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# Nursing team perception of oncological palliative care: a phenomenological study

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# **ABSTRACT**

**Introduction**: This article focuses on revealing the phenomenon of perception of the nursing care given to patients undergoing palliation before death. **Aims**: To understand the perceptions of nursing team members of palliative care in oncology from the phenomenological perspective of Maurice Merleau-Ponty; To indicate the implications of this perception for nursing practice. **Method**: A descriptive study with a quantitative approach based on the theoretical and methodological perspective of Merleau-Ponty's phenomenology. The technique of open interviews was used, with 21 nurses from a private cancer care institution. **Results**: Palliative care presents a challenge for the nursing team, as it involves an intersubjective meeting between professionals and the patient in a terminal condition. Comfort measures constitute the foundations for excellent, humanized care. **Conclusion**: We emphasize the importance of valuing the humanity of patients through actions aimed at the humanization of health practices.

**Descriptors:** Nursing, Team; Oncology service, Hospital; Palliative care.

### INTRODUCTION

The care process occurs in a context not fully adapted to the principles that should govern the care of patients undergoing palliation (according to the World Health Organization) in relation to aspects of human subjectivity, such that it must especially prioritize patients' quality of life and that of their families through the humanization of care and minimizing suffering.

The agency Cancer Research International, in its 2008 World Cancer Report, found that the global impact of cancer has more than doubled in the last 30 years. In 2008, about 12.4 million new cases of cancer were reported, leading to 7.6 million deaths worldwide. Of all forms of cancer, lung cancer had the highest incidence, with 1.52 million new cases, followed by breast cancer, which had 1.29 million new cases, and colorectal cancers, with 1.15 million new cases. Lung cancer was the leading cause of death, with 1.31 million, followed by stomach cancer, with 780,000 deaths, and liver cancer, with 699,000 deaths. The 2008 World Cancer Report also listed the most common cancer in men as prostate cancer, followed by lung, stomach, colon and rectum. In women, the most frequent was breast cancer, followed by cancer of the cervix, colon and rectum, stomach and lung<sup>(1)</sup>.

The Brazilian National Cancer Institute (INCA) estimated that approximately 489,270 new cases of cancer occurred in Brazil in 2011, the most frequent types of cancer being prostate and lung cancers in men, and cancers of the breast, colon and uterus in women. It further estimates that the most common cancers for men will be nonmelanoma skin cancer, (with 53,000 new cases) prostate cancer (52,000 new cases), lung cancer with 18,000 new cases, stomach cancer with 14,000 new cases and colon and rectum cancer with 13 thousand new cases. In women, the most frequent cancers will be

nonmelanoma skin cancer with 60,000 new cases, breast cancer with 49,000 new cases, cervical cancer with 18,000 new cases, colorectal cancer with 15,000 new cases and lung cancer, with 10,000 new cases<sup>(2)</sup>.

This tragic scenario clearly highlights the need for development of actions aimed at health promotion, which detect cancer early, action to improve patient care, and specific actions for the formation of teams for cancer treatment, as well as research and management of the Brazilian Public Unified Health System (SUS).

INCA reports that most cancer patients cannot be cured, and quality of life of these patients greatly diminishes, thus causing the need for hospital care to minimize symptoms that cannot be controlled in their own homes: hence the need for the intervention of the nursing team, which may be required at various stages of the disease, diagnosis and treatment, and even in the most advanced stages of the disease<sup>(3)</sup>.

In this context, oncology nursing team professionals may be affected by the suffering of patients and their families, and this involvement often allows the patients' feelings to affect their own emotions, thus experiencing the suffering and pain experienced by the patient. This involvement may affect the performance of the team, compromising the nursing care routines and causing serious difficulties for the professional, including depression, dissatisfaction, and stress, and even causing illness.

The World Health Organization (WHO) has established principles that should govern hospice care for the terminally ill, and for this institution it is crucial to reaffirm the importance of life, considering death as a natural process, but also establishing care that does not accelerate the arrival of death nor prolong it with exaggerated measures, the so-called 'therapeutic obstinacy.' Moreover, care should

provide relief from pain and other distressing symptoms, integrating the psychological and spiritual aspects of care, and provide a support system to help the patient to lead a life as active as possible before death. Care should also offer a support system to the family, so that they can cope with the illness of the patient and pass through the mourning period with less suffering<sup>(4)</sup>.

