A Phenomenologic Study of the Experiences of Pediatric Cancer Survivors After Hematopoietic Stem Cell Transplantation

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PURPOSE: To explore the experiences of pediatric cancer survivors in South Korea after hematopoietic stem cell transplantation.

PARTICIPANTS & SETTING: 14 survivors of childhood cancer who had undergone hematopoietic stem cell transplantation at a pediatric hematopoietic stem cell transplantation center.

METHODOLOGIC APPROACH: Participants underwent in-depth face-to-face or online interviews from October 2020 to January 2021. Data were analyzed following Giorgi's descriptive phenomenologic research method.

FINDINGS: The following four themes emerged: regaining physical strength, a wish to express the overwhelming burden, cultivating positive thinking through reflection, and living a self-directed life. Pediatric cancer survivors experienced deep appreciation toward surroundings and everyday life, engaged in broader and greater positive thinking, and strived to live a self-directed life despite physical limitations and negative emotions.

IMPLICATIONS FOR NURSING: Interventions enabling pediatric cancer survivors to express challenges and help them recover physical fitness are needed to improve their post-transplantation quality of life. These results can inform healthcare providers, nurses, and the general community to provide high-quality care to cancer survivors.

KEYWORDS cancer survivors; childhood; nursing; hematopoietic stem cell transplantation; quality of life
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Advances in medical technology have led to a steady rise in the survival rates of children with cancer (Howlader et al., 2020). The five-year relative survival rate for major pediatric cancers in Korea is 83.6% (Korean National Cancer Center, 2018). Scholarly interest in pediatric cancer survivors is also growing (Howlader et al., 2020; Korean National Cancer Center, 2018). Hematopoietic stem cell transplantation (HSCT), recognized as a fundamental treatment modality for pediatric leukemia as well as for intractable diseases, has become an increasingly popular treatment for children (Korean Blood and Marrow Transplantation Nursing Society, 2018). HSCT recipients are subjected to a high-dose chemotherapy regimen, involving more than two or three times the regular chemotherapy dosage, as well as systemic irradiation for myelosuppression (Bingen & Hoag, 2016). As a result, patients who have undergone HSCT are at higher risk for infection than those who have not, leading to greater rates of hospitalization and all-cause mortality (Chow et al., 2017).

Although HSCT is highly promising because it improves survival rates and increases hope for a complete recovery for individuals with intractable diseases, it also entails psychological and social consequences, such as relapse, long-term sequelae, and financial burdens (Lahaye et al., 2017; Park & Han, 2018). Patients can also experience deteriorating quality of life (Niederbacher et al., 2012); as they remain in protective isolation (Rossi et al., 2016), the sensory deprivation may trigger further psychosocial problems (Sinatora et al., 2017). In one study, pediatric HSCT recipients described their treatment as a painful process "going between heaven and hell" (Griessmeier, 2001, p. 255). Another study reported that pediatric HSCT recipients experienced wide-ranging psychosocial and physical effects (Lahaye et al., 2017).

Understanding the experiences of pediatric cancer survivors after HSCT from their perspective is necessary for interventions after HSCT in this population. To date, most studies have confirmed the side effects and related factors after HSCT from the perspective of pediatric cancer survivors through quantitative research methods (Karst et al., 2021; Otth et al., 2022). Through previous quantitative studies, the current authors were able to confirm the difficulties of pediatric cancer survivors after HSCT. Qualitative studies have been conducted to understand the experiences of HSCT in pediatric cancer survivors (Lahaye et al., 2017; Sinatora et al., 2017). However, such studies are scant, the number of study participants sharing their experiences was limited, and, to date, no study has been attempted in Korea. Therefore, it was difficult to understand the experiences of participants in previous studies by applying them to Korean pediatric cancer survivors who had undergone HSCT. Consequently, this study aimed to explore the experiences of Korean pediatric cancer survivors after HSCT using a qualitative phenomenologic approach (Cresswell, 1998; Giorgi, 1985; Knaack, 1984) to aid in developing intervention programs to improve quality of life.

Methods

Design

This study used Giorgi's (2009) descriptive phenomenologic research method. Rooted in Husserl's (1973) phenomenologic approach, this method focuses on descriptions of the way in which a given event or a phenomenon is experienced by particular individuals to grasp the meaning of that experience from their perspective.

