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Uncovering care for patients in the death/dying process and their families

Desvelando os cuidados aos pacientes em processo de morte/morrer e às suas famílias

Desvelando los cuidados a los pacientes en proceso de muerte/morir y a sus familias

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ABSTRACT

Objective: To understand, in terms of complexity, the conditions that influence the interactions of health professionals in the face of death and dying of hospitalized adult patients and their families.

Method: Theoretical and methodological references have been adopted, respectively, were the Complex Thought and Grounded Theory. The data were collected through semi-structured interviews between May 2015 and January 2016, with three sample groups: nurses, nursing technicians and members of the multidisciplinary team. The data analysis followed the steps of open, axial and selective coding.

Results: The category "Uncovering the care of patients in the process of death/dying and their families" and their respective subcategories present the complex interrelation of health professionals in the face of death and dying of patients.

Conclusion: Causal conditions highlight the multiple connections established for care in the dialogic process of death/dying and reveal the complexity of lifeless care.

Keywords: Death. Attitude to death. Hospice care. Hospice and palliative care nursing.

RESUMO

Objetivo: Compreender, na perspectiva da complexidade, as condições que influenciam as interações dos profissionais de saúde diante da morte e do morrer de pacientes adultos hospitalizados e às suas famílias.

Método: Adotou-se como referenciais teórico e metodológico, respectivamente, o Pensamento Complexo e a Grounded Theory. Os dados foram coletados mediante entrevistas semiestruturadas, entre maio de 2015 e janeiro de 2016, com três grupos amostrais: enfermeiros, técnicos de enfermagem e membros da equipe multidisciplinar. A análise dos dados seguiu as etapas de codificação aberta, axial e seletiva.

Resultados: A categoria "Desvelando os cuidados aos pacientes em processo de morte/morrer e às suas famílias" e suas respectivas subcategorias apresentam as complexas inter-retro-ações dos profissionais da saúde diante da morte e do morrer de pacientes.

Conclusão: As condições causais destacam as múltiplas conexões estabelecidas para o cuidado no processo dialógico da morte/morrer e revelam a complexidade do cuidado ao corpo sem vida.

Palavras-chave: Morte. Atitude frente à morte. Cuidados paliativos na terminalidade da vida. Enfermagem de cuidados paliativos na terminalidade da vida.

RESUMEN

Objetivo: Comprender, en términos de complejidad, las condiciones que influyen en las interacciones de los profesionales de la salud frente a la muerte y el morir de los pacientes adultos hospitalizados y sus familias.

Método: Se utilizaron como referencias teoría y metodología, respectivamente, el pensamiento complejo y la teoría fundamentada. Se recolectaron los datos a través de entrevistas semiestructuradas entre mayo de 2015 y enero de 2016, con tres grupos de la muestra: enfermeras, técnicos de enfermería y miembros del equipo multidisciplinario. El análisis de los datos siguió la codificación abierta, axial y selectiva.

Resultados: La categoría "Revelación atención al paciente en el proceso de la muerte/del morir y sus familias" y sus subcategorías tienen complejas interrelaciones y retro-acciones de los profesionales de la salud ante la muerte y el morir de los pacientes.

Conclusión: Las condiciones causales ponen de relieve las múltiples conexiones establecidas para el cuidado en el proceso de diálogo de la muerte/del morir y manifiestan la complejidad de la atención de un cuerpo sin vida.

Palabras clave: Muerte. Actitud frente a la muerte. Cuidados paliativos al final de la vida. Enfermería de cuidados paliativos al final de la vida.

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INTRODUCTION

Among the subjects that deserve to be discussed in society, in more depth, are terminality and death. This is because, routinely, one avoids talking about such matters and, when approached, they are usually involved in euphemisms, in order to minimize suffering. At this juncture, it is said that the person died, left, went to death, rested, among others that distance the expression "he/she died". The approach of these themes may be accompanied by feelings of fear, shame, loneliness, which together can influence the maintenance of a collective taboo about terminality and death, however, it has not always been like this[1-2].

During the Middle Ages, between the fifth and fifteenth centuries, death was a common phenomenon. Expected in the bed of people's own residence, it was a public act, especially to relatives, friends, neighbors, which is why it was not associated with feelings of shame or fear. Over the years, the meaning of death went through several transformations until it became a detestable event in the nineteenth century, as it represented a rupture in the normal course of life. This conception was intensified in the twentieth century, when death came to be considered shameful, denied, or hidden. It became, with this, a technical phenomenon, transferred to the hospital, in an attempt to be controlled by the health team, specifically by the physician[1-2].

