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ABSTRACT
Objective: To identify and understand the view of students regarding palliative care in paediatric oncology during a graduate programme. Methods: Exploratory research with a qualitative approach conducted in a school of nursing in Rio de Janeiro. Data were collected from September to November 2014, through semi-structured interviews with 20 students enrolled in the last period of a graduate programme. The data were subjected to thematic analysis. Results: The results produced two thematic units: the (un)preparedness of nursing students regarding palliative care in paediatric oncology and how the subject of palliative care in paediatric oncology is approached in the graduate programme. The students mentioned difficulties in providing this care and their lack of exposure to the topic during their graduate studies. They stated strategies to prepare for the provision of care, and talked about how the subject should be addressed in their curricular programme. Conclusion: It is necessary to expand discussions on palliative care in paediatric oncology during the nurses’ graduate programme. Keywords: Palliative care. Oncology nursing. Education, nursing. Children’s healthcare.

RESUMO

RESUMEN
INTRODUCTION

Paediatric cancer affects children and adolescents between the ages of 0 and 19 years, and corresponds to 1% and 3% of all malignant tumours in most populations. In Brazil, there is an estimated 9,386 cases of paediatric tumours every year. The survival rate has increased over the years, and currently reaches 70%. This increase is the result of early diagnosis and access to appropriate treatment(1).

Various treatments are employed in an attempt to treat and cure chronic diseases, including cancer in children. Technological advances, potent medication, and new diagnostic techniques are employed in the hope of curing patients and reinforcing care based on interventionism and curativism. However, success is not always possible because the disease may not respond to treatment, exhausting the possibilities of healing and forcing the team to adopt a new approach of care for that patient: palliative care(2).

In chronic diseases, palliative actions and care must start at the time of diagnosis and occur jointly with the treatment of the disease. Palliation gains relevance in children's cancer when curative treatment loses its effectiveness(3). In these situations, palliative care is employed to improve the quality of life of patients and their families, and help them cope with the problems associated with incurable diseases. This form of care is based on the prevention and relief of suffering through early identification, and the correct assessment and treatment of pain and other physical, psychosocial and spiritual problems(4).

Thus, patients with incurable diseases need specific care that addresses a wide range of factors. For this form of care to occur with respect, professionalism, and the appropriate techniques, the subject of palliative care must be added to the graduate healthcare curricula, including the nursing course. Moreover, chronic diseases, especially cancer, have significant demands in the entire country(5-6).

In 2001, the National Council of Education approved the national curriculum guidelines of the graduate programme in nursing that defines the principles, foundations, conditions, and procedures of nurses’ training(7).

Nurses must have a generalist, humanist, critical and reflective education that allows them to identify and act on the most prevalent healthcare needs according to the epidemiological and demographic profile. Therefore, the curricula of graduate courses in nursing should include content that is related to the health-sickness process of the population, according to the epidemiological and professional profile, and favours the comprehensiveness of nursing care(8). In countries such as the United States and Canada, this content has already been incorporated in nurses’ training, and in Spain it has been included in the curriculum in almost all schools of nursing(8).

National literature shows that some graduate courses in nursing are still based on the traditional, de-contextualised model that focuses on the pathophysiological and technical aspects of the health-sickness process and the cure and rehabilitation of disease(2). However, in some situations these professionals have to deal with the impossibility of a cure and the immensity of death, generating feelings of helplessness, frustration, and insecurity since graduation does not prepare them to cope with this stage of the disease process: the terminal stage(2, 9).

In paediatrics, palliative care must meet the biopsychosocial needs of children and ensure their dignity, quality of life, a dignified death, and the preservation of their autonomy. The healthcare professional involved in this process is seen as a point of support in the fight against the disease by the family and the child(5-6,8,10).

However, literature shows that nurses who provide palliative care to children with cancer feel unprepared to communicate bad news and have difficulties in dealing with the children at the end of life and in living through the grief. They refer to the lack of training to deal with family members, the physical and emotional burnout, the lack of continuing education, and the need to include this subject in their professional training(5-6, 8, 10).

Thus, palliative care in paediatric oncology needs to be addressed during the graduate studies of nursing since this is the first step toward awareness and preparation of the future professional(10).

