



I'm Here, Too: Being an Adolescent Sibling of a Pediatric Cancer Patient in Turkey

Melike Ayça Ay Kaatsız, PhD, RN^{a,*}, Fatma Öz, PhD, RN^b

^a Faculty of Nursing, Psychiatric Nursing Department, Hacettepe University, Ankara, Turkey

^b Faculty of Health Sciences, Nursing Department, Lokman Hekim University, Ankara, Turkey

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ABSTRACT

Purpose: This study aimed to determine experiences and needs of Turkish adolescent siblings of children with cancer (SCC) and to identify if there is a country/culture-specific risk factor for these siblings.

Design and method: In this qualitative study hermeneutic phenomenological approach was used. Eighteen eligible siblings were selected purposively from two hospitals in Ankara, Turkey. Interviews were conducted with a semi-structured form. Content and thematic analyses were used to analyze the data.

Results: The data revealed three levels of themes. The main theme was based on “*I am here, too*”. From the first moment of diagnosis, siblings need to be visible and noticed by others. They seek ways to make sense of the disease as they experience dramatic changes in all aspects of their lives (high level themes - first encounter with the disease and changes in life). They expect their parents and relatives to support them (expectations) when they turn to various methods to cope with the changes (coping styles).

Conclusions: The lack of protective psychosocial care is a basic risk factor for adolescent SCC in Turkey. Despite its various limitations, the strongest aspect of this study is that it is the first publication that determines the experiences of Turkish SCC in their own words. In addition to supporting recent findings about siblings' experiences, obtaining some country-specific findings is a strength of the present study.

Practice implications: Providing psychosocial risk assessment of the siblings' immediately after diagnosis is necessary. It can be helpful to inform parents about the risks.

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Introduction

Pediatric cancer is a potentially traumatic experience not only because it is a life threatening disease but also because it affects the psychosocial well-being (Kobayashi, Hayakawa, & Hohashi, 2015; Mu et al., 2015) and adjustment (Gibbins, Steinhart, & Beinart, 2012; Van Schoors et al., 2017) of all family members, including healthy siblings (Alderfer et al., 2015; Long, Marsland, & Alderfer, 2013; Zegaczewski, Chang, Coddington, & Berg, 2015). Research shows that healthy siblings of pediatric cancer patients are at risk for developing depression, psychosomatic disorders and post-traumatic stress syndrome (Deşat, 2014; McDonald, Patterson, White, Butow, & Bell, 2015).

In 1999, the International Society of Pediatric Oncology (SIOP) established guidelines on psychosocial issues in pediatric oncology to provide assistance to siblings of children with cancer (Spinetta et al., 1999). Based on evidence provided by Wiener, Kazak, Noll, Patenaude, and Kupst (2015), the inclusion of siblings in psychosocial care of pediatric cancer patients has been defined as one of the 15 standards of the

treatment (Gerhardt, Lehmann, Long, & Alderfer, 2015). Although there has recently been an increase in the number of studies on the effect of pediatric cancer on healthy siblings (Alderfer et al., 2015; Deşat, 2014; Long et al., 2017; Usluoğlu, 2018), little is known concerning healthy siblings' views of their own experience and of the type of support and care they need (Long et al., 2018). Therefore, more country-specific studies should address healthy siblings' views because they can provide valuable information to develop a national standard of care for pediatric cancer patients (Wiener et al., 2015) and to promote healthy siblings' access to care. The aim of this study is to explore the experiences of adolescent healthy siblings of pediatric cancer patients and to determine what type of support they need. We believe that this study will contribute to the literature not only because it is the first study to address the issue in question in Turkey but also because it considers the sample diversity and heterogeneity set forth by Long et al. (2018).

Siblings of pediatric cancer patients are often at the periphery of the family and hospitalization, from which they notice changes in the family functioning after a pediatric cancer diagnosis, the unpredictable nature of the disease and the changes it causes (Long, Marsland, Wright, & Hinds, 2015). Siblings of pediatric cancer patients have a higher risk of developing emotional, behavioral and social problems (Usluoğlu, 2018; Yang, Mu, Sheng, Chen, & Hung,

* Corresponding author at: Adnan Saygun Str., Block D, 2nd Floor, Office No: 33-14 Sıhhiye, Ankara 06230, Turkey.

E-mail address: ayca.ay@hacettepe.edu.tr (M.A. Ay Kaatsız).