This phenomenon, death, can be understood from complex thinking when it is recognized in its multiple dimensions[3]. At this juncture, it is necessary to recognize its biological dimension, unique to the individual who experiences it, but also the subjective dimension imbued with social dynamics, from the family sphere to more expressive collectivities, which, together, can clarify the social dynamics involved in the different ways humanity has, over the years, dealt with this phenomenon. In addition, death can also be considered as a dialogical phenomenon, whereas, naturally, it is part of the cycle of life and, therefore, of the development of humanity[3-4].

Therefore, in conceiving human life as complex, dealing with its terminality is also complex, which is why it needs an expanded look at death as a dynamic and complex process involving different fields of meanings and actions that may influence the quality in which this phenomenon occurs. In addition, each society has its own culture, habits, beliefs and values, which offers people different meanings for death, as well as resources for their coping[4-6].

That way, health professionals, including nursing professionals, need to understand the values underlying the different representations of caregivers, as well as to apprehend the professionals' own representations about death in order to give meaning to the care performed[2-5]. Therefore, it is necessary to understand the systems of meanings that influence the actions of health professionals in the face of terminality and death, while they may impact the care at the end of life[6-7].

Corroborating the above, based on the Theory of Complexity, defended by Edgar Morin[6], the management of care, before death and dying, can be understood as a process that continually involves order, disorder and organization in an antagonistic dynamic and in which errors, unpredictability and uncertainties contribute to the reorganization of a living system[8-9].

In light of this, it is asked: What conditions influence the interactions of health professionals in the care of patients and their families in the face of death and dying? Therefore, the objective of this study was to understand, from a complexity perspective, the conditions that influence the interactions of health professionals before the death and dying of hospitalized adult patients and their families.

METHODOLOGICAL ASPECTS

The present study presents a summary of the results of the research "A glimpse at the management of nursing care before the death/dying process"[10], presented to the Graduate Program of Anna Nery Nursing School of the Federal University of Rio de Janeiro as a doctoral thesis.

Exploratory research, with a qualitative approach, having as theoretical reference the Theory of Complexity, from the perspective of Edgar Morin, and as a methodological reference the Grounded Theory (GT), known in Brazil as Data Based Theory (DBT). The DBT explores the meaning of phenomena and allows interrelation between data, as well as constant comparative analysis and it is a research method that has been increasingly used in the field of Nursing, given its contribution in the understanding of phenomena and in the production of explanatory models and theories grounded in systematically collected and analyzed data[11].

The field research was held out from May 2015 to January 2016 and had as a scenery a general public hospital in Zona da Mata Mineira. It is an institution that is a reference in the macroregion and performs ambulatory care, physical rehabilitation, hospitalization and surgery in several specialties for pregnant women, newborns, children, adults and the elderly. This institution develops activities of teaching, research and assistance, being a practical field for activities of practice and stage of various graduations, and it has medical residency in several areas.

The semi-structured interview was used to collect data. The study participants were defined from the theoretical

sample[11]. There were three sample groups in this study: nurses, nursing technicians and members of the multidisciplinary team. The initial sample group consisted of nurses who work in the institution in the medical-surgical hospitalization areas of adults ("wards"), as this is the professional responsible for the management of nursing care, having as inclusion criteria: professionals working in the hospital where the research was conducted, regardless of gender. The following exclusion criteria were adopted: nurses who were away from the service for any reason.

It should be noted that in DBT, one of the main characteristics of the method is the comparative analysis between the data, which are collected and analyzed simultaneously. This way, although the research was initiated with the delimitation of only one sample group (nurses), the method allows, from the analysis process, the formulation of hypotheses, which may lead to the need to delimit other sample groups, in order to clarify the phenomenon investigated. This analytical conduct is what allows directing the development of a theory based on data.

In this sense, the death/dying phenomenon was rooted/grounded in the connection between the meanings of other professionals, namely: nursing technicians and members of the multiprofessional health team. The criteria for inclusion and exclusion were the same for the sampled group of nurses.

Based on the analysis of the data from the first sample group, it was understood that the management of nursing care to patients and their relatives, in face of the death/dying process, is permeated by interactions with other professionals. In light of that, interviews were conducted with 12 nursing technicians and 11 professionals from the multidisciplinary health team, including: three psychologists, three social workers and five assistant physicians, totaling 41 participants.

