even in the psychological part of the patient to soften this issue of psychological pain. Palliative care, in reality, is ultimately a preparation for death. It is what we try to do here in the health service is to alleviate the patient's suffering in the face of no longer having medical interventions that seek a cure. It means taking care! Take care that you do what you can do best for others! Since you cannot modify certain situations. But at the same time, in palliative care, you can find ways to improve some situations that the person, the patient is going through! I understand as palliative care that patient who can no longer cure, but who is brought to the hospital so that we can bring comfort to him, with care more comfort than cure.*

We can see that the fact that the participants primarily pay attention to physical care demonstrates inexperience of these professionals with palliative care.

#### **Facilitating and unfavorable aspects for palliative practice:**

This category refers to the daily practice of palliative practice from the perspective of the study participants. It can be verified that daily work is permeated by aspects that favor and hinder assistance in palliative care. In addition, we can observe that there is a professional interest in developing a differentiated assistance. For them, the availability of staff is a positive point for quality care.

*CSD 5 - Regarding palliative care, then, thus, professionals are facilitating factors of this. I think the biggest facilitator here is the professional interest itself. Because everyone, like this, the vast majority of professionals here are very interested indeed. No, people even have, we just need to mingle with these professionals and let them start walking and speaking in the same language. So you have to be very patient. Here at the clinic, most professionals, how can I say? They seek to provide the best assistance possible. Even though teams are not integrated, but they do exist. Worse is when you are in a sector that you do not have the professionals, which only really is the doctor and the nurse who is the basic and the essential. We see their attachment with the team a lot, especially when the patient stays here for more than a month. And most stay, especially oncology patients.*

To work with palliative care, it is essential to pay attention to the team profile. As observed in the speeches of the interviewees below, the characteristics of professionals are also cited as facilitating aspects of assistance in palliative care.

It is possible to notice that patients and family members project in the team the reference role of care. This fact generates what participants report as "attachment to the team". In contrast, the long length of stay of patients and family members during the hospitalization process allows the professionals to reciprocate.

*CSD 6 - The relationship with the team ends up being very close. So, I think this monitoring had to be with the professional too. Because straight we see a professional crying, who can not stay with a given patient, because it is already bad. Because of this, here we rotate patients because not everyone can handle the death of patients.*

It is possible to observe that there is a fear of participants regarding the risks of affective involvement between professionals with patients and their families. Such strategy consists of a coping mechanism, in order to facilitate the "follow the life" of the professional through the loss of the patient. Faced with the imminent process of patient death, the unprepared team tends to develop feelings of loss, anxiety and failure. If the professional has the aptitude to work in the area of palliative care, he will be able to adapt, otherwise the professional may become ill or use defense mechanisms that will keep him away from the patient to not be emotionally influenced. In the perception of the study subjects, aspects related to the lack of physical and human resources appear with aspects that hinder the assistance to palliative patients.

*CSD 7 - I think that the issue of having at least this minimal support here is a major factor. I think it is more difficult not to have, like, a suitable place, a proper ward for these patients, because, ideally, there should be at least two wards, at least for these patients. I consider that the family is important as well, and she can help or not if she has been mentored. It helps a lot even for people to focus more, to focus service on those patients. Like what we're doing here. We put the oncology patients all to ward A. We are focusing the service to provide care to those people who need the same care. We also ended up charging the issue of visiting hours and also the amount, because since he is dying we try to help him and his family say goodbye to everyone.*

One strategy used by participants to improve the emotional state of palliative care patients is to decrease the rigidity of visiting hours, the number of visitors at a time, and the allowance of several companions during shifts.

According to the participants, the motivation of the team is not enough to allow quality assistance. The lack of a protocol to guide care is cited as one of the aspects that make it difficult for the professional to act safely and in quality. It is also possible to realize the importance of having an exclusive ward for palliative care. The terminality process of life is unique and permeated with symbolism and subjectivities.

