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## COMMUNICATION IN THE MANAGEMENT OF THE NURSING CARE BEFORE THE DEATH AND DYING PROCESS

Roberta Teixeira Prado<sup>1</sup>   
Josete Luzia Leite<sup>2,\*</sup>   
Ítalo Rodolfo Silva<sup>3</sup>   
Laura Johanson da Silva<sup>4</sup> 

<sup>1</sup>Faculdade de Ciências Médicas e da Saúde de Juiz de Fora (FCMS/JF). Juiz de Fora, Minas Gerais, Brasil.

<sup>2</sup>Universidade Federal do Rio de Janeiro. Rio de Janeiro, Rio de Janeiro, Brasil.

<sup>3</sup>Universidade Federal do Rio de Janeiro, Escola de Enfermagem Anna Nery. Rio de Janeiro, Rio de Janeiro, Brasil.

<sup>4</sup>Universidade Federal do Estado do Rio de Janeiro, Escola de Enfermagem Alfredo Pinto. Rio de Janeiro, Rio de Janeiro, Brasil.

*\*In memoriam.*

### ABSTRACT

**Objective:** to understand, from the perspective of complexity, the factors related to communication for the management of the nursing care before the death and dying of hospitalized people.

**Method:** the Complex Thought and Grounded Theory were used as theoretical and methodological references, respectively. The data were collected through semi-structured interviews, from May 2015 to January 2016, with three sample groups, totaling 41 participants: nurses, nursing technicians and members of the multidisciplinary team of a public hospital in Minas Gerais, Brazil. The data analysis followed the steps of open, axial and selective coding.

**Results:** the management of the nursing care before the terminality and death involves a complex process of communication among patient, relatives and professionals, in which the interactions are permeated by the meanings of the end of life. Subjective, educational, sociocultural and institutional conditions influence nurses' interactions, generating order/disorder in the management of care.

**Conclusion:** communication represents an important challenge for nursing management because it involves different actors, given the context of uncertainties and affectivities in the process of death and dying. It is important to emphasize the importance of the nurses being open to communication with these people, because this process requires complex actions regarding the demand for training and permanent education, as well as interdisciplinary action to guarantee humanization and comprehensive care.

**DESCRIPTORS:** Nursing. Communication. Management. Death. Comprehensive health care.

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## COMUNICAÇÃO NO GERENCIAMENTO DO CUIDADO DE ENFERMAGEM DIANTE DO PROCESSO DE MORTE E MORRER

### RESUMO

**Objetivo:** compreender, na perspectiva da complexidade, os fatores relacionados à comunicação para o gerenciamento do cuidado de enfermagem diante da morte e do morrer de pessoas hospitalizadas.

**Método:** foram utilizados como referenciais teórico e metodológico, respectivamente, o Pensamento Complexo e a *Grounded Theory*. Os dados foram coletados por meio de entrevistas semiestruturadas, no período de maio de 2015 a janeiro de 2016, com três grupos amostrais, totalizando 41 participantes: enfermeiros, técnicos de enfermagem e membros da equipe multidisciplinar de um hospital público de Minas Gerais Brasil. A análise dos dados seguiu as etapas de codificação aberta, axial e seletiva.

**Resultados:** o gerenciamento do cuidado de enfermagem diante da terminalidade e da morte envolve um complexo processo de comunicação entre paciente, familiares e profissionais, no qual as interações estão permeadas pelos significados do fim da vida. Condições de âmbito subjetivo, educacional, sociocultural e institucional influenciam as interações do enfermeiro, gerando ordem/desordem no gerenciamento do cuidado.

**Conclusão:** a comunicação representa um importante desafio para o gerenciamento de enfermagem por envolver diferentes atores, diante do contexto de incertezas e afetividades no processo de morte e morrer. Destaca-se a importância do enfermeiro estar aberto à comunicação com estas pessoas, pois este processo exige ações complexas com a demanda de formação e educação permanente, atuação interdisciplinar para a garantia da humanização e da integralidade do cuidado.

