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Original Article

Preoperative care for patients in terminal stage of disease from the perspective of nurses

Cuidado pré-operatório para pacientes em estágio terminal de doença na perspectiva dos enfermeiros

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ABSTRACT

Objective: to understand the meanings attributed by nurses to preoperative care provided to terminal disease patients. **Methods:** qualitative research that used the Grounded Theory as methodological reference and was conducted in the surgical wards of a university hospital. **Results:** eleven nurses participated in the research. A theory was elaborated for the central phenomenon: Nurses caring for terminal disease patients in the preoperative period in the context of a surgical ward. **Conclusion:** nurses attribute meanings to this care that has its own particularities, that requires professional preparation and that demands, even more, an effective communication within the multidisciplinary team and in the relationship with the patient and family. **Contributions to practice:** the theory presented allows professionals to reflect on their praxis, understand the intervening conditions for ethical dilemmas and conflicts involved and consequences, as well as strategies to improve care in this scenario.
Descriptors: Palliative Care; Bioethics; Perioperative Nursing; Nursing Care; Grounded Theory.

RESUMO

Objetivo: compreender os significados atribuídos pelos enfermeiros à assistência pré-operatória prestada a pacientes em estágio terminal de doenças. **Métodos**: pesquisa qualitativa que utilizou como referencial metodológico a Teoria Fundamentada nos Dados e foi realizada nas enfermarias cirúrgicas de um hospital universitário. **Resultados:** participaram da pesquisa onze enfermeiros. Elaborou-se uma teoria para o fenômeno central: Os enfermeiros cuidando de pacientes em estágio terminal de doença no período pré-operatório no contexto de uma enfermaria cirúrgica. **Conclusão:** os enfermeiros atribuem significados a este cuidado que tem particularidades próprias, que requer preparo do profissional e que demanda, ainda, mais de uma comunicação efetiva dentro da equipe multidisciplinar e na relação com paciente e família. **Contribuições para a prática:** a teoria apresentada permite a reflexão do profissional sobre sua práxis, a compreensão das condições intervenientes para os dilemas éticos e conflitos envolvidos e consequências, além de estratégias para melhorar a assistência neste cenário.
Descritores: Cuidados Paliativos; Bioética; Enfermagem Perioperatória; Cuidados de Enfermagem; Teoria Fundamentada.

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Introduction

Palliative surgeries are offered to patients facing a chronic-fatal pathology as early as possible, with the correct indication and consent of the patient and family, to relieve symptoms, improve quality of life and minimize pain[1]. They play a fundamental role in patient care, since they aim at relieving symptoms, improving the quality of life, and providing comfort without causing premature death[2-3].

Nursing is one of the professional categories that offers more emotional wear due to the interaction and hospitalization of patients when, most of the time, it accompanies the suffering, such as pain, disease, and death process[4]. In this sense, the nurse must also turn his care beyond the patient, that is, to his family group, since these professional plays an important role in the care of the person in the process of terminality[1,4].

Nursing productions in this area, more recently, have revealed a concern with the insertion of nurses in the multidisciplinary team in the condition of participation in decision making and not only in the provision of isolated care[2,4]. In this direction, it is expected that nursing produces more reflections on its own practice in this field, to broaden the understanding of the scope of its care for patients and families, and on the obstacles and challenges that may limit its performance.

With regard to the nursing care promoted in the preoperative period of terminally ill patients, decision-making in the face of existing conflicts and ethical dilemmas should be planned and shared by all those involved in the process. The guiding question of this research was: What are the meanings attributed by nurses about the care given to terminally ill patients undergoing surgery? In this context, the objective of this study was to understand the meanings attributed by nurses to preoperative care provided to terminal disease patients.

Methods

Qualitative research from the perspective of Grounded Theory and conducted in the surgical wards of a university hospital in Northeastern Brazil, between the months of September and October 2019[5-6]. The work report follows the guidelines contained in the Consolidated Criteria for Reporting Qualitative Research (COREQ).