Participants

Participants were pediatric cancer survivors who had undergone allogeneic HSCT, and their eligibility was confirmed by physicians and oncology nurses. The specific inclusion criteria were as follows: (a) being aged 8–18 years at the time of pediatric cancer diagnosis, (b) being at least three months post–allogeneic HSCT, (c) currently receiving outpatient follow-up care without residual tumors, and (d) being aware of their cancer diagnosis and HSCT. Purposive sampling was used to recruit 14 survivors, thereby ensuring a broad range of information-rich cases for an in-depth study. Recruitment was halted when data saturation was deemed to be reached. Attrition did not occur during data collection and analysis.

All participants were Korean. The sample was comprised of six males and eight females, with ages ranging from 13 to 29 years. Their age at diagnosis was 8–18 years, and post-transplantation duration was between one and three years. Their diagnoses included acute myeloid leukemia (n = 7), acute lymphoblastic leukemia (n = 5), hemophagocytic lymphohistiocytosis (n = 1), and severe aplastic anemia (n = 1). Six participants had relapsed; one had relapsed four times and had undergone three transplantations. Five participants had received transplantations from unrelated donors, two from family members and unrelated donors, and seven from family members.

Data Collection

The authors approached a hospital in South Korea and explained the purpose of the study to its physicians and oncology nurses. The authors asked them to introduce the study to those who met the selection criteria. It was fully explained at this time that there would be no disadvantage of treatment even if one chose to not participate in the study. Patients who were interested in this research topic contacted the research assistant via telephone and arranged an appointment. While speaking with potential participants, the research assistant informed them that both the participant and one of the parents must voluntarily sign written consent before commencing the interviews. Those who expressed willingness to participate were invited for an interview at the hospital's consultation room or were interviewed at their home, per their convenience. Each participant's demographic and cancer-related information was collected prior to the interview. Originally, the authors intended the data collection to be in-depth, through face-to-face individual interviews. However, after completing one such interview, further in-person interviews were restricted because of the COVID-19 pandemic. Thereafter, the rest of the interviews were conducted online via Zoom because it has been identified as a viable method for qualitative data collection (Archibald et al., 2019). Most participants attended the online interview alone from their bedrooms or living rooms. Additional interviews were held when data needed to be confirmed from the first interview or if there were additional questions. If more than one interview was conducted, the authors alternated as interviewers. Each interview lasted about one hour, during which the interviewers recorded participants' facial expressions or feelings. None of the participants declined further interviews. The data collection period lasted from October 2020 to January 2021.

Semistructured, open-ended questions were used to gain an understanding of participants' experiences with allogeneic HSCT. A list of interview questions was developed to elicit in-depth information about their lived experiences post-transplantation. The key interview question was "What has been your experience as a survivor of pediatric cancer after undergoing HSCT?" Other questions were "How are you doing these days?," "What does having experienced HSCT mean to you?," "If there has been any change after the transplantation, please describe in detail," and "Is there anything you want to add?"

During interviews, efforts were made to ensure that participants had ample time to communicate their experiences without interruption. To prevent any data omission, all interviews were audio recorded with participants' consent and transcribed verbatim. Participants were offered a small payment for their time.

Ethical Considerations

The institutional review board of Asan Medical Center in Seoul, Korea, approved this study, and ethical standards were adhered to accordingly. Participants were informed of the purpose and method of the study and their right to withdraw at any time, and they were assured their data would be kept strictly confidential. Data collection was conducted only after participants had voluntarily provided written informed consent. For participants aged younger than 18 years, the consent of a legal guardian was obtained.

Data Analysis

Data were analyzed following Giorgi's (2009) three-step descriptive phenomenologic research method. The first step, read for a sense of the whole, involves reading participants' descriptions from beginning to end to understand the overall statement. The authors read participants' accounts three to five times to obtain a sense of their post-transplantation conditions while maintaining an attitude of phenomenologic reductionism. This attitude refers to investigators bracketing their own past knowledge about a phenomenon, considering an experience as precisely as possible solely through participants' perspectives (Giorgi, 1997). The second step, determination of meaning units, involves breaking the text into smaller units of meaning for analysis. The authors consequently divided the transcripts into units by exploring possible variations of meanings, testing their adherence to one another, and removing extraneous or nonessential meanings. Common ideas within highlighted phrases were clustered, and clusters constituted the identified themes. The third step is the transformation of participants' natural expressions into phenomenologically and psychologically sensitive expressions. In this step, each meaning unit was reviewed again to identify the ways in which participants could have expressed their post-transplantation experiences more appropriately. Two authors coded the data individually. Each author transformed each meaning unit, which was in the participants' own words, into psychologically sensitive expressions. After completing the initial coding of the data, all authors met once a week for several weeks to discuss the similarities and discrepancies among the identified codes to extract common themes. The researchers used reflection and journaling to keep these occurrences bracketed. Journaling occurred simultaneously with the reduction to attain a bias-free analysis.

