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Educational process in palliative care and the thought reform

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Educational process in palliative care and the overhaul of thinking

Objective. To know the contributions of the educational process in Palliative Care during the undergraduate level for the professional action of nurses in the care of patients at the end of life. **Methods.** This is a qualitative research, with discursive thematic analysis, based on Morin's theory of complexity. It was attended by seven newly-trained nurses and six nursing teachers from a Nursing Undergraduate Course. **Results.** It has found disruptions and the development of new ways of thinking and caring for patients at the end of life, highlighting that these patients should be treated with therapies to mitigate their signs and symptoms until death, focusing on quality of life; moreover, their psychosocial and spiritual aspects should be appreciated. **Conclusion.** The educational process in palliative care seems to be essential for nurses, as a way of organizing and systematizing patient care. It becomes indispensable that nursing programs also provide the students with the development of the awareness of the complexity of the human being and its relationship with the multiple biopsychosocial and spiritual aspects

Descriptors: education, nursing; terminally ill; palliative care.

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Proceso educativo en cuidados paliativos y reforma del pensamiento

Objetivo. Conocer las contribuciones del proceso educativo de cuidados paliativos realizado en el pregrado para el trabajo profesional de las enfermeras en el cuidado de pacientes con enfermedad terminal. **Métodos.** Investigación cualitativa con el análisis temático discursivo fundamentado en la teoría de la complejidad de Morin. Los participantes fueron siete enfermeros graduados y seis profesores del curso de graduación en Enfermería. **Resultados**. Se evidenciaron rupturas y la construcción de nuevas formas de pensar y cuidar a los pacientes con enfermedad terminal, destacándose que estas personas necesitan ser cuidadas con terapias para el alivio de los signos y síntomas hasta la muerte, por lo que el cuidado debe centrarse en el mejoramiento de la calidad de vida, valorando sus aspectos psicosociales y espirituales. **Conclusión.** El proceso educativo en cuidados paliativos fue fundamental en la forma de organizar y sistematizar la atención de estos pacientes. Es indispensable que los programas de Enfermería también promuevan en los alumnos el desarrollo de la consciencia de la complejidad del hombre y su interrelación de los múltiples aspectos biopsicosociales y espirituales.

Descriptores: educación en enfermería; enfermo terminal; cuidados paliativos.

Processo educativo em cuidados paliativos e a reforma do pensamento

Objetivo. Conhecer as contribuições do processo educativo em Cuidados Paliativos na graduação, para atuação profissional das enfermeiras no cuidado de pacientes na terminalidade. **Métodos.** Pesquisa qualitativa, com análise temática discursiva, fundamentada na teoria da complexidade de Morin. Participaram sete enfermeiros egressos e seis enfermeiros docentes de um curso de Graduação em Enfermagem. **Resultados.** Evidenciaram-se rupturas e a construção de novas formas de pensar e de cuidar de pacientes na terminalidade, destacando-se que esse paciente necessita ser cuidado com terapias para alívio dos seus sinais e sintomas até sua morte, enfocando a qualidade de vida; ter valorizados seus aspectos psicossociais e espirituais. **Conclusão.** O processo educativo em cuidados paliativos parece essencial aos enfermeiros, como forma de organizar e sistematizar o cuidado dos pacientes. É indispensável que os programas de Enfermagem também promovam aos estudantes o desenvolvimento da consciência da complexidade do ser humano e a sua relação com os múltiplos aspectos biopsicossociais e espirituais.

Descritores: educação em enfermagem; doente terminal; cuidados paliativos.