2016), which might cause them to react emotionally to the situation they find themselves in and experience the feelings of fear of loss, guilt, anger, jealousy and loneliness (Guggemos et al., 2015; Mu et al., 2015). They experience difficulties in their social (Alderfer et al., 2015) and academic lives (Gan, Lum, Wakefield, Nandakumar, & Fardell, 2017). These siblings are exposed to various psychosocial risk factors such as family conflicts, inadequate social support, premorbid stress and inability to cope with it (Gerhardt et al., 2015; Long et al., 2018; Van Schoors et al., 2017) and sociodemographic risk factors such as being a member of a minority group (Long et al., 2013), low socio-economic status (Karlson et al., 2013) and living in disadvantaged areas with poor access to health services (Dolgin et al., 1997). However, research on these factors is limited.

Long et al. (2015) argue that qualitative studies should focus more on racial and ethnic factors to assess the role of siblings in family and the meaning they attach to cancer diagnosis, because they might be affected by cultural norms and values. Knecht, Hellmers, and Metzger (2015) suggest that the experiences of siblings of pediatric cancer patients be directly determined. The aim of this study was, therefore, to present the experiences and needs of healthy siblings of pediatric cancer patients with their own words and to determine whether there were country- or culture-specific risk factors. Our research questions were as follows:

- What are the experiences and needs of healthy siblings of pediatric cancer patients?
- Are there any country- or culture-specific risk factors that differentiate siblings of pediatric cancer patients in Turkey from those in other countries?

The study sample consisted of non-bereaved healthy adolescent siblings of pediatric cancer patients. Interviews were conducted with them. Selection of this age group was determined by the fact that puberty is a time of major change for all young people, both physically and mentally. Another reason was to provide an age-homogeneous group (Wilkins & Woodgate, 2005).

Methods

Design and sample

This qualitative study adopted a hermeneutic phenomenological research approach, which allows for the best interpretation of a phenomenon (Kafle, 2013). While the phenomenological approach enables people to share their experiences from their own perspectives (Langdrige, 2007), the hermeneutic perspective adds another value to this approach, which is interpreting those experiences and conveying them to readers from a naive understanding (Lindseth & Norberg, 2004). In this study, the researcher not only provided insight into what being “a sibling of a pediatric cancer patient” means but also conceptualized their experiences.

Participants were recruited using purposive sampling. They were the siblings of in- or outpatients with pediatric cancer receiving treatment at the department of pediatric oncology and hematology unit of two large university hospitals in Ankara, Turkey. Seven hospitals with pediatric oncology-hematology units were initially contacted and only two of them granted permission to conduct the study. These hospitals provide health care services to patients from the Eastern Anatolia, Southeastern Anatolia, Black Sea region and mostly from the Central Anatolia. All types of childhood cancer are diagnosed and treated in the units. Families are informed about disease processes and treatment protocols by healthcare teams. Turkey does not have a comprehensive cancer care service, including psycho-oncological care, however, some units have psychologists

with whom patients and their family members can consult. It is true for one of the units that granted permission to conduct the study but as mentioned, there is no routine psycho-oncological care service provided.

Twenty-five eligible siblings of 20 patients were informed about the purpose, procedure and confidentiality of the study prior to participation between October 2016 and February 2017. Eighteen of them agreed to participate. The others refused to participate because of lack of time. The inclusion criteria were as follows: (1) being a healthy adolescent (aged 11 to 17 years), (2) ability to communicate in Turkish, (3) cognitive and behavioral competence, (4) having a sibling being treated for cancer (any type and any stage) and (5) living in the city where the study is conducted. The exclusion criteria were as follows: (1) lack of cognitive and behavioral competence and (2) having a cancer history. No specific test was performed to assess cognitive and behavioral competence. Those who were able to express themselves, understand the interview questions and did not need any special education and/or treatment were considered cognitively and behaviorally competent and were included in the study. None of the participants had a history of cancer and none of them were excluded due to lack of cognitive or behavioral competence (Fig. 1).

Table 1 presents information about siblings.

Data collection and analysis

Procedure

The two units were visited. Patients' parents were informed about the purpose and procedure of the study prior to participation. After consulting with the parents, the siblings' assent was obtained. In order to do this, siblings were contacted face to face or by telephone and they were also informed about the purpose and procedure of the study. Seven siblings refused to participate in the study due to lack of time. Written informed consent was obtained from both parents and siblings. Interviews were scheduled with siblings at their convenience. The interviews, which generally lasted for 30–50 min, were conducted in a quiet and comfortable room in the houses of the participants. At least one parent was present in the house during the interviews but did not participate in it. At the end of the interviews, participants received notebooks and pens as gifts. All of these stages were carried out by the first author.