Thirty-two nurses worked in wards with terminally ill patients. Eighteen nurses who had been working in surgical wards for at least six months were invited, regardless of gender, age, or post-graduation training, and 14 professionals on vacation, license, or time off and those on the night shift were not included, since they do not participate in the visits and clinical meetings that take place in the service, usually in the morning shift. There was no refusal to participate in the study. The sampling was by convenience, sized by theoretical saturation, and the inclusion of new participants was suspended as soon as the data obtained presented some redundancy or repetition for the development of concepts, making a total of eleven nurses in the final sample[7].

We used the Straussian approach to Grounded Theory with a paradigmatic model of verification and data collection by axial, open and selective coding. For data collection, the semi-structured interview technique was used[5-7]. Two interviews were conducted as a pilot, which were not considered in the analysis. The guiding question of the research was: What is your perception about the preoperative nursing care given to terminally ill patients? Since the researchers are also professionals from the same hospital, care was taken not to interrupt or interfere with their answers, and not to issue an opinion or judgment on them.

The interviews were conducted in a private environment. Data such as age, gender, time of training, time working in the area, training and specific qualification in palliative care were collected. The interviews

were then started, and there was no previous clarification about concepts. Only the audio recording of the interviews was made, and there was no repetition of the interviews. The transcriptions took up to a week. As the interviews were being carried out, data analysis occurred, following the steps proposed by the Grounded Theory: open, axial, and selective coding[5-7].

In the open coding, the data were analyzed manually, speech by speech, with the objective of identifying each idea/incident/event in the in vivo code. In this step, preliminary codes were formed, which were later grouped by similarities and differences, elaborating the conceptual codes. Preliminary codes of the speeches were searched, compiling the themes and types of statements of each one of them, being gathered in conceptual codes and allocated in a table as new codes appeared[5-7]. Saturation occurred when no new conceptual codes were presented in the interviews.

In a second step, axial coding was performed, in which the conceptual codes were regrouped into subcategories that composed categories of analysis, to obtain a comprehensive explanation about the phenomenon of caring for terminally ill patients in the perioperative period[5,7].

Finally, we proceeded to the selective coding stage in which the categories found were compared and rearranged to refine the theoretical model, resulting in two central categories[5-7]. Although the paradigmatic model chosen signals a central phenomenon, the authors felt the need to present it in two central categories that would better enable its understanding.

To classify and organize the emerging associations among the categories, we used the paradigmatic model that establishes a relationship among the categories based on the following components: phenomenon, context, causal and intervening conditions, strategies, and the consequences[5-7].

Although the method allows that during the analytical path there is the possibility of new questionings and connections between the concepts/categories for a theoretical alignment, we chose a triangulation process in data validation in which the researcher who collected the data did not transcribe it; Only after this listening, those involved in these steps were able to confront their perceptions about the contents in two face-to-face meetings[8].

In Grounded Theory, validation aims to prove that the theory is representative of the reality investigated[6]. The applicability of the substantive theory presented was evaluated by four criteria: fit, understanding, theoretical generalization and control. The theory was assessed as easy to understand by researchers who have care experience in the area studied as well as by care nurses. The result of the research was presented to the deponents who validated the presentation of the theory. As for the control of the substantive theory, some hypotheses of relationships between the subcategories were tested by other studies presented, which leads to suggest that they follow in validation by other research[6].

The study project was submitted, reviewed, and approved by the Research Ethics Committee of the institution (Opinion No. 3,148,711/2019). The invited professionals who agreed to participate in the research signed the Informed Consent Form. To ensure confidentiality, nurses are identified in the description of the results by the letter N followed by the order number of the interviews (N1, N2, N3, ...).

Results

Eleven nurses participated and there were no refusals. Of the interviewees, only one was male, and the participants had a mean age of 32 years, with a mean of 8.7 years of education and 8.27 years of professional experience. Four nurses had a specialization; four had a specialization in nursing residency; and three had a master's degree. None of the nurses had training in palliative care.

The categories were centered on the following central phenomenon: Nurses caring for terminally ill patients in the preoperative period in the context of a surgical ward. The theory presented around the central phenomenon is a substantive theory, which is close to the specific problem.

