

RESEARCH COMMUNICATION

Lived Experiences of Nursing Students with Mothers/Fathers with Cancer: Phenomenologic Approach

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Abstract

Objective: The aim of this research was to describe subjectively the lived experiences of students with mothers/fathers with cancer using a phenomenologic qualitative research method to explore life experiences of students about cancer and educational effects of it. **Methods:** The research was carried out between April and October 2008 at Odemis Health School with students training in 2007-2008 in classes 1, 2, 3 and 4. The sample was 4 students with parents having a cancer. **Results:** Assessing the results, stressed fear of death, fear of loss, communication changeover in family, role changeover in family as experiences. **Conclusions:** Subjects interpreted these in terms of future nursing education practice and expressed desires to provide more information to patients in their care. In this context, this research results contribute to professional nursing education.

Keywords: Nursing education - cancer in parents - lived experience

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Introduction

Cancer is a major health threat with respect to morbidity and mortality rate in the world. Every year cancer rates increase by 2% and every year cancer is responsible for the death of nearly 5 million people worldwide. And also 10 million people worldwide are diagnosed with cancer and 6 million die because of it every year. Cancer is the second leading cause of death in Turkey. This rate is much higher in developed and developing countries (Edwards et al., 2002; Gozum and Aydın, 2004; Karabulut et al., 2006; Akyuz et al., 2007). Despite remarkable advances in cancer treatment, it still remains to be the most feared disease among critical diseases. Most people describe it as death, pain or disorder. Some cancer patients are worried about the negative attitudes of the general public, such as bias and they are also concerned about encountering negative reactions (Fadıloglu and Yıldırım, 2006).

Cancer is a serious disease because it affects not only the individual who gets sick, but also all family members. For many people, diagnosis of cancer is accompanied with complete shock. No one believes that they or someone in their family will be diagnosed with cancer. However, cancer affects millions of families every year. One of the most challenging aspects of cancer is managing the disruption that occurs in everyday life, in addition to other life stressors (raising children, planning for retirement, working, recent divorce, etc.). When someone is diagnosed with cancer, regardless of the type of cancer, the diagnosis itself can evoke a great deal of worry and fear throughout the family. The uncertainty regarding the type of cancer, prognosis, and treatment options can be overwhelming

for patients and family members. In fact, partners and family members often exhibit more distress than the cancer patient. This distress may be a result of losing control, feeling hopeless, financial difficulties and anticipatory loss that are often associated with a cancer diagnosis. While cancer can have a substantial impact on physical health, there are also varying degrees of psychological and social implications that result from being diagnosed with and treated for cancer (Lev et al., 1998; Sammarco, 2001; Isaksenet al, 2003; Akyuz et al., 2007).

It is the same case with health staff who works with cancer patients, especially when the health staff provides care to patients in terminal period, they go through psychological problems and feelings of exhaustion. For this reason, in addition to medical treatment, psychological therapy and support should be offered to patients, families and health staff adopting holistic approach (Ödning et al., 1998; Ozkan, 2008).

As a result, cancer is a disease which influences not only individuals' lives but also family members and loved ones in many aspects such as physically, psychologically, socially, cognitively and economically. Researches conducted in this area indicate that the changes in patients' functional capabilities, body functions, looks, business, roles within family and general public, self-image directly affect care providers. Within this context, it is considered that having experience of mother/father with cancer may affect their attitudes to patients with similar diagnosis and accordingly it might have impact on their professional education.

It is considered that experience of students whose mother/father diagnosed with cancer would affect their

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professional education and communication with patients similar to their parent's diagnosis. Thus, it is critical to understand which problems students face about diseases of family members and how it affects the planning of their professional education.

The purpose of this study is to explore the experience of nursing students whose mother or father was diagnosed with cancer and its impact on their professional education.

Materials and Methods

Study Design

Based on the study's purpose, descriptive phenomenology was selected as the appropriate design to discover the essence of the experience. Phenomenology, a frequently used approach in qualitative nursing research, is focused on the experience of individuals as the major way to understand the broader meaning of people's life experiences. Phenomenologists assert that reality is not a fixed entity, it changes and develops according to people's experiences and the social context within which they find themselves (Schultz and Cobb-Stevens, 2004; Rapport and Wainwright, 2006; Dowling, 2007; Spichiger, 2009).

Sample and Setting

In this study, phenomenological approach which is one of qualitative research types was used in order to explore the experience of nursing students whose mother or father was diagnosed with cancer and within this context the impact of this experience on their professional education.