Introduction

Palliative Care (PC) is characterized as the approach that promotes the quality of life of patients and their families facing diseases that threaten the continuity of life through the prevention and relief of suffering.[1] Such care can and should be offered during any potentially fatal chronic disease. They aim to ensure an approach that improves the quality of life of patients and their families, in the presence of problems associated with life-threatening diseases, by preventing and alleviating suffering by early detection and treatment of pain or other physical, psychological, social and spiritual problems, and even in the mourning phase[1-3] In this perspective, patients requiring PC are characterized by a problem of enormous social impact and having an increasing importance in public health. In Brazil, there is not yet a PC structure adequate to the existing demands, both quantitatively and qualitatively.[4] Among the difficulties for the use of PC in Brazil, there is the way health professionals understand the health-disease process, death and dying. The scientific, technical progress of health not only increased the hope of living more and better, but also it generated difficult and complex situations about the end of life.[5,6]

Science prioritizes the pursuit of health and healing, understanding death as a failure and defeat. In diseases with slow development and poor prognosis, treatment may be more painful than the disease, and obstinate behaviors that are characterized by the continuation of healing

treatments may occur, even when it is no longer possible, leading to a medically slow and prolonged death, accompanied by suffering.[7,8] In this sense, it is not possible to think about the possibility of effective use of PC without thinking and rethinking the training of health professionals in the care of people in the death and dying process. When researching how PCs have been used in the categories of work in medicine, social work, psychology, and nursing, it has been shown that nurses refer to feeling unprepared to deal with patients who are in the dying and dying process. This lack of preparation contributes to inadequate communication with the dying patient because nurses sometimes avoid talking to the patient or giving him apologies and promises of recovery that are not true.[9]

In a study carried out with nurses who work in a PC unit, they affirmed to recognize as fundamental to adequately assess the patient´s pain for an effective care to cancer patients and in PC. However, they reported difficulties for this evaluation, both for their lack of knowledge and for the lack of specific protocols for nursing in assessing the pain of patients with cancer.[10] Thus, based on a contextualization of the Brazilian reality in PC, it is believed the need to rephrase the way how this theme has been predominantly addressed in nurses´ education. Thinking from the complexity proposed by Morin, when he states that the overcoming of the crisis in which mankind is found must be sought from education through a reform of thought through a reform of teaching, it is possible to reflect that the mission of the education is not to transmit mere knowledge, but a culture that allows understanding the human condition and helps to live, favoring an open and free way of thinking.[11]

In the perspective of complex thinking, it is considered that it is not enough that the PC theme is present in a subject or as content to be developed in a subject. It is necessary that the principles underlying this philosophy of care are present transversely in undergraduate curricula throughout nursing education. Among these principles, it is possible to visualize aptitudes and domains such as the sensitivity to deal with the human being, understanding the different aspects that involve the process of dying; the respect for the patient´s autonomy; skills for dialogue and to deal with feelings and emotions; solidarity; the social commitment; ethics; the transverse and interdisciplinary collective work, the acceptance of death as a life process and the knowledge for the management of symptoms and pain control.[11] Thus, it is understood that the possibility of an educational process in PC will only be achieved if the predominant paradigms of the university are questioned and rethought, enabling the exercise of thought. Morin[11] proposes a reform in education that leads to the thought reform, and the reform of thought to the reform of education in the university.

Therefore, it is believed that the knowledge of how the educational process has influenced the professional practice of nurses in an undergraduate nursing course that offers a PC subject can contribute to the care of the terminal patient, to the strengthening of the need for insertion of PCs into nursing curricula, as well as identify possible gaps that can be strengthened in this educational process. Therefore, seeking to qualify the care of patients who require PC, the following research question emerged: How did the educational process of nurses in PC, in undergraduate courses, contribute to their performance in the care of terminally ill patients? Therefore, the objective of this study was to know the contributions of the educational process in PC, in the undergraduate course, for professional work of the nurse in the care of terminal patients.

Methods

The research used a qualitative approach, based on the complexity of Morin. It was developed at the Undergraduate Nursing Course of the Universidade Católica of Pelotas. The study participants were 13 subjects: 7 were nurses from the course under study, who attended the course of PC and who work in the care of terminally ill patients, and 6 teaching nurses who work in subjects with the approach to terminology and PC. The subjects

agreed to participate in the study, allowing the recording of the interviews and the dissemination of data analyzed in scientific areas. Data were collected through a semi-structured interview, with prior contact with the subjects, informing them about the research objectives and, through their acceptance, day, place and time were scheduled for the individual interview, according to their availability. The interviews, recorded by a voice recorder, focused on the topic of death, terminality and PC in training, preparation and experienced difficulties in the care of terminally ill patients, among others. The statements of the graduates were identified by the letter E and the teachers by the letter D. No other identification was used in the speeches to ensure the anonymity of the study informants.