**DESCRIPTORES:** Enfermagem. Comunicação. Gerência. Morte. Assistência integral à saúde.

## COMUNICACIÓN EN LA ADMINISTRACIÓN DEL CUIDADO DE ENFERMERÍA ANTE DEL PROCESO DE MUERTE Y MORIR

### RESUMEN

**Objetivo:** comprender, en la perspectiva de la complejidad, los factores relacionados con la comunicación para el manejo del cuidado de enfermería ante la muerte y el morir de personas hospitalizadas.

**Método:** fueron utilizados como referenciales teórico y metodológico, respectivamente, el Pensamiento Complejo y la *Grounded Theory*. Los datos fueron recolectados por medio de entrevistas semiestruturadas, en el período de mayo de 2015 a enero de 2016, con tres grupos muestrales, totalizando 41 participantes: enfermeros, técnicos de enfermería y miembros del equipo multidisciplinario de un hospital público de Minas Gerais, Brasil. El análisis de los datos siguió las etapas de codificación abierta, axial y selectiva.

**Resultados:** la gestión del cuidado de enfermería ante la terminal y la muerte involucra un complejo proceso de comunicación entre paciente, familiares y profesionales, en el cual las interacciones están permeadas por los significados del fin de la vida. Las condiciones de ámbito subjetivo, educativo, sociocultural e institucional influyen las interacciones del enfermero, generando orden/desorden en la gestión del cuidado.

**Conclusión:** la comunicación representa un importante desafío para el manejo de enfermería por involucrar a diferentes actores, ante el contexto de incertidumbres y afectividades en el proceso de muerte y morir. Se destaca la importancia del enfermero estar abierto a la comunicación con estas personas, pues este proceso exige acciones complejas con la demanda de formación y educación permanente, actuación interdisciplinaria para la garantía de la humanización y de la integralidad del cuidado.

**DESCRIPTORES:** Enfermería. Comunicación. Gestión. Muerte. Asistencia integral de salud

## INTRODUCTION

Dealing with the process of death and dying is a natural necessity in life. It is, therefore, a complex dialogical phenomenon that impacts, especially, the daily life of health professionals, more precisely, those of the nursing team, given the time and approach these agents demand regarding the person under health care. In the approach to the death and dying process, communication is the key basis of care, through which interpersonal relationships are established and should be used to provide effective and comprehensive care.<sup>1-2</sup>

This phenomenon becomes even more relevant in view of the number of deaths in Brazil, since, according to the preliminary data on mortality of the Department of Informatics of the Unified Health System (*Sistema Único de Saúde* – SUS), only in the year 2016, 1,309,774 deaths were recorded. In this reality, the greatest number was due to diseases of the circulatory system, followed by neoplasms, external causes and diseases of the respiratory system.<sup>3</sup> This factor demonstrates a prevalence in relation to chronic health conditions and, possibly, an increasing perspective of this number for the next years.<sup>3</sup>

In addition to the significant number of deaths in Brazil, it is important to highlight that in 2016, there were 878,999 deaths in this scenario,<sup>3</sup> whose relevance, among others, is on the need for the quality of the care provided to the individual in the process of death and dying, since it is a significant social demand.

Therefore, there is the need for management actions that guide the thinking/acting for the nursing care of the patients and their relatives before the death and dying process, in order to favor the communication and the development of thoughts and behaviors that value the individuals as unique social subjects, experiencing a singular stage of the life cycle.<sup>4</sup>

However, it is important to emphasize the multidimensionality that exists in the process of death and dying, since each society constructs and presents its own culture, habits, beliefs and values, which offers people different meanings for death, as well as resources for its coping. In Brazil, this reality is plural, given the cultural diversity of each region. Thus, health professionals, especially nurses, need to develop skills to promote effective care in the face of this reality, which is a natural phenomenon of life, both to the individual and to their family.<sup>5</sup>

In this sense, from the emerging paradigm, it is understood that health is beyond the absence of diseases. The care for life and the process of death and dying are not limited to procedural technical actions, but they are also extended to the inter-subjective field of care practices for the human well-being. In this context, communication plays a fundamental role in human interactions, a *sine qua non* condition for the management of nursing and health care in any field of health care, especially in the hospital context, given the relationship of distance that this space confers to the natural setting of care of the person and their family, their home.<sup>6</sup>

Communication thus emerges as a means to care, as it exerts influence in the therapy and supports the health professional to better understand the subject of care, since during the communication there are possibilities for feedback that can reorient the health actions.<sup>6</sup> Therefore, communication is essential for the care management.

