

# Perceived Benefits and Challenges of Psychosocial Service Uses for Adolescents and Young Survivors of Childhood Cancer

**Kim, Min Ah**

(Myongji University)

**Yi, Jaehee**

(University of Utah)

**Choi, Kwonho\***

(Woosong University)

Psychosocial services for cancer survivors are critical for improving their quality of life after cancer. Despite a growing number of childhood cancer survivors in Korea, there is limited understanding of service experiences that support their psychosocial adjustment. This study provides a description of childhood cancer survivors' experiences with a range of psychosocial services and the perceived benefits and challenges of such services. In-depth interviews regarding experiences using psychosocial services were conducted with 30 adolescent and young adult survivors of childhood cancer. The participants noted perceived benefits and challenges of psychosocial services in the following areas: (a) financial and instrumental, (b) psychological counseling, (c) schooling and learning, (d) mentoring, (e) family support, and (f) self-help activities. This study found a strong need to improve existing psychosocial services for childhood cancer survivors and their families in Korea. This study contributes to providing developmentally appropriate psychosocial services to meet the needs of adolescent and young adult survivors of childhood cancer.

**Keywords: Childhood Cancer, Survivors, Psychosocial Services, Quality of Life**

This research was funded by the Korean Association for Children with Leukemia and Cancer, and this article is based on unpublished reports. The corresponding author acknowledges the support of 『Woosong University Academic Research Funding 2018』. This research was presented at the 8th International Society of Pediatric Oncology (SIOP) Asia Congress in 2014, Seoul, Republic of Korea.

IRB No. 201309-SB-112-03, Yonsei University

\* Corresponding Author: Choi, Kwonho | Woosong University (kwonho@wsu.ac.kr)

■ 투고일: 2018.4.2    ■ 수정일: 2018.7.12    ■ 게재확정일: 2018.9.13

## I. Introduction

Psychosocial services, as a “whole-person approach” to supporting cancer survivors (Turnbull Macdonald et al., 2012, p. 209), are critical for improving quality of life after cancer, because those affected by cancer have to deal with diverse psychosocial issues (Pirl, Jacobsen, & Deshields, 2013). After the National Academy of Medicine emphasized the need for psychosocial care for cancer survivors in 2008, psychosocial services for cancer survivors have received increased attention (Adler & Page, 2008). The academy recommended that health care providers communicate with patients about psychosocial needs, identify the unique needs of individual survivors, and connect survivors with appropriate services. Otherwise, it is “like spending all of one’s money on the latest model car and then not having the money left to buy the gas needed to make it run” (Adler & Page, 2008, pp.xi-xii).

Despite the significant benefits of psychosocial services for cancer survivors, a substantial number of cancer survivors are unable to use or are dissatisfied with psychosocial services (McDowell, Occhipinti, Ferguson, & Chambers, 2011; Zebrack et al., 2014). Particularly, developmentally appropriate psychosocial services for cancer survivors are lacking. It is critical for adolescent and young adult survivors to receive support for their developmental needs during their survivorship trajectories (Zebrack & Isaacson, 2012).

Due to the sharp increase in the five-year survival rate of childhood cancer during past two decades in Korea, from 55.8% in 1995 to 82.8% in 2015 (Ministry of Health and Welfare, 2017), the psychosocial service needs of childhood cancer survivors after cancer treatment has been increasing since the mid-2000s. Kim and Yi (2012) identified the psychosocial service needs of adolescent and young adult survivors of childhood cancer in Korea, including a strong need for psychosocial services in the areas of psychological counseling, schooling and learning, social skills, mentorship, integrated health management, self-support activities, family counseling, and public recognition and awareness. Given the increasing need for those services,

nongovernmental organizations dedicated to people affected by childhood cancer (e.g., Korean Association for Children with Leukemia and Cancer [KACLC] and Korea Childhood Leukemia Foundation [KCLF]) have been providing psychosocial services (KACLC, 2018; KCLF, 2018) in Korea. However, psychosocial services still mostly focus on addressing financial issues of families with cancer. Previous studies found that psychosocial services for cancer survivors in Korea need improvements, particularly in addressing family issues (Choi, Kim, Son, & Nam, 2014), social stigma (Kim, Yi, & Kim, 2014), and self-help activities (Kim, 2005).

The use of and need for psychosocial support in adult cancer patients has been studied in Western countries (Ernst, Beierlein, Romer, Möller, Koch, & Bergelt, 2013; Mosher et al., 2013). However, the psychosocial service experiences of adolescent and young adult childhood cancer survivors have been neglected across other countries. Thus, this study explored childhood cancer survivors' experiences with a range of psychosocial services and their perceived benefits and challenges to such service use. This study will contribute to developing developmentally appropriate psychosocial services to meet the needs of adolescent and young adult childhood cancer survivors.

## II. Literature Review

### 1. Psychosocial Service for Cancer Survivors

Cancer diagnosis and treatments often involve psychosocial challenges associated with physical, emotional, spiritual, and interpersonal aspects (Grassi, Spiegel, & Riba, 2017). Psychosocial care for those affected by cancer aims to address the “social, psychological, emotional, spiritual, and functional aspects” of the cancer journey, and is expected to be provided by an interdisciplinary team of service providers (Turnbull

Macdonald et al., 2012, p.209).

Psychosocial services in oncology provide resources related to cancer care, such as information, mental health, family services, psychoeducation, transportation, work, school, and financial assistance (Adler & Page, 2008). In the United States, a range of psychosocial services are currently being provided; the most often frequently offered psychosocial services include professionally led support groups, psychiatric consultation, genetic counseling, fertility counseling, rehabilitation therapy, and informational services (Deshields, Zebrack, & Kennedy, 2013). Other services include peer support networks, individual or family counseling, pastoral or spiritual care, employment counseling, financial counseling, exercise or fitness programs, diet or nutrition programs, child care, and transportation assistance (Deshields et al., 2013). Gunn, Turnbull, McWha, Davies, and Olver (2013) explored experiences with psychosocial services among 17 Australian adult cancer patients who resided in rural areas. The researchers found that cancer survivors who accessed the services perceived psychosocial support to be highly beneficial. Peer support programs that included healthy peers and other cancer survivors were found to improve quality of life, self-efficacy, knowledge about health care, and interpersonal skills (Crom, 2009; Zebrack, Oeffinger, Hou, & Kaplan, 2006). In addition, summer camps and adventure programs were found to be popular services that improve self-confidence, independence, and social skills (Elad, Yagil, Cohen, & Meller, 2003). Providing information also improves confidence to manage cancer-related problems (Bass et al., 2006).