Two categories were designed: Category 1 - Experiencing ethical aspects of preoperative care for patients in terminal stage of illness, with four subcategories related to causal (Managing ethical dilemmas/conflicts) and intervening conditions (Valuing the team-patient-family relationship; Recognizing the importance of professional preparation; Recognizing the importance of communication among the multi-professional team); and Category 2 - Elaborating the preoperative care for patients in terminal stage of disease, with six subcategories related to strategies (Differentiating the preoperative routine between elective and palliative surgery; Valuing the multidisciplinary approach; Focusing on improving communication and participation in decisions) and consequences (Performing surgical procedure to improve the quality of life; Respecting the patient's will; Providing clear information to the family). Figure 1 explains the relationships of the theory's factors that help to understand the phenomenon.

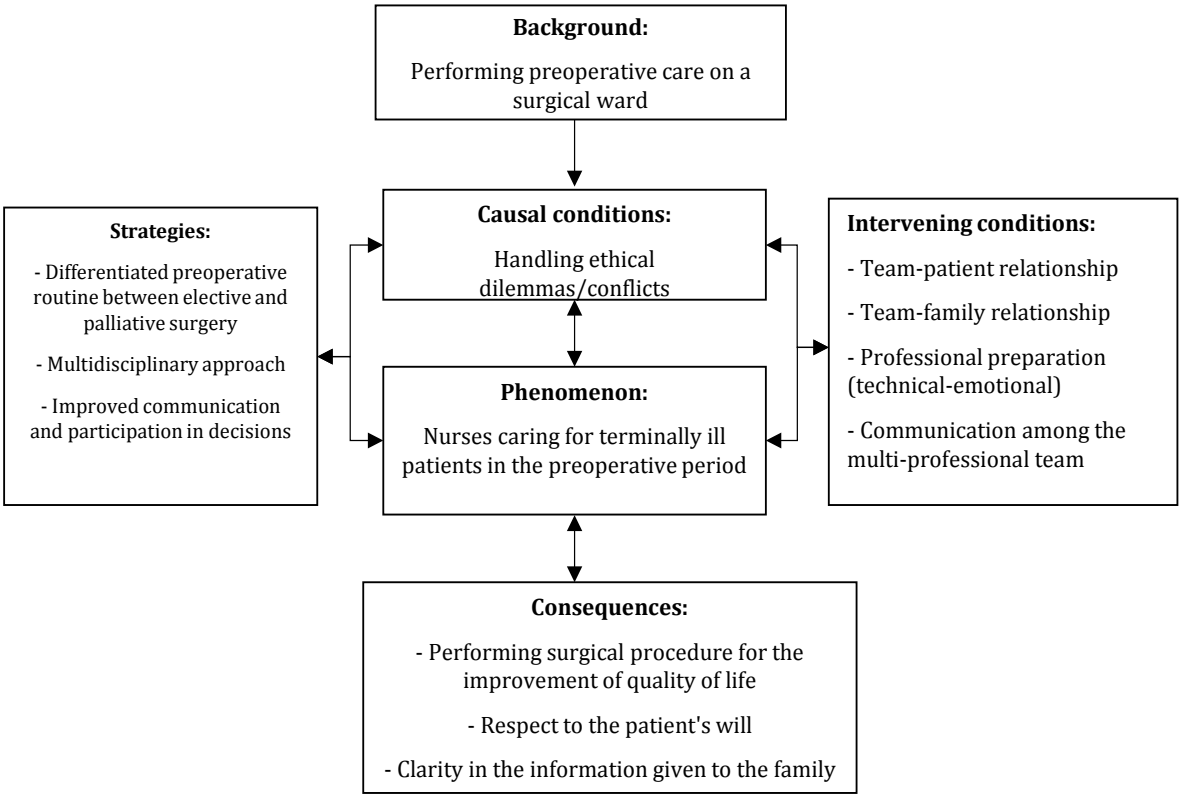

Figure 1 – Diagram of the grounded theory. Recife, PE, Brazil, 2021

Category 1 - Experiencing ethical aspects of preoperative care for terminally ill patients

Initially, the nurses were approached regarding the phenomenon, to investigate the concept they had about surgeries for patients in palliative care. Palliative surgery was associated with the procedure performed to provide the patient with a better quality of life. Only one nurse identified himself with the procedure performed with the purpose of prolonging the patient's life, which reveals that most interviewees did not attribute this meaning to palliative surgery.

