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Perceptions about the role of nurses in people at the end of life

Percepções sobre a atuação do enfermeiro às pessoas no fim de vida

Percepciones sobre el papel de las enfermeras en las personas al final de la vida

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Abstract: Objective: describe the perception of nursing students about the role of nurses in people at the end of life. **Method**: qualitative, descriptive study, with data collected at a private university in Curitiba. Twelve nursing students participated, through recorded semi-structured interviews. After transcription, the narratives analyzed using the Collective Subject Discourse Theory. Results: the narratives showed: lack of professional preparation, absence of support and absence of care management. As an ideal, death was shown without suffering, at home and close to those you love; with better communication, posture and empathy; personalization of service and; respect for the moment of death. **Conclusion**: it points out the importance of more studies and investments in better training for nursing professionals on the subject.
Descriptors: Death; Palliative care; Right to die; Nurses; Students nursing

Resumo: Objetivo: descrever a percepção de acadêmicos de Enfermagem acerca da atuação do enfermeiro às pessoas no fim de vida. **Método:** estudo qualitativo, descritivo, com dados coletados em universidade privada de Curitiba. Participaram doze acadêmicos de Enfermagem, por meio de entrevista semiestruturada gravada. Após transcrição, as narrativas foram analisadas pela Teoria do Discurso do Sujeito Coletivo. **Resultados:** as narrativas evidenciaram: falta de preparo profissional; ausência de suporte e; ausência de gerenciamento do cuidado. Como ideal, evidenciou-se a morte sem sofrimento, em casa e perto de quem se ama; com melhor comunicação, postura e

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empatia; a personalização do atendimento e; o respeito ao momento da morte. **Conclusão:** aponta-se a importância de mais estudos e investimentos na melhor capacitação aos profissionais da enfermagem sobre o tema, potencializando suas competências e as habilidades de enfrentamento específico.
Descritores: Morte; Cuidados paliativos; Direito a morrer; Enfermeiras e enfermeiros; Estudantes de enfermagem

Resumen: **Objetivo:** describir la percepción de los estudiantes de enfermería sobre el papel de las enfermeras en las personas al final de la vida. **Método**: estudio cualitativo y descriptivo, con datos recogidos en una universidad privada de Curitiba. Doce estudiantes de enfermería participaron, a través de entrevistas semiestructuradas grabadas. Después de la transcripción, las narrativas analizadas utilizando la Teoría del Discurso del Sujeto Colectivo. Resultados: las narraciones mostraron: falta de preparación profesional, ausencia de apoyo y ausencia de gestión de la atención. Como ideal, la muerte se mostró sin sufrimiento, en casa y cerca de los que amas; con mejor comunicación, postura y empatía; personalización del servicio y; respeto por el momento de la muerte. **Conclusión**: señala la importancia de más estudios e inversiones en una mejor formación para profesionales de enfermería en la materia.
Descriptores: Muerte; Cuidados paliativos; Derecho a morir; Enfermeras y enfermeros; Estudiantes de enfermería

Introduction

The word death comes from the Latin mortis, and means the end of life; finishing; destruction and loss. Clinical death occurs with the paralysis of cardiac and respiratory function; biological death, on the other hand, characterized by cell destruction, if death is considered in terms of only a biologist view. Brain death, on the other hand, characterized by irreversible and complete loss of brain functions, in which there is cessation of cortical and brainstem activities.[1-3]

The final phase of life can characterized by a closer proximity to death, around the last hours or days of life. Such a process is dynamic and complex, reflecting the particular response of the human body, regarding the various clinical events faced over time.[4]

Clinical death can, in the face of technological advances, postponed for a finite time, through the processes of resuscitation and vasoactive drugs, allowing the maintenance of life, even after the supereminence of brain death. However, it is noteworthy that, in addition to the biological and clinical aspects, the process of death and dying contemplates several dimensions,

among them the social, psychological, physical, and cultural ones, composing a kaleidoscope of meanings.[1-2]

These dimensions are equipped with different meanings, rites, beliefs and the study of the theme is essential in the training of health professionals involved in this process. The lack of preparation, reflections and dialogues about death, can contribute to them finding difficulties in making decisions, in face of these situations.[5-6]

In addition, the lack of professional preparation, since its formation, can result in the lack of comprehensive care, for people and families, who experience the processes of death and dying, which are limited to the biological sphere. Thus, negative sensations and feelings can evidence, characterized by sadness, fear, impotence, as well as a defensive posture, of denial and distancing from the care process.[7-8]

