RESEARCH ARTICLE

Experiences of Nursing Students in Caring for Pediatric Cancer Patients

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Abstract

<u>Background</u>: This study was performed to determine the experiences of nursing students in caring for paediatric cancer patients and their families. <u>Materials and Methods</u>: This qualitative survey was carried out with 14 students studying in the nursing department of the Faculty of Health Sciences of a university in Edirne, Turkey. Data were obtained through focus group interviews and evaluated based on a qualitative content analysis. <u>Results</u>: It was determined that students, for the most part, experienced problems related to communication, sadness, helplessness, fear, anxiety, resentment and anger. In addition, the students were affected most often by effects of the disease and invasive procedures on paediatric cancer patients and their families during the process of caring for them in the oncology clinic. <u>Conclusions</u>: It would be useful to inform nursing students, prior to clinical practice, about the special needs of paediatric cancer patients and families who stay in oncology clinics, and to follow up with appropriate guidance during the clinical practices.

Keywords: Clinical practice - nursing student - paediatric cancer patient - experience

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Introduction

Clinical practice constitutes an important part of the education process in nursing education (Karagoz, 2003, Pearcey and Draper, 2008; Warne et al., 2010; Jonsen et al., 2013). Clinical experience provides students with the opportunity to transfer their theoretical knowledge into practice and to transition from student to professional (Karagoz, 2003; Akyuz et al., 2007). Clinical experience is one that is perceived multi-dimensionally by nursing students, and it therefore may lead them to experience many challenges along with positive factors, such as finding meaning, personal development, self-respect and personal satisfaction through caregiving (Gorostidi et al., 2007; Hacıhasanoglu et al., 2008). It is reported that in clinical practices, students intensely experience concerns such as communication problems with patients and staff, low self-confidence, the fear of making a mistake or causing a patient harm and encountering adverse reactions, as well as difficulties in applying the theoretical knowledge they have learnt (Gorostidi et al., 2007; Hacıhasanoglu et al., 2008; Yildiz and Akansel, 2011; Taşdelen and Zaybak, 2013). In order to minimise these problems, the clinical environment must be aligned with the purposes of clinical practice, and students must be supported by educators (Elcigil et al., 2011).

Today, with advances in health care technology, the survival rates of children with cancer have increased, and cancer has become a chronic disease with prolonged periods of remission and relapse (Fayed et al., 2011;

Klassen et al., 2011; Selwood, 2013). However, despite its present status as a chronic disease, cancer is perceived as a serious disease that causes uncertainty, sadness and guilt, and which evokes suffering and death (Fotiadou et al., 2008; Klassen et al., 2011). The literature suggests that the diagnosis of cancer leads to severe psychological trauma in the child and in the child's family, causing them to experience emotional, behavioural and social problems and to exhibit more aggressive behaviours and serious adjustment problems (Wijnberg-Williams et al., 2006; Liang et al., 2007; Fayed et al., 2011; Klassen et al., 2011).

Studies have reported that even nurses trained in the care of cancer patients experience many challenges during the caregiving (Meraviglia et al., 2003; Citak et al., 2013). For this reason, health professionals caring for cancer patients must have knowledge about the nature, diagnosis and treatment of cancer, how to communicate effectively with paediatric cancer patients and their families and how to care for paediatric cancer patients and their families in the terminal period (Meraviglia et al., 2003). However, nursing students' knowledge is restricted to basic theoretical knowledge about nursing care, and their clinical experiences are insufficient. It is inevitable that students with limited theoretical knowledge and experience in caring for children with cancer and their families experience problems in clinical practice. It is therefore important to know about the overall clinical experience of students in order to make clinical practices more qualified and to minimise the negative clinical experiences of students.

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Research on the clinical practices of nursing students relates to the first clinical experiences, the difficulties that nursing students experience in adjusting to hospitals (which are a new social environment for them) and their anxiety levels (Erbil et al., 2006; Hacıhasanoglu et al., 2008; Chen, 2010; Melingavage, 2011; Yildiz and Akansel, 2011; Jonsen et al., 2013; Parker et al., 2014). Studies that have investigated the clinical experience of nursing students caring for paediatric cancer patients are few. For this reason, this study has been designed to determine the experiences of nursing students who are studying in paediatric haematology/oncology clinics. Knowledge of clinical problems experienced by students in clinics will guide instructors in making clinical training more effective. The aim of this study was to determine the experiences of nursing students in caring for paediatric cancer patients and their families in haematology/ oncology clinics.