Data analysis followed the discursive textual analysis. First, the data were unitized, by fragmenting the interviews into units of meaning. After these, they were categorized and organized into the production of a textual structure constructed by categories and subcategories, which included the description and interpretation of the data, expressed through written productions.[12] Ethical aspects were respected, ensuring the protection of rights according to the recommendations of Resolution 466/12 of the National Health Council, with the approval of the Research Ethics Committee of the Federal University of Rio Grande, according to opinion Nº 97/2013.

Results

From the data analysis, the following categories were constructed: The educational process of PC and ruptures in the way of thinking about care in the terminality and the thought reform and the PC presented below.

The educational process of PC and ruptures in the way of thinking about care in the terminality

The educational process in PC contributed to the construction of spaces for reflection on the issues that involve caring for people with life-threatening and poor prognosis. The graduates emphasized their process of approaching the assumptions of PC philosophy, such as the need to improve and maintain the quality of life and to positively influence the course of the disease, as perceived in this testimony: *A very shocking case in my performance was a 45-year-old female patient. She had an intestinal necrosis, and her bowel was very short; so, she stayed in the hospital for a couple of months with parenteral nutrition and from these two months, she made the decision that would stop everything and go home to stay with her daughter. It was very shocking to the entire staff; In fact, we did not accept such behavior at the time; and when, then, I studied a little more about palliative care, so I understood, that at that moment she had that right. This acceptance came to me more when I did the subject until then I could not understand it. Today I can; Today, I understand, in fact, that for her to remain here for an indeterminate time, with a parenteral nutrition was not provided a life with quality. She did not have the family relationship; the daughter had been able to come here only once; A five-year-old girl. So today, I understand, but at the time I had quite a difficulty* (EPC).

It is emphasized that improving the quality of life in PC means to prioritize the patient in his subjectivity, respecting his desires and needs, maintaining the coexistence with his relatives, controlling the symptoms and improving the course of the disease. Moreover, they demonstrated that the PC educational process seems to have provided space for reflection on care in terminality and the importance of the professional to help patients understand their illness, to discuss the process of their finitude, and to make important decisions to live better their time remaining, as noted in the following testimony: *I had such difficulty [...], I usually say that the subject really has changed a lot; I had even difficulty in accepting death; even the way of thinking about accepting my death or that of a family member changed after I did the Palliative Care subject. It has changed, the way we talked about supporting the person, the patient as a whole, helping him understand,*

accepting, preparing, I think this causes us to have less resistance to death (EPC).

Similarly, teachers were mobilized by student demonstrations not only to reflect and insert the topic of terminality and PC in the subjects, but also to strengthen and to be instrumental in participating more actively in this educational process for care in the terminal patient: *From the moment that the subject was placed in the curriculum and the students began to study, the students who had passed, began to make this demand and it was where the need arose, in my case, of getting Knowledge, because students began to bring these issues. So, sort of out of obligation, I started to get more of that. Moreover, then, I see that the students bring the need to discuss palliative care in the different subjects and I think we end up doing it, but more inside the hospital* (D). *I always try to address in the Child Health subject the issue of terminality, because I think that terminality you have to think it as you think birth. So, there is no way for me that is already on me, so I always approach it. Yesterday, there was a lesson, even for the students, that it was kind of shocked. I worked on the health of the child focused on pediatric oncology, because, more and more, we have more children diagnosed with cancer... because I think it is important to graduate to this market that absorbs, needs people who have sensitivity to understand this process and to deal with it, not to go away, to develop the skills also to deal with the terminality of children. So, I bring all the questions of treatment, approach, diagnoses, nursing diagnoses, during the treatment process, chemotherapeutic, radiotherapeutic, and surgical, and then, what I put it, around seventy, eighty percent of children with a diagnosis of cancer progress to cure, but from twenty to thirty per cent they develop into terminality. So, in the end, I bring the whole question of palliative care with this child that the diagnosis progresses to terminality* (D).