Interview

A semi-structured interview form based upon the literature and the clinical expertise of the three psychiatric nurses was developed. It contained questions that encouraged participants to explore and describe their experiences in their own words. The interviews began with an open-ended question: “What is wrong with your brother/sister and how did you find out about it?” Participants' responses allowed the researcher to find out about their knowledge of the diagnosis and to

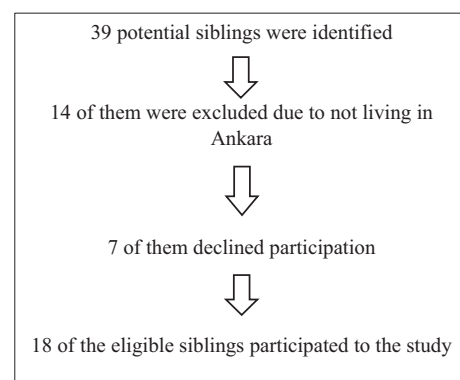


Fig. 1. Flow chart of the siblings' participation in the study.

Table 1
Demographic characteristics of the siblings.

N = 18 siblings from 14 families	
Gender	64% girl, 36% boy
Age	M (SD): 14.4 (1.85); range 11–17
Number of siblings in each family	52% more than four siblings 36% three siblings 12% two siblings
Birth order	84% older than the ill sibling
Time since diagnosis (months)	M (SD): 9.6 (8.36); range 1–24 (2 participants said they did not know)
Name of the diagnosis	44% leukemia/lymphoma 20% said didn't know the diagnosis 16% solid tumors 8% langerhans cell histiocytosis 8% Wilms' tumor 1 participant wrote only 'cancer'

lead the interview in that direction. That question also served to familiarize participants with the interview procedure. The aim of the open-ended questions was to enable participants to describe their needs and coping styles and to express dramatic changes in all aspects of their lives. Following are some examples of the open-ended questions: "In what way has your life changed since your sibling's diagnosis? How do you handle it when you feel bad? What do you usually do when you feel bad? What do you need to feel better now? What do you expect of your parents, loved ones and health care providers? What should we do to make things easier for you?" These questions were sometimes exemplified to make sure that participants understood them clearly and expressed themselves better.

Analysis

Miles et al. (2014, p.78) suggest that data collection and analysis be integrated. Therefore, as the interviews were being conducted, audio recordings were transcribed and analyzed to determine themes. Data were analyzed using thematic and content analysis, which generate conceptual tools to make sense of a phenomenon (Joffe & Yardley, 2004). Content analysis is concerned with quantitative data (frequency, correlation, cluster analysis, etc.) while thematic analysis is concerned with nuances of frequently repeated themes and in-depth examination of verbal patterns (Joffe & Yardley, 2004; Vaismoradi, Turunen, & Bondas, 2013). Content analysis is a conventional approach (Graneheim & Lundman, 2004) that numerically analyzes texts or series of visual materials (Joffe & Yardley, 2004). On the other hand, thematic analysis is a useful and flexible method which explores the relationship between themes to provide a comprehensive qualitative data analysis (Nowell, Norris, White, & Moules, 2017; Vaismoradi et al., 2013). Qualitative studies in nursing use both methods frequently (Bengtsson, 2016; Graneheim & Lundman, 2004; Nowell et al., 2017). This study used the six-step thematic analysis method developed by Marshall and Rossman (2011). The six steps are as follows: (1) transcribing and reviewing data, (2) generating initial codes, (3) generating themes, (4) reviewing and refining the themes, (5) defining and analyzing the themes and (6) producing written reports of thematic analysis. The interpretive and reflexive approach described by Mason (2002) was adopted to read the transcripts. Both researchers interpreted the data and reflected on participants' statements to understand how they perceived social facts. Doing this, the researchers sought to go beyond what the data initially present. As Mason (2002) argues, an interpreter conducting in-depth reading begins to discover his/her own perspective and becomes part of the data. The researchers frequently discussed how their views and experiences affected the way they interpreted and coded the data and determined themes. Both researchers read the transcripts separately and performed open coding. The data were coded using descriptive, in vivo and process coding methods defined by Saldaña (2013). They determined the repetition frequency of the codes and generated themes. The inter-rater reliability was 86%, and

disputes were discussed and resolved. Peer consultation was used to verify and expand the interpretations and themes. The first author reviewed qualitative studies on siblings and considered alternative explanations before finalizing the conceptual framework. Lastly, five experts in psychiatric nursing were consulted to discuss and finalize the conceptual framework (Fig. 2).