This study relied on the theoretical conceptions defended by Paulo Freire, in which a liberating and critical education occurs when students are inserted into the studied reality so they can build concepts and knowledge, that is, to be critical, they need to know the reality, and understand it or understand it to be able to reflect. His theory conceives man as the subject of his own education. In this perspective, human beings are educated mediated by the world, meaning that awareness cannot exist outside the praxis, or better still, without action-reflection(11).

The guiding question of this study, from the perspective of nursing graduates, is how is the subject of palliative
care in paediatric oncology approached during graduate studies? The aim of this paper is to identify and describe how nursing students view palliative care in paediatric oncology during a graduation programme.

METHOD

This article was extracted from a final graduate studies paper titled, “Cuidados paliativos em oncologia pediátrica na percepção dos acadêmicos de enfermagem”. This is an exploratory, qualitative study. Qualitative studies use objects that correspond to a deep space in relations, processes, and phenomena that cannot be reduced to the operationalisation of variables. This type of research helps to reveal social processes that are not fully known and relate to particular groups, and to review and create new concepts and their categories. Exploratory research seeks to provide an overview of a given phenomenon.

The research was conducted at a school of nursing of a federal university in the state of Rio de Janeiro. In this scenario, the theoretical content on oncology and palliative care in paediatrics is offered in the seventh course period during a 2-hour class, in a compulsory subject on the health of hospitalised children, with 120 classroom hours, of which 30 are for theory and 90 for theory and practice.

There is also an elective discipline on oncology that does not discuss the subject of paediatrics. In this discipline, the content ranges from the stigma of cancer in our society to oncogenesis, especially tumours that affect the Brazilian population and palliative care. The subject lasts 30 hours with classes once a week. The final assessment proposes group seminars on the main tumours that affect the population and the adopted therapeutic conducts.

All the students of the nursing course of this university attend the university hospital, the theory and practice scenario, but they do not provide care to children with cancer. However, in the vicinity of the university, in the state capital of Rio de Janeiro, there is a cancer treatment centre that is the national reference centre and a state reference centre for haematological and oncological diseases.

Twenty students participated in this study from a class of 33 nursing students in the ninth period, that is, the last period of the graduate nursing course. The students who participated account for 60% of the class.

The criteria for inclusion of these participants were students over the age of 18, and students attending the final graduate course period. The criteria for exclusion were students who had suspended the course during the data collection period, and students who worked as nursing technicians since they can refer to practical experiences that were not acquired in the graduation course.

Data were collected from September to October 2014 by means of a semi-structured interview. The interview consisted of open-ended questions, in which the respondent was asked to talk about palliative care in paediatric oncology by answering the questions, “What are your thoughts about palliative care in paediatric oncology?”, “How do you think the subject should be addressed in the graduation course in nursing?”, “Do you think you are prepared, in terms of knowledge, to take care of a child with cancer without the possibility of a cure?” The close-ended questions in the interview were used to identify the participants.

The interviews lasted around 30 minutes and they were conducted by the author of the article on a scheduled date and time, according to the availability of the participants. The interviews were recorded on an electronic MP3 device. To ensure privacy and prevent interferences during the recordings, they were conducted in empty classrooms of the school of nursing.

The interviews were transcribed in full and analysed according to the three stages of thematic analysis: pre-analysis, with skim reading of the empirical material from the interviews; exploration of the material, when the raw data are transformed into units and added to the categories; treatment and interpretation of results, when the researchers make inferences in light of scientific literature on palliative care from the perspective of nursing students.

This study was approved by the Research Ethics Committee of the institution where the study was conducted (Opinion: 751,462), and complies with all aspects of Resolution 466/12 of the National Health Council. After the research was approved, we contacted the students at the school where the study would be conducted. Firstly, the researcher introduced herself and talked about the research and the goals, and the terms contained in the informed consent statement (ICS). Subsequently, the students were invited to be voluntary participants of the research. Their acceptance was formalised with the signing of the ICS. Their anonymity was guaranteed by classifying participants in numerical order preceded by the letter “A”, for academic scholar.

All the material obtained from data collection, such as the voice recordings and transcripts, will be stored
by the researchers for 5 (five) years and subsequently destroyed.

**RESULTS AND DISCUSSION**

The analysis of the answers of the interviews resulted in two thematic units: the (un)preparedness of nursing students regarding palliative care in paediatric oncology and how the subject of palliative care in paediatric oncology is approached in the graduate programme.