Validity and Reliability/Rigor

In qualitative research, validity pertains to the correct interpretation of study findings. To ensure their credibility, the results were confirmed by several participants and three experienced pediatric hematologic oncology physicians, a clinical nurse specialist, and a nursing professor. To achieve external reliability, the authors have described the methods and procedures of data collection and analysis in detail.

Results

Four essential themes emerged from the data analysis.

Theme 1: Regaining Physical Strength

Participants stated that their health had not yet recovered and they were striving for a healthy body again.

Tired easily owing to physical weakness: After the transplantation, most participants were easily fatigued. This was one reason they could not immediately return to their studies or social lives. Participant 10 shared the following:

> I lost a lot of weight and muscle, so I feel weak. . . . It's hard to focus on studying like I used to earlier. Even when I go outside to exercise, I can't walk for a long time, and I get tired quickly.

Complications after transplantation: More than half of the participants experienced mild to severe complications. Some had to take medication or undergo surgeries owing to the complications; however, most of them accepted their new reality well. According to participant 5,

> I had a complication after the transplant. I had the graft-versus-host disease on my skin, so I think my

> skin was a little sensitive. It would dry up and itch, so I'm taking an antihistamine, which is OK to take for the long term.

Importance of self-care: Participants appreciated the value of life and perceived the importance of self-care. They attempted to exercise, sleep an adequate amount, and maintain a healthy diet. Participant 7 said,

> I'm not sure when I started exercising. After the transplant, I began doing home training, and then I got a treadmill in my house, so I started exercising on the treadmill for about 30 minutes. Sometimes, when I feel like it would be fine, I even walk slowly for an hour.

Theme 2: A Wish to Express the Overwhelming Burden

Participants described various emotions, such as fear and anger, that abruptly overwhelmed them. They were striving to resolve these feelings.

Overwhelmed feelings: Although they were cured following their transplantations, participants were still overwhelmed by feelings such as frustration, anger, depression, fear and anxiety about recurrence, and hopelessness. The degree of severity differed; some participants described hitting bottom before bouncing back, and others simply mentioned that they faced challenges a number of times. Participant 5 shared the following:

> I think what I think about the most is that I'm behind. It was hard for me because I felt like my starting line was pushed way back. . . . Sometimes I feel depressed. Of course, it's not as frequent as before. When it was severe, I thought that I wanted to jump out of my apartment on the 24th floor.

Wish to recover psychological health: Participants strived to recover their psychological health in addition to their physical health. Most felt that suppressing their overwhelming feelings could lead to relapse, so they tried to resolve them in various ways. Participant 5 said,

> Once you hit the end of hopelessness, I think you grasp onto that glimpse of hope. . . . I wrote a long message to myself on [a mobile messaging application]. I can't express those emotions to others, so I express them to myself. When I do that, it kind of lightens my mind. Now, I try to express my feelings through music, and I compose songs.

In addition, participant 11 shared the following:

> I wanted to express my hard feelings, but I couldn't because I was sorry for my family. I think it would be nice if there was someone I could talk to following the transplant, or if I could receive counseling.

Theme 3: Cultivating Positive Thinking Through Reflection

Participants viewed themselves as having been rewarded a new life by receiving HSCT. They valued life more and were grateful for the ability to lead a normal life and for their family and friends. By broadening and deepening the scope of their thoughts, they cultivated positive thinking.

Appreciating everyday life and people: Prediagnosis, participants took their everyday lives for granted. Postdiagnosis, they were grateful for these routine activities, their donors, and healthcare providers. Participant 13 shared the following:

> I got my second transplant from an unrelated donor, and the donor wrote me a letter, which was very moving. So, I decided to commit to giving to others. . . . At first, I didn't even tell my friends, but the second time around, I told my friends about my diagnosis, and I was so thankful for their support. It was really huge.