Analyzing the relationship between professional nursing team and cancer patients in the terminal phase, one realizes that human relationships are established on the basis of the work of nursing. Reflecting on this fact, with an interest in oncology, and driven by restlessness and a need to expand the theoretical and scientific knowledge of these patients and their needs, we conducted this study, aimed at deepening understanding of nursing staff regarding palliative care provided to terminal cancer patients.

The human condition is notoriously fragile and transient, since at times we find ourselves very well, and just moments later we may have to rely on a hospital and equipment in order to survive, involving, for both, professional nursing care<sup>(5)</sup>. It is essential that the care practiced by these professionals is delivered in a dignified and humane way. This observation causes great concern because palliative care should be used while analyzing the need of humanizing the care provided to terminal cancer patients.

Thus, death is always difficult for those who are trained and skilled to maintain life. And when someone accepts a role treating dying patients, he or she should be aware that they are not omnipotent and that it is the duty of nursing to care, regardless of the clinical condition presented and the success or failure of treatment<sup>(2)</sup>. In fact, every day these professionals have people's lives in their hands, but

they must always remember that, as well as life, this person has his dignity.

On the other hand, we know that is not easy to deal with terminally ill patients, because it awakens the awareness that our loved ones will also die one day, a fact before which we are totally helpless. However, there is much to learn from these patients, since they teach us that it is best to live life with the understanding that every day is unique and that we should not keep anything 'for a special occasion,' for the special occasion is now. Thus, the study aims to understand the perception of nursing staff throughout palliative care in oncology, from Merleau-Ponty's phenomenological point of view, and indicate the implications of this perception in the practice of nursing.

The study is justified by the idea of completeness and humanization advocated in the National Program for Humanization of Hospital Care (PNHAH), introduced in May 2000, aimed at ensuring access and quality of care in the Brazilian public health service (SUS) and also in the Oncology Care National Policy which establishes knowledge promotion, prevention, diagnosis, treatment, rehabilitation and palliative care as an integral offering to the user of health service<sup>(6)</sup>.

# **METHOD**

This is a descriptive study with a qualitative approach, using the phenomenological method of Merleau-Ponty, anchored on the principle that the unveiling of the phenomenon can only be achieved by understanding the perceptions of nursing staff working in palliative care aimed at cancer patients.

The survey was conducted with nurses and nursing technicians working in an institution belonging to a private healthcare network in the city of Rio de Janeiro, working actively with end-stage cancer patients in the clinical and surgical areas of this unit.

Data collection took place between May and September 2012. The criteria for the selection of subjects included willingness to participate in the study, drawing from employees who had worked for at least one year in care for patients undergoing palliation, since the research requires professional experience with cancer patients in the terminal phase. Technicians and nurses with less than one year of experience, and employees on vacation or licensed were excluded from the research. The study was submitted to and approved by the Ethics Committee of the Fluminense Federal University (Universidade Federal Fluminense – UFF, in Portuguese) under record CEP CMM / HUAP Number 364/11, which considered the ethical principles of human research.

The subjects were approached in their work environment and an Informed Consent Form was read and signed by the subjects who agreed to participate.

The research involved the full participation of 21 professionals, 15 (71.4%) nursing technicians and 06 (28.6%) nurses. The location for the data collection was decided upon by participants within their own sector of activity, however, with regard for the requirements for privacy and individuality of each of the study participants.

The technique used for data collection was an open interview, using a script consisting of open questions. The interview began with a guiding question of subjective nature that allowed for a closer dialogue sought by the inquiry: "Tell me what your perception is of nursing care to patients in palliation." In addition, we used field observation as a subsidiary method to make it possible to understand the perceptions

of the nursing team of the care given to patients undergoing palliation.

The interviews were registered using an MP3 recorder, which allowed recording the speech in its entirety so that the interviewer could focus their attention on the nursing professional, noting the emotion, nonverbal language, posture, gestures, and expressions, as well as rhythm and voice intonation. With the repetition of content in the reports of the subjects, the interviews came to an end.