*CSD 8 - We try to minimize the suffering of that moment, understand? A support, facilitating one thing or another, not being so strict with rules, because we know it's a different moment, that needs a different look. Look, I think one is missing, how do I say? It's like a protocol anyway. Because we never know. I don't think any of the professionals who are so active really know where they are going. If it is rushing, if it would be good, if it would*

*be bad, whether or not it is slowing down. I think the team had to be better worked out.*

Professionals play a very important role in the process of coping with the patient's death, acting from the stages of denial to acceptance. Often, even at the desire of family members, care is very patient-focused, so family members are cared for in a small amount of free time. The need for sector organization is cited by participants as an important step in defining the thematic aspects to be addressed in the training.

*CSD 9 - I mean, a bigger organization, because it's no use coming in and saying, Ah! Now we have a protocol for this and everything, if the professionals will not have time to be trained for it. It needs an industry organization so that we can put more training and everything into it, so that we can have a better understanding of how to deal with this situation.*

We can verify through the analysis of the statements of the statements that they consider it extremely important to access the training to improve the quality of care, being considered as one of the main tools that health professionals have to ensure safe and high quality care to patients.

#### **Interpersonal communication as an instrument in the care process:**

By analyzing the concept of palliative care we realize that effective communication is one of the structuring axes of care. However, the fragmentation of the communication process is observed both among the members of the care team as well as between professionals and family members and patients.

*CSD 10 - Here we see that professionals do not understand communication as a therapeutic instrument for both the patient and the professional, you know. They spend a lot of time here, and then we start to get attached, with the family, too. So there are many professionals here who sometimes get sad and cry in the corners or hidden when someone dies. There was a palliative [patient] that we swore, so we would [die] that day, it was already, like, gasping and everything, but when we got there, there was no oxygen, and we put a mask later, the shift officer came and complained, "Oh, you are prolonging." So we see here that there is also a lack of knowledge about what palliative care really is.*

Communication failures tend to trigger several assistance errors. Within the characteristic scenario of a teaching hospital, we realize that patients and their families are approached by different professionals and students, from different specialties and courses. According to the compiled extracts below, we realize that communication failures compromise the quality of palliative care assistance.

*CSD 11 - Nobody talks to the nurse, I mean, some yes some don't. Often note in the chart and not even warn. We get a little lost you know. Sometimes psychology even gives support, but everything is basically that. I do not see, thus, integration with other areas either. I think what makes it difficult is also the lack of communication, the lack of dialogue between the different professions, you know. I can hardly, for example, talk to the social worker or doctor. This is very difficult because I am not sure what medication has been done for the patient, and especially if*

*the patient and family are oriented about the patient's prognosis.*

We can observe in the statements of the interviewees that nursing perceives the fragmented communication, so that professionals do not interact with each other, hindering the continuity of care. This promotes a division of tasks specific to each profession, characterizing multiprofessional but not interdisciplinary care, losing the focus of comprehensive care. Communication must be effective between these professionals, so that information distortion does not occur, leading to assistance that hurts bioethical principles. When it is ineffective, uncohesive and full of laughter and / or noise in communication, we can certainly expect several consequences of these failures, as noted below:

*CSD 12 - Sometimes it is the family's option not to talk to the patient about their terminal diagnosis. At least, I don't think it's right, he has to be aware too, know what's going on. Sometimes too, one family member is informed, but the other is not so informed. Because sometimes that person does not accept so well and then when any event happens, who is that unguided person, she goes into despair and asks us to make interventions that we already know are therapeutic futilities, or even going against what the patient wanted. In fact, this only happens to the escort or family who does not accept or was not oriented. He wants us to do sometimes some procedure, both nursing and medical staff, which does not fit with palliative care. The family is in that suffering, and perhaps we could have already talked with the family, explained the situation, and also with the nursing staff, because we do not know whether or not. Is very difficult. They suffer a lot. Here they are most accompanied in this regard by psychology.*

According to the interviewees' reports, it was observed that the family members who do not accept the diagnosis outside the therapeutic possibilities of cure were not well oriented and with this, it is clear that the proposal of palliative care is not understood.