Despite the recognition of terminality and that the cure is no longer the purpose of the actions of health and nursing workers, manifestations of discomfort for not using cardiopulmonary resuscitation measures in a terminal patient can be noticed; in the reference of crying, when discussing this theme; as well as in the feeling of obligatoriness of the teacher to seek instrumentalization for care in the terminality. These manifestations of suffering seem to reflect how heavily the biomedical paradigm is inscribed in interviewees. *When I did the Palliative Care subject, I was one that said I had to reanimate the patient, what was that it was life: stop it, you have to go and call the doctor, try to revive him. Then, on a day-to-day basis, you will see that you have nothing else to do, that you will prolong the suffering of the patient. You will reanimate the patient and, soon enough, the patient will stop again, there is nothing to be done! That the patient´s time has come; but it took me a long time to accept this. Talking to the teacher, she was telling me there are things we cannot do. It arrives, at a certain point, that no longer depends on you. So, what do we have to do? We have to give that support to the patient, the best patient. However, after that, there is nothing we can do. So, at first, it was very complicated, I cried in Palliative Care classes* (EPC).

In this perspective, the care in the terminality still constitutes a challenge, since the education of the nurses prioritizes the death like professional defeat. The construction of the knowledge for the care in the terminality in the graduation made it possible, in a more systematic and emphatic way, to the graduates of an educational process in PC, to question, and put in doubt, how the care has been occurring in the terminality, allowing them to visualize and to implement other possibilities, such as when the cure of the disease does not seem possible, it is important to prioritize therapies that do not cause more discomfort than the disease, with the goal of promoting comfort and a dignified end of life: "Recognition that it is a period when people are no longer seeking healing." If we did not have this subject, perhaps, I would not know how to act; I would treat him with the same condition as a patient who has conditions of rehabilitation... that it is not that question of bringing health to him, but to bring

about that patient´s condition to be well, to feel good, to say goodbye in a good way (EPC).

Thus, ruptures with the Western culture system of ideas and the biomedical model involving death and dying were evidenced in the interviewees´ statements. Among them, there were the recognition of the uncertainty of cure being reached, changing, as the disease progresses, the perspective of healing to the perspective of care; that the patient in terminality needs to be taken care by the use of therapies for relieving signs and symptoms, so that he can live well until the moment of his death; of the need to consider the psychosocial and spiritual aspects of the patient. This perspective of care is emphasized in the following statement: *To do what he wants, right? Leaving the family member with him, not being too restrictive of family members, caring for pain [...] especially in pain. Of course, you must take care of the food, the nutrition, right? Besides the skin, integrity, everything, only the main thing is the care with the pain and the part of spirituality, in the sense that the preparation of it in relation, right? Because no one is prepared for death, right?* (EPC).

The thought reform and the PC

The discussion of PC for terminally-treated care allowed the estrangement of standardized practices in hospital institutions, such as, not dismissing care measures that are routinely offered to patients with a prospect of cure, and may be neglecting care to the patient in the process of dying and of death, as can be observed in EPC's speech: *You see. So, for example, there have been cases of me saying, 'Oh no ... that is SPP or ... it is care ... it's ... patient that is going to die, I do not know what; in a little while we will go and give some medicine'. However, he is an equal human being, right?* Thus, the understanding of the needs of patients in the terminal seems to have allowed a differentiated action and aimed at the maintenance of the patient's well-being, in the care of the biological aspects, until his death: *I took a patient to the medical clinic that was in a terminal phase; We treated him like a normal patient. What is a normal treat? Ah, it did not make any difference, because he is in the terminal phase, not..., the patient is short of breath, ah he is in the terminal phase, he has shortness of breath, understood! I am going there, I am going to change his oxygen, give a better quality to the patient, better support fo ... He is going to die, but he is going to die, but do not leave it there, God willing... give a qualityILife better, in fact, better death* (EPC).

