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Original Article

Meanings attributed to palliative care by nursing undergraduates

Significados atribuídos por graduandos de enfermagem aos cuidados paliativos

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Keywords
Palliative care; Intensive care units; Students, nursing; Bioethical issues

Descritores
Cuidados paliativos; Unidades de terapia intensiva; Estudantes de enfermagem; Temas bioéticos

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Abstract

Objective: To reveal the meaning given by the students of the fourth year of nursing undergraduate course in the experience of palliative care.

Methods: Qualitative study carried out in a population of 33 nursing undergraduates who attended the curriculum subject of nursing care for critically ill patients. The interviews were transcribed and analyzed using the methodological strategy of the Collective Subject's Discourse.

Results: The results depict the professional training that is focused on the biomedical and curative model of care, as well as unprepared to face the situations of death and dying in the context of palliative care.

Conclusion: The following meanings were unveiled by undergraduates: feelings of powerlessness and frustration in dealing with death, the dilemma between being a nurse and being a teacher and the difficulty in dealing with family members of patients in palliative care.

Resumo

Objetivo: Desvelar o significado atribuído pelos alunos do quarto ano de curso de graduação em enfermagem à experiência de cuidados paliativos.

Métodos: Estudo qualitativo realizado em população de 33 graduandos de enfermagem cursaram a disciplina curricular de assistência de enfermagem ao paciente crítico. As entrevistas foram transcritas e analisadas utilizando-se a estratégia metodológica do Discurso do Sujeito Coletivo.

Resultados: Os resultados retratam a formação profissional focada no modelo biomédico e curativo de assistência, além do despreparo para enfrentar as situações de morte e morrer no contexto da assistência paliativa.

Conclusão: Foram desvelados os seguintes significados pelos graduandos: sentimentos de impotência e frustração ao lidar com a morte, o dilema entre ser enfermeiro e ser docente e a dificuldade em lidar com os familiares dos pacientes em cuidado paliativo.

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Introduction

Scientific and technological advances that occurred in recent decades, associated with the development of therapy have contributed to the institutionalization of death in intensive care units.

However, the assistance model recommended in these units focused on interventionism and cure of the disease does not allow all the aspects of caring.[1] Especially with terminal patients who, at any given time, despite the use of highly sophisticated resources for maintaining life, have all therapeutic possibilities exhausted because of the evolutionary picture of the disease.[2]

In this scenario, palliative care is the modality of assistance in the end of life, grounded in a model of total, active and comprehensive care, legitimized by the right to die with dignity.[3]

The care in the context of palliative care differs from the curative because it reaffirms life and regards death as reality. Its aim is to improve the quality of life of both patients and their families when facing an advanced illness, by the means of prevention and relief of suffering, treatment of pain and enhancement of culture, spirituality, customs, values, as well as desires and beliefs that permeate death.[4,5]

Although there is scientific evidence on the need to prepare graduate students to face death, in the curriculum of higher education institutions of the health sector, the contextualization of this thematic has not yet been ensured in a consistent and realistic way, as shown in the literature.[6]

The teaching methods in most undergraduate courses of the health area still remain in the traditional model, often decontextualized from reality and focused on the pathophysiological technical aspects of the health-disease process. Thus, the way of caring keeps based on the Cartesian model of care, that is mechanistic and focused on healing and rehabilitation of the disease.[7]

Therefore, the death still bothers and challenges the omnipotence of health professionals, who are only taught to care for life, but not for death.[8,9] Dealing with death is distressing and exhausting, generates feelings of helplessness, frustration and insecurity since professionals are not prepared to deal with all the negative and ambivalent feelings present in the situation.[8]

In this sense, fighting death may give a false sense of power and control, and when losses occur without the possibility of dealing with grief, one of the consequences may be to get sick because of the excessive burden of suffering without elaboration, and often without space even to take care of the pain.[10] This fact forces us to rethink values and consider the broader notion of life, taking into account the spiritual dimension of the human being and the uniqueness of each being.

