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Difficulty in returning to school among adolescent leukemia survivors: A qualitative descriptive study

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ABSTRACT

Purpose: The purpose of this study is to investigate the difficulties experienced by adolescent leukemia survivors upon their return to school using qualitative study methods.

Methods: Study participants include 14 adolescents who visited a hospital for follow-up care following treatment for leukemia at a university hospital in Seoul. We investigated difficulties in returning to school using in-depth interviews. Using a semi-structured questionnaire, the researchers investigated "difficulties after termination of leukemia treatment," "difficulties in school life," "difficulties in relationships with family," and "causes of stress."

Results: Through interviews, we identified five categories of difficulties among adolescent leukemia survivors including "feelings of alienation from friends," "difficulty in studying," "Stuck being different from others", "apologetic feelings for family," and "feelings of having an uncertain future."“

Conclusion: Most adolescent leukemia survivors in the study sample complained about difficulties in friendships and academic difficulties. Changes in appearance following treatment and the focus of others on their appearance following treatment hurt their feelings, and they felt apologetic toward members of their families. Worries about incomplete recovery following treatment and the fear of recurrence tended to interfere with the feelings of adolescent leukemia survivors about their future.

1. Introduction

The number of children suffering from childhood cancer in Korea is 1084 per million (Korea Central Cancer Registry, 2016), and the incidence of leukemia in patients under the age of 14 years is 4.4% per 10 million, making leukemia the most common childhood cancer (Korea Central Cancer Registry, 2016). The five-year survival rate of patients with leukemia is more than 80% in both the US and Korea due to the rapid development of therapeutic techniques (Korea Central Cancer Registry, 2016; Jemal et al., 2009). Therefore, standard medical care for patients with leukemia including induction, consolidation, maintenance therapy and stem cell transplantation is expanding not only to survival and treatment, but also to management of difficulties following the termination of treatment and return to "normal" life in Korea as well as in western countries.

Adolescent leukemia survivors face many difficulties in returning to school life following hospitalization or outpatient treatment after diagnosis with cancer. Sixty-five to seventy-five percent of childhood cancer survivors experience late physical and emotional effects (Mertens et al., 2014), which can lead to difficulties in returning to school and adapting to society (Gurney et al., 2009). In addition, visible scars and short hair following treatment may affect the self-esteem and psychosocial function of adolescent leukemia survivors (Mertens et al., 2014).

Korean culture is based on Eastern philosophy, emphasizing self-understanding through related emotions (Bong et al., 2008). Adolescent leukemia survivors in Korea are more sensitive to the reactions and behaviors of peer groups in an atmosphere that is focused on the expression of related emotions, which tends to strengthen ties among members rather than allow for the expression of personal feelings (Bong et al., 2008). In particular, adolescence is a time to achieve important development tasks, including formation of individual values and development of relationships through social interactions with others and by experiencing sudden changes in physical, mental, social, and emotional abilities (Jeon and Kim, 2014). Major developmental tasks in adolescence involve seeking self-identity in peer groups. Ongoing hospital visits related to late effects of cancer, however, tend to result in school absenteeism and a relative lack of peer participation. This

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Table 1
General characteristics of the participants.

Age (years)	Gender	Siblings status	Diagnosis	Stem cell transplantation
20	Female	Older brother	Lymphoid leukemia	Yes
15	Female	None	Myeloid leukemia	Yes
15	Female	None	Lymphoid leukemia	Yes
16	Female	Younger brother	Lymphoid leukemia	Yes
15	Female	Older sister	Myeloid leukemia	Yes
18	Male	None	Myeloid leukemia	No
14	Male	Older sister	Myeloid leukemia	No
19	Male	Older brother	Lymphoid leukemia	No
22	Female	None	Myeloid leukemia	Yes
21	Female	Two older sisters	Lymphoid leukemia	Yes
20	Female	Two older sisters	Myeloid leukemia	Yes
15	Female	Younger brother	Myeloid leukemia	No
21	Female	None	Lymphoid leukemia	No
21	Female	Younger sister	Myeloid leukemia	Yes

consequence of cancer survival is a meaningful cause of stress in adolescent leukemia survivors (Hong et al., 2014).