Nurses who have undergone undergraduate PC subject report changes in their thinking, care for terminality, recognizing the relevance and need to consider psychosocial aspects, talking to the patient about the issues of death and of dying, supporting him and contributing to closures that allow a dignified death, can be done: *Regrading the patient, I talk to him, if he does not have any will, if there is someone he fought with a long time ago and If he wants to see, if he does not want to see, these things... if he had any place he wanted to go.... there was a patient that I came in more in touch. Then I was always on his return, talking, right? Asking things for him, remembering things, his children, what it was like for his children, that job. Because it is also a thing that... it is time to reflect on life too, right?* (EPC).

From the discussions provided in the PC subject, and according to the statements, each seems to construct and reconstruct, from their conceptions, perceptions, and experiences, the knowledge for care in the terminality. In the speeches, values in the PC philosophy were identified, and they consider the complexity of care in the terminality, going beyond the sick body, such as the need to care for the individual in its entirety, considering psychosocial and spiritual aspects and recognition of the finitude of his life. In this perspective, the care given to terminally ill patients occurs in different ways, allowing their discussion and reflection: *When the patient is lucid, conscious, he can talk, we open a space for him to tell his story... most of the time, in my point of view, he does not accept terminality or death, because no one accepts that way from one moment to the*

next. So, we try to talk to him; I have had students who have had great success in this regard, who have been able to speak even of spirituality with these patients. The patient opened up his perspective, that he was ready, that one day he knew he was going to die, that he believed in God, that he had a better place for him, but that he had to go through some things here and he had to finish. That; and of course, we, within that purpose, we do not explore the religion of the people, but rather that conception of improvement, even if that improvement is death (D). Also, the teachers' statements highlighted the importance of considering the patient in its entirety; the interest in knowing whom this patient was today, knowing his history so that he can take care of him more adequately, also demonstrating a recovery of the valorization of humanity that composes the subject, beyond the biological.

Discussion

Educational processes need to focus not on full heads but well-headed heads that is, those who develop a general aptitude to situate and address problems. This aptitude relates to questioning, to doubts, to the "ability to rethink," to problematize.[11:22] Often, instruction annihilates curiosity; using general aptitude means appropriating another educational perspective that encourages one to instigate the fundamental problems of our condition and our age. The well-made head must also connect knowledge, giving it meaning. Thus, an object, when studied, cannot be isolated from its context, which Morin, using the concepts of biology, calls ecological thinking, in the sense that it places every event, information or knowledge about inseparability with its environment - natural, cultural, social, economic and political. This perspective allows perceiving relationships and interrelation between each phenomenon in its context, relationships of reciprocity between the whole and the parts, seeking to understand how a local modification affects the whole and how a modification in the whole has repercussions on the parts.[11]

Even though ruptures have been evidenced, manifestations that still denote resistance in the complete acceptance of the PC philosophy of end-of-life care have been noticed in some statements. These ruptures with dominant thinking are possible in the view of complex thinking when it is recognized that errors, uncertainty, and illusion are part of everyday problems, and it is fundamental for the thought reform to learn to deal with them.[13] The model of health care in Brazil and the organization of undergraduate nursing courses are still predominantly based on the biomedical paradigm. This model, on the other hand, unidimensionalizes knowledge by absolutizing the dimension of healing,developing the illusion that healing must always be sought, regardless of its real possibilities. Thus, care seems to be centered on the sick body, not the individual.

The hologrammatic principle of complex thinking enables to understand the perception of death as a professional defeat. The hologram brings the idea of wholeness; the smallest point in the image contains almost all the information of the represented object; so, when you see a hologram you cannot dissociate the part and the whole. The part is on the whole, just as the whole is in part.[14] Thus, the biomedical paradigm is strongly inscribed culturally in the nurses who know, think and act from it, since each, in its singularity, contains in a hologrammatic way the all of which he is a part and at the same time part of it. In this perspective, Western culture, also registered in nurses and teachers, has the belief that a quality medicine is one that provides the best and most modern diagnostic treatment, with the expectation that there will always be better modalities in the future, strengthening the hope that today the cure is not possible, but perhaps tomorrow it must always be sought, even in extreme situations and that bring deep suffering to the patient.[15,16]