The objective of this study was to reveal the meaning given by the students of the fourth year of nursing undergraduate course in the experience of palliative care.

Methods

It is a descriptive, exploratory study of qualitative approach. The choice of this approach was due to the option to understand the meanings, motives, aspirations, attitudes and beliefs supported in the nature of the object of the study.[11]

It was carried out in the undergraduate nursing course of a public university in the state of São Paulo that has activities of care, teaching and research. The subjects consisted of enrolled students who attended the discipline of nursing care for critically ill patients (taught in the seventh semester), with internship experience in adult, pediatric and neonatal ICU.

Four guiding questions were designed with the objective to make students reveal their experience in caring for patients in palliative care hospitalized in intensive care units, namely: Tell me, what did the experience of caring for patients in palliative care mean to you, throughout the discipline of nursing care for critically ill patients?; In your perception, what contributes to facilitate the assistance to patients in palliative care?; In your perception, what were the greatest difficulties faced when providing care for patients in palliative care?

After the interviews, the speeches were transcribed and analyzed using the methodological strategy of the Collective Subject's Discourse.

The development of research followed national and international standards of ethics in research involving human beings.

Results

In the second semester of 2012 the interviews were made with all enrolled students (total of 33). Among them 97% were females, aged between 21 and 27 years, 23 years old on average.

From the analysis of the interviews transcripts were identified the central ideas and the key phrases. The speeches of the three themes that emerged from the guiding questions were also organized. Below are presented the themes with their respective central ideas and the Collective Subject's Discourse:

Theme 1. Experiencing the process of caring for patients in the context of palliative care

Central ideas:

- Unique experience as an undergraduate;
- Complex care;
- Fear, insecurity and immaturity;
- Possibility of providing comprehensive care;
- Emotional unpreparedness;
- Perception and appreciation of the pain of others;
- Concern on offering death with dignity;
- Security transmitted by the teacher;
- Importance of the relationship with family members.

Collective Subject's Discourse

Caring for a patient in palliative care is quite different, it's very complicated, you can read 500 thousand articles, you can look in the literature, but it is a situation you will never know unless you experience it. Now I can look at caring in a different way, it used to be a medical issue and I focused on the problem, now I look at the patient as a whole. It is very complex; in the beginning we are afraid and insecure as, besides personal blockages, there are many devices and a lot of technology. I used to be very insecure during procedures, felt a little afraid of causing something to the patient, some discomfort; they are people and we want them to be well, but at the same time we are still quite immature. Although we are in the fourth year, we still do not have enough emotional background to take care of this type of patient, but with the mentoring teacher it gets smoother. For me, it also brought the appreciation of the pain of others, now I value much more the situation of that person who is not able to talk, move, and interact. The professionals of the nursing team are the only ones in this area that have perception of the pain of others. I learned to give more value for life, for the patient, even knowing there is no more healing, there is no more prognostic. You learn to give more value for life, for your patients, even though you know they will not be cured and there is no prognostic, you try to give the best you have to contribute to a death with dignity. One should also be sensitive to realize that the patient is placed in a social environment, and nursing care must learn to deal with the pain of the family. It was like caring for a patient with a good prognosis; while life exists, care exists and concomitantly, there are us, nurses.

Theme 2. Facilities recognized by undergraduates in the context of palliative assistance

Central ideas:

- Teaching practice
- Interdisciplinarity
- Communication
- Love for the profession
- Systematization of nursing care
- Concern about death with dignity
- Humanization in care

Collective Subject's Discourse

To provide any kind of assistance we need to be sensible and put ourselves in the place of patients because you will do to others what you would like them to do to you. Having teachers by our side also facilitates care as they transmit security. When performing duties, the interaction with the interdisciplinary team facilitates care because there is sharing of knowledge. Communication is key, a facilitator

of care and essential in the shift change. The systematization of care made the assistance easier during the internship because through it we were able to undertake a complete service and collect important information that served to all staff. Humanization and respect are essential and whenever possible, the family was allowed to remain with the patient at this delicate moment. We cannot think only of healing, we have to think about providing humanized care, so that patients have a death with dignity. In order to work with palliative care one must love the profession to provide assistance of quality.