Thinking positively: During the recovery period, participants had time to ruminate on what they missed and to reflect on their past experiences. After the transplantation, decreased parental pressure allowed them to broaden and deepen their thinking in a positive manner. By cultivating positive thinking, they felt a sense of maturity. According to participant 5,

> I think I've become more mature than my peers. You know, I only stayed home after the transplantation, so I had a lot of time to think alone. So, I spend a lot of time thinking.

Theme 4: Living a Self-Directed Life

Participants experienced intrinsic growth and changed life values after undergoing HSCT. They considered a mature, self-directed life that focused on the fulfillment of their own ordinary needs.

Ordinary but mature life: Because participants felt grateful and appreciated their everyday lives, they were motivated to live better. This meant fulfilling their own needs, setting goals that satisfied them, and being mature and considerate of others rather than trying to be perfect. Participant 13 said, "Before the transplant, I didn't really appreciate everyday life. . . . I think I'm trying to live a more ordinary life, an everyday life."

Being independent: As participants adjusted to their new realities, they became more focused on themselves. As a result, they actively tried to live a self-directed life by finding and engaging in things they wanted to do or were good at. Participant 5 shared the following:

> I was sick, so I had a lot of time to myself at home to think, so I think I was able to find many things I want to do. This might have not been so if I wasn't sick. . . . I try not to waste time, and I do things that I want to do. . . . I also find things I should do.

Discussion

This study explored the experiences of pediatric cancer survivors after they underwent HSCT. Four themes based on the analysis of participants' narratives emerged.

The first theme the authors identified was regaining physical strength, corroborating previous findings of most pediatric cancer survivors who had undergone HSCT and experienced complications (Hierlmeier et al., 2018). Similarly, a systematic review reported that pediatric cancer survivors who have undergone HSCT are at high risk for serious chronic conditions that can reduce their quality of life because HSCT affects nearly all organs (Lawitschka & Peters, 2018). For example, graft-versus-host disease substantially affects patients after organ transplantation (van der Lans et al., 2019). During the transplantation process, patients experience muscle weakness, fatigue, and impaired physical functioning because of prolonged isolation, hospitalization, and adverse reactions to medications (Rossi et al., 2016). Despite these complications, participants described fatigue as the most severe problem and strived to recover their physical fitness.

However, participants viewed themselves as having been reborn after the transplantation. They understood the importance of health and self-care, corroborating previous studies that reported that pediatric cancer survivors attempt to practice healthy lifestyles and manage their health to avoid complications (Kusaka et al., 2020; Lehmann et al., 2014; Phillips & Jones, 2014; Sharin et al., 2020). Therefore, pediatric cancer survivors who have undergone HSCT should be provided with support and encouragement to engage in physical activities and to exercise consistently.

The second theme was a wish to express the overwhelming burden. One study of pediatric HSCT recipients reported that as many as 25% of participants experienced psychosocial problems that required counseling or drug therapy (Hierlmeier et al., 2018). Another study found that HSCT recipients had difficulty maintaining their confidence and resilience owing to fatigue and complications, and they were emotionally labile or distant (van der Lans et al., 2019). Depression, anxiety, and stress are three psychosocial problems typically experienced by HSCT recipients (Di Giuseppe et al., 2020; Nance & Santacroce, 2017). Long-term survivors who have undergone allogeneic HSCT have been identified as highly vulnerable to exhibiting negative psychological outcomes (Kenzik et al., 2015). In addition, although pediatric cancer survivors rarely experienced long-term psychological problems, HSCT was a risk factor for long-term psychological issues (Bitsko et al., 2016). These results suggest that HSCT recipients are a high-risk group for psychological problems (Di Giuseppe et al., 2020).

Despite recommended standards of psychosocial support for pediatric cancer survivors (Michel et al., 2019), a study by Hendriks et al. (2020) showed that the support provided is inadequate. Therefore, nurses and hospital officials should devise specific plans to assess the psychological states of patients even after they have completed the treatment regimen (Bitsko et al., 2016). In addition, interventions and counseling

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- Despite the physical limitations and overwhelming negative emotions post-transplantation, pediatric cancer survivors came to appreciate their surroundings and everyday life; engaged in deeper, broader, and more positive thinking; and strove to live an ordinary but self-directed life.
- To improve their quality of life after transplantation, interventions that enable pediatric cancer survivors to express their emotional burden and help them recover their physical fitness are needed.
- Healthcare providers, nurses, and the community can deepen their understanding of pediatric cancer survivors who have undergone transplantation, providing high-quality care for a healthy body and mind.

programs must be developed to provide sustainable psychosocial support to survivors.