## 2. Unmet Service Needs of Cancer Survivors

Psychosocial care is highly valued and perceived to be beneficial among cancer survivors (Stanton, 2012). However, many cancer survivors report unmet needs not addressed by psychosocial services. McDowell et al. (2011) conducted a study in Australia and reported that approximately 14% of cancer patients reported using a

psychosocial support service. Female patients and those with more positive attitudes toward seeking help were more likely to use psychosocial support services after cancer (McDowell et al., 2011). Forsythe et al. (2013) found more than half of adult cancer survivors reported that they did not discuss psychosocial concerns with health care providers, nor did they seek professional counseling or support groups after their cancer diagnosis. Most survivors did not want or recognize the need for such services, indicating a lack of awareness of psychosocial services. Only a few reported that they did not use the services due to certain barriers, such as a lack of information about or perceived unavailability of services. Previous research conducted in South Korea found that a lack of information regarding psychosocial services was identified by parents of childhood cancer survivors as a barrier to the use of such services (Choi et al., 2014; Kim, 2017).

Pediatric cancer patients and survivors can also benefit from psychosocial support (Askins & Moore, 2008; Steele, Mullins, Mullins, & Muriel, 2015). However, they face a lack of developmentally appropriate services. In particular, adolescent and young adult cancer survivors have developmentally distinctive psychosocial service needs (Arnett, 2000; Morgan, Davies, Palmer, & Plaster, 2010). In a prospective study of adolescent and young adult cancer survivors aged 15-39 years, Zebrack et al. (2014) found unsatisfied needs for information (57%), counseling (41%), and practical support (39%) at 1 year following diagnosis. Psychosocial services for adolescent and young adult survivors should concern identity development, including sexual identity, body image, and autonomy, to minimize the negative effects of cancer and promote a sense of normalcy (Arnett, 2000; D'Agostino, Penney, & Zebrack, 2011; Shama & Lucchetta, 2007). Zebrack and Isaacson (2012) suggested the use of developmentally appropriate psychosocial services for adolescent and young adult cancer survivors, including informational, practical, emotional, interpersonal, and existential and spiritual services. Rabin, Simpson, Morrow, and Pinto (2011), in a study of 20 young adult survivors aged 18 to 39 years, identified behavioral and psychosocial programs needed, including those for physical activity,

relaxation, emotional support, provision of information, and nutrition services.

In Korea, currently only a few nonprofit organizations (NPOs), including KALCLC, KCLF, and the Korean Childhood Cancer Foundation are known to provide psychosocial services to childhood cancer survivors. How childhood cancer survivors experience psychosocial services in Korea, however, is not known. Thus, perceptions of psychosocial support by Korean adolescent and young adult cancer survivors should be examined.

### III. Methods

#### 1. Participants

In the cancer literature, a cancer survivor is defined in different ways. In the United States, the National Cancer Institute (2014) defined a cancer survivor broadly as “an individual from the time of diagnosis, through the balance of his or her life” (para. 2). To make the concept of survivorship more specific, the American Society of Clinical Oncology recently defined long-term survivors as “individuals who have successfully completed curative treatment” or “those who are transitioned to maintenance or prophylactic therapy” (McCabe et al., 2013, p.632). Considering prevalent definitions in Korea, our study defined a cancer survivor as an individual who has completed cancer treatments and remains alive.

Eligible participants were adolescent and young adult childhood cancer survivors who had completed cancer treatment at the time of the study. We specifically recruited adolescent and young adult survivors of childhood cancer, aged 15 to 39 years, who were diagnosed before age 18. We purposively included a heterogenous group of participants regardless of recurrence or diverse perceived late effects, to explore the comprehensive service needs of these groups.

Fifteen men (50.0%) and 15 women (50.0%) participated in the study, and their ages ranged from 18 to 35 years ( $M = 22.7$ ,  $SD = 3.9$ ). Most participants had a high school education (63.4%), were unmarried (90.0%), and were not in the workforce (73.3%). For more than half of the participants (66.6%), their monthly household income was lower than 4 million Korean won (KRW), which is less than the average Korean household monthly income (in 2013, 4.04 million KRW; Statistics Korea, 2014). Ages at diagnosis ranged from 2 to 18 years ( $M = 11.6$ ,  $SD = 4.3$ ). Years since diagnosis ranged from 5 to 26 ( $M = 12.4$ ,  $SD = 5.8$ ). Participants reported undergoing chemotherapy (96.7%), radiotherapy (50.0%), stem-cell transplantation (16.7%), and surgery (13.3%). Their cancer types included hematological cancer (56.7%), brain or central nervous system tumors (13.3%), or other tumors (30.0%). Fewer than a quarter (23.3%) experienced recurrence or a second cancer diagnosis, and 26.7% reported experiencing physical late effects. Participants' demographic and medical characteristics are presented in Table 1.

**Table 1.** Participants Characteristics (N = 30)

| Characteristics                  | n (%)      |
|----------------------------------|------------|
| Age in years (M±SD)              | (22.7±3.9) |
| Gender                           |            |
| Male                             | 15 (50.0)  |
| Female                           | 15 (50.0)  |
| Education                        |            |
| High school                      | 19 (63.4)  |
| Undergraduate or graduate school | 11 (36.6)  |
| Marital status                   |            |
| Unmarried                        | 27 (90.0)  |
| Married                          | 3 (10.0)   |
| Employment                       |            |
| Employed                         | 8 (26.7)   |
| Not in workforce                 | 22 (73.3)  |

| Characteristics                        | n (%)          |
|--|----------------|
| Monthly household income               |                |
| < 2 million KRW                        | 10 (33.3)      |
| 2 million KRW - 4 million KRW          | 11 (36.6)      |
| > 4 million KRW                        | 9 (30.0)       |
| Age at diagnosis in years (M $\pm$ SD) | 11.6 $\pm$ 4.3 |
| Time since diagnosis (M $\pm$ SD)      | 12.4 $\pm$ 5.8 |
| Treatment received (multiple)          |                |
| Stem cell transplantation              | 5 (16.7)       |
| Surgery                                | 4 (13.3)       |
| Chemotherapy                           | 29 (96.7)      |
| Radiotherapy                           | 15 (50.0)      |
| Other                                  | 6 (20.0)       |
| Cancer type                            |                |
| Hematological cancer                   | 17 (56.7)      |
| Brain or central nervous system tumor  | 4 (13.3)       |
| Other tumors                           | 9 (30.0)       |
| Recurrence or second cancer            |                |
| Yes                                    | 7 (23.3)       |
| No                                     | 23 (76.7)      |
| Perceived physical late effects        |                |
| Yes                                    | 8 (26.7)       |
| No                                     | 22 (73.3)      |