The most notable area of stress for young people in Korea is pressure for academic excellence (Park et al., 2016). In the context of prevalent preoccupations with success throughout Korean society, it is important for young people to go to a good college, which is based on getting high scores on entrance examinations and focusing on studying (Bong et al., 2008; Jeon and Kim, 2014). Therefore, in the educational environment in Korea (Bong et al., 2008; Jeon and Kim, 2014), adolescent leukemia survivors experience difficulty in achieving their academic goals due to neurocognitive problems caused by chemotherapy and radiation therapy (Mertens et al., 2014; Gurney et al., 2009; Kahalley et al., 2013).

School life is a significant part of the social life of adolescents in Korea because they spend most of their time at school and are required to observe their duties as a student, thereby devoting themselves to their studies (Kim et al., 2012). School maladjustment can lead to larger, longer-term social problems, including disruption to school life (Kim et al., 2012). To help adolescent leukemia survivors successfully return to school life and grow into healthy adults, it is necessary to identify their unique difficulties in view of developmental processes and sociocultural backgrounds. Studies on aspects of adolescent leukemia survival in Korea are very few, however, and research on late physical and emotional effects of cancer survival (Hong et al., 2014), quality of life (Hong et al., 2014), resilience (Hong and Park, 2015a), meaning of life (Hong and Park, 2015b), and difficulties in returning to school life has been conducted on a limited basis only as part of social adaptation processes among cancer survivors (Hong et al., 2014; Cho and Park, 2017; You, 2006). The difficulties that young cancer survivors face in returning to school life may be the starting point of social adaptation processes, but in the context of Korean society, school life challenges represent the starting point of difficulties that persist throughout life for cancer survivors.

Accordingly, this study identifies the difficulties that adolescent leukemia survivors experience in their school life within the sociocultural context of Korea. We aim to contribute to the development of programs that will improve the quality of life of childhood cancer survivors through better adaptation to school.

2. Methods

2.1. Study design

This study is a qualitative study using thematic analysis, conducted to investigate the challenges experienced by adolescent leukemia survivors in returning to school life following cancer treatment. Thematic analysis is a method for identifying, analyzing, and reporting patterns within data (Braun and Clarke, 2006). Themes were extracted through six phases, which are designated as becoming familiar with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing a report (Braun and Clarke, 2006).

2.2. Participants

The participants of this study are 14 adolescents who visited a hospital for follow-up care following treatment for leukemia at the Seoul Metropolitan University Hospital. A single nurse recruited participants who had returned to their social lives following successful completion of leukemia treatment and who were able to fully express their difficulties in readjusting to social and school life. A study investigator explained the purpose of the study to participants via phone, clarifying that participants could refuse or discontinue the interview at any time. Subsequently, participants made their own decision to participate in the study. For participants under 19 years of age, the content was first explained to a parent or guardian to obtain their consent and then explained to potential participants to obtain their consent. Participants under 19 years of age, their caregivers, and participants older than 19 years of age signed an informed consent to participate in the study, and in-depth interviews were conducted in comfortable circumstances. Participants ranged in age from 14 to 22 years, three participants were males, and 11 participants were females. Six participants were survivors of acute lymphoid leukemia (ALL), seven were survivors of acute myeloid leukemia (AML), and one was a survivor of chronic myeloid leukemia (CML) (Table 1).

2.3. Data collection

Prior to data collection, the Institutional Review Board (IRB) of the hospital approved this study (IRB no. MC16OISI0089). The duration of study was September 2016 to May 2017, and the investigator conducted in-depth interviews with participants about difficulties in returning to school life following the termination of treatment for leukemia. Interviews were conducted from one to three times, lasting 30 min to 2 h every time. Participants were invited to select a preferred café where interviews were conducted in order to ensure that the participants felt comfortable. Using a semi-structured questionnaire, the researchers investigated “difficulties after termination of leukemia treatment,” “difficulties in school life,” “difficulties in relationships with family,” and “causes of stress.” Interviews were recorded with the consent of participants, and the responses of the participants in the interviews were manually recorded using field notes. Following an interview, a research assistant listened to the recording and wrote a transcript, which the researcher confirmed by reading the transcript while listening to the recorded interview. Second interviews were conducted by telephone as necessary to confirm any ambiguous meaning in the first interview or to analyze and identify data that needed supplementation.

2.4. Data analysis

The research investigators consistently compared difficulties in returning to school life among the participants through the theoretical expression method, which extracts a sample based on concepts and hypotheses obtained through continuous comparison (Strauss and Corbin, 1998). In order to grasp the various concepts and categories through in-depth interview data, analysis was carried out until the point of theoretical saturation, in which similar content repeatedly appears and new categories do not appear (Guba and Lincoln, 1989).