*CSD 13 - We have a lot of patients and sometimes we just do the procedures you know. But when it's palliative we already tell family members: "Ah! if it stops, it stops, "" And no one will revive? "So sometimes it's just that. This gets complicated because sometimes we don't know if the doctor has talked to the family. So much so that we even have that craze, receive the shift and say: "Is there anyone exclusive palliative?" Which is precisely for that, if you stop, we know that will not run with the cart. What we see here sometimes. It happens a lot of patients stop and revive, revive, revive, then, after he intubated: Ah! do not. It is palliative, palliative exclusive. When you see in the chart one doctor said it was palliative and the other said it was not. You have to come to an agreement, talk to each other. Discuss the case together with nursing and other areas. But then the patient sometimes stays in the tube in that suffering. So I always like to talk [with family] about this problem that has happened to see if you are aware, "Do you know that when you have a break, you want it to revive or not?"*

## **DISCUSSION**

Palliative care is an approach that improves the quality of life of patients and their families in the face of problems associated

with life-threatening diseases through prevention and relief of early suffering, impeccable assessment and treatment of pain and other physical, psychosocial problems, and spiritual. It aims at establishing care that does not accelerate the arrival of death or prolong it with disproportionate means, and provide a support network so that the patient can live an active life until death comes, and also support the family so that she can face the disease and the period of mourning (Matos, 2018 and Morais, 2018). To work with palliative care, the professional uses a set of knowledge that evolves with science and technology. With all health practice, diagnostics, prescriptions, care and assistive techniques should be based on scientific evidence, with concepts and techniques validated by rigorous scientific studies that prove their efficiency and safety (Faria, 2017). The in-depth knowledge of palliative care allows assisting each patient with quality and sensitivity, seeking alternatives that guarantee a better end-of-life quality and a dignified death, in an interdisciplinary care structure that together with the family can guarantee care, comfort and pain relief (Faria, 2017). The purpose of care is primarily to alleviate human suffering by preserving dignity and providing means to deal with crises and the experiences of living and dying. In order to ensure rapid relief and well-being, all possible interventions, both medicated and non-medicated, should be considered, such as emotional support, distraction techniques, comfort, therapeutic touch, massage, relaxation, etc.... (Andrade, 2017 and Achury, 2015). It is noteworthy that the causes of suffering are interdependent, that is, it will not be possible to control the patient's pain completely without also dealing with the psychosocial causes of suffering and vice versa (Faria, 2017). Doctor Cicely Saunders spelled out the concept of total pain, which confirms that a person suffers not only from the physical harm they have, but also from the emotional, social and spiritual consequences that the nearness of death can bring to them (Achury, 2016).

Prioritizing pain control of patients can develop misleading thinking about care centered on the physical aspects of the patient. However, we can observe the intrinsic subjectivity of this approach, since for the patient in palliative care, with the certainty of a near death and the concerns, frustration and various emotional problems, ensuring priority physical care has its humanistic scope by not allowing the patient experiences this phase feeling severe pain (Hakanson, 2016 and Alcântara, 2018). The profile of the palliative care team refers to sensitive care and education, which require actions of physical and affective proximity so that many orientations are implemented in practice. The professional should improve skills aimed at the systematic evaluation of signs and symptoms, so that, when inserted in the multidisciplinary team, can participate in defining priorities for each client, interaction and family dynamics, and especially to strengthen clinical guidelines, so that the therapeutic goals set are achieved (Faria, 2017). The way professionals relate to each other and also to their patients acts to improve patients' quality of life, as it is considered as therapeutic and restorative (Edwin, 2016). It is essential that the entire care team not only likes what they do, but also realizes the importance and value of the essence of care, from basic principles to complex actions and exercise them with mastery of knowledge and technique (Arrieira, 2017). The care team should be very familiar with the situation of patients without therapeutic possibilities of cure to help them and contribute to an improvement (Britto, 2015). The emotional aspect of health professionals is relevant and should be taken into

consideration, as they take for themselves defense mechanisms used as an aid in coping with the death and dying process. Being prepared for the maintenance of life, death and dying in their daily lives, they produce feelings of frustration, sadness, loss, helplessness, stress and guilt. Most of the time, unpreparedness leads the professional to move away from the situation (Saviato, 2016).

