The discourse of nursing students about the palliative care with the hospitalized elderly*

El discurso de los estudiantes de enfermería sobre los cuidados paliativos a los ancianos hospitalizados

O discurso de estudantes de enfermagem sobre o cuidado paliativo ao idoso hospitalizado

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ABSTRACT: This study proposal sought to identify the perception of the student from the last year of the nursing graduate course about the finiteness of the elderly in the context of palliative care. The participants were twenty students who revealed the difficulties in relation to the care with the hospitalized elderly, the fear of death and of being unable to deal with this situation. There is a need for previous preparation of the student to develop the care with the elderly, with an emphasis on skills and abilities to be enhanced in the work routine.

Keywords: Attitude to death; Students, Nursing; Palliative Care.

RESUMEN: Esta propuesta de estudio trató de identificar la percepción del estudiante del último año del curso de graduación en enfermería de la finitud de los ancianos en el contexto de los cuidados paliativos. Los participantes fueron veinte estudiantes que mostraron las dificultades en relación con el cuidado de ancianos hospitalizados, el temor de la muerte y de no saber lidiar con esta situación. Hay una necesidad de preparación previa del estudiante para desarrollar la atención a los ancianos, con énfasis en las habilidades y capacidades para ser perfeccionadas en la rutina de trabajo.

Palabras clave: Actitud frente a la muerte; Estudiantes de Enfermería; Cuidados Paliativos.

RESUMO: Esta proposta de estudo buscou identificar a percepção do estudante, do último ano do curso de graduação em enfermagem, sobre a finitude do idoso na perspectiva do cuidado paliativo. Participaram vinte estudantes que revelaram as dificuldades em relação ao cuidado ao idoso hospitalizado, o medo da morte, e de não saberem lidar com essa situação. Há necessidade de preparação prévia do estudante para desenvolver o cuidado a esse idoso, com ênfase nas competências e habilidades a serem aperfeiçoadas na rotina de trabalho.

Palavras chave: Atitude frente à morte; Estudantes de Enfermagem; Cuidados Paliativos.

Introduction

The World Health Organization (WHO) defined, in 2002, Palliative Care (PC) as an approach or treatment that improves the quality of life of patients and their families facing problems associated with life-threatening illness (WHO, 2006). The PC must gather the skills of a multiprofessional team to help the patient and family members to adapt to life changes imposed by the disease, as well as to promote reflection necessary to cope with the irreversible condition and/or the possibility of death (Inca, 2015).

Added to the deficit in the level of professional training in palliative care and other factors, the current challenges for dissemination of this new care mode collide in a paradigmatic issue, from the moment death is seen as a failure, facing the investments for the cure and/or maintenance of life at any cost. Thus, one of the great difficulties of medical

professionals is to recognize the "palliative care patient". Many times, the person dies without enjoying the benefits for the comfort and quality in the final stage of his/her life (Hui, *et al.*, 2013).

The care with the well-being, with the reduction of pain and suffering are central points in the PC philosophy. This type of care involves the attempt to comply with the will and the dignity of the person until his/her very last moment as well as the professional assistance to relieve physical, psychological and spiritual symptoms. The PC team must be multiprofessional, however, the nursing professional accompanies the terminal patient over time, since this becomes dependent on his/her care (Pinho-Reis, 2019). The recognition of the final stage of life can be difficult, but it is extremely necessary for the care planning and preparation of the patient and the family for the loss and death. Even after the patient's death, the palliative care team should give attention to the process of family mourning: how the death occurred, the degree of comfort and the impacts brought to the family and the interdisciplinary team. The post-death family assistance can and should be initiated with preventive interventions (Inca, 2015a).

From this convergence, nursing students need incentives to develop skills to deal with the elderly because, at some moment in the academic or professional life, they might come across the hospitalized elderly person or in the household context, who, consequently, may be in the process of death and requires palliative care.

In this sense, practical activities with the patient under PC are a true laboratory for creation of individual and shared knowledge. Without these activities, these students unable to achieve consistent training for the palliative care (Feuz, Rosewall, & Willis, 2015). This becomes obvious when one realizes that the training in any other health area is based on a theoretical-practical approach (Costa, Poles, & Silva, 2016).