Materials and Methods

Sample and study design

This study is a descriptive qualitative study. Participants in the study consisted of 36 students who studied in the nursing department of a university's Faculty of Health Sciences in the 2011-2012 spring semester in Turkey/ Edirne and who completed the Children Health and Diseases Nursing course. The study sample consisted of 14 students who volunteered to participate in the study, which was carried out between the dates of 27 February 2012 and 2 March 2012.

The Children's Health and Diseases course comprises 14 weeks with 6 hours of theoretical and 12 hours of practical training. During the course, each student has a clinical practice of 12 hours in the Paediatric Haematology/Oncology Clinic of the University Hospital. Clinical practices are conducted in collaboration with course instructors and clinical nurses. The Paediatric Haematology/Oncology Clinic has a capacity of 15 beds.

Data were obtained by conducting focus group interviews through a questionnaire and semi-structured guide containing some characteristics of the students. The questionnaire consisted of questions, such as age, gender, status of giving care for cancer patients and the number of paediatric cancer patients whom the students have given care. Three semi-structured, open-ended questions were used during the interviews: *i*) What are the problems you experience when caring for children with cancer? *ii*) What are the emotions you have experienced when caring for children with cancer? *iii*) What has most affected you when caring for children with cancer?

Data collection

Data were collected through focus group interviews by the researchers. The interviews were carried out with 2 groups in a quiet classroom environment within the school and using an oval seating arrangement. The first author conducted the focus group interviews. Other authors made observations and noted important points about the interviews. The interviews were terminated when the data started to repeat. Each interview lasted 80-90 minutes and

was recorded using audio recording equipment.

Data analysis

A qualitative content analysis was used for analysing the data, and audio recordings were analysed at the end of the interviews. The data was grouped by their contents. The researchers coded the data independently of each other. A code list was then generated, after which the codes were compared. Based on the comparisons, themes and sub-themes were created. The researchers discussed the created codes and themes until they reached a consensus (Cokluk, 2011).

Ethical approach

The students were informed about the purpose and implementation of the study. The students who agreed to participate in the study were informed that their names would not be used in the research and that they could leave the study at any time. Each student provided oral and written consent and voluntarily participated in the study. A written permission was obtained from the Faculty Board for the study.

Results

The participants consisted of 9 females and 5 males with a mean age of 20.9±1.2 (min.: 19- max.: 24). The average number of children with cancer cared for by the students in the haematology/oncology clinic was 2.4±1.6 (min.: 1; max.: 6), and 13 of the students had a caregiving experience with adult cancer patients. A majority of the children whom the students provided with care were diagnosed with leukaemia. Three of the students had a family member with cancer, and two of them had lost a relative to cancer. Three main themes were identified during the focus group interviews.

Theme 1 relates to problems the students experienced in the haematology/oncology clinic. All the students stated that they had problems during the process of caring for children with cancer. Related sub-themes concern communication problems and a lack of knowledge and experience.

Communication problems

The problems most often experienced were those related to communication. The students stated that the communication-related problems were due to the lack of contact information for the paediatric cancer patients and their families, as well as aggression demonstrated by them. They described these problems as follows:

"The children were either unresponsive or showed their response with anger and by using slang words. When I wanted to communicate, the child shouted at me and asked me to leave the room. The child refused the treatment and care. I thought that their reactions was normal."

"When I wanted to communicate with the child, he she did not want to talk to me and used bad language."

"The child rebuffed me when I wanted to play with him/her. He/she began crying when I insisted."

"I could not communicate with the children. I did not even know how to approach the children. I could not find

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the right sentences."

"I did not know how to communicate because the children had cancer. Since they were away from school, I could not ask any questions about school, and I was afraid to ask questions related to their disease. I was experiencing problems and did not spend enough time with the children because I have not been sufficiently trained."

"I was having trouble communicating because the children were introverted. Some of them could be aggressive. It took time for them to trust."

"The child refused to be treated. He did not know why he was hospitalised. I tried to communicate by playing games. But he/she was unwilling."

"I was avoiding communicating with my patient, who was in pain. I did not want to communicate."

"I was having trouble communicating because he/she was both a child and a cancer patient. I tried taking advantage of his/her addiction to computers and succeeded in communicating. We played computer games together. I did not have any communication problems after I earned his/her trust."

"I could not get close to the child because he/she was crying and afraid during invasive procedures."

"I entered the room to take an anamnesis of the patient I was caring for. He/she was alone. He/she began to cry when he/she saw me. I did not know what to do. I tried to calm him/her down. But he/she began to cry more. At that time, his/her mother entered the room and shouted at me because I entered the room while the child was alone."

"I could not ask the mother any questions about the child's disease. She was worried, thinking that the child's condition had changed."

"After spending a long time with the children, we had a connection between us. It was hard for both of us to leave at the end of the day."