2.5. Rigor

In order to secure the authenticity of this study, the quality of research was managed by applying the four criteria of credibility, transferability, dependability, and conformability proposed by Guba and Lincoln (1989). Before an interview, the researcher arranged telephone conversations with research participants in order to establish an interview location. During the interview, the participants were asked open questions and exchanged information in a relaxed environment to describe their difficulties in returning to school life following cancer treatment. The researcher listened closely to the stories of participants in a neutral and uncritical manner. The research assistant listened to recorded files to exactly transcribe stories as expressed by participants, and the researcher confirmed written transcripts by listening again to the recordings. Data analysis was conducted until theoretical saturation was reached. Two of the study participants confirmed that the data were consistent with the difficulties experienced by all of the participants. A researcher with a great deal of qualitative research experience verified the process of data analysis and the results according to standard procedures of the ground theory method.

3. Results

The challenges of adolescent and youth leukemia survivors in returning to school were extracted through interviews in five categories and 11 concepts (Table 2).

3.1. Feelings of alienation from friends

Most of the participants had to discontinue school life due to hospitalization, which meant they could not return directly to school due to follow-up care after treatment. Upon resuming school life, leukemia survivors had little time or opportunity to meet with friends because they were short of classes and frequently left school early due to health problems.

Table 2
Categories and concepts.

Categories	Concepts
Feelings of alienation from friends	Difficulty in getting along with friends Being upset about not being able to spend time with friends.
Difficulty in studying	Hard to follow study due to blank spaces Feeling apologetic to friends
Stuck being different from others	Getting hurt by other's view Feelings of resentment about being different from others Burdened by the excessive care (special treatment) of others
Apologetic feelings for family	Feeling apologetic to parents Feeling apologetic to siblings
Feelings of having an uncertain future	Desperation with physical limitation Fear of recurrence

- *I only attended morning classes and didn't participate in the school workshops, it didn't feel good, a little bit, when I had to sit alone in the back and only watch. (Female, 20 years old)*

In addition, problems and concerns related to health often excluded the survivors from groups and physical activity. This lack of engagement with peers made it difficult for our research participants to maintain friendships and caused them to feel alienated.

3.1.1. Difficulty in getting along with friends

Most of the participants could not go to school due to inpatient treatment and thus could not carry on with friends. This lack of peer interaction made it difficult for research participants to engage with friends and thus made them feel alienated.

- *When I didn't go to school and would meet up with my friends, should I say that we didn't have much to discuss, when they talked about things that I didn't know about, I felt a little alienated … Thinking that if I went to school, if I wasn't sick, that I could have join them made me a little depressed. (Female, 15 years old)*

In restarting school life, some female participants had difficulty establishing close relationships with other female students, many of whom had found groups of close friends during the participants' absence from school due to illness. Needing to take shortened lessons in school to recover health or to leave school due to subsequent care interfered with participants’ opportunity to be with friends at school.

- *In my third year in high school, the other kids already were friends since the first year so, the girls played in cliques, so the kids who were already friends played together, just like that, I felt that I couldn't approach them to become friends and those things were difficult. (Female, 22 years old)*

3.1.2. Being upset about not being able to spend time with friends

Most research participants were excluded from peer group activities due to health problems or concerns in school life. Participants reported that it was especially difficult to observe physical education (PE) classes, which are an enjoyable part of the school day when friends get a chance to run and interact.

- *Physical education class was the hardest. Since my bones were so weak, I couldn't participate in physical exercise or instead sat alone – those times were a little difficult. (Female, 22 years old)*

3.2. Difficulty in studying

Most of the participants were more concerned about their health than about academic achievement after being diagnosed with cancer. While participants were deeply relieved about their survival following termination of treatment, most felt that it was difficult to keep up with the academic progress of their peers due to gaps in their studies. Taken together, these results indicate that lagging behind in academic performance and ongoing health problems in a competitive school environment created further difficulties for leukemia survivors.

3.2.1. Hard to follow study due to blank spaces

Most of the participants kept up with school curricula via the internet during interrupted periods of study due to treatment. However, participants reported that they were not able to fully concentrate on studying because of symptoms and the side effects of treatment. In restarting school life, gaps in the academic progress of leukemia survivors due to treatment led to the burden of having to catch up to the academic progress of friends.