In this context, the study aims to contribute to the Gerontological Nursing addressing the finiteness of the hospitalized elderly, with emphasis on the professional training of nurses, from experiences during the academic journey, highlighting to the student the ability to deal with death and applying the palliative care in his/her care practice.

For this reason, the objective of the study was: To identify the perception of the student from the last year of the nursing graduate course about the finiteness of the elderly in the context of palliative care.

It is of utmost importance to put the student as the focus of this process, knowing his/her emotions facing the death, his/her abilities and skills to overcome these feelings, with the purpose of providing pain and suffering relief, and quality of life to the hospitalized elderly.

Methodology

This is a descriptive study with a qualitative approach. According to Leopardi (2001), it is to understand a problem from the perspective of the subjects who experience it, i.e., part of their daily life, satisfaction, statements, surprises and other emotions, as well as in the perspective of the researcher him/herself.

The research participants were the students from the last year of the nursing graduate course, regularly enrolled in the teaching institution in the study. The selected scenario was the Nursing School of a Government Institution in Rio de Janeiro. For the participation in the study, the subjects should meet the following criteria: Inclusion: (a) acceptance and availability to participate in the research; (b) students from the last year of the Nursing graduate course; (c) who had already experienced the care with the elderly in the hospital setting. Exclusion: (a) nursing students not from the last year of the graduate course; (b) who had never cared for the elderly in the hospital setting.

Thus, data collection began after the approval of the Research Ethics Committee of the Anna Nery Nursing School/UFRJ, CAAE: 28914914.2.0000.5238 and Opinion: 630.084, approved on 04/29/2014.

The data collection was performed through a semi-structured interview, from a preestablished instrument, which focused on the process of death and dying of the hospitalized elderly in the perception of nursing students. The interviews were conducted after schedules in conditions of comfort and privacy, were recorded after the signature of the Informed Consent Form, taking into account Resolution n. 466/12 (Brazil, 2012). The interviews were recorded on audio MP3 format, and subsequently fully transcribed and analyzed. The analysis was based on the Collective Subject Discourse (CSD). It is a proposal for the organization and tabulation of qualitative data of verbal nature, obtained through interviews, which seeks to express the thoughts of a collectivity, as if this collectivity was the issuer of a discourse (Lefrevre, Crestana, Cornetta, & Vitória, 2003).

The participants were 20 students regularly enrolled in the last year of the Nursing Graduate Course of a Government University located in the state of Rio de Janeiro. Although there are more than 20 students in classes, the researcher had difficulty to reconcile the hours between the penultimate and last term of graduation with the data collection, due to the relatively short estimated time and the main, because most of the class had never had contact with the hospitalized elderly in the process of death and dying, many mentioned having had contact with the process of death and dying, but not with the elderly, but with hospitalized clients from other age groups.

Results

For the approach of the results and analysis, the research was based on the Collective Subject Discourse (CSD) (Lefrevre, Crestana, Cornetta, & Vitória, 2003a), which is a proposal for the organization and tabulation of qualitative data of verbal nature, obtained from interviews, newspaper articles, materials of weekly magazines etc. The collective subject is expressed, then, through a speech of what could be called as a first (collective) singular person. It is a syntactic I who, at the same time that signals the presence of a single collective discourse subject, expresses a collective reference as this "I" speaks by or on behalf of a collectivity (Lefrevre, Crestana, Cornetta, & Vitória, 2003b).

As a practical example for understanding this data organization, we can say that the collective subject discourse has the objective of gathering the statements of a group of people about a certain subject, in order to highlight the similar thinking within a set of ideas, even with their own opinions, but that in some moment may have a common way of thinking.

According to the research, the process of death and dying of the hospitalized elderly, according to the students, constituted a similar set of opinions regarding the desire of the nursing student in dealing with and facing death and the finitude of the hospitalized elderly.