With the predominance of technocentrism, in contemporary times, a posture shows the interdiction and denial of death. The advancement of health technology, at the same time that arouses greater interest from patients, families and health professionals, contributes to making death aseptic, distant, silent, and lonely. Because, she moved from homes to hospitals and, in addition, the process of dying prolonged, occurring with greater suffering. Death, which started to occur in hospitals, ends up distancing people from the dying process, which sometimes accompanied by the unpreparedness of health professionals in relation to the topic, since their formation.[7-8]

Faced with this scenario, academic interest and scientific production on the subject has increased, bringing up reflections on what would consider a dignified death, promoting individual and collective reflections on the theme. Issues such as what is desired at the end of life and how the family's participation will be at that moment, should be shared with health professionals, as long as they are not desensitized to the complexity of this process.[1-2,5 -6.8-10]

Decent death has been associated with the concept of orthothanasia, which advocates emotional and spiritual support, comfort for refractory symptoms and minimization of invasive interventions, which prolong life immeasurably. Orthothanasia contemplates the acceptance of death, respect for human dignity, the participation, and autonomy of the subject and his family, with emphasis on the importance of having spaces in which it is possible to talk about the process of dying in the family and collective scenario, without interdiction or denial of the matter. In this sense, it understood that the essence of a dignified death could achieved when the individual is at peace with himself, having, as far as possible, his wishes fulfilled and being supported by the family or by a flow of affections. In addition, for that, it is necessary to invest in the training of health professionals[9,11-12].

Thus, orthothanasia should focused from the beginning, permeating the work of all health professionals, including nurses. Because, caring for people in the process of dying involves the dignity of the human being and depends on the attitude of professionals capable of respecting the pain and suffering of others, understanding the significance of this moment for those involved.13-14 For this, these professionals need knowledge and skills development to act in this scenario.[6,8]

Specifically, the nurse, from legal point of view, respect the right to exercise the autonomy of the person or his / her representative, when making decisions, which must occur in a free and informed manner. These decisions permeate their state of health and treatment, in addition to their comfort and well-being. It is also emphasized that, in cases of impossibility of communication with the patient, the nurse must respect the Anticipated Directives of Will (ADW) about care and treatment, including the situation of death and post-death.[15]

Correlating these thoughts with the training of nurses, it is highlighted that during the academic life, the construction of the students' professional identity occurs, influenced by social interactions. In addition to the influence of teachers, there is also the influence of nurses

working in practice. Thus, the students' perceptions about the professional performance of nurses influenced by the way the profession is exercised, affecting their way of thinking and acting.[16]

Thus, the objective that guides this study is to describe the perception of nursing students about the role of nurses towards people at the end of life.

Method

The study designed based on a qualitative approach, organized according to the technique of the Collective Subject Discourse (CSD)[17], and based on the Theory of Social Representation (TSR). The TRS considers the dialectical relationship between the social and the individual, so that one influences and influenced by the other in a mutual and constant way. Thus, the inner universe and its external constituents contribute to the construction of new knowledge.[18]

The research took place in a private university, located in the city of Curitiba. The participants of the study were twelve undergraduate nursing students at that university. The criteria in inclusion were academics regularly enrolled in the Nursing course, at the institution where the data were collected, in December 2019, signing Term in Consent Free and Enlightened; who had already undergone clinical practices, in which it was possible to contact situations specific to the process of dying and dying.

Students, who met the inclusion criteria and accepted to participate in the research, did not give up on the process, during data collection. Thus, academic nursing students participated in a study at a private university in the city of Curitiba, who had previously had academic experiences in caring for people in the process of dying and dying. The students invited to participate in the study in person, in the classroom, at a time previously agreed with the coordination of the course, so that it did not compromise academic activities.

For the selection, the snowball method used, in which the first participant indicates the next and so on.[19] The first expressed interest in participating in the research, after the presentation of the study objectives, in the classroom. Then, his interview was scheduled and, after the end of the interview, he indicated the next participant. Thus, data collection performed, ending with 12 nursing students.

For data collection, a script for the semi-structured interview developed, consisting of two guiding questions related to the themes of the perception of nursing students about the role of nurses with people in the process of dying and dying. The questions were "how do you see the nurse's performance towards people at the end of life today" and "how do you believe that the nurse's performance should face the process of death and dying?".