## 2. Procedures

Semi-structured in-depth interviews regarding service experiences were conducted with 30 childhood cancer survivors from November 2013 to January 2014. Participants were recruited in Korea through purposive sampling by contacting leaders of self-help groups for childhood cancer survivors. We also attended cancer-related meetings and conferences that were held during the study to announce the study and identify potential eligible participants. Through this process, several



eligible individuals voluntarily participated in the study. Hour-long interviews were conducted face to face or by telephone by three researchers who were trained and proficient in qualitative study methods. Telephone interviews were conducted with participants who did not want face-to-face interview or were in remote areas. Interview topic guides covered experiences with psychosocial services and the benefits and challenges of those services. Open-ended questions and probes were used to facilitate participants' responses. Participants were informed of the purpose, procedures, benefits of participation, right to withdraw, confidentiality, and the audio of the study. Participants were provided with gift vouchers with a value of approximately 20 thousand Korean Won (KRW). Researchers took notes of verbal and non-verbal expressions while interviewing. Interviews were transcribed, and personal information was deleted. Repeated comparison between transcriptions and recordings were conducted to reduce omission or incorrect entries of participants' verbatim responses. Qualitative data were collected until theoretical saturation was reached. The study was approved by the institutional review board of the affiliated university (201309-SB-112-03).

### 3. Analysis

Qualitative data were analyzed, using thematic analysis, described as "a method for identifying, analysing and reporting patterns within data" (Braun & Clarke, 2006, p. 79). Thematic analysis was chosen for this study because it provides a rich account of qualitative data (Braun & Clarke, 2006) from cancer survivors. Researchers collaborated throughout the entire process of data collection, coding, memo writing, analyzing, and interpreting. Data and researcher triangulation were used to develop thick description and interpretation of qualitative data (Denzin, 1970). First, all authors had good knowledge of childhood cancer survivors and qualitative research skills, and were deeply involved with the data analysis plan. We read the written transcripts multiple times to familiarize ourselves with the data. When uncertainty

arose in the transcripts, audio recordings of the interviews were checked for accuracy. Specifically, we followed criteria for good thematic analysis reported by Braun and Clarke (2006). Initial codes and analytic memos were derived inductively by interactive collaborations between the first and second authors. When initially coding data, we tried to give full and equal amount of time and attention to every word and phrase, which helped prevent excluding significant parts of data and achieved comprehensive coding. Codes were used to review the initial transcriptions, which were recoded repeatedly to increase the validity of analysis. Through those analytic processes, codes were collapsed into broader categories, themes, and comprehensive topics. Finally, six themes were named and defined. These themes were checked among three authors and examined against the original dataset when agreement was not obtained. ATLAS.ti was used to analyze the qualitative data.

## IV. Results

Participants reported experiences related to the use of services and challenges encountered by childhood cancer survivors and families in the following areas: (a) financial and instrumental services, (b) psychological counseling, (c) schooling and learning, (d) mentoring, (e) family support, and (f) self-help activities.

### 1. Financial and Instrumental Services

Participants reported receiving financial or instrumental support through diverse channels. Some received help with medical expenses from the national government through a program designed for low-income individuals. Others received scholarships or treatment expenses through hospital, private donor, or company contributions.

We didn't have enough money at home. I was going to receive a stem cell transplantation. But it was too expensive. So, my mom got counseling from a hospital social worker. With the help of the hospital social worker, I received financial support. (Male, 26, leukemia diagnosed at 16)

Participants mentioned that instrumental support was helpful. Some participants reported receiving indoor bicycles or laptops, through NPOs or private contributions, to use while hospitalized or home. One participant who had to take a photo to apply for the GED exam mentioned that receiving a wig was a great help. In many cases, financial need motivated them to seek professional help from social workers or other stakeholders.

Participants said they felt that financial and instrumental support tended to be one-time and limited to those who met eligibility criteria that did not apply to many participants. As illustrated in the following quote, some families suffered financial damage from cancer treatment but could not receive support due to their unrealistic expectations of their ability to meet the criteria. Other participants who received financial support also suffered financially because one-time support was not enough to cover expenses for long-period treatment.

We had financial challenges at that time [of diagnosis and treatment]. But we owned a house on paper and had a car. So, we could not receive financial support or benefit from the government. However, our house was on the verge of foreclosure. They heard that my parents owned a house, so we couldn't get financial support. If we had financial support, it wouldn't have been so bad, I think. (Female, 24, leukemia diagnosed at 11)

Complicated service application procedures also were a barrier to receiving financial service, as one participant mentioned. "We were sent to this place and that place. This place says, 'Go to that place,' and that place says, 'Go to this place.'... The application procedure [for financial support] is too complicated." (Male, 20, brain tumor diagnosed at 15)

## 2. Psychological Counseling

Almost all participants reported experiencing psychological difficulties, including depression, distress, anxiety, or posttraumatic symptoms, and needed professional psychological services during or after cancer treatment. Most participants, however, did not seek the services due to the public stigma attached to psychological counseling. Some participants also doubted the effectiveness of counseling services in Korea.

I made appointments for psychological counseling just in case it would help me. But I didn't show up to the appointments... because of negative perceptions of psychological counseling. I still have difficulty with communicating with others. So, I think I would like to have a counseling service, but it is still difficult for me to get there. (Male, 27, osteosarcoma diagnosed at 14)

Only a few participants reported seeking professional services for psychological difficulties. Some participants reported going to psychiatrists on their own or through referrals from their oncologists. However, it was difficult to receive professional counseling or treatments. One participant mentioned that a psychiatrist had just prescribed medicine that could help insomnia or depression, without proper counseling or treatments. Some participants expressed frustration about not receiving the kinds of professional help they were seeking for their psychological issues.

There is a doctor who cares for cancer, but no doctor cares for my heart. So, it was very hard when I was in the hospital, and it was also very hard when I was discharged from the hospital. I think I would have been more comfortable if somebody told me that what I was going through was very natural and normal and not my fault. I thought that I had to suppress my feelings, so I used to go psychiatrists and get medicine for sleeping. I only tried to suppress my mind but not [face] my challenges and get help for it. (Male, 21, leukemia diagnosed at 18)

Some participants who acknowledged the need for psychological services actively sought a range of psychological services, such as art therapy, family counseling, and group counseling through school or NPOs. Although these services helped them share their difficulty after cancer treatment, some providers did not use appropriate methods to heal their wounds. As described in the following quote, participants were not satisfied with the quality of the services and felt that the provider did not have a great understanding of childhood cancer survivors and their families: “They just do counseling without understanding us.” Another survivor said that the counseling that he received was an “island” approach because no other systems, such as family and social, were taken into consideration.