The interviews were concluded based on the theoretical saturation, which was achieved with the repetition of information and the absence of new elements for the consolidation of the categories found[11].

The interviews were digitally recorded and transcribed in full. The analysis of the data occurred simultaneously to its collection and followed the steps proposed by the DBT: open, axial and selective codings. In open coding, the data were analyzed line by line in order to construct the preliminary codes. After this, they were gathered, by similarities and differences, from the elaboration of the conceptual codes. In the axial, the data were regrouped in order to obtain a more precise explanation on the phenomena, seeking to relate the subcategories to their categories, as well as to develop their properties and dimensions. In the selective coding, the subcategories and categories found were compared and analyzed continuously with the purpose of integrating and refining them, in order to identify the central category. Finally, the paradigmatic model was used to organize and present the data, which consisted in six components: context, causal conditions, intervening conditions, action/interaction strategies, consequences and central phenomenon[11].

It should be emphasized that the theoretical matrix was validated in September 2016 by 11 validators and that this research was approved by the Research Ethics Committee on April 29, 2015 [Presentation Certificate for Ethical Assessment (CAAE) 41743414.9. 0000.5238].

The participants received information about the survey and had ample freedom to accept or decline the invitation. They signed the TCLE following the determinations of the National Research Ethics Council and were granted anonymity, the identity of which was replaced by the initials of the sample groups, so that they were thus used: NA (nursing assistant), NT (nursing technicians), P (psychologist), SW (social worker) and AP (assistant physician), followed by the interview number.

RESULTS AND DISCUSSION

The categories "Uncovering care for patients dying/dying and their families" and "Considering the complexity of human life in the face of illness and death" characterize the causal conditions of the theoretical model "Looking at the management of nursing care of the death/dying process" and reveal multiple interfaces to the dying and death of patients admitted to nursing homes. It should be noted that, in DBT, the causal conditions are those that allow the appearance of phenomena[11].

This article presents the category "Uncovering Care for Patients in the death/dying process and their families", which consists in four subcategories: Establishing connections for patient and family care in the dialogical process of death/dying; Revealing the complexity of care to the lifeless body; Demonstrating specificities of patient and family care in the death and dying process and Presenting opinions and aspects of the nursing team's behavior regarding the death/dying process of a patient in the ward.

In the subcategory Establishing connections for patient and family care in the dialogic process of death/dying, aspects of the interactions from the professionals of the multidisciplinary team with patients in terminality and with their relatives are highlighted.

It is seized, from the analysis process, that the professionals observe the patients in terminality and their relatives, seeking to identify their needs and attend them.

We begin to observe more closely the signs the patient is presenting, the demonstrations that he is not well... the things that appear as dyspnea, a lowering from the level of consciousness, something that shows that something bad is about to happen. (NA1)

We have, I think it is more or less this kind of relationship: it is affection, it is attention, it is psychological preparation, it is strength for the patient, it is strength for the family. (NA 7)

Research participants demonstrated that they interact with patients' relatives to provide them with support, tranquility and comfort, demonstrating empathy and acceptance regarding the death/dying process. In addition, the professionals mentioned that care for the patient before the death/dying process should be performed as quietly as possible, promptly, delicately, unhurriedly, "very carefully," with respect and that it should always seek the best for the patient, which converges with results of other studies[12-13].

I think it has to be as quiet as possible and at the same time with promptness, but to solve the situation. But it has to be very delicate, very carefully, without hurry because, unfortunately, we get very mechanical in this profession. (NT 2)

The participants highlighted the development of a link between some professionals and certain patients and their families in the face of the death/dying process, especially those from the nursing team. In the meantime, they take as an explanatory basis for this phenomenon the fact that these professionals stay closer in direct care to patients. Therefore, the quality of the connections between the care elements - professionals, patient, family - is a principle validated by Complexity Theory in recognizing that the interaction between the parts of a system allows it to be more than the sum of the constituent elements.

There is always a patient that we have a bond, something in him moves you. (AP 5)

It's like that, when you take care of that patient, direct care of him/her and you get attached to it, that moves us a lot (NT 5)

As a complex system, disorder mechanisms also exist in this process, for example, the interaction of health team professionals with patients and their families is permeated by contradictions and disorders. Professionals do not always welcome the family in the desired or expected way, and not all of them show a disposition for the necessary reception[8,13-14].