Profile of the Nursing graduate students from a Government Institution in Rio de Janeiro

This first step sought to present and characterize the profile of the students from the last period of the nursing graduate course. There was a higher prevalence of females (95%), with 19 participants, compared to males (5%), with only one participant. Through the speeches, we observed the statements with placement of female adjectives, for this reason in relation to gender, women represent the majority, they were the only ones most of the time, as can be seen in the following discourses:

"Ifelt a little fragile because it is very difficult to care for an elderly person, we must have a whole psychological preparation, physical, emotional preparation, to take care of that elderly, especially in the case of the process of death. So I was very saddened that I tried to do my best at least while I was there taking care of him, and I couldn't see him progress. So I felt a little incapable because I was a student." (CSD: D 11, D13, D14).

From the analysis of the speeches of nursing students, they reported having to pass through many difficulties, such as: coping with death, fragility in caring for the elderly in dying process, inability to cope with the process of death by being a student. Then, when analyzing these difficulties in the training process, we can emphasize the need to address and prepare more the students during their graduate course to cope with the process of death of the hospitalized elderly, because they will experience this challenge in professional practice.

Oportunity to care for the hospitalized elderly during the death-dying process

The second step analyzed the characteristics related to the experience while nursing students in the care with the hospitalized elderly in the death-dying process. The students' discourse revealed the concern with the professional training, and, for this reason, the future nurse must assess his/her availability for patient care in conditions of finitude. His/her values, concepts and prejudices in relation to death, and regarding his/her personal experiences of loss of a family member and/or loved one, his/her positioning facing the mourning and feelings involved in this whole process.

"I took care of two elderly people, one for two days and the other for four days because they were in different sectors. Well, the first time I had a patient in the death-dying process was at Carlos Chagas in 2013, and I also had contact with other patients, but I most followed him up, so I focused on him. There were other patients that I had contact with during graduation, but since our internship length was very fast, I could not see how patients proceeded. The family was close, following the death process, each day his picture was getting worse. But sometimes you treat a patient that talks to you and you know he's going to die and you know he's already in his final moments, that's very difficult. This one I had contact with, unfortunately passed away, but we did everything, I followed his case, he was very debilitated, he had kidney failure, he was on hemodialysis, he was already very old, he was almost 90 years old, had lost weight and was well dehydrated. We tried to do our best for him, but he was a patient whose family members themselves were already aware that there was not much to be done, but we never give up, always try to the end to see how the patient will react." (CSD: D7; D14; D1; D9; D14).

According to the reports, contextualizing the speech in a common point, we realized how difficult it is for nursing students to deal with the elderly in the process of death. Many students addressed the question of the presence of relatives, some of them conformed with

the patient's status, other accompanying throughout his/her course. But what stood out from the statements is their dedication to the care and concern not to give up, persisting until the end to see how the patient will evolve. This attitude makes a difference in the care, because even in the process of death, the patient has the right to be cared for with a dignified care, and the learner can provide comfort and quality of life in those moments.

From the students' experiences, they also reported the most common comorbidity that directs the patient to conditions of finitude, which is cancer. This disease often brings irreversible effects when discovered late, and consequently brings death to several people, including the elderly:

"A lady with breast cancer, it was complicated because she was lucid and was aware of everything that was going on. She had cancer in stage of metastasis. That's why I was happy to help her, because even with her sister's presence, the patient hardly talked and let anyone approach her. We managed to get a very good approach, when the internship schedule was over, we stayed with her talking and she would tell her life story. When the patient is at a very advanced stage and no longer has a life perspective, we only try to give him comfort, but prolonging life is not ideal. So, for me, the family has to know about the process of death because many times the person knows he's going to die, but the family does not. The family has to be prepared above all for the process of death." (CSD: D1; D3; D6; D11)

It is possible to identify, in the next discourse, the essential role of the nursing staff to monitor and devote more time to the elderly with Alzheimer's disease, mainly during hospitalization, because the elderly is in a state of vulnerability during this process, and the Alzheimer's disease may worsen. In addition to the cognitive worsening, there may arise problems arising out of the hospitalization itself.

"The lady had Alzheimer's, she treated me like her daughter and every time I met her she kept repeating the same story and I had other things to do and she needed that attention. So, I had to stop doing some things to direct the attention to her. The patient was already terminally ill and I think she had

cancer too, some degenerative disease, so I ended up dedicating her a time with care, a greater attention. I couldn't get to the family and talk, that she was going to die and that there was no more possibilities, the sector staff was responsible for that. We created a great bond because a friend and I took care of this patient every day during the graduation internship. So we can understand this patient's life, relationships, fears, longings." (CSD: D12; D11; D15).