I just wished [I could] slow down and relax in counseling, but it was too hard to be deeply involved in the first meeting. When I get counseling, I want to be understood and be empathized with. But the therapist seemed to be trying to solve the problem quickly. So, I became more hurt. (Female, 20, neuroblastoma diagnosed at 5)

### 3. Schooling and Learning

Most participants did not attend school while receiving treatment and, therefore, had difficulty in catching up on school work. Some participants did not have any educational opportunities during or after treatment because they did not have information on what options they had about education, or no services were available at that time. Thanks to a policy change, those who received treatment more recently could use hospital and online school services to get credits for graduation and to catch up on missed school work during or after treatment. Online school involves participants’ socializing with their peers and teachers, even during treatment. One participant mentioned that thanks to online learning with video chat during treatment, it was a great pleasure to meet friends and feel connected to peers. Further, this helped her adjust to school after treatment.

Online-learning was helpful for me in providing opportunities to communicate with other friends and teachers, as a student, not a patient. (Female, 22, neuroblastoma diagnosed at 12)

Participants still had difficulty with schooling because not all hospitals had school services or the quality of educational services did not meet their expectations. Different age groups of patients participated in educational programs in hospitals, but the programs focused mainly on children, and, thus, it was not adequate or too easy for adolescents. Overall, online schooling was not sufficient to meet their educational needs. There was no system of follow-up with the participants to determine whether they understood the content. They merely received credit for graduation once they logged in and worked with the content, regardless of understanding. Most participants felt that schooling services did not consider participants' level of understanding in education and could not help them catch up on school work.

This program allows us to get credit for graduation but does not meet our educational needs. We just logged into the program and worked with the content, but we did not study at all. I tried to study, but it was so hard for me to study during treatment. So, I got a high school degree, but I did not "study." So, I had to face challenges when I tried to go college and take an entrance exam. (Female, 24, osteosarcoma diagnosed at 15)

Some participants reported receiving private lessons or private institutions, paying for them out of their pocket, during their treatments. Other participants reported receiving one-on-one visits supported by NPOs or hospitals. It was difficult, however, to receive consistent services due to eligibility criteria and time restrictions. For example, the services were available only during a vacation period and not sufficient for patients to catch up on school work. Further, most of the teachers were volunteer college students who were not trained for such a purpose.

Volunteer teachers, who were mostly college students, were often late because their priority was not us. They sometimes did not teach sincerely and would say, "This is enough for today." (Female, 22, leukemia diagnosed at 11)

#### 4. Mentoring

None of the participants received mentoring services through structured programs during or after treatment. Only some participants received a limited mentoring from other cancer survivors whom they met through self-help groups. Even such informal mentoring and interaction, however, was helpful for them. As described in the following quotes, survivors said they felt that their feelings were validated by other mentors or survivors, whose advice about topics such as school reentry, peer relationships, and careers was valuable. Participants preferred mentoring or advice about employment, marriage, and university life from those who already experienced treatment and survivorship and were at a similar age and age of diagnosis.

I used to talk about my diagnosis and treatment. My mentor changed me. I still think, stupidly, "What if I was not diagnosed with cancer?" Whenever I think such things, my mentor helped me. I feel as if my mentor cleanses my thinking. (Female, 22, leukemia diagnosed at 11)

In addition, participants were recommended by the hospital or an NPO to provide mentoring services to newly diagnosed childhood cancer patients or survivors who just finished their treatment. As indicated in the following quotes, they felt proud of their growth and rewarded.

One child with cancer said, "I just need someone to talk to, I do not need a computer or a piano." So, the girl was introduced to me (as a mentor). She was a quiet girl, but she really enjoyed meeting with me. When I was receiving treatment, I also needed a person who I could talk with, who could understand me, who could open one's ears

for me. The girl said, "I will be a mentor for other children with cancer after the treatment, like you. Let's keep in touch." My heart gave a flutter when I heard it. I was proud of it. She said that she felt better after meeting me. I think that the mentoring activities will help cancer treatment. (Female, 22, leukemia diagnosed at 11)

Because these mentors had not received any training, they experienced a great deal of anxiety. It was difficult for them to talk openly with a mentee with cancer who was not ready to open up. In addition, their past trauma as cancer patients and survivors would come up again, which they found difficult to handle.

I know that mentoring is helpful for childhood cancer patients. But they are still fighting with cancer, between life and death. Whatever I help them with, I can't help with their cancer. I don't want to be a mentor because I am afraid that the child with cancer that I meet will get worse or die. Then I will get hurt again. (Male, 21, osteosarcoma diagnosed at 14)

## 5. Family Support

Survivors reported participating in family support activities, such as family retreats or sibling camps that were held by hospitals or NPOs. Through these activities, they were able to spend quality time with their families and share their feelings with them. Such opportunities helped the participants refresh their battle against cancer and build strong bonds with their family and encourage communications. Further, they could share information and experiences with those who had similar experiences.

I was going through puberty at that time. The family camp refreshed me and allowed me to spend time with family outside the hospital. (Female, 22, leukemia diagnosed at 12)

Many participants wanted to participate in sibling camps, where they could rebuild



bonds with siblings, even long after cancer treatment. There were age restrictions, however, and young adult survivors were not able to participate in the camps. They felt frustrated about the age restriction and said, “The most important thing is that we share the same experiences, although [we are] not the same ages.” Because most were adolescents or young children, young adult survivors could not share their difficulties.

I know there is a camp for siblings of children with cancer. But there is an age limit for the participants and [it’s] usually for elementary students. My older sister was a middle school student... So, it was hard for her to get such opportunities. (Female, 22, leukemia diagnosed at 11)

My older brother was a high school student, so he did not want to join the program with younger students. (Female, 20, neuroblastoma diagnosed at 5)

## 6. Self-Help Activities

Most participants participated in self-help activities for cancer survivors supported by NPOs. They held workshops regularly and planned their long-term activities to build strong bonds among members. For example, they would go to the hospital and play with childhood cancer inpatients to provide respite care for their parents. They also held seminars for parents to provide information about treatment experiences and share their hope for treatment. They shared information and feelings related to cancer experiences, helping them realize they were not alone. They described being happy that there were places where they were needed, which helped them to feel fulfilled.

