RESEARCH ARTICLE

Life experiences of adolescents with cancer in Turkey: a phenomenological study

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Abstract

Objective: To explore life experiences of adolescents after cancer diagnosis.

Method: The phenomenological qualitative study was conducted at the paediatric oncology clinic of a university hospital in Edirne, Turkey, from March 15 to April 1, 2016, and comprised semi-structured interviews with adolescents aged 10-18 years diagnosed with different types of cancer. Data was analysed using Colaizzi's method.

Results: Of the 12 adolescents, 7(58.3%) were boys and 5(41.7%) were girls. The overall mean age was 14.92±2.19. Mean duration of life post-diagnosis was 2.87±2.94 years (range: 1-11 years), and all (100%) of them had undergone chemotherapy. More adolescents experienced shock, sadness, fear, anxiety, curiosity and uncertainty when they learned their diagnosis. Changes related to family included missing their siblings and parents, and feelings of guilt, anger, and sibling jealousy. Adolescents stated that they missed their schools and friends, feared stigmatisation, abandonment and changes related to future. They wanted a stress-free life, to have an occupation, to continue school, and to be independent.

Conclusion: Cancer changed adolescents' relationships with family and peers, and their feelings and thoughts regarding future. It is important that health professionals, especially nurses, recognise and understand such changes to provide quality care.

Keywords: Life experiences, Nursing care, Phenomenological study, Adolescent. (JPMA 69: 1464; 2019).

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Introduction

Cancer, which is a chronic disease, is one of the most serious health problems in many regions around the world.[1-3] Cancer causes many physical, psychological and social changes. Age is one of the most important variables affecting the diagnosis and treatment of cancer.[4] While the cancer process results in fewer reactions during infancy and childhood, it becomes harder in adolescence.[2,5,6] Being diagnosed with cancer during adolescence can result in still greater stress. In adolescents, cancer can be perceived as causing a distortion in body image, resulting in rejection by peers[7,8] loss of independence, disruption in friendships, relationships, having effects on sexual maturation, and disruption of plans for the future.[6,9-11] All these factors result in increased stress, anxiety, and depression in adolescents.[12]

Adolescents have different reactions to cancer and its treatment. While some accept the situation, other adolescents display rebellious and dangerous behaviours in order to prove their independence.[6,9,13,14] As such, it is very important to make it possible for adolescents who receive a diagnosis of cancer to express their feelings and concerns, to increase their capacity for coping with stress, to help them, and to increase their general ability to adapt to the disease.[6,9,15,16]

Cancer may affect a wide range of adolescent's life domains.[17] Studies have highlighted that adolescent's experiences and outcomes are very different about cancer.[18] Walker et al. stated that adolescents face individual and social challenges during cancer treatment.[6] The negative and positive effects of being diagnosed with cancer are not known in adolescents.[18] In literature, it is reported that adolescents are not understood by health professionals and they need to be supported during treatment.[19,20] It is also very important that health professionals, especially nurses who spend the most time with patients, should meet adolescents' needs.[10,19,21] In order to achieve this, nurses should know life changes of adolescents with cancer.[6,15] To increase adolescents life quality, more studies are needed.[9]

With this goal, several researchers have suggested that there should be more qualitative studies involving cancer patients.[6,9,15] An examination of literature shows that there are few studies on understanding the changes in adolescents' life after cancer diagnosis and such a study is very much needed in Turkey.[16]

The current study was planned to fill the gap in order to help health professionals, especially nurses, to understand the life experiences of adolescents after cancer diagnosis.

Subjects and Methods

The phenomenological qualitative study was conducted at the paediatric oncology clinic of a university hospital in Edirne, Turkey, from March 15 to April 1, 2016. After

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obtaining permission from the Trakya University School of Medicine scientific ethics board and the Chief Physician's Office, the sample was raised using snowball sampling which is a technique generally used where potential participants are hard to find.[22] Prior to the study, 45 adolescents were listed in the paediatric oncology clinic and all of them met the inclusion criteria which had nine items: they had to have the cancer diagnosis at least a month ago; had stable general condition; had to be literate; aged between 10-18 years; open to communication; could speak and read Turkish; had to be physically able to participate in the interview; had no audio-visual problems; and had to be willing to participate. It was thought that it would be difficult to analyse data from all those who met the criteria, and, as such, snowball sampling technique was used, and it was applied until data saturation was achieved. Socio-demographic characteristics of the adolescents were noted using a survey form which was in Turkish language.