The interviews were transcribed as a whole and in their entirety, respecting the construction of sentences, grammatical errors and pauses that occur during speech. In possession of the transcribed interview with nursing staff and field observations, the comprehensive analysis of interpretive meanings that emerge from speeches and field observations was performed, allowing us to build categories of analysis, which are located in the structure of the phenomenon (essence). The data were analyzed according to a phenomenological trajectory<sup>(7)</sup>, which consists of three phases: 1) description of what manifests itself to consciousness as experiences, 2) performing the phenomenological reduction, a posture of bracketing our natural attitude toward things, and 3) the identification of invariants of the addressed phenomenon. Indeed, a descriptive and comprehensive analysis is performed, searching out the meaning of the whole. Then the units of meaning are formed and the work of translating from crude language to scientific data is done, and finally the synthesis of the meaning units is presented and the sense of the experiences reported is obtained<sup>(8)</sup>.

The data collected were analyzed and interpreted to allow their articulation into broader categories that relate to the concepts of perception grounded in the Existential Phenomenology of Maurice Merleau-Ponty.

In order to minimize possible psychological risks to research participants, with consideration for research subjects coping with the final care process of patients, it was possible to rely on the support of a hospital psychologist for eventual complications. However there was no need for psychological intervention at the time of data collection.

The interpretation of the data was performed according to the insights of existential phenomenology, drawing particularly on the thought of Maurice Merleau-Ponty. This process was completed with the establishment and elucidation of two major categories discussed in the study.

# **RESULTS**

Of the 21 participants, it was possible to establish that 15 (71.4%) of the respondents were nursing technicians, among which 13 were female and two male. The nurses numbered 6 (28.6% of respondents), four female and two male.

The data analysis shows that the essence of the phenomenon in question, involving professionals' perception of nursing care to patients in palliative care, became visible, and the importance of comfort measures was found to be a key category in the results.

This category represents the perspectives of the phenomenon studied, and reflects how research professionals express these perceptions on palliation, while experiencing the real-life work of palliative care. This way, the essence of the nursing professional's perceptions about palliative care, and the central importance of actions of comforting terminally ill patients, with a genuine intersubjective meeting, was known.

### Palliative care as comfort measures

Analyzing the discourse of the nursing team, it was possible to identify and bring to discussion the category of comfort measures in the research. Without a doubt, technicians and nurses believe that providing comfort is the foundation of excellence in humanized care and assistance, focused on the quality of life of the patient. The research results in this category pointed to the relevance of comprehensive measures of comfort:

I believe that my perceptions of patient under palliation care promotes the improvement of this patient, not improvement, the comfort of patient for the best care for him, for the patient. (Professional 02)

Well, the view I have today of a palliative care for these patients is not only strictly focused on nursing care, but on providing comfort to the patient as much as possible. For example, not only a change in position, but also a conversation, attention, and hear the family, guiding them about how to care for the patient, how to return attention to these patients, because the palliative care is a vision far beyond a simple nursing care, it involves the social part, involves the spiritual part, and mainly involves the family. (Professional 11)

According to what was received from the patient in palliative care, patient has no chance given by physicians, so on entering the room and provide nursing care, we seek to promote greater comfort to patient, well-being ... In my opinion, there's nothing else to do. (Professional 18)

Despite the professional nursing staff reporting comfort, welfare, care and patience, (among others) as being essential parameters for the quality of life of patients in palliative care, the interview with professionals also show that that care provided to patients undergoing palliation is restricted to the physical body, and the care is offered in a mechanized manner:

It is a patient that we're used to treat mechanically, right? And most of the time we arrive already doing the palliative medicine to minimize his pain. (Professional 17)

The nursing technician even though sometimes lack patience, we have to provide such care, affection, comfort to the patient and family as well. Because the patient goes and the family end up staying. (Professional 19)

The health professionals who participated in this study acknowledge that comfort and humanization of care for patients who are in palliative care are essential to achieving a quality of life worthy of, and respectful to, patients. However, the evidence unveiled in this study suggests a major conflict between the ideals of professionals and the care practice observed, which was for the most part concerned with the physical body, so the discourse of the subjects clashes with their experience in practice.