I feel stronger bonds with peer survivors in the self-help group, stronger than [those with] my old school friends. So, I became more involved with self-help group activities. (Female, 19, osteosarcoma diagnosed at 13)

We share everything, such as trauma at the time of diagnosis and treatment, our current feelings, and what challenges us... We can open up about anything with survivors, that we had difficulty with other friends without cancer experiences, or what we could not share with parents. We experience the same feelings with our own parents. We also share the same physical challenges, so it is comfortable for us to do activities together. (Female, 22, leukemia diagnosed at 12)

Self-help activities are not mandated or open to all members. Therefore, participation is not consistent and focused on socialization among members. Because most members are adolescents or young adults, leadership and financial support is lacking. One participant mentioned that consistent activities for a common purpose should be developed and that a facilitator can help strengthen the group activities.

We need someone who wants to work with us and facilitate our meetings. We can suggest, "We want to do this activity, and how about doing this?" and the facilitator can give us direction for our meetings. (Female, 22, leukemia diagnosed at 11)

## V. Discussion

This study indicates the strong need for and benefits of services to improve existing psychosocial care for childhood cancer survivors and their families in Korea. Standards for pediatric psychosocial care for children with cancer and their families has been developed in the United States. These standards include monitoring for neuropsychological deficits, support for psychological issues, assessment of financial hardship, yearly psychosocial screening, support for siblings, and help with social interactions and school reentry (Wiener, Kazak, Noll, Patenaude, & Kupst, 2015). Our study participants reported using several types of services, but they were very

limited compared to services recommended by a standard of care in pediatric oncology in the United States. Consistent with a previous study (Gunn et al., 2013), our study participants reported on their service experiences, particularly benefits and challenges related to psychosocial services. The study results indicate that developmentally appropriate services for adolescent and young adult survivors in Korea are still in their embryonic stage.

Consistent with findings that assessing cancer-associated financial hardship is a significant part of standard of care in pediatric oncology in the United States (Pelletier & Bona, 2015), assessing financial support for childhood cancer patients comprised much of the support for childhood cancer survivors in South Korea. Our study findings indicate that there is still a need for financial and instrumental support. The Korean government founded the Financial Assistance for Childhood Cancer program in 2002, through which children with cancer can receive financial support up to 30 million KRW per person, per year (Ministry of Health and Welfare, 2017). Indeed, our study participants reported that financial and instrumental support was beneficial for their survivorship journey and recovery. This support, however, was determined based on household income, not on service needs. In South Korea, those who do not meet the eligibility requirements for financial and instrumental support may feel frustrated. Some reported that complicated service application procedures also were barriers. Therefore, a needs and financial impact assessment of childhood cancer survivors should be conducted to provide support more systemically for cancer survivors, and financial counseling should be offered through the hospital or related NPOs. Professional health care providers should develop appropriate resources for those cancer survivors.

In our study, few participants experienced psychological counseling due to stigma strongly embedded in Korean society. This is unfortunate, given the great need for mental health services among cancer survivors (Kim & Yi, 2013; Whitney, Bell, Bold, & Joseph, 2014). Those who experienced psychological counseling reported a lack of provider understanding of childhood cancer or survivors, which led to

dissatisfaction with services. Although awareness of psycho-oncology has been increasing in Korea, integrated services from psycho-oncologists who have a good understanding of childhood cancer and professional counseling skills are not currently being provided in pediatric oncology departments of hospitals (Hahm, Shim, Kim, & Kim, 2007). Even in NPOs, there are no formal training programs for counselors who are providing psychosocial services for childhood cancer survivors. Psycho-oncology health care professionals with an accurate understanding of childhood cancer should be cultivated through education and training. The stigma attached to psychological counseling also needs to be addressed through psychosocial awareness programs among professional stakeholders.

Schooling and learning was an important area for adolescent and young adult childhood cancer survivors. Our study showed that current services are not consistent and do not meet educational needs. Thus, more structured and professional help in terms of education is needed, especially due to the competitive educational environment in Korea. In 2005, given the needs of childhood cancer survivors regarding schooling, the Special Education for Disabilities Act (Ministry of Education, 2013) expanded services to children and adolescents with childhood cancer, and educational services are provided in hospital schools or through the internet. Although this legislation protects the educational rights of adolescents with childhood cancer, it does not provide structured services for survivors to adjust to school life (Choi, Kim, & Nam, 2015; Nam & Choi, 2013). Childhood cancer survivors still experience a range of issues in school, including those related to peer relationship or academic performance (Yi, Kim, Hong, & Akter, 2016), and educational services provided by hospitals or NPOs are unsatisfactory (Choi et al., 2015). Opportunities for education among childhood cancer survivors should be provided, because they affect their future.

Mentoring was found to be very helpful for both the mentors and mentees. Trained peer mentoring can be beneficial when caring for those with a chronic disease, such as cancer, in the community (Ussher, Kirsten, Butow, & Sandoval,

2006). In particular, mentoring can lessen the stress of cancer survivors and promote health behaviors (Choi, Kim, & Song, 2016; Dennis, 2003). Despite these benefits, our study participants felt anxious about the potential negative impact of their peer mentoring on mentees, because mentoring can provide mentees with inaccurate information (Huntingdon et al., 2016); thus, training in monitoring should be provided. Guidelines for training of mentors should be developed to provide effective help and to protect the mentors from becoming retraumatized.

Support for family members who are an important support network for childhood cancer survivors is critical, whether through a family retreat or sibling camps. Our study found that, in South Korea, individualized services to address various psychological challenges that the family faces are very limited. The participants reported a lack of programs for various age groups. This maybe because there is limited funding, which is based on a lack of awareness of the need to support the family of childhood cancer survivors (Choi et al., 2014). In Korea, families of childhood cancer survivors reported the need for services related to family support, including psychological counseling for parents, couple and marriage counseling, and counseling regarding parenting (Choi et al., 2014). Psychosocial care in pediatric oncology should include comprehensive family support across treatment (Kazak et al., 2007). A service model that supports Korean family of childhood cancer survivors should be developed.

Self-help activities were found to provide a deeper understanding of self and a sense of community for childhood cancer survivors, which is consistent with previous literature (Kim, 2005). Direction and resources for group activities, however, were lacking. In particular, a lack of leadership role and continuity of group activities were challenges, and encouragement of active participation was needed. Recently, KACLC (2017) provided training for leaders to help parents of children with cancer to help them cope when a child is being treated. More structured direction and leadership training for self-help activities are needed to help families to cope with the physical and emotional challenges of cancer survivors.