A semi-structured interview form was developed in the light of literature.[6,8,10,12,15] It consisted of questions on four themes, namely: 'What did you feel when you first learnt about your diagnosis?', 'What has changed in your family relations?', 'What has changed in your friendship relations?' and 'Did your thoughts regarding the future change?; These questions were pretested with three adolescents to ensure the questions were understandable and answerable. On the basis of pretesting, the interview form was revised where needed.

Data was collected in a quiet interview room located in the paediatric oncology section where the adolescents could easily express themselves, voice recordings could be made, and distracting stimuli were eliminated. The semi-structured interview took 30-60 minutes until data saturation was achieved. The interviews' language was Turkish.

In the interviews, both a voice-recording device and note-keeping were used. At least three researchers were assigned to each interview. The first researcher managed the interview. The second observed, posed additional questions for explanation when necessary, and took notes on important subjects (e.g. facial expression, voice tone, gestures). Thus, possible data losses were prevented and data was adapted to the research questions. The third researcher recorded the interviews against the initials of each participant, controlled the voice-recording device during the interviews, and thus prevented data-loss. In order to avoid data-loss, the manuscripts were translated from Turkish to English. Then the English-language revision of manuscript was done by a native speaker, and the authors checked all the manuscripts about meaning and grammar at the end of the editing phase.

Data was analysed using Colaizzi's phenomenological method which helped to determine adolescent's life experiences.[23] The interviews were listened to repeatedly to gain a general sense and understand the life experiences of the adolescents. They were scripted with Microsoft Word and important situations and explanations were included. The authors followed the Colaizzi's steps for phenomenological data analysis for identifying and grouping themes with similar characteristics (Table-1). At the end of the Colaizzi's process, each researcher formed detailed explanations and definitions regarding the subject which were consolidated and sub-themes were determined. Codes and any discrepancies were discussed before consensus on emerging themes was achieved. To increase the reliability and to verify the results, a specialist working in the same paediatric oncology clinic was consulted. All of the interviews were heard by the specialist and he was requested to formulate themes. After all these procedures, the emerging themes were discussed with a child psychiatrist until a final consensus was reached. When the themes and subthemes were finalised, the adolescents were invited to comment on the study's result and the themes/subthemes with the intention of approving the results.

Results

Of the 12 adolescents, 7(58.3%) were boys and 5(41.7%) were girls. The overall mean age was 14.92±2.19 (range:

Table-1: The steps in Colaizzi's phenomenological data analysis.

1. Read and write all the participant's description of the experiences under study
2. Extracting significant statements
3. Formulation of meaning of these significant statements
4. Organising formulated meanings into clusters of themes
5. Exhaustively describing the investigated phenomenon
6. Describing the fundamental structure of the phenomenon
7. Returning to the participants

Table-2: Characteristics of the participants (n=12).

Participants	Characteristics					
	Age	Gender	Cancer type	Time since diagnosis (years)	Status of education	Kind of therapy undergone
Adolescents	11-13: 3 14-16: 5 16-18: 4	Male: 7 Female: 5	Osteosarcoma: 4 Lymphoma: 2 Brain tumour: 3 Leukaemia: 3	< 1 years: 1 2-3 years: 6 > 4 years: 5	Yes: 9 No: 3	Chemotherapy:12 Radiotherapy: 6 Surgery: 8

11-18). Mean duration of life post-diagnosis was 2.87±2.94 years (range: 1-11 years), and all (100%) of them had undergone chemotherapy (Table-2).

Four major themes were identified (Table-3) and examples of patient narratives according to the themes and their respective subthemes were collated (Table-4).

The first theme related to feelings experienced when first learning the diagnosis. It had three subthemes: 'feelings of shock, sadness, fear', 'feelings of anxiety, curiosity, uncertainty', and 'lack of information about cancer'.