In addition, the nursing care management before death and dying is understood as a process that continuously involves order, disorder and organization in an antagonistic and complementary dynamic, in which errors, unpredictability and uncertainties contribute to the reorganization.<sup>7</sup> Thus, it is in the act of communication that, from the care interactions, one can know the demands of the patient and, therefore, better intervene. In this way, it is questioned: in the hospital context, what factors influence the communication process for the management of the nursing care before the death and dying process?

Although the possible answers to this questioning may not present a linear relationship between cause and effect, because they are complex phenomena,<sup>7</sup> it is sought to understand the field of meanings that structure the problematic on the agenda, as well as the conditions to better think and develop mechanisms of care for the demands of the death and dying process in a specific context - the hospital.

Thus, it was the objective of this research to understand, from the perspective of complexity, the factors related to communication for the management of the nursing care before the death and dying of hospitalized people.

## METHOD

Exploratory, qualitative research, having as theoretical reference the Theory of Complexity, from the perspective of Edgar Morin, and as a methodological reference to the Grounded Theory (GT). This is characterized as a method developed from a set of analytical resources that can generate a theoretical matrix explaining the phenomenon investigated.<sup>8</sup>

The participants of the research were part of three sample groups, the first one being made of nurse assistants. However, it is worth mentioning that, in the GT, the delimitation of the sample group for the development of the research is initially done preliminarily, that is, a research based on data directs, in the course of its analytical process, which other social actors will be necessary for the explanatory conformation of the phenomenon under investigation. This is only possible because, in GT, data is collected and analyzed simultaneously. In this process, researchers have analytical resources that help to understand the need for new sample groups, since it is possible to use theoretical memos throughout the research, from which hypotheses may arise that reveal which other contexts (spatial or subject) the phenomenon is rooted/grounded to.<sup>8</sup>

From the meanings that emerged from the first sample group, the data revealed the following hypotheses: being this a complex phenomenon, its multidimensionality can be affected from the interactions, in the field of perceptions/meanings, by other professionals who are not nurses? How does this occur from the perspective of nursing technicians, since they make up the nursing team? How does this phenomenon undergo inter-retroactions from the meanings attributed by other health professionals?

The inclusion criterion in the study was: nurses working in the medical-surgical hospitalization areas of a general public hospital in the Zona da Mata Mineira region, with experience in this context equal to or over than two years. The following exclusion criteria were adopted: nurses who were away from the service for any reason; nurses who were not working in direct care, that is, in patient care.

Nurses who used to develop health care in the hospital context in the sectors of medical-surgical hospitalization of adults were selected. Considering the specificities of the care settings, a transversal perspective was sought to observe the different experiences of the death and dying process that could influence the field of meanings of the research participants.

During the investigative process, with the help of memos, the data revealed the hypothesis that to understand the object of research it would be necessary to understand its multidimensionality. This implied the need to consolidate the data from the perspective of other actors that directly influenced the management of the nursing care in the process of death and dying.

From this process, the 41 participants who made up the research were divided into 18 nurses (first sample group), 12 nursing technicians (second sample group) and 11 members of the multiprofessional health team (third sample group), being three psychologists, three social workers and five assistant doctors.

The semi-structured interview was used as a technique for data collection in all groups, conducted from May 2015 to January 2016 and recorded in digital media. The interviews were conducted in

rooms chosen by the study participants inside the hospital. The data collection was concluded after reaching theoretical saturation, namely: when the categories presented explanatory density capable of responding to the research problem. This occurs when, during the analytical process, the data no longer presents variations in the properties and dimensions that constitute the concepts. Thus, it is conceived that the categories are already developed, with the ability of, together, in the paradigmatic model, allowing explanation to the investigated phenomenon.<sup>8-9</sup>

The setting of this investigation was a public hospital in Zona da Mata Mineira. This institution provides outpatient care, physical rehabilitation, hospitalization and surgery in several specialties to pregnant women, newborns, children, adults and to the elderly, setting itself up as a reference hospital in the macro-region. The institution develops teaching, research and care activities, it is a field of activities of practice and internship of several graduation courses and has medical residency.