Thus, the source of data was the interview conducted at the university, in a private room, destined for this purpose. All interviews recorded, with an average duration of one hour. There was no one else in the room, apart from the researcher and the participant. After conducting the interviews with the 12 participants, the data saturation noticed, considered when there is a recurrence of information.[17] Thus, the data collection ended, and their transcription began.

Four researchers, after training for this activity, two Nursing students, and two Nurses performed the data transcription. The transcripts totaled about 50 typed pages, in which the subjects' expressions and language vices maintained. For data analysis, the DSC techniques were used. This technique seeks to make socially shared opinions explicit, through artificial subject that make up the collective discourse. Thus, according to the TSR, the expressions used during the interview can synthesized through the organization of an impersonal subject, who supports the CSD. This discourse is capable of expressing social representation on a given theme, in view of the collectivity in which research participants are inserted.[17]

The transcribed data were organized and, in accordance with the CSD, the key expressions identified, looking for the central idea, which is a name or linguistic expression that

describes, in a synthetic and precise way, the meaning, or the meanings of the analyzed speeches. 17 the central ideas explained in table 1. Moreover, the DSC, organized from the central ideas, was synthetically written in the first person singular, as recommended by the CSD technique, is shown in table 2.

It should be noted that the study was conducted in accordance with the provisions of Resolution 466/2012, 510/2016 of the Ministry of Health.[20-21] It was approved by the Research Ethics Committee, according to protocol number 3,684,508 (CAAE : 21392619.2.0000.8040).

Results

Twelve participated in the study-Nursing students. According to the participants' sociodemographic characterization, it highlighted that the female gender predominated, with ages ranging from 19 to 48 years, with a greater proportion of participants between 18 and 25 years.

Regarding experience in the field of Nursing, six participants reported having previous experience as nursing technicians, an experience that varied between one and eight years; and six others reported not having work experience in Nursing, except through mandatory internships proposed by the university.

According to the proposed objective, in this study, the individual testimonies constituted the speeches, from where the central ideas emerged, shown in chart 1:

Table 1 - Summary of central ideas

Lead Question	Central Idea
1. How do you see the role of the nurse towards the person at the end of life today?	Lack of professional preparation, with mismatches in professional posture and empathy.
	Absence of technical and emotional support for care.
	Absence of prioritization and management of palliative care.
2. How do you believe that the	Structuring individualized protocols for care.

nurse's performance should be in the face of the process of death and dying?	Better communication, posture, and empathy with staff, patient, and family.
	Personalization of care and respect for the moment of death.

Table 2 shows the central ideas and their respective DSC.

Table 2 - Central Ideas and Collective Subject Discourse

Central Idea - 01	Collective Subject Discourse - 01
Lack of professional preparation, with mismatches in professional posture and empathy	*Currently, nursing professionals do not put themselves in the other's place. They should have more respect at the end of their lives. Sometimes we see a lack of respect; exposure of the person; excessive buzz in the post and in corridors; that look of pity. This kind of thing cannot exist, because each person has his life story and it must respected. The training of nurses should include care for people at the end of life, but even teaching has become a mechanical means, as well as the routines of hospitals.*
Central Idea - 02	**Collective Subject Discourse - 02**
Absence of technical and emotional support for care	[...] people know more or less how to handle the situation. Sometimes they stand still, without reaction, not knowing what to do. They do not know how to treat the person and the family. Then they too are lost, not knowing how to deal with those feelings.
Central Idea - 03	**Collective Subject Discourse - 03**
Absence of prioritization and management of palliative care	*Nursing care is very methodical and busy. With this hospital and collection routine, there is no time for nurses to dedicate themselves to differentiated care. Routine never prioritizes someone who is dying, never prioritizes someone who is going to die. Life is what matters, so it doesn't matter to them. In practice there is a lot of rush, overload. There's a lot of fantasy about reality. When they change this structure of the nurse's work, perhaps it can be given due attention to this.*
Central Idea - 04	**Collective Subject Discourse - 04**
Structuring protocols for care	*I think there should be a protocol to followed, give direction to the nurse, because he often does not know how to deal with this type of situation. There should be a routine to be followed, but with humanization values. The nurse should know how to teach and develop techniques for this specific care.*
Central Idea - 05	**Collective Subject Discourse - 05**