Even though there was no theoretical basis in their statements, underlying what was exposed, pertinent issues regarding patient autonomy and other ethical aspects were raised, as presented in the following subcategories.

The subcategory Managing ethical dilemmas/

conflicts is clearly exposed in the following statement: *There are many conflicts, about what will be said, even about the patient choosing what will be done and what will not be done, because many times he doesn't even know how serious it is, so it is difficult to respect the patient's wishes if the family, which is the first to be informed, doesn't tell the patient, and forbids the doctor to tell the patient* (N1).

However, they revealed that around the issue of prognosis there is also a silence for the patient on the part of the family and/or the multi-professional team: *There are many families that do not even tell the patient, so he does not even know, most here do not know. Many times, the family doesn't want him to know, they think it's worse, that he will sink, so he kind of loses his voice, the patient* (N9).

The need to respect the patient's will was recurrent in the statements, such as requiring from the team an initial preparation of family members to enable a cultural change in the understanding that the patient should be spared precise knowledge about his health problem and therapeutic and surgical procedures: *Respect for the will of the terminally ill patient is everything, it must be respected* (N3). *There have already been cases of the patient saying "no, I want to go home, I want to die at home"* (N9). *Here, when the team takes a lot of young patients and talks directly to the patient, the patient has more autonomy to decide about his treatment, about the intervention, to do or not to do* (N10).

The difficult acceptance in relation to the loss of the patient and the feeling of frustration/inability were present in the statements of most interviewees. These statements reflect the subcategory Recognizing the importance of professional preparation, considering the technical and emotional abilities and competences involved: *I find it difficult to lose a young patient. I am working on it, but I feel a lot of difficulty when you see the patient there and you can't do anything for the cure, it's kind of frustrating. We feel frustrated* (N1). *Feeling... of incapacity, of not having anything else to do, there is nothing that will cure this patient, so the feeling is of incapacity* (N9).

Also, in this subcategory, the nurses reveal how they still feel that the care provided to patients' needs in this context is still incipient, referring to the lack of preparation and technical knowledge and unpreparedness of the multi-professional team: *We are not prepared. We received no support, no guidance, no training to deal with this patient* (N1). *Lack of knowledge, lack of preparation as well, both emotionally and in terms of how far I can go with my profession in relation to this patient* (N9). *We are still very primary in this care; the team needs to be better prepared to work with terminally ill patients* (N10).

The subcategory Valuing the team-patient-family relationship was expressed in statements that revealed that, for nurses, there is clarity in the information given to the family by physicians for the inclusion of relatives in this process and, consequently, better adherence of the patient to treatment or therapeutic/palliative proposal: *I realize that the participation of the family is unique, because it is the basis of the patient, it is what will give all the support and, even, they are the bulwark of the patient's adherence to treatment* (N3). *I think that the relationships and the clarity of the events in dealing with this family must be very well done, so that they can really understand what is going on and feel a participant in this process* (N4).

The subcategory Recognizing the importance of communication among the multi-professional team was also highlighted. The lack of integration among professionals, either in the lack of communication, or in the lack of multidisciplinary visits and discussions, hinders the nurses' participation in the decision-making process: *There's not really much conversation with the team itself. There isn't multi-disciplinarity, to sit and talk, there isn't* (N1). *There have been situations that I have seen here, the patient without any perspective was taken to surgery and, it is something closed to doctors, our participation is minimal* (N5). *First, we don't even participate, so we don't know why certain surgeries take place* (N6).