The terminality of life is a phase that causes various emotional changes, and the nursing professional has a differential approach, involving not only the physical aspects, but also the psychosocial aspects (Britto, 2015). Professionals are subject to two types of anguish in coping with death, which is conceptualized in the acceptance of the death of family members or people affectionately related to it, consequently the confrontation with death causing terror and fear of the unknown, also prevails the feeling of powerlessness. For the work done and the feeling of loss resulting from the moment (Andrade, 2017). Care with palliative patients should have a greater involvement, creating an affective bond, thus maintaining the approach of the person, being perceived as a behavior that is governed by care and safety, and that if the commitment bond is broken at death, it ends up causing feelings of loss, tearing and confusion of feelings donated to the patient, generating grief and confrontation with separation (Saviato, 2016). When the professional is face to face with the imminence of death provoking these different reactions that encompass a whole process of overcoming. Some people tend to withdraw from experiencing fear, others begin to value the remaining time and come to see life more simply, which favors an adaptation to this new experience (Andrade, 2017).

By providing quality care to patients, the provider gains the respect and acceptance of the family. The relationship between health team professionals and patients and family members strengthens frequent monitoring and the pursuit of satisfaction of health needs. Realizing the need for a differentiated look at the moment of confrontation that patients and family members are experiencing, it is essential that there be a flexibilization of institutional rules and norms (Matos, 2018). Communication between professionals is one of the structures of palliative care. It is essential that communication be effective, both among members of the nursing team and among the various professionals inserted in care practice. Lack of communication between professionals causes fragmentation of care and represents poor quality of services offered (Lima, 2015). The importance of effective communication in palliative care is not only required in the context of the team. The family also needs to be educated at all times of care, as it will often be the decision-making process (Lima, 2015). The work of health professionals should be interdisciplinary, that is, integrated and coordinated in working protocols perfected in periodic case discussions, registration and communication integrated with the medical record. The empowerment process is one of the key tools that health professionals have to ensure safe and high quality patient care (Arrieira, 2017). Empowerment of the palliative care team is a fundamental strategy for pain control and symptom relief. Due to the particularities of the profession, nurses are the professionals who most frequently evaluate pain, response to therapies, occurrence of side effects, collaborate in the reorganization of the analgesic regimen, propose non-pharmacological strategies and assist in adjusting attitudes and expectations about pain. The treatments (Hakanson, 2016). However, it is essential that the nursing team acts in an interdisciplinary manner with other

professionals, having as its work objective the integral care of the person with qualified listening, emotional support and reception of stories, feelings. There are people who express their final desires and who must be met, within the possibilities, prioritizing what is important to provide comfort and dignity, but there are also those who cannot express themselves, and these also need to be heard and welcomed (Saviato, 2016). This study has limitations, the main one being the difficulty of generalizing the findings. Another limitation of this study is the fact that it was conducted in a sector that is still in the implementation phase of a protocol for assistance in palliative care.

## Conclusion

We found a gap in the scientific evidence showing a superficial perception of the real meaning of palliation, where it is still centered on the patient's physical-biological needs and mainly restricted to pain relief. Within palliative care, pain control of the patient is considered as the mainstay of care, however it cannot be considered as exclusive. Through reading the participants' experiences we can also see the need for preparation, both regarding the mastery of technical knowledge and understanding of the meaning of palliative care, as well as preparation focused on the emotional aspects of professionals, since they were listed as factors that characterize the lack of preparation of the palliative team. It is essential to highlight as limiting factors the need for studies that bring the perception of all involved in the care process, namely patients, family, care staff and managers.

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