Theme 3. Palliative care: feelings, difficulties and necessities

Central ideas:

- Difficulty in the relationship with family members;
- Difficulty in dealing with death;
- Difficulty in establishing non-verbal communication;
- Feelings of powerlessness and frustration;
- Concern about death with dignity;
- Complexity of care;
- Incomplete information in medical records;
- Failures in interpersonal communication.

Collective Subject's Discourse

For me the biggest difficulty of assisting these patients is to know that they will go. The fact of dealing with death is itself complicated, because at first comes the feeling of powerlessness; it is difficult to accept the idea that your patient, the one you often cared for over a long period, with whom you have a bond, is there with you, but there is no longer the chance to offer a curative treatment. We, health professionals, have a blockage with death that must be overcome; we finish graduation wanting only to heal and to save lives, but in palliative care we have to understand that we should offer the best for the patient to die with dignity. The theme of "death" must be treated very well in the classroom; we talk a lot about life but no one speaks of death, it is treated as if it was not going to happen to anyone, to any patient, and when you care for a patient in palliative care death is very close. We must also realize that time is a facilitator and it causes us to shift to accept death more easily. Another difficulty is that these patients do not interact with you, they are totally dependent, and a lot of people are needed to treat one patient only, besides being quite complex. On the other hand, dealing with the family is very complicated because they are very fragile and in university we do not learn to manage this kind of situation. The patient's impossibility to communicate also hinders the assistance, as it is important to know the feelings of patients; whether they are in pain, cold or hungry, among other sensations. In order to do so, we must use all the knowledge in communication that was acquired during the first years of university. Incomplete medical records also hamper the transmission of information about the patient, apart from communication problems among the staff team that should be interdisciplinary.

Discussion

This study made it possible to reveal the meaning given by the students of the fourth year of nursing undergraduate course in relation to the experience of caring for patients in palliative care.

Despite the recent construction of this philosophy, there is a considerable number of studies on the issue in all levels of care in the country, especially after implementation of the National Program for Pain and Palliative Care.[12] However, the gaps in the training of health professionals have been identified in the literature as a barrier to the care for patients that are outside the therapeutic possibilities of cure.[5]

Palliative care transcends the traditional care model as it is guided by a holistic, interdisciplinary, humanized approach without interventions to advance or postpone death. The concept of death that still prevails in the academic and professional fields is related to failure because they are taught to take care of life and not of death,[13] as evidenced in the reports of participants.

The death is still considered a defeat, it is as if there was an imaginary fight in which dying means losing the battle.[14,15] Palliative care does not necessarily determines the failure of health interventions, but it is a different care approach, which aims

to improve the quality of life of patients and their families through the relief of pain and suffering, symptom control, together with psychosocial and spiritual support.[5]

Despite these considerations, feelings of helplessness and frustration when dealing with death were revealed in the reports. These data were corroborated in a study carried out with undergraduates who cared for terminally ill patients, and that attributed the difficulties to their own inability to accept death, their unpreparedness and inexperience.[16]

Given this context, the national education guidelines for undergraduate nursing courses bring the need for training professionals who are ready to face death and qualified to provide care based on ethical and humanistic principles.

In the discipline of nursing care for critically ill patients, part of the program is an organized space for guidance and discussion with the group about the difficulties experienced in the internship, especially the ones related to dealing with death. It is noted that perceptions are subjective and individual, and often linked to previous death experiences of loved ones who were hospitalized in the intensive care unit in similar conditions.