I've seen colleagues, like this, leaving the room, the accompanying is at the door, and goes there to make bureaucracy to notify doctor, funerary, paperwork, all [...] leaving to the doctor the role to inform. (NA 3)

I think the doctor should be more present. Often the doctor gives excuses. I don't know if it's an excuse or if it's true, the real thing that is happening. The doctor says that he is in postmortem care to the patient and does not receive the family. So, the nurse doesn't have [...] Don't have to do this after death care? Does not the nurse have to be with the body? (NA 16)

Authors reflect that professionals may, sometimes, fail to provide shelter to patients' relatives in termination or after death, because they are involved in routine agitation, bureaucracy at death, and even because they avoid dealing with these situations[15-16].

In addition, the participants pointed out failures in the communication with patients and relatives, and wear and tear resulting from their reactions to the death/dying process. They mentioned that the family often did not have an open discussion with the doctor about the clinical condition and the prognosis of the relative. They consider that it is necessary to guide the patient's family in the end, to talk about the death/dying process and to invest more and more in education about this process, so that everyone - patients, family and professionals - can deal better with the experience of terminality and of death. Of course, it is not only education that can transform this situation, but it is one of the pillars for this to happen as pointed out by various authors[12-14,16-19].

And with the family issue, I'm not usually talkative unless the doctor has already explained. Because I think it's a very flawed question. Doctors don't explain the seriousness of the case and this is even a very bad situation because the family stays on top of nursing. (NA 5)

The previous speech expresses the opinion of a nurse about the communication of the doctors with the relatives of the patients, in which the failures generate wear in the interaction of the nursing professionals and relatives.

One physician pointed out the need for the multidisciplinary team to help the family member cope with the death/dying process of the loved one and the relevance of the professionals to help each other in the face of needing to deal with patients and family members in the face of terminality and death. The relevance of the work of this team has been discussed in the face of terminality and death[20].

So, embrace the family member who, many times, doesn't see death as we see, is not prepared. Give attention to this familiar and, in a way, try to embrace. Sometimes he doesn't accept the doctor's speech well, but the multidisciplinary team involved, it can help. Help each other. (AP 1)

Another highlighted point in the interaction with patients in terminality concerns the transference of these from the wards to intensive care units within the hospital itself. Often, relatives and professionals request that the terminally ill patient be transferred to the intensive care unit.

Because in the ward we live with death more sporadically [...] The patient, usually, if we are waiting for him to die, he is usually referred. When the patient worsens and is not a patient with terminal cancer, usually he is referred to the ICU, there are other things. Usually he doesn't die with us. (NA 9)

Another concern of professionals in the care of terminally ill patients is the relief of pain and other unpleasant symptoms that patients may present, as well as relieve pain in the family[17,19].

This subcategory revealed that professionals seek physical and not physical (emotional, spiritual, among others) comfort in the face of the death/dying process, recognizing the complexity of life and the delicacy of this moment. In the seek for the comfort of patients in terminality, professionals use different strategies such as medication administration, dialogue, therapeutic touch and modifications in nursing care in order to avoid patient wear[18,20].

This set of factors allows, therefore, to consider that these professionals, when recognizing and valuing the multiple dimensions imbued in the care and in the process of death and dying, value the very complexity that exists in this phenomenon, since they mark the care in an extended and multidimensional perspective.

Participants stressed that promoting comfort and privacy for the dying patient and their family means providing quality care, and that futile treatments, which are those that do not bring benefits to them, should not be performed, because it would constitute in dysthanasia, cooroboring with authors[18,20].

What we try to do is to give privacy, if there is no screen we put the screen; the maximum comfort possible. (NA 14)

[...] we try to offer a quality care, providing comfort for the patient in that fragile moment of the family. (NT 6)

The relief of the pain and unpleasant symptoms that patients present as a result of the disease or treatments performed was a recurring theme in the speeches of the participants, such as:

Respect above all with someone else's pain. (NA 3)

The manifestation of pain in the patient in terminality generates a discomfort in the professionals and the participants report that the relief of this should be the priority of the nursing team.

Although they report the importance of patients' pain relief in terminality, it was identified that the team is not always able to alleviate it effectively, and that failures occur from the non-prescription of analgesics in relation to the characteristics of the pain presented by the patient and, even the non-administration of opioid medications by nursing professionals. Such notes have already been highlighted by other authors[18].