*Palliative Care: finding intersubjectivities* 

The intersubjective encounter occurs between two subjects. In a true intersubjective encounter the subjects become responsible for each other, and this responsibility is called love of neighbor, love in which the ethical moment dominates<sup>(9)</sup>. This perspective may be seen in the study, showing nursing staffs' perception of patients in palliative care, corresponds to the same standard of relevance in a care based on respect, dignity, humanization and qualified hearing. Although there are programs and protocols that guide the quality of this study, we can see that nursing staff are concerned to provide quality care and respect for the rights of the patient. However assistance is still provided in a mechanized manner, and is heavily oriented to care for the physical body and the routines inherent to the work process.

It is important however to realize that this restlessness in unveiling the phenomenon occurs mainly because there are aspects that involve people. The search for a fresh perspective to unravel and understand the phenomenon under study is undertaken not only in the preparation and technical-scientific foundations of the professionals, but also in the experience of others and experiential approach to professional practice.

My perception is to have the greatest possible care, affection and attention. Even though the patient has no chance, even if later on he will pass away, we must have affection for the patient and family, do the care. We have to promote comfort, we must have patience. (Professional 19)

I believe yes they are very important care, maybe palliative, but it's very important, very valuable yes, not just drop the patient in bed and leave it there and walk away without anyone by his side, without a person to give a word of comfort. I think it's very, very important. (Professional 12)

Well, besides the care that we have to provide nursing, huh, I guess the patient is in need of much attention, right? The patient is in need. It takes us to have a friendly word with him, try to understand his side. Sometimes he just does not want a nurse, sometimes is a patient alone who has no one and ends up needing a word; we understand, sometimes it is not the pain itself that he's feeling, he's in need of this care; we pay more attention. (Professional 07)

In this perspective, the members of the nursing team, in their coexistence with and experience of care for people in the process of palliation acquire a knowledge of themselves and others, establishing an intersubjective encounter, related to comfort care.

That's because comfort measures enable comprehensive interactions in caring for the patient's body, in a subjective perspective on their existence, involving the perception of human suffering, and offering a degree of humanization through this intersubjective meeting occasioned by the personal entanglements involved in care. This corroborates the premise of phenomenology by unveiling the phenomenon of perception in relation to knowledge of the body, feelings, behaviors, and relationships established with others in the dynamic world, and which suffer changes all the time.

### **DISCUSSION**

In palliative care, the key challenge is to enable a better quality life before a patients'

death. To achieve this, one must respect and put into practice the principles of palliative care. Facing the suffering scenario which the palliative care patient is in, it becomes important to implement a service policy based on respect for the dignity of the patient associated with psychological support. "The point of view of the patient as a subject of a life and history and not as a prisoner of a disease." (10).

The word 'comfort' drives us to reference the body and the speech of subjects of perception. Merleau-Ponty states that: "the Cogito shall be revealed to me in a situation, and it is only under this condition that transcendental subjectivity may, as Husserl says, be an intersubjectivity" (7:198).

In this sense, intersubjectivity in the relationship between nursing professional and patient is experienced in a particular situation of care, and in this everyday interaction the staff member relates the signifier 'comfort' to palliative care, since he perceives labor practice as the experience that refers to the intersubjective encounter, i.e., between subjects and their subjectivities.

For there to be an effective understanding of an experienced phenomenon, the perspective of Merleau-Ponty suggests that it is necessary to consider a few key words: perception, intentionality and consciousness. As Merleau-Ponty states, we have to go "to the root of subjectivity with their ideas about the body-subject, subject intentionality and meaning."<sup>(11)</sup>.

In fact, the philosophy of Merleau-Ponty enters the scene to assign meanings to the phenomena of perception, since the understanding of the relationship between time and space in the routine of a nurse is mediated by bodily relationships as being in the world. Accordingly, when understanding the interactions established between the body, consciousness

and experience, and these related to being in the world, informed by phenomenology of Merleau-Ponty, it is evident that patient care, dispensed by the nursing staff throughout the care process, is unidirectional. In this process, there is no understanding of the physical body that occupies a place in space, and which establishes relationships with others all the time, and is the subject precisely as being in the world that surrounds him.