The data analysis occurred simultaneously to its collection and followed the steps proposed by the GT: open, axial and selective codings.<sup>8</sup> In the open coding, the data were analyzed line by line in order to construct the preliminary codes, step known as microanalysis. Subsequently, they were brought together by similarities and differences, from the elaboration of conceptual codes. In axial coding, the data were regrouped in order to obtain a clearer explanation of the phenomena, in order to relate the subcategories to their categories, as well as to develop the properties and dimensions of the categories. In the selective coding, the subcategories and categories found were continuously contrasted and analyzed with the purpose of integrating and refining them, in order to identify the central category.

Finally, the paradigmatic model was used to connect the categories in order to favor the understanding about the investigated phenomenon. Its structure is based on the following components: phenomena, causal conditions, intervening conditions, context, strategies of action/interaction and consequences.<sup>8</sup>

It is important to highlight that the theoretical matrix underwent a validation process in September 2016, by 11 validators, all of whom were nurses. The average age of the validators was 40.5 years old, the average training time was 15.27 years and the average time of performance in the hospital area was 11.63 years. The process involved the explanation of the process of validation and request of the signing of the Free and Informed Consent Term (FICT), the completion of a questionnaire with the characterization of the validator group; presentation of the research in audiovisual device, supported by the PowerPoint software and distribution of printed material with the main findings of the research; group discussion and individual opinion for validation; acknowledgment of the participants and opening for suggestions and opinions.

The matrix, therefore, was considered validated in the Adjustment and Understanding criterion without changes. Regarding the Generalization, a validator analyzed that the theoretical matrix may have some different components when involving pediatric care and patients in intensive care units.

The research was approved by the Ethics Committee in Research with human beings; the respondents received all the information about the research, especially regarding the objectives and procedures, and were given total freedom to accept or refuse the invitation. They also signed the FICT, following the determinations of the National Research Ethics Council, and the anonymity of the participants was guaranteed, with their identities replaced by the initials of the sample groups. Thus, they were used as follows: N (nurse), NT (nursing technician), P (psychologist), SW (social worker) and D (doctor), followed by the respective interview number.

## RESULTS

The results presented in this article comprised the category Emphasizing aspects of communication before the process of death and dying, which, in the use of the Paradigmatic Model,



described in the methodology, is configured as an intervening factor to the central phenomenon that emerged from the research, namely: Glimpsing the management of the nursing care before the process of death and dying. It should be highlighted that, in GT, the intervening conditions are those that mitigate or alter the development and/or impact of the phenomena.<sup>8</sup>

The category presented is based on three subcategories: Highlighting aspects of the communication process among professionals, Addressing the process of communication with the family of the patient before the process of death and dying, and Addressing the process of communication with the patient before the process of death and dying. All of these subcategories are detailed below.

### **Highlighting aspects of the communication process among professionals**

The category presents the influence of communication on the (inter)actions among health professionals. One aspect addressed by the participants concerns the communication of the multidisciplinary team about the patient's terminality and the behaviors to be or not taken, as illustrated in the following section.

*We alert the nursing staff and I always call a professional. I always call a medical professional so that they can be with me listening to this family member's need (N16).*

As a complex phenomenon, the communication process seems to suffer contextual influence, as well as it can influence this same context in a relationship of interdependence. This assertion is valuable for the management of care while it allows understanding organizational aspects that influenced communication and, therefore, the quality of health care.

*I had a patient in palliative care, [...] when we come and call everybody, it works well. I think now people are interacting more, talking more [...]. What I think is that we are moving, it is the beginning (D5).*

The use of instruments to promote care management, such as the request of nurses' opinion to the multidisciplinary team, was a resource that emerged as a possibility to trigger the team interaction in the work process. With this, there was an exchange of information, which could occur through the formal fulfillment of the request in the interconsultation (opinion) or given in an informal way, through a conversation among professionals.