**The (un)preparedness of nursing students regarding palliative care in paediatric oncology**

The interviewed students reported that the difficulties in dealing with children with cancer without the possibility of a cure are related to emotional and personal issues, and difficulty in working with palliative care.

No. I can’t. I don’t see myself as a professional prepared to care for children. For physical, personal, emotional reasons, so [...] (A1).

Take care of children under no circumstances [...]. I have no structure for that (A6).

No preparation. None. We don’t have any preparation. I believe, I don’t know, I believe that neither I nor most of my colleagues are prepared to take care of a child, in this situation (A12).

I don’t feel the slightest bit ready, I can’t deal with the emotional side of working with children. I am very touched by the issue [...] I don’t feel emotionally prepared to face a child in palliative care (A19).

The possibility of taking care of a child with cancer in palliative care is repelled by some of the interviewed students. They reported lack of affinity with paediatric patients or personal and emotional difficulties in dealing with children suffering from an incurable condition.

In some situations, the student and future professional will face difficulties when confronted with a death situation in academic life. To overcome these obstacles, it is important to consider the context in which the student is inserted to promote a welcoming environment that encourages new learning experiences (2). Since the teaching-learning process does not focus on the professor and the classroom, there is little chance of solving this practice problem (11).

Care for children involves the child, the family, and their expectations that the healthcare workers will provide care with the purpose of a cure. Having to interrupt that natural flow of life that involves growing, becoming an adolescent and an adult, and getting old to then die puts the professional in an unexpected situation. This is probably the reason why some respondents reported lack of emotional preparation to cope with this situation (2).

Given the complexity of palliative care, the National Academy of Palliative Care (“ANCP”) indicates that therapeutic measures should surpass the control of the physical symptoms; care should include psychotherapy and spiritual support for patients and their families. In addition, an adequate programme should include spiritual support and psychotherapy for the healthcare team, as well as continuing education (3).

Palliative care in paediatric oncology involves various aspects, such as the inability to cure the patient, the interrupted life expectancy of the child, and the end of a fragile being that is protected in our culture and family. Therefore, this subject must be addressed in graduate nursing studies to prepare healthcare professionals (6). Freire states that dialogicity and the essence of education are the practice of freedom; therefore, to improve the education of students, the topics must be addressed in the teaching-learning environment and mediated by dialogue with stimulating critical reflection regarding reality (11).

The participants stated that the lack of preparedness to deal with a child with cancer without the possibility of cure is mostly due to the lack of contact with the subject in nursing graduate education. Furthermore, they mention that the absence of information, or a superficial approach, makes them feel insecure regarding this practice.

I don’t feel prepared at all. I know the basics of the basic (A2).

I would like to have more information, training. Also if I got to the sector of children’s oncology I would need training to get there (A3).

Not a bit prepared. I think that, until today I haven’t come across any case of advanced or severe oncological disease, I don’t feel prepared (A10).
I've never worked in this area [...]. I don’t feel prepared, I think college did not prepare me for this either, for this situation. (A7)

I don’t know much about this because in the course we aren’t exposed to it, we don’t have contact with this type of subject or with that kind of knowledge to know how to handle the situation [...] I think the professionals should be prepared better, for the sake of awareness (A8).

Well, I don’t have much of a clue because in college it was not discussed much. This stage of palliative care, even more so in children (20).

The Law of Education Bases and Guidelines (“LDB”), in chapter IV, article 43, recommends that higher education must stimulate knowledge of the problems of the present world, especially at regional and national level, and provide specialised services to the community.(13).

Although the discussion and studies on the philosophy of palliative care are growing, there are still education gaps because it is based on the biomedical model that seeks to cure using technical knowledge, which becomes an obstacle in the care the patients without the possibility of a cure(14). Teaching still focuses on curing and death is still related to failure. It is still conceived as an end, and not as part of a social construct, and it is not merely a biological event(2). There is a gap in the education of healthcare professionals in palliative care, and graduate programmes do not prepare the future professional to deal with terminal patients or to recognise the symptoms and manage the situation in a humane and active manner(15).

The lack of reflection on the practice of palliative care prevents the graduate students from understanding its purpose, which is to ensure the comfort and well-being of those who do not have the prospect of healing. Freire considered dialogicity and the essence of education as being the practice of freedom. So, when we established dialogue, we facilitate the knowledge of reality in order to understand and reflect upon it(11).