So, the medication issue gets a little tied to the doctor. I think it lacks more coherence as well. Sometimes the patient is in a lot of pain and they do not usually go over a certain limit. Because we are used to 'moderate pain, dipyrone; stronger pain, tramadol. Only!'. It's hard to see morphine in a ward. (NA 14)

This report draws attention to the need for health professionals to be able to care for patients in terminality, with an emphasis on the urgency of relieving their pain adequately, guaranteeing them a dignified and quality life, while it lasts. In addition, they emphasized the need for professionals to have sensitivity and knowledge to manage patients' pain. If the professionals do not use opioids in the treatment of intense pain, it can be inferred that most patients are undertreated regarding their pain[18,20].

The priorization of the body care by the nursing team was cited by some study participants, as well as the ability to avoid conversations with terminally ill patients and their families.

I see this a lot: 'listening is the job of the psychologist. So I'm going to act in pain, do medication, do some dressing [...] but I don't want to talk to the family too much'. (P 2)

I see that the work of nursing is very focused on this issue of care, but even more bodily care. (SW 3)

The results lead to the reflection about the priorities in the care of the person in terminality. It is considered that care with the patient's body is very important, but it is not always the most necessary or urgent. Each patient has

needs and brings specific demands. The attentive look of professionals should seek to recognize this, in addition to the need to improve communication techniques with patients and their families[18,20].

In the subcategory entitled Revealing the complexity of lifeless-body care, the participants pointed out the care taken with patients after death, noting that nursing professionals provide care not only during life, but also to the body.

The professionals recognize that the technical procedures with the patient's body are performed by the nursing technicians and that, sometimes, they receive help from the nurses in this preparation, since, in most cases, they are absorbed in other activities related to the death of the patient, ranging from bureaucratic activities to family care[13].

The technicians are left with the procedure of arranging the body and we do this intermediation between the family and the doctor and the patient who died. But with a much greater focus on bureaucracy, paperwork, protocol, like that. (NA 6)

It is considered that the preparation of the body should be better structured and reworked to respect the privacy of the body and respect the other patients and companions, since nursing care should exceed the biomedical model and technical issues[13].

Because in many ways the team already starts working inside the ward and involves other patients, other companions and such. So this could be more structured and reworked. (NA 16)

On the one hand, some other flaws, such as disrespect to the body, occur in this process and are cited by the participants, which indicates that professionals need to be prepared for this moment and develop skills that go beyond the technical issue when dealing with the body without the patient's life[13,19].

So, I think there are people who have no respect at all. Even after the person has passed away and everything. Sometimes at the time you're doing that first tidy up in the body, there are people who disrespect, our colleagues and such. Jokes, that sort of thing, like that. (NT 2)

On the other hand, some statements show that nursing professionals prepare the patient's body with respect by recognizing it as part of the care that must exist in both life and death.

To me, it doesn't matter if it's just the body, I'll respect it until the time that it's taken out and deliver him there. I do everything as if he were alive, as if he were feeling. So, for me, the nursing care, ours, rendered in the post-death [...] I do so. I'm like this. (NT 8)

The specificities of patient care and family members in the process of death and dying present diferences, from the perspective of health professionals. These make comparisons in the care they offer to these and other patients hospitalized who are not in terminality, such as greater vigilance to vital signs and symptoms presented.

It is seized from the data that the care given to these patients and also to their relatives should be differentiated, since the death/dying process is a peculiar moment in the life of these people and that the professionals must pay special attention to the demands that they present in order to try to promote the best possible care.

It must be a more specific care for that situation [...] Trying, how do we say? Trying to give him a moment, differentiated. To him and his family, too. (NA 2)

When there is a patient who, without a prognosis, let's say so, I try to give a greater attention to this patient even knowing his prognosis. (NA 12)

Other notes of this subcategory are the deficiencies in the care given by the professionals in the process of death/dying. These occur both in the care of the patient and in the care provided to their family and are not restricted to nursing, but permeate the interactions of the professionals of the multidisciplinary team[18,20].

I don't think we care about the family! We don't take care of the family! We do our work, continue doing it normally without worrying about the family. (NA 13)

I still see the exercise of this care as very flawed yet. That's what I see. Sometimes even non-existent. So I think there is a lot to do, especially regarding the support for the person, you continue with full care for him at that time. (NA 17)

Some causes of the failures are pointed out by the participants and involve the lack of knowledge of the professionals, the distance between some professionals and the patients in the process of death/dying and their families, the work overload and the lack of integration of the multiprofessional team to the care of the patient and his family[13-14].