Research universe included the students of Odemis Health School' who were attending class 1, 2, 3, 4 in 2007-2008 education years. We had only five students whose mother or father with cancer and one of them refused to participate in the research. Four students whose mother/father was diagnosed with cancer were included in this research as samples (n=4).

Data Collection

This qualitative and descriptive study used semi-structured questionnaire from students who were volunteered to participate in an in-depth interview that was conducted between April and October 2008. All of the interviews were done by the researchers who received full training on qualitative research.

By using phenomenological approach, experience of students was explored and the impact on their professional education has been defined. Students who participated in the research were questioned about their experience with their cancer parents and they were made to express freely the changes in their attitudes towards their parents and research questions were asked to them. With the consent of the students interviews were started. Tape recorders were used during the interviews. These interviews were conducted in quiet places and students were encouraged to express their feelings. Each interview took approximately 30-45 minutes. After interview, voice recordings were transcribed on paper and participants were contacted to reconfirm their statements.

Interviews began with broadly open-ended questions specific to the purpose of the study: "How has the disease

of your father/mother affected your life? This was followed by some more open-ended questions such as: "How has the disease of your father/mother affected your nursing education?" These questions were formulated in the interview guide, which was generated from the issues identified in the investigators' clinical practice, an extensive review of the literature, and in consultation with both methodological and clinical experts. Also, during the progress of the interviews, some questions were provoked by the statements of the students.

Data Analysis

Various methods are used in phenomenological data analysis. The most commonly used methods for phenomenological data analysis are Voethan Kaam, Giorgi and Colaizzi's methods (Hwang et al., 2004; Duffy, 2005). In this research, analysis of interview transcriptions was based on Colaizzi's phenomenological methodology. During the analysis, oral descriptions of the students' informants' were read separately by researchers to gain a general understanding. Significant statements and phrases about the objectives of the study were identified. Meanings were formulated from these significant statements and phrases. The formulated meanings were then organized into clusters of themes. Results of the data analysis were integrated into a description of the experience.

To achieve final validation (Colaizzi, 1978; Wong and Chan, 2006), two informants were selected randomly and contacted again to read the descriptions; they agreed that the analyses had accurately represented their personal experiences. Common themes were created by merging similar statements for every category.

A manuscript about the study was written in Turkish following completion of the study and analysis of the interviews. The students' statements were then translated into English, retaining the original meaning. The English translation was then back-translated into Turkish by a bilingual speaker to make sure that the translation was accurate. Finally, two translations were compared with the original meaning of the Turkish version.

Ethical Considerations

This project was approved by the Ethics Committee of the Odemis Health School. Students were volunteers who agreed to be involved in the study and were fully informed about the purpose of the study. Students included in the study were informed about the study and written permission was obtained to interview and make audio recordings. Only the research team knew the names of the individual students.

Results

First of all answers of the students to the questions were categorized and recorded. 36 subjective statements were taken as raw data. At the second stage, 4 common categories were assigned and they were named as facing cancer, cancer perception, changes in individual and family life, impact of pursuing nursing education and approach to cancer patient.

Finally, themes identified from raw data obtained from

students with a phenomenological approach are defined as fear of death and loss, communication breakdown in family, role changes within family as mother and patient and identifying cancer patients according to the fact that whether they provide care for their mother/father. Table 1 demonstrates the profile of the students interviewed. Some data related to the characteristics of students' mothers/fathers are given in Table 2.

Theme 1: Fear of Death and Loss

Fear of loss is equated to fear of death. Many people are afraid of losing someone they love dearly because they will leave this life soon and they want to make sure that the relative concerned is being looked after properly (Akyuz et al., 2007). Students had experienced fear of death and loss.

- “Cancer is a lethal disease, I was scared of it.” (Student 4)
- “My fear of death emerged with anxiety when I hit a certain age because I thought I could have cancer...” (Student 2)
- “Because of the fact that I can have cancer, I am having regular check ups. I may be dying..” (Student 1)
- “When I heard first, I cried. I was afraid of death and I felt like my father was going to die right away.” (Student 4)
- “I was afraid of death, disease, and losing health.” (Student 3)
- “In my opinion cancer was the disease of the age, but I was thinking that we wouldn’t experience it in our family. Suddenly, it started to be seen everywhere and slowly it started to occur in family circles.” (Student 2)
- “My mother was unexpectedly diagnosed with cancer. Fears stroke my heart. I wondered what was going to happen, how she was going to be healed or was she going to be healed” (Student 1)

Table 1. Some Data Related to Students’ Socio-Demographic Characteristics

Sample No	Variable	Student 1	Student 2	Student 3	Student 4
	Age	22	21	22	22
	Class	4	2	3	3
	Success of the school situation (Self assesment)	Good	Good	Mediocre	Good
	Transcript	85.2	85.7	69.6	85.9