- *I had a university and major in mind, but after an absence from studying for two years, it was very hard to catch up within one year. I put in a great deal of effort in that respect, but it was very difficult. (Female, 22 years old)*

In particular, most of the participants encountered difficulties in math, which is not a subject wherein a student is able to jump to the next section if the previous section has not been understood. This situation increased the psychological pressure on participants because Korean society emphasizes academic achievement.

- *The gap between the first year of middle school to the last year in high school is huge. I was in the hospital for most of the time, so I wasn't in any condition to do anything. It was too difficult to keep up since I stopped my studies during middle school. It was just vague. Vagueness … when will I catch up? Subjects like math were very difficult to catch up in. (Female, 20 years old)*

3.2.2. Feeling apologetic to friends

Participants felt apologetic to their friends for feelings of responsibility for average class grades being low due to their own low grades. This is relevant in the context of Korean competitive school life wherein each class's average grades and test results are compared. Participants in the study were scored according to the same academic standards of their peer groups, even though our participants did not perform commensurate to peers in group performance evaluations for health reasons. The participants seemed depressed and were apologetic, saying things such as, “I got it for nothing.”

- *There was a situation where I had to go to the hospital due to a fever when I had to make a presentation for a group activity, so I could not do the presentation. I was very sorry … My friends were trying so hard to get the most points and I thanked them. (Female, 16 years old)*

3.3. Stuck being different from others

Most of the study participants were hurt by the attention of others due to the nature of how their appearance changed because of treatment. They tried to go unnoticed and blamed themselves for being different from others. Even when their hair grew back and their health recovered, the participants were constantly conscious of the extent to which others considered them in regard to their illness. The excessive attention of others was burdensome, because the participants considered it in terms of being seen differently.

3.3.1. Getting hurt by other's view

During follow-up care after treatment, most of the participants herein had little or no hair. They tended to wear hats while out in public due to being self-conscious about how they were viewed by others. The participants were worried about their external appearance before they returned to school, thinking that peers might make fun of the way they looked.

- *I really hated that I didn't have hair. So, I didn't like going out at all. When I did go out, I always put on a hat, a hat on top of the hat … at first I was very conscious of people, I thought people were looking at me, even though they weren't … (Female, 15 years old)*

At school, they were hurt by the staring of peers and by what others said about their appearance behind their backs.

- *When I was in elementary school, my friends said, "why is he/she wearing the hats and masks, and go back to home skipping classes in the afternoon?" (Female, 21 years old)*

3.3.2. Feelings of resentment about being different from others

Participants suffering from decreased physical strength.

- *When I riding a bicycle with my friends, I was physically weaker so often asked them to rest a little. At that time, I was sad about fact that my friends are so fine, and I am sick alone. I had a physical problem, brining problem getting along with my friends. (Male, 18 years old)*

They also suffered from peer comments about changes in their appearance following leukemia treatment. As a result, the participants resented that it was “only me” suffering leukemia in comparing themselves to their friends.

- *One time during class a friend suddenly took the hat off another friend's head, at the time I thought how can such a bad kid be so healthy when I, who was trying to live like a good person, had something like this happen, I was resentful. (Female, 21 years old)*

3.3.3. Burdened by the excessive care (special treatment) of others

Participants were also worried that their friends would reject them due to excessive care from teachers at school. The participants “just hated” any special treatment because they did not think of themselves as being different from others. Nevertheless, the leukemia survivors' friends tended to show them excessive care, thereby causing the participants to think that others considered them permanently impaired.

- *The teacher did not get angry with me and told me it is okay not to clean up, and like when my class was being punished, I got many exceptions. I was worried that if teachers treat me that way even though I could do those things too and it was okay, my friends would not like it. (Female, 15 years old)*

3.4. Apologetic feeling to family

Most of the participants were sorry for grumbling to their parents who had been by their side in support during their periods of treatment. The participants were also sorry to see their parents spend a disproportionate amount of family money on extra expenses out of concern for the participants' health with their return to school. In addition, participants felt apologetic toward brothers and sisters who had been marginalized during treatment periods because parental care had focused on the participants.

3.4.1. Feeling apologetic to parents

Most of the participants were sorry that they had released stress through grumbling and complaining to their mothers during treatment periods. Participants felt ongoing fatigue in their normal lives, too. Worried parents tended to spend more money than they could afford for the participants to travel to school by taxi, unlike friends who typically arrived to school by bus. The participants felt sorry about these circumstances.