The students managed to establish a bond of trust with the patient, and could magnify their moments of experiences, with effective nursing interventions. In addition to creating bonds, students understand the feelings that bother the patient and, from active listening and empathy, achieved more than trust, they achieved learning to deal specifically with the finiteness of the elderly with cancer and Alzheimer's disease.

These diseases many times bring emotional imbalance to the patient, and the balance becomes plausible when the professional knows exactly how to act, especially when he/she stimulates the control of emotions involved.

Description of the clinic where the student followed up/took care of the hospitalized elderly

The third step analyzed the data related to the clinic and/or specialty where the student followed up and cared for the elderly person, the feelings/emotions involved in care and skills/knowledge that the nursing students would like to acquire about the process of death and dying of the hospitalized elderly. The main clinics where the student followed up the elderly and the main sectors cited were: Medical Clinic and ICU:

"When I took care of him in the orthopedics he was not so bad, he had just come to a surgery. So, after the surgery that didn't work out too well, it triggered a little bit of the situation and he ended up in the ICU. When I went to take care of him, I didn't even recognize that I had treated him in orthopedics." (CSD: D7).

"She was an elderly woman, she was in the yellow room, where the most critical patients were and needed intensive care. She had a stroke and was a few days with sedative and mechanical ventilation. When she had a cardiac arrest in which I participated performing cardiac massage with the Nurse's supervision, the patient returned with vital signs, but then came arrests and she died after the fourth attempt. I also had the opportunity to take care of a lady in PCI-VIII and IX in the surgical clinic in sector 10 C. The patient was brain-dead due to several cardiac arrests." (CSD:D17, D4)

Through the speeches, we understand the real fragility of the hospitalized elderly in the Intensive Care Unit, because many depend on mechanical ventilation, sedatives, invasive procedures, among other needs. Due to these complications, there becomes crucial to understand the moment the hospitalized elderly are facing and, from this, outline goals to minimize this pain that precedes the death, especially when the elderly are in this scenario. With this, it is also important to assess the location of hospitalization of the elderly: if it offers minimum conditions of comfort and humane treatment in order to reduce the suffering of this patient. All these factors are relevant in the assessment of the elderly in the death and dying process.

Feelings/emotions involved in the care with the hospitalized elderly

Subsequently, the feelings and/or emotions involved in this care with the hospitalized elderly in the process of death were discussed with the research participants. Many reported the feeling of powerlessness, disappointment, fragility, difficulty in dealing with the death:

"It was complicated, it's hard to deal with death, we feel powerless, it was another wrench, because giving the news to the family that the patient passed away is difficult. However, it is a limitation we pass through in this health area. I feel a little incapable because I'm a student. When I wanted to go back to the sector to see her again I found out that she had passed

away, it was a difficult situation for me. I was very sad and when I saw her empty bed I cried because I had spent a week taking care of her, despite knowing that she was in the death and dying process. So, for me, death is very difficult to deal with even if it's an elderly person and a natural process, for me it is still very difficult to deal with this death-dying process." (CSD: D1, D5, D7, D8, D9, D11, D13, D15, D18).

It is distressing to become aware of finitude, because people do not expect death, but life (Costa, Poles, & Silva, 2016). Although the elderly person is in an environment of hospitalization, learners did not expect to come across death, but rather the improvement of the prognosis and thus a probable discharge of the patient. Then, accepting this process is something very difficult and the feelings of sadness, helplessness, pervade students, because they are not prepared for this, and they will face such situation in their professional life.

Knowledge/skills that the nursing student would like to acquire about the death and dying process of the hospitalized elderly

Before ending the interview with the students, they were asked about the knowledge/skills that they would like to acquire about the death and dying process of the hospitalized elderly. Thus, they raised several possibilities, bringing a contribution to the nursing graduate course with ideas relevant to their own learning:

"It would be the family's relationship with the professionals themselves about the death-dying process, because it is still a taboo for students, so we only learn by experiencing it. Students could see more broadly what the patient likes and wants. The professor should highlight this approach that we should try to establish. And having some kind of content to help this patient in a palliative way, stimulate him to do things he likes, that care makes a difference." (CSD: D2, D3, D5).