Table 2. Some Data Related to Students’ Mother/Fathers’ Disease

Sample No	Variable	Student 1	Student 2	Student 3	Student 4
	Mother’s Occupation	Housewife	Housewife	Housewife	Housewife
	Father’s Occupation	Free	Pensioners	Farmer	Pensioners
	Sick people	Father	Mother	Father	Mother
	Age	49	42	52	49
	Diagnosis	Lung Cancer	Hodgkins Lymphoma	Squamous Carcinoma	Breast Cancer
	Disease Duration	2 year	8 year	1 year	7 year
	Treatment	Chemotherapy + radiotherapy	Chemotherapy + radiotherapy	Surgery	Chemotherapy + radiotherapy +Surgery
	Prognosis	Relapsed (Bone metastases)	Remission	Remission	Remission

Theme 2: Communication Disruption within Family

Family members may have differing views about cancer and its treatment. Students talked about communication problems of parents who have cancer and other family members. One student told that her mother didn’t show herself to them and all students said that their family members couldn’t talk to each other.

- “I tell my brother that he is going to be fine, yet he doesn’t believe me. He can be aggressive in the way he speaks. I tell him not to treat my brother badly and not to make him upset” (Student 4)
- “My mother didn’t show herself to us. My sister was too young, me and my auntie did together the daily routines my mother used to do.” (Student 3)
- “I shared my problems with my boyfriend, yet I couldn’t tell anyone else. I couldn’t share them with my father as I did with my boyfriend. The reason for that was my father.” (Student 3)
- “My father stayed away from me after diagnosis. My father didn’t share his feelings with any family members. When he kept silent we couldn’t communicate with him.” (Student 2)
- “I don’t want to look into his eyes” (Student 2)

Theme 3: Role Changes within Family (Mother - Consultant)

Three students mentioned seeing their mothers/fathers as more emotional and vulnerable during cancer treatments; in response, they were more affectionate and they helped out by housework. Most of the students said that they feel like their mother/father after this experience. In addition to this, all students said that they acted consultant role as nurse, and doctor.

- “My mother was not at home, and when she was not there, I was responsible for the housework. Our mother who used to do everything was no more there. I was like a mother...” (Student 1)
- “I am treating my friends like my mother. I am not able to shout at anyone or get angry with them. I have had very strong feelings of pity and motherhood.” (Student 1)
- “Having knowledge of prognosis, I can guess what will happen next. I can decide when to inform the doctor urgently.” (Student 4)
- “My mother expects me to mention more about my father’s condition. She wants from me to give promising news.” (Student 2)
- “My role within family, changed, I am daughter,

healthcare provider..." (Student 4)

- "I disclosed the fact by reading books to my dad and he listened. We read the reports together, my mother also joined us." (Student 2)
- "I was calm as I got more scientific information about cancer." (Student 1)
- "Because I am a nurse, my mother and my father ask me about every disease to me." (Student 2)

Theme 4: Identification (identifying patients with father/mother)

All students told that patients liked their mothers/fathers and they acted like a mother/father to their patients. One of them took the role model as a mother nurse who cares without professional questioning.

- "As soon as I saw cancer patients, I wanted to train them. I wanted to tell them "Don't worry, there are treatment options." (Student 2)
- "She reminded me of my mother, and I wanted to inform the relatives of the patient to prevent them from being upset. I saw my mother's face on her face" (Student 1)
- "I would like to inform patients in detail." (Student 3)
- "After my father got cancer, I wanted to give more information to these patients." (Student 3)
- "When my mother encountered the disease, she didn't know anything, for this reason I explained everything about the disease to the patient." (Student 4)
- "I behaved her as if she was my mother, I wanted to explain them everything and I did, I told them not to worry." (Student 1)
- "A nurse explained everything to my mother. I take her as a model, and I would like to become a nurse like her." (Student 1)

Discussion

In this study, we analyzed the experience of nursing students whose mother or father was diagnosed with cancer and within this context the impact of this experience on their professional education. This impact was summarized under four main themes. Although each story was unique, some concepts were more prominent and it was seen that the experience of cancer had important effects on family life.