Ethical issues

The ethical dimension of the study was discussed based on the approach adopted by Miles et al. (2014, p.68), who addresses a number of questions that authors should ask themselves regarding ethical issues and reflections on qualitative research. This study is the first step of the first author's PhD thesis. The second author is the supervisor, who is a psychiatric nursing professor that has conducted reviews of studies on siblings of children with cancer. Having taken a course on qualitative research, the first author conducted a qualitative study within the scope of the course and performed an integrative review of the psychosocial status of family members of pediatric cancer patients to have a good grasp of the issue.

Most parents were supportive about the study as they stated that their children needed it and would appreciate that someone listened to them. This highlights the significance of the study, which was approved by the Non-Interventional Clinical Research Ethics Board of Hacettepe University. This board evaluates the studies in detail within the scope of the principles of getting informed consent, being honest and reliable, not harming, protecting privacy and data. All seven hospitals with pediatric oncology-hematology units in Ankara were contacted and only two of them granted permission to conduct the study. Participants were informed about the purpose, procedure and confidentiality of the study prior to participation. In accordance with the regulations of the board, both written and verbal informed consent was obtained from participants or their legal guardians (for children under the age of 18).

In qualitative research, the place where an interview is conducted affects reflexivity. Gagnon, Jacob, and McCabe (2015) recommend that interviews be conducted in an environment which makes both the interviewer and interviewee feel comfortable and safe and facilitates the interaction between them. To achieve this, participants were asked where they would like to be interviewed (the hospital, his/her own house, the researcher's office) and they chose their own houses due to accessibility and comfort. All interviews were conducted in a private room with only the interviewer and interviewee being present, and distractions (telephones, tv, etc.) were minimal.

All interviews were conducted, transcribed and translated to English by the first author. A professional editing service was also provided for the English translation.

Results

The data revealed three levels of themes (Fig. 2). The main theme was based on "I am here, too," which emerged from the statement of a sibling and connected the other high-level themes. From the first moment of diagnosis, siblings needed to be visible and noticed by others (parents, health care professionals, friends, etc.). They seek ways to make sense of the disease as they experience dramatic changes in all aspects of their lives (high level themes - first encounter with the disease and changes in life). They expect their parents and relatives to support them (high level theme - expectations) when they turn to various methods to cope with the changes (high level theme - coping styles). The sub-themes that deepen these themes are explained below. Direct quotes were used to present participants' perceptions and views. Participants' ages and genders are given in parentheses at the end of the quotes.



Fig. 2. Conceptual map of the healthy adolescent siblings' cancer experiences.

First encounter with the disease

Understanding that something is wrong

Although most participants have a feeling that something is wrong, their parents do not provide enough explanations to them. The siblings believe that their parents may not be sharing detailed information with them because they do not want to make them worry: "My parents did not tell us much... They were not talking much so that we would not get scared. Then, as the situation got worse, they said, 'We are going to the hospital, you have a responsibility now.' Things are pretty serious now. They tell me that I am a grown up and aware of things and so I should have a plan for my life" (16 y, girl). Despite their parents' protective attitudes, participants figure out what is going on from their parents' conversations and their own observations. Some of them are misinformed by the Internet concerning their sibling's condition. "My parents told me very little about it. I asked my mom 'Is that all?' and she said, 'that's what the doctor said.' Then I asked 'But, how so? It is too vague!' I do my own search when I think that my parents hold back some things. Some of the information you come across is sad, but some is good. It is complicated... Of course, with that vague diagnosis, I sometimes thought that my sibling suffered from things that he actually did not" (15 y, girl). Participants report that their parents often warn them not to upset their siblings. Furthermore, they want them to be careful about risk of infection.

"Cancer is a scary, bad thing"

Some participants, who hear or come across such words as cancer, tumor, lymphoma or leukemia, think and expect the worst. They try to make sense of the disease by associating it with the images they see in media, posters, etc. before. Information obtained from the social and physical environment affects the meaning that they attribute to cancer. For example, a participant stated, "I saw it in the brochures, they have all lost their hair, so, it does not look like a good thing." Some participants do not want to find out about their sibling's condition because they are afraid of what they would hear. "I didn't want to learn more about the disease back then and I don't want to learn now. I don't think any good will come of leukemia" (11 y, boy). Some participants associate cancer with hair loss and death. "When I heard that she had

cancer, I thought she was going to die. She was on a lot of medication, her hair was falling out..." (13 y, boy). Some parents teach siblings about the importance of protection against infection in this period by explaining the effect of the disease on the immune system.