*[...] I have also oriented them not necessarily a formal opinion, but to pass me the cases. At the infirmary "x", they pass me [...]. It also happens, now not so much. This facilitates communication and work (P1).*

In this same logic, another resource used was the rounds, periodic meetings that take place in some nurseries, when the different professionals of the multidisciplinary health team have the opportunity to discuss the patients' cases and the behaviors they consider appropriate, considering the specific context of the patient and updated scientific evidence.

*[...] people use lots of rounds to talk, discuss cases [...] to get in touch with other knowledge, they even generate questions that can be developed from there (P3).*

A difficulty that may occur in the communication between professionals is related to the lack of clarity in work process relationships, especially regarding medicine and nursing.

*Sometimes the attending doctor is not a single person, it is a group or it has not made it clear if it is to invest or not in that patient and each one that arrives, every call that arrives, has a different conduct (D4).*

Considering that care for the patient extends to their family and, therefore, the communication process should also address this area of care, the next subcategory is relevant.

## Addressing the process of communication with the patient's family before the process of death and dying

The testimonies showed that the relatives of the patients in terminality, in the infirmaries, questioned the nursing professionals about the clinical and prognostic of their beloved ones. On this occasion, they showed expressive doubts and concerns about the clinical condition, especially despite the possibility of reversion of the case or the severity of the clinical condition. However, they seemed to have difficulty speaking openly about the process of death and dying.

*It has happened for a relative to arrive and talk about their family member who is hospitalized, who is very sick, 'will the treatment solve it?', these kind of things. But it never got to the point of reaching the death (N12).*

The nurse's communication with the patient's family presented, for some occasions, a relationship of interdependence with the communication process between the doctor and the family.

*The first thing, I try to understand with the doctors, talk to know what the family is aware of, to know, sometimes, to know what we are dealing with. If the family is aware, to know who is aware, because sometimes the patient does not know the diagnosis (NA9).*

The interactions and retroactions of the process of communication, health care and nursing were not limited, as complex systems, to the scenarios in which these processes occurred, because they were connected to the identities of those who were cared for. It implies the assertion that the reality outside the hospital, that is, the life dynamics of these patients and their families, had unique characteristics that could influence the work process for health. Among these issues were the family dynamics and the professional's understanding of the limitations and possibilities for the communication process to address issues related to the patient's health status, prognosis and treatment.

*You are used to dealing with the behavior, with the temper of a person and, in fact, other people appear. Sometimes you do not know how you are going to approach it. You are always in the middle of relating to one family member only, and others appear and you do not know how you are going to talk, what the family wants: 'Does the family want everyone to know? Does the family want you to restrict the visit?', Do you understand? And this process, at the time, fails because you have no knowledge regarding the opinion, the preferences of the family member and it gets complicated that way (N16).*

Different participants saw failures in communication with patients' families, especially on the doctor's part. In the field of relational skills, nurses reported that doctors in the process of communicating with families did not present sensory attitudes in speech or were not clear in the understanding of these families. Thus, they considered that this reality interfered negatively in the experience of the relatives before the process of death and dying.

*What makes me anxious, which I always comment on, is that many doctors do not tell the family clearly about terminality. Then I think it is bad for everyone. The family cannot experience it, be around, call everyone, and then they get lost. Sometimes the attending doctor, in an attendance of some sort of intercurrent, has to explain to the family about the decision to intervene or not. So imagine you having to discuss this in a moment, in the imminence of an intercurrent (NA9).*

The communication of the death of a patient to their family was usually made in the institution by telephone, when there was no companion or family member in the hospital at the moment of death of the patient. This form of communication was questioned. There were considerations that the communication of the death to the patient's family, by telephone, occurred in a mechanical, insensitive way.

*We contact the family to report the death over the phone, which is another thing that I find very complicated (N12).*



The (inter)action of nursing professionals with the family after the death of a patient was aimed at providing support and comfort, as well as information, including the possibility of donating organs/tissues.