It is known that knowledge is not a copy of the reality, but a translation that is reconstructed through perception. The perception of each nurse is the translation and reconstruction of signals captured and encoded by the senses. In this way, perception represents the world view, its

subjectivity, composed both of fears and desires, of each subject, interviewed, so that it is subject to errors. The fears and desires that surround the complexity of finitude multiply the risks of error, because, at the same time that death is biological, it is impregnated with culture and predominantly, denies our mortality.[14] It is observed the advance in the technologies of the Science and poverty in dealing with the fundamental issues of humanity.[14] Meanwhile, nurses who have graduated and who have undergone PC subject, in reporting strangeness of standardized practices in hospital institutions, demonstrating the development of their sensitivity to identify that these patients need to be cared, for a dignified death, for the rescue of humanitarian issues. Problematizing, to be surprised by daily facts, with established relationships, to be intrigued by what is considered natural, demonstrating the need to review the rationalities imposed by society and also by the very construction of subjects, nursing workers.[17] Also, recognition of mortality allows the confrontation of the uncertainty of life, translated by the uncertain destiny of each, recognizing the limits of knowledge. No matter how much has been evolved in the discoveries for the cure of diseases and the management of chronic diseases, maintaining the quality of life of the individual, some are still incurable and with poor prognosis, hindering to control by the curing treatment programs. The nurses, during their training, must learn to deal with these uncertainties and apparent failures, developing skills to strategize, from the care needs of each patient. The strategy continually seeks to gather the information collected and the accidents encountered during health care.[11]

It is understood that dealing with the uncertainties in health care is to recognize that any treatment, once initiated, is unpredictable as to its results, since it is inserted into a game of interactions and feedbacks in the environment in which it is carried out, that can divert it. The cure and even lead to an outcome contrary to what was expected (death).[13] The exercise of thought, based on the philosophy of PC, enabled the student to reflect on the complexity and multidimensionality of the patient in the process of dying and death, considering, besides biological needs, the social, psychological, family and spiritual dimensions, recognizing that they are not isolated but are interdependent. It is necessary to develop the student´s ability to consider the patient´s human condition, which can be understood by the construction of the consciousness that each belongs to the human species, being at the same time a cosmic, physical, biological, cultural, cerebral, spiritual human being.

As limitations of this study, there is the non-inclusion of other categories of health professionals. Interdisciplinarity is one of the principles of palliative care, producing new studies about the relationships among these professionals can contribute to the construction of strategies in the care of terminally ill patients, enabling a dignified death. Also, the performance of other researches in nursing courses that investigate experiences of the educational process in palliative care can contribute to a better understanding of this subject.

The conclusion of this study shows that the educational process in a PC subject has contributed to the care of terminally ill patients. It was evidenced the construction of new ways of thinking and caring for patients who experience the process of dying and death. Among these new ways of thinking, it should be pointed out, as more relevant, that the patient in the terminality needs to be taken care by using therapies to relieve their signs and symptoms, so that he can live well until his death, focusing on the quality of life; the need to consider and value the psychosocial and spiritual aspects of this patient; and also the strangeness and discomfort regarding the non-use of measures of care and comfort. The work also demonstrates that the PC education process seems essential for nurses as professionals who care for people throughout their life cycle, health and illness situations, life and death, especially if they consider issues so present today related to the development of science and the consequent prolongation of treatments of cure of patients in the terminality, through means considered

disproportional and extraordinary, causing extreme suffering to these patients, their relatives and even the professionals who attend them.

For an educational formation for care in terminality, considering how terminality and death are commonly perceived and experienced in Western culture, it is necessary to have more organized and systematized spaces, to trigger doubts and questions to reflect on the issues involving death and dying. In this sense, for ruptures with the biomedical paradigm and advances in the quality of care in the terminal patient, it is considered essential the development of the consciousness of the complexity of the man and the interconnection of the multiple biopsychosocial and spiritual aspects. It is critical that education is oriented toward building awareness that all these components are important and need to be involved in care.

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