The students also stated that the clinical nurses did not sufficiently communicate with the children, and that their approaches to the children were not appropriate. A student described this situation by stating, "Nurses are not goodhumoured. They do not spare time for children who are out of treatment. They are inadequate in their knowledge of child psychology. They have left the children's care entirely to the children's mothers. They can be cold-blooded."

Lack of knowledge and experience

Another problem that the students experienced during their clinical practice was a lack of knowledge and experience. The students stated that they did not have enough information about how to care for a child with cancer and that they were inadequately trained regarding the disease and its course, as well as the appropriate psychosocial approach.

"The fact that the families had more knowledge about the disease than me was preventing me from communicating with them. I could not ask any questions about the child's disease. I was feeling inadequate and unable to communicate."

"The fact that the family had more information. They were constantly questioning what I was doing because of my status as a student. They thought my knowledge was inadequate and wanted to do the care themselves."

"The most important problem I had was my inexperience: I had never cared for a child with cancer before."

Theme 2 focuses on the emotions that the students have experienced. The related sub-themes are sadness, helplessness, fear, anxiety resentment and anger.

Sadness and helplessness

The students expressed the emotions of sadness and helplessness they have experienced in the following sentences:

"It was very upsetting for me that the mother was crying with the child during the procedures."

"They were constantly praying. This situation made me feel helpless and sad."

"The procedures performed seemed as if they were in vain; I felt helpless."

"I thought that these children were not like healthy children at all; healthy children would play games with their friends, without having to deal with problems. The fact that the children here were unhappy and tired, and had no desire to play games made me so unhappy."

"I entered his/her room and played games with him, which put a smile on his face. However, it pained me to know that he would be unhappy again when I left the room. I told him that I wished I could always make him happy."

Fear and anxiety

The other emotions experienced by the students were fear and anxiety. It was discovered that the students feared and worried about making mistakes, losing their patients, hurting children and losing their control; moreover, they feared that the same thing would happen to themselves and their relatives.

"I was afraid that girls losing their hair would be affected negatively and be upset for my hair."

"My patient had widespread metastases, and I was afraid he/she would fail to recover. I was afraid that my patient would not be there, and that I would find that I lost him/her when I would come back a week later."

"What if something like this happened to my child in the future? What would I do?"

"I was afraid to hurt the child I was caring for. I was afraid to approach him/her even to get information."

"That the mother's eyes were filled with tears made me feel like crying while receiving the history from the family. I could not control myself."

"I was unable to act professionally. I felt like crying, I was thinking like a mother."

"Would I act like this if I were a mother? Would I be that patient?"

"I was so scared when one of the children had to undergo a lumbar puncture. I said to myself, 'What if something like this happens to my relatives?!"

Resentment and anger

The students also experienced resentment and anger. The reasons for this included the fact that the children had cancer, there was no definite treatment for the cancer and the measures for preventing cancer were not given enough attention.

"When I first saw the child, I thought, How could something like this happen to such a small, innocent child? I wished he/she would heal and that the disease would disappear..."

"I was feeling resentment about why a definitive treatment for cancer still could not be found."

"I noticed that we did not give due importance to the protection of health. Why do we just treat the disease? Why do we not place importance on methods of prevention?"

Theme 3 pertains to situations/incidents by which the students were most affected in the process of caring for children with cancer. The sub-themes here are invasive interventions and effects of the disease on children and their families.

Invasive interventions

The experiences during the procedure of bone marrow aspiration affected the students the most.

"When the doctors and nurses entered the child's room for the bone marrow aspiration procedure, the child was aware of the procedure to be performed because he'd had the procedure before. The child began to cry and scream, 'Mom, Mom!' I was so touched when the child hugged his mother when she came back after the procedure."

"It was so touching for me that the child was crying 'Mother, do not leave me!', and the mother was crying in desperation while waiting outside during the bone marrow aspiration procedure."

Effects of the disease on children and their families

The students expressed the situations which affected them the most in the following sentences that show how the disease affects children and their families:

"I was very affected when one of the children spoke with his father and hugged him at the entrance to the clinic (that door was a border for me). To me, there were two different world, one on each side of that border."

"Children were affected by each other's outward appearances. Two of the girls with an Acute Lymphoblastic Leukemia diagnosis had alopecia. The hair of one of the girls had grown back. The other said joyfully while tapping her head, 'Your hair has grown back!' Then she touched her own head, and her face fell. She noticed that her own hair had not grown back."

"The child refused me when I wanted to play with him/her. That he/she said that he/she did not want to play games and was alone all the time affected me."