Changes in life

Loss of normality

All participants experience disruptions in their family lives. It is remarkable that some participants emphasize especially the changes in relation with their fathers. Especially female participants aged 15 to 17 years, who viewed their fathers as figures of authority, state that seeing their fathers feeling sad and crying affected them deeply. "My father cried at the hospital and he cried at home. It was the first time I had seen him cry... This affected me so much, I went to the small room and I cried, too" (16 y, girl). According to participants, their fathers help more with the housework and their care. "...People were just coming in and out of our house back then. My mom and dad and my aunt and my cousins were always coming and going. When my dad showed up, he cooked for us and took care of us. It was normally my mom that used to do those things" (15 y, boy). However, some participants think that it is their mother who runs the family, and therefore, they feel incomplete when she is away. Although they know that their sick sibling needs their mother more than they do, they cannot help but yearn for their mothers' attention. "I feel my mom's absence. Although she gets mad from time to time, she has a different place in my heart. I mean, it is a different feeling when I get back home from school and she opens the door" (16 y, girl). Changes in family routines also affect school life. Participants have difficulty concentrating on lessons and worry about their siblings' condition. Especially those 16 to 17 years of age who prepare for college entrance exams are worry about the future. Moving for treatment underscores the significant change in children's lives because they have difficulty adapting to school life and making new friends. Some participants put the blame on moving to another city for everything they have been through: "The disease is why we are here... I am generally confident, I can talk to new people easily, but the first time I got here, I hated school. I started school, thinking that I would get out of this place once the disease was treated but it just keeps me from adjusting... Moving has affected my life very much..." (15 y, girl).

Growing up suddenly

Changes in family routines put more responsibility on the shoulders of participants and prevent them from spending time alone. Caring for their sick siblings and housekeeping and/or cooking restrict their social lives. One of the participants describes the "lost childhood" very vividly: "I have never paid a visit to the hospital, never, because I have to take care of my other siblings... I don't feel like I'm missing out on anything though, because I feel like a housewife now. I feel like I have kids that I have to cook for and do chores for, and I also feel like I have a job. School, work, home... I go to work as well; I'm doing an internship. I work, I study, and I take care of the whole house" (17 y, girl). Healthy siblings not only have to take on more responsibility, but they also have to run the risk of infection and spend more time with their sick siblings, which negatively affects their social lives. They cannot go out and hang out with friends as much as they have done before. Those who are more involved in household chores and in the care of their siblings feel like adults. "I feel like I am a little bit more mature than I used to be... I try to be a bit tidier at home. I used to fight with my siblings but now I take care of them and try to do things that make my brother happy" (13 y, girl).

Emotional strains

Participants feel sad, angry and lonely, and therefore, sometimes experience emotional strains throughout their siblings' experiences with cancer. They felt the saddest when they found out about their siblings' illness and seeing physical changes in them and their families going through difficult times during treatment. The second most common

feeling among them is “longing.” Some of them express a longing for their siblings and parents while others miss their friends. *“I really miss my friends and my home... When I was feeling bad, I used to meet friends or go out and do something else... Used to, used to... I keep saying ‘used to’ now”* (15 y, girl). Some of the siblings stated that he/she felt neglected by their mothers and/or parents but, it is understood that especially older siblings who were over the age of fifteen were aware of the causes. Nevertheless, some siblings (even though they were aware of the reasons) seemed to have resentment to this situation, was feeling lonely and experiencing an implicit anger. The idea of neglect and not being noticed was sometimes made the siblings feel offended: *“Of course, I sometimes cry, sad but true, and I snap at my mom. I go like ‘I’ve had enough of this! I’m here, too! Just leave her [sick sibling] be and let’s do something together!’ I know that she is doing her best, but it’s just not enough... So, I feel like I don’t have a mom. For two years... I feel like my mom is not there”* (16 y, girl). Another common feeling among participants is “anger.” They are angry at the illness and all the problems that it causes, and they take their anger out on their parents or friends. They are also afraid of losing their siblings.

Coping styles

Although participants use more than one coping strategy, they mostly use emotion-focused strategies, especially “avoidance,” “sharing their feelings” and “engaging in sports, music, and arts.” Some of them try to stop themselves from thinking or talking about their siblings’ conditions while some others are on their phones all the time to distract themselves. Being overly-busy with the telephone and/or internet is considered as a kind of avoidance by the authors. One of the participants’ statement clearly indicates the way she uses avoidance response: *“There is this door and there are a lot of emotions behind that door. I am shutting that door... I’m just shutting it because if I don’t, we can’t figure it out, I mean, we can’t overcome the disease. Like, even now, I just cannot talk about the traumas that I saw my sister go through or the pain that we went through and the fear that we had when we took her for biopsy... The feeling is so intense, it is not something that anyone can overcome, but, of course, when I go back home, that door opens a little bit, so there are times when I cry...”* (17 y, girl).