These services may exist. However, it is still difficult to implement them for cancer survivors and they are fragmented, thus not meeting cancer survivors' comprehensive service needs due to the lack of an overarching policy. Most importantly, despite existing service and resources, public awareness of psychosocial services for pediatric cancer survivors and family members is very low, which could be one of the major reasons why psychological and social interventions are not systematically implemented in Korea. Thus, it is not surprising that health insurance currently does not cover psychosocial intervention programs in hospitals. Therefore, improving public awareness and establishing specific guidelines and policies regarding implementing psychosocial services for childhood cancer survivors are needed. To address these challenges, in September 2016, the Ministry of Health and Welfare (2016) announced the creation of the Center for Integrated Support System for Child and Adolescent Survivors of Cancer, where childhood survivors can use psychosocial services to address their long-term complications, and emotional and social challenges. Recently a few NPOs also made efforts to provide integrated services for childhood cancer survivors who complete cancer treatments.

Our study has several limitations. First, our study participants were long-term survivors who had been diagnosed with cancer 12.4 years ago, on average. Thus, the study findings were retrospective and may differ from those concerning services that are currently provided. Future studies should examine the prevalence of service use among adolescent and young childhood cancer survivors through their survivorship journey, using more representative samples. Second, our study did not examine the effects of sociodemographic or medical characteristics, such as cancer type, recurrent or second cancers, and physical late effects, which may have a differential impact on service experiences and quality of life (Badger et al., 2013). For example, those who experienced recurrence or had physical late effects may have greater needs and varying experiences of psychosocial services. In addition, service experiences can vary, depending on various psychosocial services providers, such as social workers, chaplains, psychologists, psychiatrists, and mental health nurses.

Future studies should consider the sociodemographic and medical factors of the patients and service providers. Finally, our study focused on service experiences reported by childhood cancer survivors. As such, perspectives from caregivers or siblings were not included in this study. Because cancer is a disease that affects the whole family, psychosocial services for cancer survivors should target not only patients with cancer but also their family. Future studies should examine service experiences from the perspectives of caregivers or siblings.

## VI. Conclusion

People who complete cancer treatment may have psychosocial service needs and program preferences in a range of domains. Our study contributes to the understanding of benefits and challenges of psychosocial services. Current services and programs are quantitatively limited and not meeting the unique needs of childhood cancer survivors and their families. Standards for pediatric psychosocial care for children with cancer and their families has been developed in the United States (Wiener et al., 2015). Particularly, psychosocial services for adolescent and young adult cancer survivors are recommended to be developmentally appropriate (D'Agostino et al., 2011). Age appropriate and culturally tailored standards of psychosocial care should be developed and implemented in Korea.

With more integrated psychosocial services, childhood cancer survivors can better address the challenges they may face following their cancer diagnosis and have a better life in the community. Such practice guidelines for psychosocial service among cancer survivors will promote the quality of life of cancer survivors and their families during the various phases of their cancer survivorship trajectory.

김민아는 연세대학교에서 사회복지 학·석사학위를 받았고, 미국 University of Southern California에서 사회사업학 박사학위를 받았으며, 현재 명지대학교 사회복지학과에서 조교수로 재직 중이다. 주요 관심분야는 장애인복지 및 의료사회복지이며, 현재 암 서바이버십, 장애인 및 만성질환자의 사회통합 등을 연구하고 있다. (E-mail: minahkim@mju.ac.kr)

이재희는 이화여자대학교에서 영문학 학사학위를, University of Michigan에서 사회복지학 석사학위를, University of Southern California에서 사회복지학 박사학위를 받고, 현재 미국 University of Utah 사회복지학과에서 조교수로 재직 중이다. 주요 관심분야는 의료사회복지이며, 현재 트라우마의 긍정 및 부정적 영향, 암서바이버십, 개입 프로그램 개발 및 평가 등을 연구하고 있다. (E-mail: jaehee.yi@utah.edu)

최권호는 연세대학교에서 사회복지 학·석·박사학위를 받았으며, 현재 우송대학교 사회복지아동학부 사회복지전공 조교수로 재직 중이다. 주요 관심 분야는 의료 및 보건 사회복지이며, 현재 아동복지, 사회복지교육, 암서바이버십 등을 연구하고 있다. (E-mail: kwonho@wsu.ac.kr)



## References

---

- Adler, N. E., & Page, A. E. (Eds.). (2008). *Cancer care for the whole patient: Meeting psychosocial health needs*. Washington, DC: Institute of Medicine.
- Arnett, J. J. (2000). Emerging adulthood: A theory of development from the late teens through the twenties. *American Psychologist*, 55(5), pp.469-480. doi:10.1037/0003-066X.55.5.469
- Askins, M. A., & Moore, B. D. (2008). Psychosocial support of the pediatric cancer patient: lessons learned over the past 50 years. *Current Oncology Reports*, 10(6), pp.469-476.
- ATLAS.ti. Version 7.0 [Computer software] (2012). Berlin, Scientific Software Development.
- Badger, T. A., Segrin, C., Figueredo, A. J., Harrington, J., Sheppard, K., Passalacqua, S. et al. (2013). Who benefits from a psychosocial counselling versus educational intervention to improve psychological quality of life in prostate cancer survivors? *Psychology & Health*, 28(3), pp.336-354. doi:10.1080/08870446.2012.731058
- Bass, S. B., Ruzek, S. B., Gordon, T. F., Fleisher, L., McKeown-Conn, N., & Moore, D. (2006). Relationship of internet health information use with patient behavior and self-efficacy: Experiences of newly diagnosed cancer patients who contact the National Cancer Institute's Cancer Information Service. *Journal of Health Communication*, 11(2), pp.219-236. doi:10.1080/10810730500526794
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), pp.77-101. doi:10.1191/1478088706qp063oa
- Choi, K. Kim, S. H., & Nam, S. I. (2015). Service needs of educational achievement and school adaptation among childhood cancer survivors. *Adolescent Culture Forum*, 44, pp.126-155. doi:10.17854/ffyc.2015.10.44.125
- Choi, K., Kim, M. A., & Song, H. S. (2016). Experiences of stomach cancer survivors