- *It takes about 30 ~ 40 min to school by bus. However, after I became sick it was harder to wake up in the morning. It becomes disease if keep being fatigued. So, my mother was worried about it and let me take the taxi to school. It caused a lot of money and I really felt sorry to mother. (Female, 22 years old)*

3.4.2. Feeling apologetic to siblings

Most of the participants stayed in the hospital with their mothers during periods of hospitalized treatment. Because of this, their father or relatives cared for the siblings at home. Sometimes siblings had to take care of themselves. The study participants reported that they “always” felt apologetic to their siblings.

- *It was obvious that my parents had a hard time, and my sisters were* *young students too, but they often were at home and had to take care of meal without parents. Those things make me always feel thank and sorry for the sisters. (Female, 20 years old)*

3.5. Feelings of having an uncertain future

Because the health of leukemia survivors is not certain following treatment, ongoing health concerns often rob young people with leukemia of opportunities to face the challenges of the future. Fear of recurrence has often slowed the steps of participants in their journey toward the future.

3.5.1. Desperation with physical limitations

Most participants gave up on their own desires due to the side effects of treatment and poor physical fitness following treatment.

- *I want to be a nurse, doctor, or a teacher, but I cannot be them all, because my school grades need to be very good for it. My sister always gets good grade and she often stay up at night studying. However, I cannot stay up and study. It will be very difficult. (Female, 15 years old)*

Additionally, participants reported that they were not able to pursue their interests because of their parents' and other people's concerns.

- *I was going to get a part time job at a restaurant but my parents were against it because it would require a lot of physical strength, then I tried to get a part time job at a clothing store and I disclosed in advance that I have physical problems, and they declined to hire me. (Male, 18 years old)*

3.5.2. Fear of recurrence

Most of the participants experienced instability in their well-being due to fear of recurrence. One participant likened the fear of recurrence to “being a blown-up balloon that is leaking air.” During follow-up care after treatment, the participants were full of fear about recurrence when waiting for their own laboratory exam results prior to seeing doctors in outpatient departments or in hearing news about recurrence in friends who had been diagnosed with and treated for the same disease.

- *After getting your blood work and then seeing the doctor, is nervousness the right word? Like a deflated balloon? Because of the nervousness, like a blown up balloon where the air is leaking … that feeling. (Female, 20 years old)*

Participants stated that the fear of recurrence came from the prospect of repeating treatment processes that they knew were torturous for not only themselves, but also their parents.

- *If it occurs again my parents will have a hard time again … Also I don't even want to remember how difficult it was when I was taking chemotherapy. So I am very afraid of it and could not even study. (Male, 18 years old)*

4. Discussion

Pediatric leukemia survivors are vulnerable to the social, cognitive, and educational changes that come with maturity to adulthood and can experience psychosocial difficulties (Kahalley et al., 2013). It is essential to recognize that adolescence is a period when young patients begin a social life away from therapeutic environments and experience difficulties (Mertens et al., 2014). The most prominent change in adolescence is the expansion of interpersonal relationships. Friendship is especially important during this period, as life begins to extend to the world outside the home (Jeon and Kim, 2014; You, 2006). As seen in the results of this study, adolescent leukemia survivors show difficulties in friendship. In restarting school following treatment, adolescent leukemia survivors struggle in getting along with friends with whom they have not had consistent interaction. The same concerns have been reported in previous research. The work of You (2006) reports that adolescent leukemia survivors did not have friends during periods of treatment due to being frequently absent from school, and that they tended to worry about whether they could regain friends once returning to school. As a conclusion of that study, adolescent leukemia survivors were shown to be depressed during periods of follow-up care for reasons involving the difficulties of friendship and frequent absences from school due to time in the hospital. In a previous study (Hong et al., 2014), hospital visits related to late effects of cancer, absences from school, and a lack of participation in peer activities were reported to be important stressors for adolescent leukemia survivors. This may have a negative impact on the development of self-identity in peer groups, which is a major developmental task of adolescence. Therefore, a follow-up management system considering the school life of adolescent leukemia survivors should be constructed so that these young people can experience positive growth through friendship (Jeon and Kim, 2014).