*I think the most difficult time there is to tell the family, which is sometimes a difficult time, where we already have a complicating factor, which is having to talk about the issue of organ transplants at this time of difficulty, sadness, loss of the beloved one and you are working with the family at that time to give them news of the death (N17).*

Some reports mentioned the participation of other professionals, in addition to the nursing team, in the (inter)action with the family regarding the communication of a patient's death. They suggested that members of other categories participate in the process of communication of death to the family. They indicated that the multiprofessional team should approach the patient's family at that time.

*Inside the hospital, if it is the case of a patient who died here with the family member present, at the time the relative was here in the hospital, I think this news should be given in a team, not only the nurse, not only the doctor, but the whole team. I think this job would be better. (SW1).*

*I think there could be the participation of some other higher level professional, as a social worker. Because for us to approach the family, because it is up to the nursing, the nurse to communicate. This is a delicate part of communicating, but someone will have to communicate (N6).*

Regarding the (lack of) knowledge of the diagnosis and prognosis by the relatives of the patients, the participants made notes that, generally, the families perceived that the patient was in terminality, but there were cases where the family did not perceive or did not express an understanding regarding the condition.

*I initially approach the family, talk to the family. Usually, I try not to talk directly to the family. I try to check first what the family thinks the patient has (MA2).*

*The same has happened here in the sector when we have a death, then we go to talk, explain: 'But it was bad already. You knew that this could happen'. Or, sometimes, the person did not even expect (NT8).*

In addition to the interactions for the process of communication between the professionals in the interdisciplinary health team, the connections between this team and the patient's family, it is necessary to consider the issues related to the process of communication with the main actor of that context, that is, the patient himself/herself.

## **Addressing the process of communication with the patient before the process of death and dying**

It was expressive the amount of professionals, in this research, who reported not talking or avoiding to talk with the patient in terminality about the process of death and dying. They reported that the patients also did not look for them for dialogue, as illustrated in the following section.

*I never start talking to the patient about it, out of fear. And I even have some fear that they might come to comment on something (NT3).*

There are reports that some professionals expressed not lying to the patient but omitted information about their diagnosis and prognosis in an attempt to alleviate the severity of the situation, especially when the patient was elderly.

*So you have a forty-year-old patient, forty-five years old, who has a whole life schedule, who has a child, has a child to care for, who has everything, and you will not inform the patient? There is no way! We end up protecting the elderly a little more. Because we think they have lived through so much, why are we going to [...]. And the elderly is deep down the one who knows most of things (D4).*

It has been reported that doctors sometimes questioned whether the patient was able to receive the news of the termination of life, which generated an important problem when professionals

preferred to talk to the patient about the prognosis of terminality. Such behavior is justified because they tended to overprotect the patient in the face of the prognosis of terminality from the omission of the information, believing that they would not deal well with the news of the terminality and, with that, would tend to refuse the treatment.

In addition, the speeches pointed out that doctors, generally, in the face of a terminal illness, talked first with the patient's family. In this way, they would call the family to talk away from the patient and talked openly about the diagnosis and prognosis of the beloved one.

*And he [doctor] stays, sometimes, with this question that I have already heard: 'will the patient be able to receive this news?'. So, what does he do? He calls the family, tells the family, and does not tell the patient. Then you have a serious problem because the family tends to overprotect the patient, because they think he will not take it, that he cannot know, otherwise he will not accept treatment. This is very common (P1).*

Often, family members would ask the professionals, especially doctors, not to tell the patients about their diagnosis and prognosis. It was observed that the professionals tended to talk with the family and not with the patient about the diagnosis and prognosis. However, family members generally would not want the patient to know about their health, in an attempt to spare them from suffering. Sometimes the professional had the urge to talk to the patient about their diagnosis and prognosis, but he did not do so at the request of the family. Thus, professionals would choose to do what the family requested, most of the time.