The students reinforced the lack of exposure to the subject in the graduate studies curriculum in nursing of the university, especially in children with oncological disease in palliative care. Due to the high demand of patients with oncological diseases for hospitals and the morbidity and mortality profile of the Brazilian population, we must clearly address the subject of oncology during graduate studies with greater depth(13).

To address the subject of death with the nursing student, it should be considered a social construct with different meanings according to the shared senses that are built from the social, cultural, and historical influence of each individual(2, 11). The proper training of these future professionals will provide an ethical and human attitude that helps them provide quality care to patients with a terminal disease.

The National Curriculum Guidelines (“DCN”) advocate the formation of a nurse practitioner who is qualified, reflective, and ready to act on the social reality. Consequently, some educational institutions formulate their curricula and exclude specific disciplines that they believe are more appropriate for post-graduation specialisation studies to meet the requirements of generalist training(15).

When there is no adequate preparation and a lack of awareness and instrumentalisation to deal with this clientele, professionals can experience dissatisfaction, frustration, and suffering that may even compromise their mental health(11). This fact could be different if health workers were more prepared to deal with this situation, and consequently provide ethical, humane and quality care(16).

Given the lack of professional curriculum content that addresses human finitude(9), the nurses do not feel prepared to deal with people in palliative care, and end up making excuses and promises of recovery to patients who are on the verge of death(17).

When they talk about preparation to deal with children with terminal cancer, they stress the importance of developing strategies to facilitate the provision of palliative care, such as art therapy, toys and drawings or courses, training and enhancements to approach the subject.

Since the start of college, all the stages that I completed were geared toward children and I am good with art therapy, with all the drawing part, the playing, I think I feel more comfortable dealing with that actually [...]. So I think it would be easier for me to provide care that way (A16).

I think that the professional has to like the area because the family and the child will need a lot of support and emotional support. So, in terms of knowledge, I may not know everything, but with practice and with the day to day, we can improve, get more references for reading (A14).
I would even seek further information on my own, not just because of the discipline. [...] I didn’t get a chance in the internship to care for children with this demand. So, to me the matter is still theoretical, but I believe that with a preparation I can provide this care (A5).

I will try to learn more about it to do my best in that shift, right? (A4).

The students mentioned the use of preparation and coping strategies to deal with children with terminal cancer. According to them, searching for literature on the subject and approaching the families can make them feel more confident to provide palliative care in paediatric oncology.

Strategies to cope with this phase of childcare can also be an important resource in the healthcare practice. Another strategy would be to create a more playful and welcoming environment.

By promoting a space that encourages playing, the professionals can get closer to the children and enable their integration with the other hospitalised children in the same situation, have fun with them, and help them understand the moment and procedures they are undergoing and will still undergo (18).

One resource that should be used for children to understand the therapeutic procedures they will undergo is the therapeutic toy. With this resource, nurses can draw closer to the world of children and understand their needs (18).

It should be noted that when there is no adequate preparation on the part of these workers, they have difficulty in dealing with the family, the child and themselves, which generates physical and psychological burnout (10). In this sense, the National Academy of Palliative Care suggests the adoption of a continuing education programme for professionals in the health team, as well as spiritual support and psychotherapy (8). It is through this support that the professionals receive information on how to deal with the feelings that emanate from this care, and from the resulting reflections, considering they are more equipped to provide qualified care (16).

The healthcare team that works with palliative care must plan its actions to improve the quality of life of patients, and this planning must be shared with the children and their families. Furthermore, it is worth noting that palliative care in paediatrics is applied to a variety of complex and chronic conditions that go beyond cancer, which reinforces the need to better address this subject (19).
One study sought to explore the contribution of education in palliative care to the training of graduate students in nursing in two universities in Spain. The nursing students reported that the course of palliative care was essential and favourably contributed to their personal and professional development.

In this study, the respondents also mentioned the moment the matter should be addressed during graduation. In this point, they had different opinions. Some spoke of the need to address the subject at the beginning of the programme so they could be better prepared by the end of the course. Others stressed the importance of addressing the topic in the middle or at the end of the programme, which is when they would have more knowledge to keep up with the complexity involved in palliative care.

I think it should be approached in the middle of the course, due to the importance of this topic, right? There should be a discipline that focuses on oncology or graduate studies should offer a training course like that, for a short time. Like 60 hours, something like that (A9).