More adolescents learned their diagnosis from a doctor, but not immediately. They were informed about their disease after they were hospitalised. Most of them said they were not informed sufficiently about their diagnosis,

Table-3: Categories and sub-themes obtained from data analysis.

Theme	Subtheme
The feelings experienced when first learning about the diagnosis	◆ Feelings of shock, sadness, fear ◆ Feelings of anxiety, curiosity, uncertainty ◆ Lack of information about cancer
Family relations	◆ Missing family ◆ Missing siblings ◆ Jealousy of siblings ◆ Feeling guilty
Friendship relations	◆ Missing friends ◆ Lack of support
Thoughts regarding the future	◆ Stress-free life ◆ Having an occupation ◆ Continuing school ◆ Being independent

Table-4: Themes and subthemes and examples of narratives (n = 12).

Themes and Subthemes	Examples of Narratives
The feelings experienced when first learning their diagnosis ◆ Feelings of shock, sadness, fear ◆ Feelings of anxiety, curiosity, uncertainty ◆ Lack of information about cancer	- "I was afraid (heaving a sigh). What's wrong with me?" ~ (R, 11 years old male). - "I was sad (surprised). I was just so sad. I was afraid of dying.. Hmm, then I thought about things like getting treated, getting better and such" ~ (D, 13 years old female). - "I was afraid because everyone was afraid. Uncertainty. What was going to happen? Would it hurt? What will happen after this? How long will this last? You can't stop thinking about those"~ (M, 17 years old female). - "I was very sad. I asked how this disease could show up? Why me? I cried a lot. The uncertainties scared me. Would I undergo surgery? What will happen? What will they do? I was very curious" ~ (S, 18 years old female). - "I didn't know what was happening. They said it would pass with medicine. When I saw I was getting better, I wasn't afraid anymore" ~ (B, 14 years old male).
Family relations ◆ Missing family ◆ Missing siblings ◆ Jealousy of siblings ◆ Feeling guilty	- "When they gave me medicine, I would get angry with my family. I wished I could die. I wanted to die at that moment instead of taking the medicine. I wanted to die, but then I would think about my parents, about what they would do if I did. Then I thought life is beautiful." ~ (S, 18 years old female). - "My family relations got better (laughing). For example, my mother and father started to give a lot of attention to me. They got whatever I wanted. I had a computer at home. I told my father to get a laptop for me. He said 'No'. After I got sick, I told him and he got it at once.' ~ (B, 14 years old male). - "My siblings weren't uncomfortable with the situation (M, five siblings). But my middle sibling got affected. How can I put it…, my previously mischievous brother got more organized. In the end (hmm) he started housework at a very young age. He had to. He had to grow up fast (crying)" ~ (M, 17 years old female). - "My little brother loved my father very much. He's a little jealous. My father gives me more attention now. Once, I said it's so good I got sick since they give me so much attention (laughing)" ~ (D, 14 years old female).
Friendship Relations ◆ Missing friends ◆ Lack of support	- "My friends told me 'get well soon'. Some said 'aaa, an infectious disease', bringing me down. I said I would get better and defeat this" ~ (Y, 13 years old female). - "Someone in the class was making fun of me saying I was disabled. I didn't want to go to school at all that day. I wanted to strangle and kill that child then and there" ~(D, 13 years old female). - "I had a girlfriend and she supported me. I wanted her to leave me, but she didn't (laughing). Sometimes too much attention from her would smother me" ~ (Ç, 17 years old male). - "When your hair falls out and you, how can I say it… get different, it feels strange when you look at the mirror (crying). You say, 'Is this me?' Hmm… how can I put it, you get used to it. Then it just continues" ~ (M, 17 years old female). - "The worst part of this disease is not being able to go out. Sometimes, when I went out, I would be angry when people stared at me. But now I don't care at all" ~ (E, 17 years old male).
Thoughts regarding the future ◆ Stress-free life ◆ Having an occupation ◆ Continuing school ◆ Being independent	- "I want to go to Bursa. I've got aunts there. I'm going to go to Uluda? (mountain in Turkey). I want to ski. I never went skiing, but I want to learn. I thought about going to Istanbul. I like the weather there. I want to hang out with my friends like before" ~ (A, 15 years old male). - "I wanted to study and have an occupation. Like an architect or a lawyer. Now I want to be a state officer and relax and not make myself too busy. I consider this because it would be easier. When it's easy, it doesn't stress me out. I don't want stress. I want to live my life from now on. I don't want to do anything else. My only goal is to study, have a job, marry, and have kids"~ (S, 18 years old female). - "Normally I'm not a patient person at all. Not this much. I endure well, I think. I'm not strong and have my weak points. I wasn't aware that I would be this scared when they drew blood" ~ (E, 15 years old male).