In this process, the undergraduates begin to relive the event that occurred with loved ones and the hitherto veiled difficulty in dealing with the fact emerges, because the way people die remains in the memory of those who are still alive.[17]

To do so, the cumulative social experiences of each student and their social context must be considered, in order to build a welcoming environment from there, where students feel part of the whole and are totally open to new learning. In addition, the teacher must be aware that it is not just a matter of treating current contents in the classroom, but also rescuing knowledge from a broad perspective, so that students can interpret their experiences and their learning in social life.[18]

It is also a fact that there are still many questions about how the process of death and dying has been worked in the training of nursing undergraduate students, because the education for caring for people in the dying process requires consideration of the human existence, about the act of thinking, and acceptance of one's own finitude.[19]

Thus, should also be taken into account the preparation of teachers for approaching the subject during the internship, when in occurrence of death. A study on death in hospitals showed that nursing faculty acts without reflection in such circumstances, often separating actions from feelings.[20]

At this time, there is the dilemma between being a nurse and being a teacher and with that, the attitudes expected from the professional as well as the acceptance of students are not always put into practice because they also depends on one's conception of death. [19]

Death, besides being a biological event, is also a social construction that can be experienced in different ways by professionals according to the meanings shared for this experience, since they are influenced by historical, social and cultural contexts. Therefore, it should be conceived as a process and not as an end, and thus be worked as such throughout the undergraduate course.[21]

The teaching activity is the foundation of a good education and contributes to the construction of a society that thinks and transforms. However, for this to be possible, teachers must assume their true commitment and face the path of learning to teach, a responsibility that needs to be worked on and developed.[22]

Also bearing in mind that caring is not a simple task or relationship, but a two-way street in which professionals are continually challenged to teach, learn and have a conscious dialogue, whether with the client, the family or the interdisciplinary staff.[23]

In the analysis of interviews it was possible to grasp the difficulty of students in dealing with the families of ICU hospitalized patients inside the context of palliative care. In this context the family should be understood as a social unity that may or may not have legal or cosanguinity bonds with patients, and whose involvement is essential for the humanization of care.

Even when the family is emotionally shaken and weakened it continues to occupy a prominent role in the lives of patients, contributing with making them feel protected, safe, loved and supported in this situation of immense frailty.

In the terminal phase of the disease, the families often hide their feelings from patients, in an effort to transmit false joy and not demonstrate grief with the proximity of death.[24] Recognizing the uniqueness of the patient and their loved ones in this time of their lives requires from professionals a profound respect for the human condition and feelings about death, as well as consideration for the demands of care, and these should all be taken into account in the formation of the future professional.

Communication is the cornerstone in the context of palliative care and an integral part of health care, which is not just only an exchange of messages. It is also a subjective and complex process that occurs among people with different experiences, cultures, values, interests and expectations who express unequal thoughts.[25] Therefore, communication should be valued and encouraged.

The perception of nursing students attributed to the experience of caring for patients beyond therapeutic possibilities of cure portrays the training focused on a biomedical and curative model of care. The analysis of the speeches shows that participants are not prepared to handle and experience the process of death in the ICU, although some participants have reported the concern in offering a death with dignity.

Although the discipline of nursing care for critically ill patients has space for reflection on the theme in its timetable grid, as suggested in the literature, the results show that maybe this is not enough to meet the demands of forming professionals and building their own knowledge.

Education for death should also address the awareness of students to feelings and reflections about the subject in a broader way and an approach that disconnects it from the hospital context only, as well as theoretical and multidisciplinary approaches that bring the richness of various points of view.[10]

In this paradigm shift, a range of information must support teaching in undergraduate courses and it needs to be disseminated and combined with a knowledge that does not end in the classroom, but should be a starting point for spaces of individual and collective reflection that trigger changes in the nursing care practice.[26]

Approaching these issues also leads us to reflect on the role of educators, on our own conceptions of finitude and also the acceptance of death as part of life, thus revealing the scenery that sustains it.[27]

Conclusion

The following meanings were unveiled by undergraduates: feelings of powerlessness and frustration in dealing with death, the dilemma between being a nurse and being a teacher and the difficulty in dealing with family members of patients in palliative care.

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Collaborations

Germano KS contributed to the design, collection and analysis of data and writing the paper. Meneguin S collaborated with design, project design, analysis and interpretation of results, drafting and revision of the article for publication.

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