In the discourse above, students bring several issues, such as: family relationship with the professionals; knowing what the patient likes and wants to do in the final moments and the palliative care as the difference in assistance. According to Kubler e Ross (Kübler-Roos, 2008a) in care with terminal patients, their suffering should be alleviated, in addition to keeping an attitude of listening and affection, reminding them that they have feelings, desires, opinions and the right to be heard. Nevertheless, when death is considered a taboo by the caregivers themselves, they can prevent, with their anxiety, the patient from sharing his/her pain with them. Then these can be strategies to be initially addressed in graduation.

Discussion

The health concept becomes complete only when it has its meaning expanded beyond the biological issue and covers the whole biopsychosocial and spiritual sphere in which the individual is inserted and defined. This complexity must always be considered when providing health care, either curative or palliative. Due to this importance, there arises the current trend of transformation of the curricular lines for graduating health professionals with the insertion of nuances of humanization (Costa, Poles, & Silva, 2016a). Transformation that is reflected in the search for expansion of education in PC, being an important step in the recent regulations of Palliative Medicine (Resolution CFM n. 1.973/2011; Oliveira, Ferreira, & Rezende, 2013).

In this way, there is a need for training of a professional capable of dealing with the subjectivity. This change, however, constitutes a major challenge: how to teach in classrooms the best way to provide words of comfort? To understand patients' real needs? To practice empathy? (Costa, Poles, & Silva, 2016b).

The speech of the nursing students, however, highlights the need for the prior preparation of this care, specifically, in the work performance. This training, according to the interviewees, should include, in addition to the technical knowledge about palliative care, information on skills and abilities to be enhanced in the work routine.

The antagonistic statements of empathy and exclusion from the care end up complementing each other in a cycle of processing and learning. The student, in a moment, approaches the patient and shares his/her pain and, in another, distances emotionally to be able to continue providing care without negatively affecting his/her emotional aspect. After

this rest period, he/she returns with empathy, starting a new cycle. Although this process is generalized, this cannot occur in the same way to all, considering, at this point, the individual aspects. The time when each stage occurs, the degree of empathy, the level of emotional distancing and the learning process are different for each student (Costa, & Poles,& Silva, 2016c)

Finally, the student's path to overcome the challenges posed by the palliative care generates knowledge that can be adapted from the professional to the personal context. This process of formation makes them better human beings, capable of developing in their relationships, spaces of reception and expression of feelings, such as pain and suffering (Duarte, & Almeida, & Popim, 2015). Approaching death creates a time relativity, valuing their passage and, consequently, valuing the use given to it. Each second with the patient in the final phase of life should be used in favor of his/her comfort, and, when this is achieved, the omnipresent feeling is of gratification to be spending their own seconds of life by practicing good (Costa, Poles, & Silva, 2016d).

Conclusion

The study revealed the need to address in the graduation the theme regarding the palliative care with the hospitalized elderly, because the experience of nursing students resulted in a minimum of time below what would be ideal for the professional practice.

The fact that part of the learners did not pay attention to care with the elderly hospitalized, focusing on the needs when they are in the death and dying process, brings the consequence of death being a taboo subject, and the absence of the theme in professional training.

It is very important, within the context, and whenever possible, to treat the family as a partner in the care required by its loved one. Therefore, from the students' reports, we confirm the importance of disclosing to family members the real need of the elderly person, and sharing with the whole family the patient's evolution, whether with a bad or good prognosis, offering an emotional support with competent professionals for this function.

Therefore, it is important to empower the nursing team, involved in the care with the patient, 24 hours per day.

Nursing students require an internship hour load with more hours focused on palliative care, reinforcing the concepts of thanatology and care with the hospitalized elderly in the death and dying process. However, students need to understand the fears and anxieties of the patient in his/her final hours of life.

This study is expected to contribute to carrying out changes in nursing education, mainly in the graduate syllabus, with a view to improving with opportunities to elevate the experiences and prepare for professional practice and the participation of students in spaces intended to discuss and review their practices.

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