I think that palliative care needs to be addressed later in the programme, right? When we are really in contact with the internship stage. Because certain subjects are covered in the beginning, so we study for that moment. Sometimes the content is very important, that we, being students, leave aside (A5).

It should be approached during college, both at the beginning and at the end, it is important we stress that we start with one mind-set and finish with another [...] So if we have a basis for palliative care in college, we will enhance our care (A16).

Nursing education should encourage a general qualification required for the future graduate to overcome the challenges of the profession and the production of knowledge; stimulate the practice of independent learning for progressive intellectual and professional autonomy; boost the recognition of skills and competences acquired outside the school environment; and strengthen the relationship of theory with practice.

Thus, we see the importance of learning that can put theory into professional practice, and the search of knowledge that meets the needs of the population. The teaching-learning relationship is not a simple task or relationship, but a two-way path in which the learners and educators are continually challenged to teach, learn, and maintain a conscious dialogue. In this sense, the level of contact with the subject of palliative care must be processual and transversal during graduate studies to ensure the progressive acquisition of knowledge.

A study conducted in Spain explored the contribution of a course on palliative care offered to graduate students in nursing of two universities, one public and one private, in the second and third year of the graduate programme. The authors of this study found that the adopted strategy provided a comprehensive overview of the subject and helped students interact, communicate, and understand patients, and led them to reflect on death, which contributed to their personal growth, and finally, helped the students confirm the importance of this course in the nursing curriculum.

During the interviews, the students also stressed the importance of research on palliative care in paediatric oncology. They stated that research on this subject could guarantee that it is addressed in the graduate nursing programme.

I like the questions and certainly, the research will contribute to a possible change in the nursing course (A9).

I think this research is important because it is an area that is not really addressed [...] The research, I think that would help the subject be more addressed, in the case study, in the internships, everything! (A17).

I think it is important, that really is a necessary topic (palliative care in paediatric oncology) and a necessary activity, but there is this whole taboo when it comes to palliative care, especially in paediatrics, in the area of oncology (A18).

The students stressed the importance of research, since, for them, palliative care in paediatric oncology is still a subject that is rarely talked about, discussed, and addressed.

The finiteness, the impossibility of curing children is a difficult subject to tackle because it triggers a wave of emotions. The care of children with this prognosis puts nurses in a delicate situation since they have to learn to deal with the process of death and dying as the possible end of a lifecycle.

Although many children and adolescents are in the advanced stages of cancer, the structure of palliative care has not yet managed to meet the demands of this population.
Knowledge generated by research and the awareness of the Brazilian population about palliative care is essential for the Brazilian health system to consider these patients who have no hope of a cure.

**FINAL CONSIDERATIONS**

The students of nursing have some insecurities that are reflected as feelings of unpreparedness to provide care to children with terminal cancer. This unpreparedness is related to personal difficulties or lack of contact with the subject during graduate studies. To satisfy this demand, the students cite strategies that range from extensive reading on palliative care to the use of art therapy with children.

Many of the students recognise the importance of the subject of palliative care in paediatric oncology in graduate studies in nursing. In their view, the topic can be approached during their academic training.

The survey contributed to the school, which was the research scenario, by supporting discussions on the current graduate curriculum in nursing. It is important not to think only in palliative care, but also the demands of the diseases that accompany the epidemiological profile of the Brazilian population. Moreover, the education of nurses proposed by the National Curriculum Guidelines (“DCN”) should be addressed since it advocates a critical-reflective professional who can act in different scenarios and provide a more humane and better quality care.

The statements of the students serve as a good parameter to detect the gaps that truly exist in practice. Palliative care in paediatric oncology involves a series of complex subjects, namely the impossibility of a cure, the break in the life expectancy of a child, and the end of a fragile, angelic life that is protected in our culture and in the family. In the face of so much tension, we can understand the anguish and sense of unpreparedness of the future nurses.

In order to prepare future nurses for this practice, the students need awareness strategies, such as group dynamics, that are based on critical-reflexive learning since a space for group discussion helps them overcome the condition of object and become the subject of the produced knowledge.

A limitation of this study is the scarcity of publications related to the teaching of palliative care in paediatric oncology in nursing graduation courses, which could have extended the discussion and allowed the comparison of this research with other studies. Further studies are therefore recommended to address the subject in relation to both nursing education and the training of other health-care professionals.

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