*I think the doctor is rarely so clear with the patient. I think he is clearer with the family. I think they do say sometimes to some patients, what they have, but they do not speak so clearly of that terminality that is so imminent (N9).*

## DISCUSSION

Health care is complex because it is dynamic, multifaceted and involves different people (professionals, patients, family/community) that establish inter-retro-actions. Care is provided between/with people in different health situations, scenarios and contexts, with people who have different representations.<sup>10-11</sup>

Regarding the aspects of the communication process among the professionals, it was observed that the health team communicated about the clinical and psychological condition of the patients and sought to discuss issues to improve patient and family care. However, professionals avoided talking about death, as well as recognizing the limitations of life, since awareness of the death of the other evoked death itself, which is a part of the man's adaptation to the world by stimulating self-knowledge and self-criticism. Therefore, reflections about the termination of life and death can guide us to understand these phenomena and have impacts both on personal life and on the professional practice.<sup>2,12</sup>

Regarding the reaction of doctors to the diagnosis of a serious illness in patients, a study indicates that the question to be raised does not concern whether or not to tell the patient, but how they would share it with the patient. The professionals stated that many faced the diagnosis of a serious illness as a death sentence, mentioning the case of a cancer diagnosis. Many really associate a malignant tumor with a death sentence. However, it should be pointed out that this information must be shared with the patient, not necessarily related to imminent death. Talking about death and dying to patients, as long as they want it, is essential. It is worth highlighting that this can serve as a reflection on life and death, enabling its maturation.<sup>13</sup>

The doctor must show to the patient and their family that they will face this battle together, that they will not be abandoned and that he will seek all the possibilities to alleviate the suffering, when he cannot intervene to prolong their life, never taking away all the hopes of the patient. According

to research, the patient's (re)action does not depend exclusively on the way they (do not) receive information about their diagnosis and prognosis, but this influences their thoughts, feelings, and attitudes a lot.<sup>13</sup> An important step before being explicitly stated to a patient about their terminal illness is to try to discover their needs, strengths, weaknesses, and their (re)actions. The researcher points to the need for health professionals to face death with serenity to be able to help patients and their families, as observed in interviews.<sup>13</sup>

The request for an opinion by the nurses to the multidisciplinary team and the rounds carried out in some infirmaries showed to be resources that contribute to the approach and communication of the professionals, generating positive outcomes on the care before the process of death and dying.

There is an extensive network of connections before terminality and death. It was reported that most doctors do not expose the patient's situation to the other team members, possibly because they do not cope well with the death and dying process. However, this silence can disrupt the care provision and often makes communication difficult.

Communicating about terminality and death is often not easy as it involves affectivity. Health professionals also suffer from issues related to death. It needs to be clarified that, first of all, these professionals are human. In addition, most were not prepared by society and professional training to deal with this aspect of care. Nor do health institutions address these essential issues with workers.<sup>2,11,13</sup>

Many professionals put off talking to patients about their diagnoses and prognoses, but such postponement does not benefit the patient and may increase their isolation and pain. In addition, this behavior serves to put the professionals on the defensive.<sup>11,13</sup> While the opposite brings the nurse closer to the care of the patient and their family, making the process of dying more intimate and probably less vicarious.<sup>14-15</sup>

Regarding the process of communicating with the patient's family regarding the death and dying process, it was pointed out that some family members questioned nurses and nursing technicians about the possibility of their beloved ones getting better, but they did not usually talk openly about the process of death and dying.

Faced with these situations, not all the nursing professionals talked to patients' relatives about the severity of their illness. It was identified that the nursing communication with the relatives of the patients was significantly crossed by the doctor's communication, corroborating other studies.<sup>15-16</sup>

Regarding this (inter)action, insensitivity and lack of clarity were listed as communication failures of some attending doctors towards family members. Such behaviors made it difficult for the family members to experience the death and dying process, as well as the health professionals' performance.<sup>15-18</sup>

The characteristics of good communication with the family listed by professionals were: clarification about the patient's condition; clarification of doubts; use of language accessible to family members; empathy; objectivity and clarity; communication about Palliative Care, when the indicated is to hear the opinion of different relatives.<sup>14,17</sup>

Some professionals believe that patients do not ask about the severity of their illness by not understanding it or not wanting to know the truth and having to deal with it. However, others recognize that sometimes the patient is waiting for the professional to have the initiative to say something about the death and dying process.

Regarding the (lack of) knowledge about the diagnosis and prognosis, it is generally believed that families realize that their beloved ones are in terminality, but there are cases in which families are unaware of such a situation or do not manifest their understanding, possibly because of the denial of the situation.<sup>12,15-16</sup>

In addition, relatives often have distinct knowledge about the diagnosis and prognosis of their beloved ones. The (lack of) knowledge of the relatives generates reactions as a constant request of the nursing team and/or requests for transferring the patient to the ICU.