Cancer is a difficult disease for the whole family. Family members were all worried and sad, as the disease was frightening and strange (Bjork et al., 2005). The first thing that comes to mind is that cancer is equal to death. The most natural and inevitable fear is death. The most common emotions that accompany cancer are fear of loss, fear of death, concerns about the future, stress resulting from the disease and changes during therapy badly affect patients and their loved ones more than other diseases do. There are many kinds of losses that family members experience when one of them is ill. To the children it may seem like they have lost both parents because one is sick and the other is looking after them. Each member may feel

a loss of security about the future realizing that anyone of them might be threatened with illness (Akyuz et al., 2007; O'Baugh et al., 2008) Beliefs and reactions of family is generally acts like a patient's mirror. Families think that disease cannot be treated and thus they experience the fear of losing the patient. Within this context, cancer inevitably causes the patient to confront the possibility of their own mortality for the first time. Especially for conscious family members having a loved one diagnosed with cancer evokes feeling of fear of death (Akmansu, 1996; Irmak et al., 2008). The fact that students who participated to in the study experienced feelings of death and loss is parallel to the findings in literature.

The most common reactions of the family who faced with cancer diagnosis are sadness, fear, agitation, confusion and distancing behavior. Families try to cope with the disease based on their social and cultural structure. During this stage, emotional difficulties can arise in family due to disrupted future plans and communication barriers. Accordingly, unity of family is affected in many ways (Lev et al., 1998; Gurkan, 2005). In our study, students stated that they benefited from sharing their experiences with their friends, especially with friends just like themselves, as they often felt isolated and tended not to communicate openly at first with their parents and siblings. Study results indicate that communication breakdown in students' families can be seen as a result of cancer.

It is thought that depending on role changes in family, taking on the role of mother for students whose mother is diagnosed with cancer results from compensating role changes in family. Providing assistance to prevent disruption in family communication and loss of roles is a desired behavior in accordance with the social and cultural structure of students. The students assumed many additional responsibilities at home when they got sick; again supporting the extant research finding suggesting that family roles and routines often get disrupted (Davey, et al., 2005).

In addition, receiving health education has an impact on the students assuming caregiver role within family. In other words, it is observed that obligation of providing care for the patients remains with nursing students. Although cancer diagnosis and treatment can vary among institutions, health team generally includes surgeons, internal diseases specialists, radiotherapists, oncologists, psychiatrists, psychologists and social service specialists and nurses. Today, a great number of nurses are specialized in the care of cancer patients and their knowledge and clinical experience is quite impressive. Most of these nurses dedicate themselves to cancer patients considering feelings of patients and their relatives (Spichiger, 2009). Within this context, the fact that nursing students keeps their professional roles in their families is parallel to the education they have received. Despite the fact that receiving nursing education can be burdensome, it is assumed that the education has positive impact on students since they can provide more conscious care to their fathers/mothers.

It is not easy to understand emotional, psychological, economical and family concerns of patients who are under lethal risk and to help them. Especially the health

team who work in the oncology unit or intensive care unit remembers death every day and provides service to those patients who do not react to medical care. The staff do not have any tool to check or measure the results of service they have provided. As the time passes, all these make health team distressed and become exhausted. In general whole health team tries very hard to make patients better; all members of health team know that death is as natural as life, though they often experience conflict due to feelings of guilt and grief (Ferrell and Winn, 2006).

In a review of the literature on the concept of caring, the conclusion reached was that caring is a complex phenomenon. It could be described as a process including moral, cognitive and emotional components as well as caring behaviors, and it is culturally derived (Bertero, 1999; Corner, 2002). In this context, the experiences affect the process of care. Identification is an important factor in perception and learning and it must be overcome. Otherwise, professional behavior can adversely affect the process of care.

Having a mother/father diagnosed with cancer negatively affected students with respect to their attitude against patients in clinical practice. Research findings indicate that students whose mother/father was diagnosed with cancer were compared them with the patients that they cared for. It is argued that on the one hand transferring life experiences to patients helps students to improve their ability of empathy and on the other hand it will be too far from being a professional and later on it will cause exhaustion and make them wearisome individually.

The results of this study cannot be generalized because of the methodology and small sample size. Translation could be a limitation because some words lose their original meaning from one language to another.

In conclusion this study fulfilled the purpose of exploring the experience of nursing students whose mother/father was diagnosed with cancer and understanding its impact on their professional education by means of phenomenological approach. It is considered that the results of the study will bring new dimensions to nursing education.

The following suggestions are made based on the results of the study. Although the obtained data is specific to study group, it is thought that experiences of students whose mother/father was diagnosed with cancer and conclusions drawn from the study can be effective in nursing education. Defining students' experiences related to their attitudes towards cancer patients is an important guideline for developing individual education plan and it will make great contribution to the professional education of the students. It was observed that exploring the experiences of students' qualitatively and allowing them to express themselves help them to improve their awareness on this subject.

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