- providing peer mentoring in Korea. *Korean Journal of Social Welfare Studies*, 47(2), pp.89-114.
- Choi, K-H., Kim, S., Son, Y-E., & Nam, S-I. (2014). Psychosocial service needs of families with childhood cancer. *Korean Journal of Family Social Work*, 45(9), pp.171-197.
- Crom, D. B. (2009). "I think you are pretty; I don't know why everyone can't see that": Reflections from a young adult brain tumor survivor camp. *Journal of Clinical Oncology*, 27(19), pp.3259-3261. doi:10.1200/JCO.2009.22.1978
- D'Agostino, N. M., Penney, A., & Zebrack, B. (2011). Providing developmentally appropriate psychosocial care to adolescent and young adult cancer survivors. *Cancer*, 117(S10), pp.2329-2334. doi:10.1002/cncr.26043
- Dennis, C.-L. (2003). Peer support within a health care context: A concept analysis. *International Journal of Nursing Studies*, 40(3), pp.321-332. doi:10.1016/S0020-7489(02)00092-5
- Denzin, N. K. (1970). *The research act: A theoretical introduction to sociological methods*. Chicago, IL: Aldine.
- Desields, T., Zebrack, B., & Kennedy, V. (2013). The state of psychosocial services in cancer care in the United States. *Psycho-Oncology*, 22(3), pp.699-703. doi:10.1002/pon.3057
- Elad, P., Yagil, Y., Cohen, L., & Meller, I. (2003). A jeep trip with young adult cancer survivors: Lessons to be learned. *Supportive Care in Cancer*, 11(4), pp.201-206.
- Ernst, J. C., Beierlein, V., Romer, G., Möller, B., Koch, U., & Bergelt, C. (2013). Use and need for psychosocial support in cancer patients. *Cancer*, 119(12), pp.2333-2341. doi:10.1007/s00520-002-0426-4
- Forsythe, L. P., Kent, E. E., Weaver, K. E., Buchanan, N., Hawkins, N. A., Rodriguez, J. L. et al. (2013). Receipt of psychosocial care among cancer survivors in the United States. *Journal of Clinical Oncology*, 31(16), pp.1961-1969. doi:10.1200/JCO.2012.46.2101

- Grassi, L., Spiegel, D., & Riba, M. (2017). Advancing psychosocial care in cancer patients. *F1000 Research*, 6, p.2083. doi:10.12688/f1000research.11902.1
- Gunn, K., Turnbull, D., McWha, J. L., Davies, M., & Olver, I. (2013). Psychosocial service use: A qualitative exploration from the perspective of rural Australian cancer patients. *Supportive Care in Cancer*, 21(9), pp.2547-2555. doi:10.1007/s00520-013-1812-9
- Hahm, B-J., Shim, E-J., Kim, H-K., & Kim, J-H. (2007). History and current status of psycho-oncology. *Journal of the Korean Neuropsychiatric Association*, 46(5), pp.413-420.
- Huntingdon, B., Schofield, P., Wolfowicz, Z., Bergin, R., Kabel, D., Edmunds, J. et al. (2016). Toward structured peer support interventions in oncology: A qualitative insight into the experiences of gynaecological cancer survivors providing peer support. *Supportive Care in Cancer*, 24(2), pp.849-856. doi:10.1007/s00520-015-2853-z
- Kazak, A. E., Rourke, M. T., Alderfer, M. A., Pai, A., Reilly, A. F., & Meadows, A. T. (2007). Evidence-based assessment, intervention and psychosocial care in pediatric oncology: A blueprint for comprehensive services across treatment. *Journal of Pediatric Psychology*, 32(9), pp.1099-1110. doi:10.1093/jpepsy/jsm031
- Kim, J-S. (2005). A grounded theory approach to the experience of leaders in self-help group for parents of children with cancer. *Korean Journal of Social Welfare*, 57(2), pp.405-434.
- Kim, M. A., & Yi, J. (2012). Childhood cancer survivor's services needs for the better quality of life. *Journal of Korean Academy of Child Health Nursing*, 18(1), pp.19-28. doi:10.4094/jkachn.2012.18.1.19
- Kim, M. A., & Yi, J. (2013). Psychological distress in adolescent and young adult Childhood cancer survivors in Korea. *Journal of Pediatric Oncology Nursing*, 30(2), pp.99-108. doi:10.1177/1043454213478469
- Kim, M. A., Yi, J., & Kim, J-S. (2014). Stigma experiences and psychosocial

- responses to stigma among childhood cancer survivors. *Mental Health and Social Work*, 42(2), pp.121-150.
- Kim, M. S. (2017). Families with youth cancer survivors: their needs and policy implication. *Health and Welfare Forum*, 252, pp.47-63.
- Korea Association of Childhood Leukemia and Cancer. (2017). Retrieved February 8, 2018, from [http://www.soaam.or.kr/board/index.php?code=notice&cat=&s\\_txt=%ED%99%9C%EB%8F%99%EA%B0%80](http://www.soaam.or.kr/board/index.php?code=notice&cat=&s_txt=%ED%99%9C%EB%8F%99%EA%B0%80)
- Korea Association of Childhood Leukemia and Cancer. (2018). Retrieved March 2, 2018, from <http://www.soaam.or.kr>
- Korea Central Cancer Registry, National Cancer Center. (2017). *Annual report of cancer statistics in Korea in 2015*. Sejong, South Korea: Ministry of Health and Welfare.
- Korea Childhood Leukemia Foundation. (2018). Retrieved February 8, 2018, from <http://www.kclf.org>
- McCabe, M. S., Bhatia, S., Oeffinger, K. C., Reaman, G. H., Tyne, C., Wollins, D. et al. (2013). American Society of Clinical Oncology statement: Achieving high-quality cancer survivorship care. *Journal of Clinical Oncology*, 31(5), pp.631-640. doi:10.1200/JCO.2012.46.6854
- McDowell, M. E., Occhipinti, S., Ferguson, M., & Chambers, S. K. (2011). Prospective predictors of psychosocial support service use after cancer. *Psycho-Oncology*, 20(7), pp.788-791. doi:10.1002/pon.1774
- Ministry of Education. (2013). *Annual report of special education in Korea*. Sejong, South Korea: Author.
- Ministry of Health and Welfare. (2017). *Manual of financial assistance for the people with cancer*. Sejong, South Korea: Ministry of Health and Welfare.
- Morgan, S., Davies, S., Palmer, S., & Plaster, M. (2010). Sex, drugs, and rock 'n'roll: Caring for adolescents and young adults with cancer. *Journal of Clinical Oncology*, 28(32), pp.4825-4830. doi:10.1200/JCO.2009.22.5474