The subcategory Presenting opinions and aspects of the behavior of the nursing team before the death/dying process of a patient in the ward brings the view of the par-

ticipants from this study about the reaction of the nursing professionals to the interactions with patients in terminality.

The involvement of the nursing team in the management of care is recognized by different professionals. It leads care to patients and families, identifying needs, accepting the demands, coordinating interventions that seek to effect the mutual relations, the interretro-actions[8]. Generally, before the doctor, it is the nursing who solicits the opinion of psychology.

Usually it is like this: before the doctor asks, the nursing has already asked me. (P 1)

An analysis that is extracted from the data is that the nursing technicians are sensitive to the needs of the patients and family and bring demands to the nurses and, sometimes, to professionals of other categories, being involved and seeking to attend the needs of care of the patients in terminality.

They (nursing technicians) sometimes observe things that we have not noticed and come to us asking for this family issue, to have a more comfortable place for the family. They always comment. (NA 2)

Another one brings as a focus the views and behaviors of the nursing team before the death/dying process of a patient in the ward. The participants understand that there is a decrease or even lack of sensitivity of some of these professionals to the death/dying situation, valuing the maintenance of routines of the hospitalization unit, disregarding the needs of the patients and their families, fragmented care to the patient. These findings corroborate findings from other studies[13-14].

I think we have been working here with professionals for many years, in general I think it has gotten a bit mechanical. I think, not a little, very much! It became very mechanical. (NA 4)

The professionals point out that there is suffering related to the death/dying process of a patient. Some participants consider that it is important to demonstrate to the family that the health team also suffers from the process of termination and there are professionals who do not know how to act when it comes to expressing or not their suffering to the family.

It is important to show, I think, in my opinion it is important to show the family that we are human beings too and that we get touched by that, the situation of the family. Because sometimes the family may even think that 'it is very easy for her to give me this news, that the situation will not unfold well, that the patient's condition is very serious'. (NA 4)

The speeches demonstrate that professionals deal with important psychic issues in the care of patients in the death/dying process and their relatives, and confirms the authors' assumptions that there is a need for greater guidance and follow-up from the professionals seeking to guarantee the health of the worker[5,13-14].

In addition, statements that patients and family members should receive psychological support were recurrent in the interviews. Most participants consider that this support should be offered by psychologists exempting themselves from this (co)responsibility.

The role of the members of the nursing team as aggregators and mediators among other health professionals, patients and family members is another aspect that is identified. Especially the nurse is seen as a mediator and aggregator among other professionals who take care of the patient and his family.

Because the nurse has a role, although not much described, but in practice, very aggregator. They have this role of aggregating people. (NA 4)

What I realize is that there is this proximity and that it acts much as a mediator between the other categories. It is who will actually report and make this link with the multiprofessional team. I realize this nursing role a lot. (P 2)

In this sense, the complex thinking seeks a look that reconnects the dimensions of man and life, seeking to recognize the micro and macro issues involved, understanding management from the perspective of historical and socially constructed health practices, recognizing the uncertainties, disorders, contradictions and tensions in the context of life and work[4,9,19].

In a way that organizational recursion denies simplification and uniqueness, breaking with the linear idea of cause and effect, in which products and effects are both products and producers of what produces them[8-9].

FINAL CONSIDERATIONS

The results allowed us to understand that the causal conditions of the presented phenomenon highlight the multiple connections established for the care of the patient and his/her family in the dialogical process of death/

dying, reveal the complexity of lifeless-body care, are related to patient care specificities and family members in the process of death and dying and demonstrate that nursing professionals have different opinions and behaviors regarding the death/dying process of a patient in the ward, which impacts the care taken.

A limitation of this study was having been conducted in only one location, at a time and scenery historically dated, in a particular cultural context, another was that it focused care management on the adult death/dying process. In this way, more research is needed in this area, in different scenarios and with a focus on the process of death/dying of children and adolescents.

Some phenomena that emerged in this study deserve future investigations, given their density and deep interconnection with nurses' practice in face of terminality and death. New research may be developed to better understand the relationship of spirituality to the death/dying process, discussions about the training of health professionals on issues related to the termination of life, and deepening of research on the implementation of palliative care.

It is proposed that professionals recognize and understand the conditions that influence their interactions, so that they are reflexive and critical to their performance, managing care with a thought and a look that reintegrates the whole, considering the singularity of the parts and the interaction among them, thinking of the process as a living, dynamic organism.

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