Category 2 - Preparing preoperative care for patients with end-stage disease

About perioperative nursing care, the nurses identified it with principles of palliative care, such as favoring comfort and quality of life. Statements emerged regarding the subcategory Differentiating the preoperative routine between elective and palliative surgery. The care routine takes on a differentia-

ted character for patients who will undergo palliative surgery from a holistic perspective, although, further on, the nurses report that from the procedural point of view, the routine is the same as for elective surgeries; that is, the emotional and experiential context is different, however, in practice, nurses are not always able to make adaptations in the nursing process for these patients: *What we do more is comfort, try to give comfort as a nursing team, of analgesia that is prescribed, of comfort, of getting close, of talking, of trying to improve a little the emotional of the patient and do everything to make him feel better* (N1). *I try to give the patient as much comfort as possible, emotional support is very important, not only for him, but with the family members* (N5). *We give all the information about the surgery in the preoperative period, also give some notion of the postoperative period, reduce doubts, and focus on the issue of the terminal patient giving comfort, a word of support* (N3). *In the performance of nursing in relation to the preoperative period, we will do all the preparation prescribed by the physician, ...and prepare the patient emotionally, reduce doubts, reduce anxiety, because all this will influence...* (N8).

Regarding the subcategory Providing clear information to the family, the nurses referred to the lack of clarity in the information provided by the physician to the patient, making the nurse-patient relationship difficult. The nurses advocated the need to make an honest speech with the patient to facilitate the team's work, so that all professionals have the same approach, from which the category Focusing on improving communication and participation in decisions emerges simultaneously: *We end up having to have a very good way of talking, because the doctor often doesn't talk* (N1). *You must make an honest speech to the client, but if the medical team doesn't communicate the case to us, it becomes difficult* (N6). *Difficulty with the line of thought of the doctors, because when you have transparency with the client, it is easy for the whole team* (N6). *I think that there should be more of a multidisciplinary approach, some meetings before the surgeries, with the nursing team, the medical team, psychology, social work. To really prepare this patient, the emotional of this patient, of the companion for the risks and the seriousness of what he has* (N1). *The difficulty is more the question of psychological support for the patient, you know! But what we miss here, is more of this support and psychological follow-up* (N11).

For nurses, the focus of the multi-professional approach in this context is expressed in two subcategories: Performing surgical procedure to improve the quality of life and Respecting the patient's will, because only in the proposal of multi-professional integration is it possible to achieve the idealized care: *Sometimes the patient is not so aware of this terminal issue, of palliation, and we have to know what he wants or what he would want, when he cannot speak* (N10). *Sometimes the patient doesn't even know what he has, he asks us, and we don't know how far we can go. Only by working as a team can we assist the patient with his right* (N1). *Palliative surgery is when you will try to give the patient a quality of life* (N5). *We end up giving the patient a perspective that that surgery, even in the palliative stage, will result in quality of life, the whole team gets involved so that the patient suffers less and has a good result from the surgery* (N6).

Discussion

Considering that Grounded Theory refers to the methodological pole of the research, the interpretative process of the results was conceptually based on the concept of palliative surgery and the same principles of palliative care[1,3-4,9-10].

Although palliation may cause increased survival, it is not pertinent to elect a palliative procedure based solely on the desire for this increased survival[1,3]. The lack of clarity in the indication of some surgeries for patients in terminal stage of disease with indication of elective surgeries that are often not palliative, but curative, can be a conflict when there is no multidisciplinary discussion or when there really are dysthanasic surgical treatments, resulting from the professional commitment to save the patient's life incessantly, linked to the feeling of defeat in face of the patient's death[1,9-11].

The indication of a surgical procedure for terminally ill patients should always go through the mediation of a palliative care advisory team[9,11]. In some cases, mediation becomes indispensable, so that all involved can come to a consensus about the decision made.

A recent proposal to evaluate care in palliative surgery foresees four goals that focus on respect for the person's will and on communication: discussion of the goals of surgery with family and multidisciplinary team, discussion, and clarification of non-verbal communication codes with the patient for the postoperative period, consideration of the need for consultation with a palliative care specialist service, and evaluation of the possibility of hospice without surgery or after surgery[12].