"The situation that most affected me was that the playground in the oncology clinic was empty, while playgrounds in other clinics were full of children."

"One situation that affected me was the child asking his/her mother, 'When am I going to play with my friends outside?'"

"We were playing games with the child. I was affected by the child who said, 'I am tired, I do not want to play anymore. A healthy child would never say that."

"We were drawing pictures with the child. He/she dropped its pen and asked me to wash it and give it back. He/she said that this was because the pen was contaminated. It was so touching to hear that from a 3-year-old child."

"A 16-year-old girl underwent a hysterectomy procedure. It was sad for me to realise that she would not be able to have children."

"The practice I was having in the haematology/ oncology clinic was over. I was at another clinic. The child I cared for in the oncology clinical asked for me (for establishing vascular access). I was called to the clinic. I was very impressed by the behaviour of that child."

"We raised money for Christmas and bought gifts for the children. It was wonderful to see the joy on their faces when we gave the gifts."

"It was affecting me a lot to think a child would die, while I could not stand even the deaths of adult patients, and the thought that the child might not be there the next week when I came for my practice."

"I was affected at seeing the children lose their hair, and looking tired and depressed."

Discussion

In this study, communication problems have been identified as the major problem for students completing a clinical practice in a paediatric oncology clinic. Yildiz and Akansel (2011) reported that students who encountered adult cancer patients for the first time experienced communication problems since they knew nothing about effective methods, and another study reported that first-graders experienced problems in establishing and maintaining communication with patients in their first clinical practices (Mete et al., 2011). Students also stated that they had communication problems due to the aggressive behaviours of children and their caregivers. The literature suggests that student nurses are at a great risk of becoming the victims of aggressive patients (Nau et al., 2007). Gorostidi et al. (2007) reported that students are afraid to work with aggressive patients. Nau et al. (2007) emphasise that nursing students are exposed to patient aggression in clinical environments and, for this reason, students must receive training on aggression, aggressioncausing factors, self-confidence in coping with aggressive patients and development of communication skills, such as assertiveness and empathy.

It is difficult to communicate with paediatric cancer patients and their families. Silva et al. (2010) reported that families with children who have been diagnosed with cancer experienced problems associated with communication, stress and roles, and Liang et al. (2007) reported that paediatric cancer patients and their parents experienced emotional, behavioural and social problems and exhibited more aggressive behaviours. In addition to the knowledge and skill required to care for children with cancer and their families, communication is an important component with regard to this type of care. Knowledge of effective communication skills is much more important in cases where the anxiety of children and their families is increased, such as in cases of cancer in children (Xie et al., 2013). Citak et al. (2013) also reported that nurses working in paediatric oncology clinics experienced communication problems, had difficulty in maintaining professional communication and requested that training programs on this subject matter be arranged. The same study reported

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that nurses experienced inadequacy, exhaustion and avoidance of communication with children with cancer and their families as the result of communication problems they had experienced. While patient-nurse communication is very important in professional practices, patient-student nurse communication is mentioned much less frequently in the literature (Suikkala and Leino-Kilpi, 2005). However, students having negative communication experiences during clinical training experienced the feeling of failure and the fear that they could not be successful in nursing practices and communication (Suikkala and Leino-Kilpi, 2005). For this reason, students must be supported in clinical practices in order to minimise adverse communicationrelated experiences. The necessity for nursing students to be provided with training on communication skills is emphasised in the study during which Xia et al. (2013) evaluated the communication skills of the nursing students during their clinical practices.

The use of therapeutic games as a method used in communication is important for children to cope with stress and to maintain their emotional and physical well-being during hospitalization (Li et al., 2011). It is important for health professionals to be aware of the importance of games in the lives of children and to accommodate this requirement for paediatric hospital patients, and use it especially in solving communication problems. In this study, students stated that they established communication with children using the game method. In addition, students who were aware of the need for children to play games realised the negative effects of the disease with regard to the children's ability to play games, and they reported that this situation affected them much.

In this study, students also noted that clinical nurses did not sufficiently communicate with children with cancer and their families. In a qualitative study performed by Pearcey and Draper (2008) in which the clinical experience of students was investigated, the students stated that no actual (effective) communication was in place in the clinic and that the nurses did not communicate with the patients. In the study, this situation was expressed as follows: "There wasn't a lot of communication at all, really. They (nurses) don't communicate with the patients." For this reason, health professionals providing paediatric cancer patients and their families with care should receive training on effective communication, clinical nurses should serve as role models for student nurses, students should receive training on communication skills prior to clinical practices and, in particular, communication should be supported on the first day of the students' clinical practice.