The participants who wanted to relax and share their feelings often talk to their friends and spend time with them while some others are engaged in sports such as football and volleyball. Another coping strategy that they use is “catharsis.” Two participants write while two others cry to pour out their hearts. Some others are so worried about their siblings that they do not do anything else, however, they make a mention of some other coping strategies such as spiritual coping: *“Well, I don’t have any material welfare or anything, but I feel very good spiritually. My brother’s condition has taught me a lot spiritually. I now appreciate my parents and my brother, and I know what sacrifice means and how hard it is to make sacrifices... I now appreciate having my brother. I appreciate especially my mom. You know what they say, ‘you don’t know what you have until it’s gone,’ that’s it. It has been an instructive experience for me”* (16 y, girl).

Expectations

Regaining normality

Participants want their mothers and old lives back and state that family problems should not be projected onto children. Some of them state that fathers should take more responsibility in family affairs. They need their parents and relatives to be more attentive and helpful and their friends to be more emotionally supportive. Reminiscing about her old routines, one participant points out that small details which seemed minor at first have become significant to her: *“...I didn’t appreciate my mom before. I never cared about such things; they were just never important to me. But then it dawned on me; mother is everything there is to a child”* (16 y, girl).

Open and empathic communication

Participants expect their parents and all other people around them (friends, teachers, relatives, neighbors and health care professionals) to be more understanding of their situation. Some of them are troubled by the fact that they have difficulty understanding healthcare information and the terminology that doctors use. They state that doctors should be more attuned to their patients’ needs and more conscious of patient care relationship. *“There are always new interns coming and going anyway. By the time you get used to one, a new one shows up. I hate the newbies, they hurt my sister, such big heads and dull attitudes... I think med students should get some sort of psychology or communication courses. They should make sure that the family is comfortable, especially at the time of diagnosis, and doctors should be compassionate and empathetic...”* (17 y, girl). All participants wish these interviews had been conducted earlier as they need somebody to talk to and share their feelings with. They think that mothers of patients can understand and help each other because they go or have gone through the same things: *“Like, they are at the hospital now; I mean two or three mothers in the same room. I think that they should be friends and spend time together there. They need people around them for support. I think that they all need each other to get through this because they are going through the same thing”* (16 y, girl).

Making his/her own way

Naturally, all participants want their sick siblings to recover soon and get back to normal family life. They see this as a prerequisite to set their own course in life. Especially older participants want to go to a good college. One of the participants stated that she had had a tough time dealing with the situation and stressed that health professionals should help siblings of pediatric cancer patients to make their own way especially right after diagnosis: *“Well, they are always concerned about him... Like, if it wasn’t for you, no one would come and talk to me and I would just hit rock bottom. It’s not like I’m too stressed or anything right now, but you should have seen me at my worst, I mean, a little after the diagnosis, I could have used some help. Children should get more psychological support and should be taught that they should hold on to life because there is nothing else they can do; you feel that no one is there for you... If you don’t help yourself, no one can. That’s what I’ve realized”* (16 y, girl).

Discussion

This study investigated the effect of cancer diagnosis and treatment on siblings of pediatric cancer patients. The results show that siblings of pediatric cancer patients feel a loss of normalcy, experience emotional strains and take up more responsibility. It needs to be visible that they are struggling to exist in this process, and this need forms the basis of their experiences. Therefore, this central theme is conceptualized with the phrase of *“I’m here, too”*. Siblings’ experiences are described within this central theme as: (1) first encounter with the disease, (2) changes in life, (3) coping styles and (4) expectations. They seek ways to make sense of their siblings’ condition, change their needs and expectations and use various coping strategies to deal with stressors. However, they need more understanding, empathy and open communication. All participants go through almost the same process; however, older ones are more worried about the future. In addition to this, it is an interesting finding that needs to be examined in terms of cultural aspects that some siblings had changes in relations with their fathers, and indicated that they were more active in housework. Only large cities have fully-equipped cancer screening and treatment centers, and therefore, cancer patients and families are forced to move to different cities for treatment and care. Among the risk factors associated with the adolescent siblings of children with pediatric cancer in Turkey are the stress experienced by the high school students who are trying to be enrolled in a good university by being successful at university entrance exams

and the lack of psychosocial services provided by the cancer treatment centers.