because of which they felt shock, fear, anxiety and uncertainty. Most of them said that after the diagnosis, they wanted to be informed about their overall treatment procedure and they want to have a say in their treatment.

The second theme was about family relations. It had four subthemes: 'missing family', 'missing siblings', 'jealousy of siblings', 'feeling guilty'.

The adolescents said their families were more concerned about them than usual, that they were pleased with this attention, and that sometimes this excessive attention disturbed them. Some adolescents stated that they missed their siblings, that their siblings were jealous of the attention that was given to them, and that they felt guilty because of this.

The third theme was about friendship relations. It had two subthemes: 'missing friends' and 'lack of support'.

Some adolescents said they could not see their friends at all because of their illness and that they missed their friends very much. All the adolescents said they understood the value of school and of their friends better while going through their illness. Most of the adolescents said their friends helped them throughout the illness process, although some had negative attitudes.

Most of the adolescents stated that the loss of hair and having to wear a mask made them sad and that they were negatively affected by the reactions of other people.

The final theme was about thoughts regarding the future. It had four subthemes: 'stress-free life', 'having an occupation', 'continuing school', 'being independent'.

The adolescents felt that the experiences they had during their illness process had given them a chance to really get to know themselves, and they generally perceived themselves as resilient, hopeful, patient and stubborn. Most adolescents stated that getting a cancer diagnosis had given them positive experiences in addition to their negative experience.

Discussion

Healthcare professionals, especially nurses, should assess and understand the changes in adolescents' life after being diagnosed with cancer. The current study provides important data related to relationships in adolescents during and following cancer treatment from the perspectives of key informants. It is important for nurses to consider all subthemes of adolescents' life-changes to design and implement interventions when caring for them.

The study found that adolescents experienced shock, sadness, fear, anxiety, curiosity and uncertainty when they first learned of their diagnosis. In a study investigating the experiences of adolescents and young adults five years after being diagnosed with cancer, Doukkali et al. reported that some were very scared at first and felt that they had become someone else because of the physical changes; however, their lives went on and they did not want to abandon their dreams.[2] Docherty et al. reported that when they first learned of their diagnosis, adolescents and young adults with cancer experienced excessive stress and anxiety.[24] Belpame et al. reported that on first learning their diagnosis, adolescents and young adults with cancer felt "weird" and could not believe it was true.[10] Olsson et al. stated that adolescents and young adults knew very little about cancer and that instead of being told of their diagnosis by the health professionals, they learned about it through online research and were deeply disappointed.[5] Ramphal et al. stated that adolescents and young adults experienced stress and anxiety because they knew little about the symptoms or the treatment for cancer.[13] In a randomised controlled study where Kyle et al. gave cancer awareness training to adolescents at schools, their awareness level was found to increase, and the adolescents informed the people in their immediate environment, thereby decreasing the stress experienced.[25] Recent studies have shown that the stress experienced by adolescents, young adults, and their families decreases when they are given information by a health professional.[6,9,26] As can be seen from these studies, when adolescents do not know about cancer and its treatment, more intense stress is experienced when their cancer diagnosis is given to them. For this reason, it is very important to inform the adolescent and his/her family at the time of diagnosis, and to provide the adolescent with support.