The third theme was cultivating positive thinking through reflection. Participants cultivated the ability to think positively after receiving HSCT. Previous studies have also reported that pediatric cancer survivors gain an altered life perspective and positive attitudes as they experience the value of life anew (Brown et al., 2016; Duran, 2013; Lehmann et al., 2014; Phillips & Jones, 2014). Adult survivors of hematologic malignancies who received transplantations have been reported to have matured after their experience (van der Lans et al., 2019). Similarly, adult survivors who received HSCT stated that their experiences resulted in higher sensitivity toward other people's pain (Kusaka et al., 2020). The results of the current study suggest that, similar to adult cancer survivors, children develop positive thinking through reflection during recovery post-HSCT.

Participants also believed that they had been rewarded with a new life and deeply appreciated their family and others around them. Previous studies have demonstrated how pediatric cancer survivors build strong bonds with their parents (Belpame et al., 2019), attribute importance to maintaining healthy interpersonal relationships (Sharin et al., 2020), and develop strong desires to help others (Belpame et al., 2019). Based on these findings, it is recommended that nurses and other hospital staff help survivors develop and use empathy and altruism.

The final theme was living a self-directed life. A study by Sharin et al. (2020) found that although HSCT recipients had difficulties adjusting to their everyday lives initially, they nevertheless adjusted by accepting their new identities, focusing on activities that were significant to them, and strengthening their resilience. In addition, some survivors enjoyed a highly enriched life as they reorganized their priorities and focused on activities that added meaning to their lives (Sharin et al., 2020). This is consistent with previous results in which long-term survivors of pediatric cancer viewed living an ordinary self-directed life as positive growth (Kim, 2017) and showed a strong sense of independence despite having strong relationships with their parents (Belpame et al., 2019). However, a study on adult HSCT recipients reported that several participants developed negative self-concepts as they underwent financial hardships after losing their jobs and facing increased medical and living costs (Brice et al., 2017). Therefore, there may be a marked difference between the post-transplantation experiences of adult and pediatric HSCT recipients.

A major strength of this study is that it attempted to provide more insights into relationships in the lives of pediatric cancer survivors post-HSCT. By promoting this exploration and paying attention to these experiences, the authors' findings could contribute to not only improving the quality of life of these patients but also facilitating their effective adjustment to society, allowing them to live healthy and positive lives.

Limitations

Despite the strengths of this study, a few limitations must be noted. The participants consisted of survivors whose transplantations had been conducted within the past three years; therefore, the results do not reflect long-term post-transplantation experiences. It is recommended that future studies analyze long-term experiences with participants at least five years post-HSCT. In addition, the age of the participants ranged from 13 to 29 years. All participants were adolescents at the time of data collection, and only two were aged younger than 12 years when they were diagnosed with cancer. Therefore, an understanding of the lived experience of younger pediatric cancer survivors has not been fully attained. In addition, it appears that the lived experience related to HSCT could vary greatly between teenagers and adults, owing to the differences in the developmental stages of life. This is a major limitation of this study. Therefore, further identification of the differences between adult and pediatric survivors' experiences would help to strengthen this study. A separate analysis of the experiences of adults and teenagers could be a direction for follow-up studies in the future.

Implications for Nursing

The results of this study highlight the need for education and intervention programs that promote appropriate physical activities for survivors. In addition, the findings may serve as a basis for follow-up research to develop and test education and intervention programs aimed at improving the quality of life of survivors. The most important highlight is the need for periodic counseling or interventions that can allow survivors to express their feelings and emotions. These interventions would help children, such as those in the current study, to cultivate the ability to think, act, and live positively.

Conclusion

Pediatric cancer survivors revived deep appreciation toward their surroundings and everyday life, engaged in positive thinking, and strived to live ordinary self-directed lives despite their physical limitations and overwhelming negative emotions. These results highlight the need for education and intervention programs that promote appropriate physical activities for pediatric cancer survivors who have undergone HSCT but, most of all, the need for periodic counseling or interventions that allow them to disclose their feelings and emotions that they do not otherwise reveal to people. These interventions would help children, such as those in the current study, to cultivate an ability to think positively.

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