Some of the studies show that siblings of pediatric cancer patients experience the same challenges regardless of country or culture. Long et al. (2015) report that siblings do not fully understand what is going on but suspect something is wrong, and therefore, they seek ways to make sense of their siblings' condition and develop strategies to adapt to changes in family roles and functions. Although most participants know that their siblings have cancer, some of the parents do not know that their healthy children know about their siblings' condition. Some of the siblings think that their parents are reluctant to provide detailed information about the disease in order not to upset them. Those parents avoid talking about cancer because they want to protect their children, however, no matter how hard they try to hide a cancer diagnosis, most children suspect something is wrong and find out about their siblings' condition on their own. Research shows that being open and honest with children helps them cope with the cancer diagnosis of their siblings. However, their understanding of illness depends on their age and readiness (Gerhardt et al., 2015; Long et al., 2015; Long et al., 2018; Mu et al., 2015; Spinetta et al., 1999; Yang et al., 2016). Similarly, some of our participants do not want to learn more about their siblings' condition. Children get information from various sources, and those who have insufficient or incorrect information might end up feeling more anxiety because they might think the situation is worse than it actually is. They should, therefore, be provided with information about diagnosis and treatment depending on their age and readiness (Gerhardt et al., 2015; Spinetta et al., 1999). The process of interpreting the cancer of the siblings is another similar finding to the literature. It is a universal finding that the siblings associate the disease with death and hair loss based on their previous observations or knowledge (Long et al., 2015; Yang et al., 2016). No matter which culture such studies are performed in, siblings assign similar meanings to cancer and similarly react emotionally. Children often express sadness, anxiety, fear, anger and despair (Gerhardt et al., 2015; Guggemos et al., 2015; Houtzager, Grootenhuis, Caron, & Last, 2004; Long et al., 2015). Not only changes caused by cancer but having to move to another city for treatment take its toll on children. Fully equipped cancer screening and treatment centers are located only in the major cities in Turkey so, necessitates moving for treatment can lead to secondary trauma for families. Therefore, it is recommended that psycho-social care services should be integrated in these centers and services should be carried out to cover all family members from the moment of diagnosis.

Our participants report decreased academic achievement and increased responsibility, which is similar to the results reported by previous studies (Gan et al., 2017; Gerhardt et al., 2015; Guggemos et al., 2015; Kobayashi et al., 2015; Long et al., 2013; Long et al., 2015; Yang et al., 2016; Zegaczewski et al., 2015). Our theme "Growing up Suddenly" is similar to the theme "Having to Assume a Parent-Like Role" proposed by Long et al. (2015) because, in both studies, participants are more involved in the care of their siblings and have more responsibility. Cancer negatively affects family normalcy and forces children to assume new roles and responsibilities. It is, therefore, imperative that they be provided with peer-based and family-based support.

It is considered as a novel finding that some fathers are more involved in household chores and have changed in relationship with their children. It is already known that there are some gender and cultural differences with respect to parents' experience of cancer (Clarke, McCarthy, Downie, Ashley, & Anderson, 2009; Da Silva, Jacob, & Nascimento, 2010; Moghaddasi et al., 2018). These studies show that the stressors perceived by mothers and fathers in this process are different and their perceptions of their changing roles are influenced by their culture. However, these kinds of changes in the relationship between children and their fathers is unique to Turkish culture. In our study, it is mostly female participants affected by their fathers' emotional distress, which confirms Gibbins et al. (2012), who argue that fathers act stronger and emotionally support other family members as it is

traditionally expected of them. The Turkish family structure is based on both gender and generational hierarchies. There is also a collective cultural structure with strong kin ties (Ataca, Kagıtcıbası, & Diri, 2005). The father is a figure of authority and has limited communication with his children (Ataca et al., 2005; Tamm, Kasearu, Tulviste, & Trommsdorff, 2018). Authority and respect become more and more prominent in the father-child relationship as children grow up. When they achieve puberty, they become more distant from their fathers (Ataca et al., 2005). Although the Turkish family structure has been undergoing a change in recent years, the traditional aspects are still alive in the Eastern and Southeastern parts of Turkey, where most of our participants come from. Emotionally challenging processes, such as cancer, seem to downplay the traditional paternal role. Further research should address the effect of cancer on paternal roles in Turkey.