Students expressed that they experienced intense emotions during their practices and that the emotions they experienced most were sadness, helplessness, fear, anxiety, resentment, and anger. Cancer is associated with helplessness, unbearable pain, fear, uncertainty and death (Chen, 2010; Klassen et al., 2011). Chen (2010) reported that nursing students had experienced anger, fear, depression, stress, helplessness and guilt in the paediatric clinic. Children and their families experience feelings of intense fear and despair with the diagnosis of cancer (Cernvall et al., 2013). A qualitative study has determined that families with children with cancer experience anxiety, sadness, depression, exhaustion, guilt, anger, frustration and

social isolation (Klassen et al., 2011). Anxiety and sadness are the feelings most experienced by children with cancer and their families (Wijnberg-Williams et al., 2006; Liang et al., 2007; Klassen et al., 2011). Parallel to the sadness that cancer patients experience, students experience the same feeling with a strong sense of empathy (Gorostidi et al., 2007).

Clinical training is one of the most important causes for concern in nursing education (Gorostidi et al., 2007; Hacıhasanoglu et al., 2008; Melincavage, 2011). Research results suggest that the concerns experienced in clinical practices adversely affect the success of students; students with increased anxiety cannot well observe the requirements of their patients and therefore lose their trust. This adversely affects the relationship between the patient and the student (Melincavage, 2011). This study discovered that students feared making mistakes, losing or misinforming their patients, experiencing a loss of control and that the same would happen to their own siblings and children. Hacıhasanoglu et al. (2008) reported that the students experienced more fear and anxiety at the beginning, especially on the first day of their clinical practices, and Gorostidi et al. (2007) reported that harm to patients, experiencing a loss of control in communication with patients and communicating with patients suffering caused the students to experience stress. Similarly, it was found in several studies that students feared misinforming patients (Suikkala and Leino-Kilpi, 2005; Gorostidi et al., 2007; Cıtak et al., 2013). Altıok and Ustun (2013) reported that students experienced an inability to control their emotions and sustained a fear of failure while patients suffered and endured pain, and Mete et al. (2011) reported that first-graders had experienced the fear of making mistakes in clinical practices. Taşdelen and Zaybak (2013) reported that nursing students experienced a mid-level stress during their first clinical experiences, Erbil et al. (2006) reported that nursing students visiting hospitals for the first time for the purpose of clinical practice experienced anxiety and Yildiz and Akansel (2011) reported that nursing students who encountered adult cancer patients for the first time experienced fear and anxiety. A study reported that nursing students experienced anxiety in clinical practices due to the lack of professional knowledge and skills (Mete et al., 2011). Another study reported that 68.3% of nursing students fear having a negative experience during clinical practices, 34.9% of them fear making a mistake in practice, 11.1% fear the death of his/her patient and 11.1% fear hurting patients (Bayar et al., 2009). Although most of the students have previous experience in caring for adult cancer patients, their knowledge about the care of paediatric cancer patients is lacking, and they do not have any paediatric clinical experience. One study reported that, for 84.6% of the nurses, knowledge of paediatric cancers was very limited (Meraviglia et al., 2003). The study emphasised the necessity of arranging continuous training programs for nurses on clinical trials for cancer patients, genetic, complementary treatments, pain management, cancer and end-of-life care (Meraviglia et al., 2003).

The students stated that they were affected by their patients who had to endure pain and suffering, and that they had difficulties in controlling their emotions. It is emphasised in the literature that nursing students experience a loss of control in their relationships with patients due to insufficient practical experience (Gorostidi et al., 2007). Altıok and Ustun (2013) reported that nursing students experienced difficulties when they were unable to control their emotions due to their patients' pain and suffering.

In this study, one of the procedures which affected the students the most was the bone marrow aspiration procedure. Bone marrow aspiration, a significantly invasive procedure that is used for the diagnosis and treatment of cancer, causes pain. In this study, and consistent with these findings, the students said that they were greatly affected by the children in pain and who were suffering. They also stated that they had difficulties in controlling their emotions and were even avoiding communicating with the children.

To conclude, it is found that nursing students in haematology/oncology clinics experience significant communication problems, that their knowledge of, and experience with, cancer are inadequate and problematic, that the feelings they experience most frequently are sadness, helplessness, fear, anxiety, resentment and anger and that they are affected negatively by the application of invasive procedures and by the physical, psychological and social effects of the disease on the lives of children and their families. For this reason, it will be useful to inform nursing students about the special needs of children hospitalised in oncology clinics, their families and their characteristics, communication problems that may be experienced and their causes, as well as effects of the disease and appropriate psychosocial approaches. In particular, nursing students must receive adequate guidance in the first days in their clinics, prior to clinical practices.

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