Better communication between staff, posture and empathy with the patient and family	*The nurse should include the family member in the assessment, to provide better care. You should train the team so that they know how to respect that person, treat that person with respect and dignity. It is not enough for the nurse to think only of himself and the team to do wrong, to do the opposite. You can't just make your own schedule and leave. Even at the end of life, a person deserves attention. It had to be a care with all the attention, love, and affection that I could have.*
Central Idea - 06	**Collective Subject Discourse - 06**
Personalization of care and respect for the moment of death	*The service should be more personalized. We should know how to deal with the person's religion, treated within their reality. Do not look with pity that this person is dying. Make each day a special day, a good day; even in the simplest things. After all, for that person it is the end of his life, he wants to treated well; wants to feel good. In such cases, love is essential. Love what you do, love a person who is about to leave. Also, be aware. The knowledge of this stage, respecting life, history. Understand that nobody wants to be in a hospital, taking a compassionate look.*

Discussion

Faced with the first guiding question, which was "how do you see the performance of nurses towards people at the end of their lives today?" Three central ideas described the lack of professional preparation, with mismatches in professional posture and empathy; the absence of technical and emotional support for care; and lack prioritization and management care for this audience.

In relation to the lack of professional preparation, with mismatches in the professional posture and empathy towards people in the process of dying and dying, it emphasized that it is essential that nurses, since their formation, can understand this process. For this knowledge to learned, education must contemplate broader spheres, other than just biological ones, appropriating contents that interface with sociology, anthropology, psychology, philosophy, religions and even the inclusion of the self-knowledge and intimate work, involving the

emotional sphere. Formal education on matters of death and dying can contribute to the construction of new meanings and new ways of organizing and carrying out nursing interventions, aiming at a more complete human development.[5]

Therefore, in their education, it is important that nurses rescue empathy, so that they can provide support to the people under their care and their families, in a sensitive way, without generating guilt and fears, adding, also, the importance of the development of specific communication skills, which makes the link between that involved.[22-23]

Respect for people in the process of dying also permeates the assessment and fulfillment of their needs and desires, physical, social, spiritual, and emotional; assisting in solving unfinished tasks; controlling refractory symptoms; overcoming the taboo related to death, linked to the hegemonic biomedical and technical model, which can prioritize curative treatments and prolong life in any way. It is necessary to readjust paternalistic and authoritarian attitudes in the care relationship, providing clear information and working to expand access to palliative care.[11]

With regard to the lack of technical and emotional support for care, it is vital to monitor the nursing professionals who provide assistance and manage care for people at the end of life. It observed that some nursing professionals acquire some strategies for hiding feelings derived from care for this audience, including a cold interpersonal relationship, in order to avoid attachments, allowing a way to avoid further suffering.[22]

Despite the intention to remain in a professional environment, which theoretically would be exempt from involvement with the pain of the other and, despite the adoption of postures that try not to emit conflicting feelings on a personal level, such emotions fluctuate on a professional and personal level, which can affect both the scenarios. Thus, it is worth emphasizing the need to create spaces in health care institutions, so that nursing professionals can periodically vent their emotions when working with people in the process of dying and dying.[22]

For the central idea regarding the lack of prioritization and management of care for this public, it appears there are numerous factors that can hinder the management of care for people in the process of dying and dying. Among them, failures in communication between doctors, patients and family members; the lack of integration of the multidisciplinary team; the presence of patients who are not dying, in the same inpatient unit and even, in the same ward, in close beds; the excess of bureaucratic activities for nurses; the work overload and the turnover of the nursing team. In addition, the absence of continuing education and debates on the topic is described; lack of material resources for assistance; inadequate physical structure; inadequate use of physical space; gaps in the communication of difficult news; and absence of multidisciplinary care protocols.[24]

For the second guiding question, “how do you believe the nurse's performance should be in the face of the process of death and dying?” The CSD highlighted the following central ideas: the need to structure protocols for the care linked to such a process; the need for better communication, posture and empathy with the team, the patient and the family and; personalization of care and respect at the moment of death.

Regarding the need to structure protocols for the care of people at the end of life, the DSC reveals a misalignment in relation to the other central idea, which denotes the need for personalization of care and respect for the moment of death.