It was found that the intention of the family members and doctors to conceal information was generally perceived as an attempt to protect patients from suffering. Sometimes, family members may feel overwhelmed with information about their beloved ones and pressured by having to decide on what to inform the patient or not.

Some professionals defend the patient's right to know their diagnosis and prognosis, while others believe that the patient is not always prepared to know. Finally, it was identified that professionals need to be prepared to communicate difficult news and support patients and family members.<sup>12,15-17</sup>

Some evidence-based communication strategies can help communicate difficult news to patients and family members effectively, such as the SPIKES and PEWTER protocols.<sup>1617</sup>

It is believed that to think about nursing in a complex way is to see it working as a care system, recognizing the self-organization of this system, interspersed by autonomy, interdependence, inter-retro-actions among the human beings involved in caring. Thus, the health area deals with dynamism, uncertainty, unforeseen, conflicts. At the same time, the care system organizes itself from these inter-retro-actions, which integrates, at the same time, order-disorder-organization in the work routine and enhances personal, professional and organizational similarities and differences, aiming at a better integration with the social environment and improvement of the practice, evidencing the uniqueness of the nursing performance as a care profession.<sup>19-20</sup>

One limitation of this study is that it was carried out in one place, at a time and in a historically dated setting, in a particular cultural context. In addition, it was specifically focused on communication, on the care management, on the death and dying process of adults. Thus, more research is needed in the area, in different settings and with a focus on the death of patients of other age groups.

## CONCLUSION

It is considered that the objective of the research was fulfilled, since the factors related to the communication for the management of the nursing care before the death and dying of hospitalized individuals were understood from a complexity perspective.

The results of this investigation reaffirm that the interactions transform the lives of the people before the death and dying process, and that the communication developed between professionals-family-patients is permeated by orders and disorders, unforeseen, contradictions and uncertainties.

The management of care in adult medical-surgical units is a challenge for nurses, as it involves working with a multiprofessional team, in which each one has a different perspective and behavior. Therefore, the nursing care management involves the inter-retro-actions among complex human beings, who experience care from their formations and developed relationships.

From this perspective, it is important to emphasize the importance of the nurse being open to communicate with patients, family members and other professionals of the health team, because this process requires complex actions with the demand for training and permanent education, interdisciplinary action to guarantee humanization and comprehensive care.

Faced with this, professionals need to broaden their perception by being reflexive and critical towards their actions. Managing the nursing care requires a look that reinstates the whole, which considers the uniqueness of the parts and the interaction among them, thinking of the process as a living, dynamic organism with uncertainties and contradictions. The communication process, in the management of the nursing care for the death and dying process, occurs in a multifaceted and interdependent way with other social actors. However, it is necessary to think about the development of competences so that communication in this sphere can be the best possible.

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## NOTES

### ORIGIN OF THE ARTICLE

Article extracted from the thesis - "Glimpsing the management of the nursing care before the death and dying process" presented to the *Escola de Enfermagem Anna Nery, Universidade Federal do Rio de Janeiro*, in 2016.

### CONTRIBUTION OF AUTHORITY

Study design: Prado RT, Leite JL.

Data collect: Prado RT.

Data analysis and interpretation: Prado RT, Leite JL.

Discussion of the results: Prado RT, Leite JL, Silva ÍR, Silva LJ.

Writing and / or critical review of content: Prado RT, Leite JL, Silva ÍR, Silva LJ.

Review and final approval of the final version: Prado RT, Silva ÍR, Silva LJ.

### ETHICS COMMITTEE IN RESEARCH

Approved by the Ethics Committee in Research with Human Beings of the *Escola de Enfermagem Anna Nery*, *Certificado de Apresentação para Apreciação Ética*: 41743414.9.0000.5238

### CONFLICT OF INTEREST

No any conflict of interest.

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### CORRESPONDENCE AUTHOR

Roberta Teixeira Prado

enfbeta@yahoo.com.br