The coping styles that participants use depend on their age, personality and the severity of their siblings' condition. Those who see some signs of recovery focus more on the positive aspects of their traumatic experiences. However, they mostly use "avoidance" as a coping strategy, which is similar to what Long et al. (2015) describe as "distraction." Long et al. (2018) also report that changes in family routines and reduced parental attention force children to cope with their problems alone, which might even make them completely unaware of the emotions they avoid. Some of our participants, however, use some effective coping strategies as they receive social support and spend time with friends or other loved ones. Research shows that social support, especially peer support improves children's psychosocial adjustment (Alderfer et al., 2015; Gerhardt et al., 2015; Zegaczewski et al., 2015). Some of our participants turn to spirituality to deal with suffering. Their beliefs bring to mind the concept of "posttraumatic growth," which, according to Kamibeppu et al. (2010), is a long-term result of cancer in survivors and their siblings. It is also referred to as resilience (Alderfer et al., 2015; Gerhardt et al., 2015; Long et al., 2018; Van Schoors et al., 2017). Future studies on siblings of pediatric cancer patients should address posttraumatic growth, or resilience. Our findings regarding participants' self-reported needs and expectations are consistent with the literature (Lövgren, Bylund-Grenklo, Jalmzell, Wallin, & Kreicbergs, 2016; O'Shea, Shea, Robert, & Cavanaugh, 2012; Tasker & Stonebridge, 2016). They hope that their sibling will recover as soon as possible so that their mother will return home, and everything will go back to the family life before the sibling was diagnosed with cancer. They also expect healthcare providers to be more open and understanding and emotionally supportive. Lövgren et al. (2016) also report that children need more psychosocial support and want to be more involved in the care of their siblings. On the other hand, in a study evaluating the needs of the siblings from the perspectives of nurses (O'Shea et al., 2012), nurses stated that children should be provided with appropriate information and support and should be involved in the care of their sick siblings, and their needs should be recognized by health care professionals. However, healthcare professionals fail to do so due to certain reasons (Long et al., 2017; Sint Nicolaas et al., 2017). To ensure that the psychosocial needs of siblings are met, the psychological status of children should be assessed immediately after diagnosis and monitored on an ongoing basis. Moreover, open lines of communication with siblings are needed to support them psychologically (Gerhardt et al., 2015; Long et al., 2017; Sint Nicolaas et al., 2017; Spinetta et al., 1999; Wiener et al., 2015).

The findings of this study indicate that healthy adolescent siblings of pediatric cancer patients in Turkey should be addressed. The fact that treatment centers are located in the central provinces and so the family has to move is one of the risk factors that can contribute to additional psychosocial burden for all family members. Participants' self-reported experiences are similar to those of their peers in other countries. Changes in relationships between some participants and their fathers was found, which is a country-culture-specific finding that warrants further investigation. The failure to provide a comprehensive, standardized and routine psycho-oncological care service results in neglecting

the needs of healthy siblings as well as parents. While parents may be in contact with health care providers when dealing with sick children, healthy siblings remain in the periphery of both the hospital and the family.

Limitations

The fact that the interviews were conducted by using a semi-structured interview form might have led to using a deductive approach on interpretation of the three high-level themes (changes in life, coping styles, expectations). Consequently, this may have limited the findings. However, during the interviews it was seen that probing questions helped participants who had difficulty expressing themselves. The inability of expressing emotions or inability of pouring out fully is again, a culture-specific situation. Future studies can use different methods or spend more time with participants before interviewing them. Another limitation was that the sample consisted only of adolescents, therefore, the results cannot be generalized to other age groups. It is recommended that future studies integrate the accounts of siblings with cancer into their analysis as well.

Implications for nursing practice and further research

We believe that this study will guide Turkish pediatric oncology nurses to improve the care and support provided to healthy siblings of children with pediatric cancer. Nurses (and other health care professionals) should be aware of possible risks and take precautions to make sure that siblings of children with pediatric cancer are not adversely affected by the situation. Parents should, therefore, be informed about possible risks at the beginning of treatment. The psychosocial status of those children should be assessed at frequent intervals. It should also be kept in mind that adolescents in Turkey prepare for college entrance exams and their siblings' condition might affect them negatively. Therefore, educational seminars and peer support programs should be established to support them. Moreover, future studies should focus on other at-risk groups (younger population, children with a history cancer, etc.) to provide a more comprehensive picture of the experiences of Turkish healthy siblings of pediatric cancer patients.

Conclusion

This study determined the experiences and needs of Turkish adolescent siblings of children with pediatric cancer. They have difficulty adapting to new family roles and routines, mostly use several coping strategies and expect health care professionals to support and understand them. Despite its limitations, this is an important study that makes a unique contribution to the literature because this is the first study that allows Turkish adolescent siblings of children with cancer to share their experiences in their own words. In this context, it is thought that it contributes to international literature in terms of providing sample diversity and giving information about cultural-national situations.

Declaration of competing interests

The authors have no funding or conflicts of interest to disclose.

Author contributions

Study design: MAAK, FÖ, Data collection: MAAK, Conceptualization and data analysis: MAAK, FÖ, Study supervision: FÖ, Manuscript writing: MAAK, Critical revisions for important intellectual content: FÖ.

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