The search for personalization and individualization of care should not base on protocols, which depersonalize dying. An individualized care plan will based, among other issues, on the free expression of preferences for medical treatment, through ADW. This will is unique and needs a collective effort to ensure its fulfillment.[12]

The need for personalization of care and respect the moment of death is fundamental for the remaining quality of life of people at the end of life, characterizing the individualization of care. The active participation of subjects in the care process can contribute to maintaining this

quality of life, regardless of the time they have left, before death.[24] The appreciation of what is being lived by people can and should help health professionals to listen, welcome and to emphasize yourself with what people feel and live in critical moments of life. This is not an easy task, however, fundamental for the decision taken to respect the patient's dignity.[25]

The central idea that explains the need for better communication, posture and empathy, sets up the representation of the desire for this practice. It is noteworthy that the communication process in the management of care for people in the process of death involves several social actors, including the entire multidisciplinary team, the family, and the person himself. Faced with this scenario, the development of skills should be sought so that communication is the best possible.[23] The inclusion of disciplines in courses by health professionals, who addressing, with greater emphasis, themes of death and dying, may be a relevant strategy to correspond with the desire expressed in the CSD.

These themes even addressed in the National Palliative Care Policy, which promotes the institution of disciplines that address care in the face of death, both in undergraduate and graduate courses. Such policy also highlights the need to offer permanent education courses for health professionals, encouraging multidisciplinary work and promoting the social dissemination of the themes that interface with Palliative Care.[12] It also emphasizes the importance of communication, with the transmission of clear and objective information, with space for the clarification of doubts, the readaptation of the communication process, when there is a need to inform bad news, and also highlights its essential function in maintaining the therapeutic bond.[26]

Professional unpreparedness, being a point evidenced in the CSD, can enhanced with the lack of permanent education and updates on the topic, lack of knowledge and training, which may contribute to the image of the nurse's work in the face of the death process not being

exemplary. Consequently, it can reflect on trivialization, negligence, and even indifference in situations such as finitude of life, for not knowing how to deal with the issue.[27-28]

In view of the results presented, it highlighted that what would considered ideal in view of the role of the nurse, given the care for people at the end of life, is very far from the real, for the analyzed community. It is necessary to review the process of training nursing professionals, permeating the discussions involving technicality, the biomedical model of care and the medicalization of death. Debating the theme and seeking its insertion in the pedagogical projects of the Nursing courses, are actions that can contribute to the constitution of a new social representation about care aimed at people who are in the process of dying and dying.

As pointed out by the TSR, debating the topic can also contribute so that these subjects do not passively reproduce the behaviors perceived in their professional practice, and can represent the death process in a positive and less distressing way.[17] It understood that this representation could contribute especially for the improvement of care for people who are facing the process of dying.[24, 29] It is noteworthy that there is a limitation, in the study, regarding the fact that its participants, nursing students, linked to a single institution private education.

Conclusion

The present study, developed on the theoretical basis of TSR and methodological on the CSD, emphasized the perception of its participants, nursing students, about the role of nurses in end-of-life situations.

After analyzing the CSD, it is possible to state that the following representations stood out, which corroborate with studies that address this theme: the difficulty in dealing with loss and the denial of death; death as a source of fear, suffering and sadness; the trivialization of dying; life principles and beliefs as influencing collective opinion; dignified death as one in which there is no suffering and together with those you love; the lack of humanization in care;

professional unpreparedness; the absence of technical and emotional support to nurses and the gaps in academic training on the subject.

As an ideal, the CSD emphasized assistance that respects the person's biography, directed to their individual and multidimensional needs, reflected in comprehensive care; assistance capable of avoiding pain and other symptoms; humanization at work; respect for the person's wants and needs. It also highlights the relevance of effective communication between nurse / patient / family, providing empathy and compassion, which can bring more affinity in relationships, well-being, and harmony between all.

However, the importance of further studies and investments in training for nursing professionals pointed out, enhancing the specific coping skills regarding their technical and emotional difficulties for the environment in which they inserted. Thus, it will be possible to reduce the burden of stress and insecurity, which can cause defensive mechanisms in these professionals, such as denial and apathy towards the process of dying and death.

As a contribution to the reflections on care and, also, to training in the Nursing area, there is a great need for disciplines focused on Thanatology and Palliative Care to be contemplated in the academic environment. In addition, the relevance of sharing experiences, difficulties, successes, and challenges that permeate caring for the public in question emphasized, citing, as an example, the organization of study groups, language workshops, and spaces for discussion of cases and experience reports.

It believed influenced student influences his environment. It needs to integrate a collaborative culture, which reflected in health work, with a view to understanding the multidimensional health care needs of the person at the end of life, as well as their family members, caregivers and other health professionals.

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