The problem around finitude involves, mainly, the delimitation of treatment for individuals with terminal diseases and the process of death and dying, leading to ethical and even legal problems[11]. For persons with life-threatening diseases, the practice of orthothanasia is adequate, as it allows death to happen at its own pace, without subjecting the person to useless treatments and unnecessary suffering, looking at the human being as a unique individual, valuing his biopsychosocial aspects and autonomy. There is evidence that patients and families accept palliative surgery and that, even if they do not achieve clarity in understanding the prognosis, they identify the surgery as beneficial, but this understanding must depend on the dialogue with the team and on the space to clarify doubts[13-14].

The nurses recognized a lack of knowledge and technical and emotional preparation to deal with the terminally ill patient. Even today, professional training in healthcare is still based on a biomedical model centered on hospitalization, medicalization and with a focus on cure, even if to the detriment of care, and death ends up being reaffirmed as something unwanted or linked to failure[15]. The nurses revealed that they recognize that the process of care has brought an exclusively technical and reductionist characteristic, in which the professions have been working in isolation, in a non-integrated way, which would favor an interdisciplinary look and the joint growth of those involved, aiming at the improvement of care[14-16].

For the individual on palliation and the family to have a broad, holistic assistance, it is necessary to consider the biopsychosocial and spiritual being to be supported by the multi-professional team, which will allow the patient and his family to be always accompanied, including the elaboration of mourning[15]. A recently validated questionnaire for patients and family was based on three questions: Should I have surgery? What could I expect if the surgery is successful? And What could I expect if the surgery goes wrong?[17]. With these questions, a range of discussions and possibilities of understanding about palliative surgery opens, which directly impacts decision-making.

There is an international model to approach palliative surgeries called palliative triangle[18]. In this model, for decisions to be made in this area, the surgeon, the patient, and the family must be considered as shared decisions that increase adherence, acceptability, and that are more effective and correct in the relationship between the moment of life and symptoms. Although this model is an advance by extending the surgical decision to other actors besides the physician, the lack of the team as a fourth actor to be considered is a considerable flaw in the process[16].

It is necessary to aggregate the principles of palliative care in the surgical routine for patients with life-threatening diseases[18]. Preoperative care of patients in palliative care must favor emotional support by considering and orienting the patient about the possibilities of problems in the trans operative period, such as the risk of poorly managed pain, constipation and paralytic ileus, end-of-life skin alterations, discomfort, and respiratory distress[1].

Study limitations

The present study was limited to refer to the reality of only one service. The hospital, the study setting, still does not have a palliative care advisory service, did not present recent initiatives of continuing education in this area, as well as not having protocols and routines for surgical patients in palliative care.

This contributes to a possible bias in the selection of the sample and the results could be somewhat different in hospitals more structured for this specialized care.

Contributions to practice

A theory is presented that allows professionals to reflect on their praxis and understand the intervening conditions for the ethical dilemmas and conflicts involved and consequences, as well as strategies to improve care in this scenario.

Conclusion

Nurses attribute meanings to this care that have their own particularities, that require professional preparation, and that demand even more of an effective communication within the multidisciplinary team and in the relationship with the patient and family. The theory allowed us to identify that, in practice, the teams need to improve the communication and discussion processes for decision making.

Authors' contribution

Conception, design, analysis, and interpretation of data: Leite NL, Santos ACL, Cavalcanti ACBS, Cavalcanti ATA, Gomes ET, Püschel VAA.

Writing of the article or relevant critical review of the intellectual content: Leite NL, Santos ACL, Cavalcanti ACBS, Cavalcanti ATA, Gomes ET, Püschel VAA.

Final approval of the version to be published: Leite NL, Santos ACL, Cavalcanti ACBS, Cavalcanti ATA, Gomes ET, Püschel VAA.

Agreement to be responsible for all aspects of the manuscript related to the accuracy or completeness of any part of the work to be properly investigated and resolved: Leite NL, Santos ACL, Cavalcanti ACBS, Cavalcanti ATA, Gomes ET, Püschel VAA.

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