In fact, these relationships established between the patient and health professionals are not perceived by consciousness, which enables the phenomenological reduction, i.e., puts that experience in brackets and releases the 'look' to be available for the immediate understanding of what is shown to consciousness. Thus, "once again, my human eyes only focus the object, even if through the horizons, it refers to all others (from different angles I see the central object of my current view)" (7:107). That's because our vision, our perception occurs in perspectives, in profile; when we see a phenomenon we are facing its bias, for this being inexhaustible and giving itself each time to the experience. In other words, the phenomenon is perceived by the subject from a limited perspective because this is its way of showing itself, while it receives, at each moment, a partial view of the object, i.e., aspects of care as a phenomenon perceived in their practice.

Bodily comprehension is established in the relationships of a human being and through his or her body as an expressive and inexhaustible space in relation to the totalities of body parts. It is noteworthy that no experience is equal to another. The experiences are unique and occur between the relations and interactions between humans. Palliative care is an art, in which human relations take a leading role and allow the preservation of the quality of life of a person even in a complex

situation, provide a peaceful death and ease the grieving process<sup>(12)</sup>. Thus, the meaning and understanding of palliative care has an amplitude that trespasses the word itself. The unveiling of the dimensions of the phenomenon "palliative care" is based on promoting dignity, protection, comfort, pain relief, physical, spiritual and psychological suffering, open communication with the patient, interdisciplinary action, family support, humanized care and an individualized treatment plan.

The expression of feelings by patients is extremely positive for coping with death. <sup>13</sup> "If on one hand the situation of terminality undermines the long awaited healing, on the other it opens the possibility of a deepening of this human relationship." <sup>(14)</sup>. However, it is not an easy task for health professionals to seek to understand this situation as a whole, breaking some long-established paradigms in health care which have been consolidated over time.

In Merleau-Ponty's view, we are developed to some extent, i.e., always exposed to the perception of others and therefore we are the intersubjectivity: "The transcendental subjectivity is a subjectivity revealed, to know itself and to others, and to this title it is an intersubjectivity"(7:485). Thus, one should not ignore the objective world: on the contrary, the existence of perception and its subjectivity only becomes possible because the objective world exists, allowing us to "see" things in different perspectives over time. It is through consciousness and the objective world that we experience our experiences and understand the subjectivity as linked to the perception within the phenomenological field. It should be stressed that we must be open to perceiving the other in its existential dimension, noting that "the absolute position of one object is the death of consciousness, since it immobilizes the entire experience, as well as a crystal introduced in a solution causes it to instantly crystallize"(7:109).

Anyway, the experience of the dying process in the clinic brings the possibility of finitude as an inalienable part of existence, which involves learning to live with the constant duality of life and death in daily care. In the context of palliative care, the multiform transdisciplinary approach evokes a set work for the dignified death, "established in the ecstasy of deep reflection and concentrated in the serenity of attitudes that value the human dimension of the subject in the process of death and dying." (15:4989).

# CONCLUSION

We emphasize, first, that the study presented brought a sample of nursing care of patients who are in palliative care and nursing staff's perception of the care provided to these patients. We considered only the speeches of the study subjects, even if were technicians and nurses. Thus, our results and conclusions are limited to these professionals and the methodology applied.

Universities do not currently offer an adapted curriculum to prepare nurses to work with patients in palliative care. Thus, there is a degree of unpreparedness of these professionals in the field of work which is reflected in healthcare practice.

It is necessary that the nursing team integrate into a multidisciplinary care setting, where there is no pride, but a perception that is achieved by understanding the patient's interpretation of their perceptions and, with this, performing the transformation of reality presented. For this purpose, what is necessary is not only technical knowledge, expertise and

updates through the educational institutions, but also education in dealing with the human body through initiatives aimed at the humanization of health practices.

It is suggested that nursing staff who attend to patients and relatives in palliative cancer care, provide care with several key elements: focus on caregiver, emotional & spiritual support, clarifying values, and especially those related to finitude, providing specific services to promote the reduction of anxiety and (for nurses) monitoring the protection of patients' rights.

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