Although our findings show that the adolescent leukemia survivors tried to focus on school and to study when they returned to school following treatment, they had persistent difficulties. This is consistent with the findings of previous studies (Edelstein et al., 2011; Harshman et al., 2012; Bava et al., 2017) in which treatment with chemotherapy and radiotherapy in growing children was shown to cause neurocognitive disturbances, such as learning disabilities and memory disorders, which may have a negative impact on academic achievement. One aspect of treatment for survival in young leukemia patients is withdrawal from the social atmosphere (Bong et al., 2008; Jeon and Kim, 2014) which, in Korean society, is characterized by enthusiasm for academic achievement in order to select a good university and prepare for the admissions process. In this culture, adolescent leukemia survivors try to focus on academics, but it is difficult because of gaps in education and treatment sequela. Neurocognitive dysfunction is the most common aftereffect of treatment, impacting up to 40% of leukemia survivors (Buizer et al., 2009). There is a need for learning support tailored to the level of leukemia survivors in consideration of the gaps in schoolwork and neurocognitive dysfunction resulting from treatment.

Differences in the appearance of adolescent leukemia survivors, such as short hair, may affect the self-esteem and psychosocial function of survivors following treatment (Mertens et al., 2014). Adolescent leukemia survivors experience problems with school and peers related to anxiety, depression, despair, social isolation, physical injury, and disease (Liang et al., 2008). In this study, participants also felt that the attention of their peers was focused on their short hair and other physical signs of treatment for their illness, which caused them to feel hurt and negatively impacted. In addition, while they were grateful for the courtesy of teachers at school, they worried that excessive concern for their well-being on the part of teachers would be seen by others as special treatment. Adolescent leukemia survivors want to be acknowledged as normal in the sense that they require no different treatment, and they want to have a stable identity with their peers, but the reality of how they are treated by others is counter to this desire for normalcy (You, 2006). These adolescents are upset by others who see and treat them differently in school activities and social interactions because of their experiences with cancer diagnosis and treatment (Li et al., 2013). If left as is, this disparity between perception and reality may cause psychosocial problems in adolescent leukemia survivors (Çavuşoğlu and Sağlam, 2015). Peer-based therapy and training programs for social skills (Barakat et al., 2003) are necessary to reduce social isolation among adolescent leukemia survivors and to facilitate their normal development.

Adolescence is a challenging period for young people moving. Even if outcomes are not always successful, young people learn and grow through the challenges of adolescence. However, participants in this study often gave up when their parents objected to their attempted endeavors with physical activities or jobs, and sometimes they did not participate in peer-group activities because of the concerns of their parents and teachers. Parental protection and over-surveillance of the activities of adolescent leukemia survivors hinder their ability to grow into independent adults by maximizing their abilities (Mertens et al., 2014). In previous research, Gordijn et al. (2013) reported the possibility of parental underestimation of survivors, finding that parents of childhood leukemia survivors were more aware of the fatigue of survivors and of lower life quality in adolescent leukemia survivors. Nevertheless, concerns about the late effects of disease in young leukemia survivors must not be ignored. Therefore, individualized services are necessary to provide guidelines to parents and educators on appropriate activities according to survivor health conditions.

5. Limitations

Because participants might not agree to be interviewed when their difficulties are acute, long-term interviews are needed on a continuous basis from the beginning of treatment in adolescent leukemia patients. In addition, quantitative research is necessary for a larger number of participants in various regions in order to identify specific difficulties in adolescent leukemia survivors according to diagnosis age and periods of treatment.

6. Conclusion

In this study, participants had difficulties in initiating or rekindling relationships with friends at school following termination of treatment, and they felt alienated from their peers. As adolescents, who naturally take self-identification very seriously, participants were hurt by perceptions that their physical changes due to leukemia treatment caused them to seem different from their friends. Excessive concern and special treatment by others was a burden rather than a benefit, because it confirmed for participants that others thought of them as being different from their peers. They blamed their appearance for making them different from others. In a social environment that emphasizes the importance of academic work, the participants were frustrated by the demands of preparing for college admission and reported that schoolwork was hard to follow, despite their efforts, due to gaps in education because of treatment for their illness. In a competitive school environment that regularly compares class averages and test results, the participants felt apologetic to classmates for their own low grades. The participants also felt sorry for the demands they made on their parents, who were by their side during treatment and who cared for them on an ongoing basis. This feeling was the same toward siblings who had been left out of parental focus because of the demands of their illness. Some participants gave up on what they wanted due to their physical limitations. Further, the pain they experienced during treatment caused a fear of recurrence. Participants reported being sometimes unable to do anything because of the fear of recurrence.

Taken together, these findings show that it is necessary to develop programs to help caregivers and healthcare providers to grasp the difficulties faced by adolescent leukemia survivors and to fully and immediately support them, so that they can readapt to school life and grow to fulfill their desires.

Conflicts of interest

No conflict of interest reported.

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