When speaking about their family relations, the adolescents in the current study stated that they experienced feelings such as missing their siblings and parents, guilt, anger, and sibling jealousy. They also stated that their parents showed them intense attention and that their siblings were consequently neglected. In a study investigating the effects of childhood cancer on family relations, Silva-Rodrigues et al. found that families only thought about the child with cancer and neglected the other children, and that uncertainties about the treatment process negatively affected all family relationships.[14] Bellizi et al. found that cancer affected the relationship between the adolescent and his/her family positively and strengthened it;[18] whereas Docherty et al. found that cancer affected the family relations of adolescents and young adults positively, while it affected their friendship relations negatively.[24] In other studies, adolescents and young adults with cancer were found to have better health behaviour when supported by their families, peers, health professionals, and other people.[24,27] In a study in which Ferrari et al. expressed the experiences of adolescents with cancer by turning them into song lyrics, some of the adolescents stated that the only winner in their battle with cancer would be themselves, and that they would do it for their families.[7] In another study, Olsson et al. stated that adolescents and young adults wanted activities where they could feel comfortable, express themselves, and be supported.[5] The current study indicated that many adolescents could not earlier express themselves, with some even talking only to their mothers, and that the interviews conducted in the study made them feel better, with many feeling comfortable in expressing themselves for the first time. For this reason, it is very important that adolescents are informed immediately about the diagnosis and that the health team creates an environment where adolescents can express themselves. There is a need for the formation of social support groups.

In our study, the adolescents were found to experience a longing for school and friends, and fears of being stigmatisation and of abandonment. While some adolescents stated that their friends supported them, others stated that they were exposed to stares because of changes in their physical appearance. A study by Yeh found that although their friends took pity on them when they learned about their illness, adolescents with cancer did not want their friends to learn about their disease, and that they did not want to go to school once their friends found out.[8] The study conducted by Barnett et al. found that adolescents with cancer needed peer support and desired psychological help.[9] Doukkali et al. reported that participants did not want to go to school after the diagnosis, but that those who did continue with their studies had greater success at school.[2]

When asked about their thoughts on the future, the adolescents in the current study said they wished to continue with school, live a life without stress, and be independent. It was also found that career choices had changed as result of their illness, and that they wanted to live lives free of stress and travel a great deal rather than working towards a serious career. Yeh also found that the career choices of adolescents changed after cancer diagnosis and that they wanted to travel a lot.[8] In a qualitative study by Fauske et al. with adolescents with osteosarcoma, it was found that before their illness, most of the adolescents had desired to be professional sportsmen, but that this opportunity no longer existed as the adolescents could no longer spend their spare time on sporting activities.[12] In some studies, adolescents expressed the fear of not being able to have children, coupled with a general sense of anxiety. It was also found that cancer negatively affected and changed the plans adolescents had regarding their future.[12,15,18]

The single-centre nature of the current study is its limitation which restricts the generalisability of the results.

It does bring to light, however, the fact that adolescence, which is the period of passage from childhood to adulthood, is a special and stressful period. When an adolescent is diagnosed with cancer during this period, when he/she is trying to win autonomy, it affects family and friendship relationships as well as thoughts and feelings regarding the future. For these reasons, the adolescent needs special support and attention. Adolescents, both because of the characteristics of their age and also because of their cancer, may reflect their thoughts and feelings in different ways and may have unexpected reactions. It is important for the health professionals working with adolescents, and especially for nurses, to know what difficulties they may face in their care of these adolescents and to have realistic aims in the care process. For this to happen, the nurses must first understand the adolescents and their life changes.

Results of the current study suggest that information regarding the disease and treatment process should be given to every adolescent diagnosed with cancer from the moment such a diagnosis is available. This should be done by members of a multidisciplinary team, a support group should be formed, and the adolescent should be directed to programmes that help in coping with stress. In addition, school cooperation should be enlisted in presenting programmes concerning the disease and its management, and the importance of peer support should be stressed. Activities that allow adolescents to express themselves should also be encouraged.

Conclusion

Cancer changed adolescents' relationships with family and peers, and their feelings and thoughts regarding future. It is important for the health professionals working with adolescents, and especially for nurses, to know what difficulties they may face in their care of these adolescents and to have realistic aims in the care process. For this to happen, the nurses must first understand the adolescents and their life changes.

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