- Mosher, C. E., Hanna, N., Jalal, S. I., Fakiris, A. J., Einhorn, L. H., Birdas, T. J. et al. (2013). Support service use and interest in support services among lung cancer patients. *Lung Cancer*, 82(1), pp.162-167. doi:10.1016/j.lungcan.2013.06.020
- Nam, S. I., & Choi, K. H. (2013). School reintegration, adjustment difficulties, and services for childhood cancer survivors. *Korean Journal of Social Welfare Research*, 38, pp.181-215.
- National Cancer Institute. (2014). *About cancer survivorship research: Survivorship definitions*. Retrieved from <http://cancercontrol.cancer.gov/ocs/statistics/definitions.html>
- Pelletier, W., & Bona, K. (2015). Assessment of financial burden as a standard of care in pediatric oncology. *Pediatric Blood & Cancer*, 62(S5), pp.S619-S631. doi:10.1002/pbc.25714
- Pirl, W. F., Jacobsen, P. B., & Deshields, T. L. (2013). Opportunities for improving psychosocial care for cancer survivors. *Journal of Clinical Oncology*, 31(16), pp.1920-1921. doi:10.1200/JCO.2012.48.0566
- Rabin, C., Simpson, N., Morrow, K., & Pinto, B. (2011). Behavioral and psychosocial program needs of young adult cancer survivors. *Qualitative Health Research*, 21(6), pp.796-806.
- Shama, W., & Lucchetta, S. (2007). Psychosocial issues of the adolescent cancer patient and the development of the Teenage Outreach Program (TOP). *Journal of Psychosocial Oncology*, 25(3), pp.99-112. doi:10.1177/1049732310380060
- Stanton, A. L. (2012). What happens now? Psychosocial care for cancer survivors after medical treatment completion. *Journal of Clinical Oncology*, 30(11), pp.1215-1220. doi:10.1200/JCO.2011.39.7406
- Statistics Korea (2014). Statistics Korea. Retrieved August 5, 2014, from [http://kosis.kr/nsportalStats/nsportalStats\\_0102Body.jsp?menuId=1&NUM=39](http://kosis.kr/nsportalStats/nsportalStats_0102Body.jsp?menuId=1&NUM=39)
- Steele, A. C., Mullins, L. L., Mullins, A. J., Muriel, A. C. (2015). Psychosocial

- interventions and therapeutic support as a standard of care in pediatric oncology. *Pediatric Blood & Cancer*, 62(S5), pp.S585-S618. doi:10.1002/abc.25701
- Turnbull Macdonald, G. C., Baldassarre, F., Brown, P., Hatton - Bauer, J., Li, M., Green, E. et al. (2012). Psychosocial care for cancer: A framework to guide practice, and actionable recommendations for Ontario. *Current Oncology*, 19(4), pp.209-216. doi:10.3747/co.19.981
- Ussher, J., Kirsten, L., Butow, P., & Sandoval, M. (2006). What do cancer support groups provide which other supportive relationships do not? The experience of peer support groups for people with cancer. *Social Science & Medicine*, 62(10), pp.2565-2576. doi:10.1016/j.socscimed.2005.10.034
- Whitney, R. L., Bell, J. F., Bold, R. J., & Joseph, J. G. (2014). Mental health needs and service use in a national sample of adult cancer survivors in the USA: has psychosocial care improved? *Psycho-Oncology*, 24(1), pp.80-88. doi:10.1002/pon.3569
- Wiener, L., Kazak, A. E., Noll, R. B., Patenaude, A. F., & Kupst, M. J. (2015). Standards for the psychosocial care of children with cancer and their families: An introduction to the special issue. *Pediatric Blood & Cancer*, 62(S5), pp.S419-S425. doi:10.1002/abc.25675
- Yi, J., Kim, M. A., Hong, J. S., & Akter, J. (2016). Childhood cancer survivors' experiences in school re-entry: Focus on academic problems and peer victimization. *Children and Youth Service Review*, 67, pp.263-269. doi:10.1016/j.childyouth.2016.06.022
- Zebrack, B. J., Corbett, V., Embry, L., Aguilar, C., Meeske, K. A., Hayes-Lattin, B. et al. (2014). Psychological distress and unsatisfied need for psychosocial support in adolescent and young adult cancer patients during the first year following diagnosis. *Psycho-Oncology*, 23(11), pp.1267-1275. doi:10.1002/pon.3533
- Zebrack, B., & Isaacson, S. (2012). Psychosocial care of adolescent and young adult

patients with cancer and survivors. *Journal of Clinical Oncology*, 30(11), pp.1221-1226. doi:10.1200/JCO.2011.39.5467

Zebrack, B., Oeffinger, K., Hou, P., & Kaplan, S. (2006). Advocacy skills training for young adult cancer survivors: the Young Adult Survivors Conference at Camp Māk-a-Dream. *Supportive Care in Cancer*, 14(7), pp.779-782. doi:10.1007/s00520-005-0906-4

## 청소년 및 초기성인 소아암 경험자가 인식한 심리사회적 서비스의 이익과 한계

김민아  
(명지대학교)

이재희  
(유타대학교)

최권호  
(우송대학교)

암 경험자를 위한 심리사회적 서비스는 암 진단 후 이들의 삶의 질을 증진시키는 데 매우 중요하다. 소아암 장기생존 경험자의 증가에도 불구하고 우리나라는 이들의 심리사회적 적응을 지원하는 서비스 경험에 대한 이해가 부족하다. 따라서 본 연구는 소아암 경험자가 인식하는 다양한 심리사회적 서비스 이용 경험을 알아보고, 서비스의 이익과 한계가 어떠한지에 대해 탐색하는 것을 목적으로 한다. 이를 위해 암을 경험한 청소년 및 초기성인 30명을 대상으로 심리사회적 서비스 경험에 대한 개별 심층 면접을 실시하였다. 연구 참여자들은 (1) 재정 및 도구적 지원 서비스, (2) 심리상담, (3) 학교복귀 및 교육지원, (4) 멘토링, (5) 가족지지, (6) 자조활동의 각 영역에서 심리사회적 서비스의 이익과 한계를 보고하였다. 본 연구는 소아암 경험자와 가족을 위한 심리사회적 서비스 개선의 필요성을 발견하였다. 이를 통해 청소년 및 초기성인 경험자의 발달단계에 따른 욕구를 충족시키는 적절한 서비스 개발에 기여할 것이다.

주요 용어: 소아암, 경험자, 심리사회적 서비스, 삶의 질

본 연구는 한국백혈병소아암협회의 지원으로 수행되었고, 미 출간된 연구용역보고서의 자료를 부분적으로 활용하였음. 교신저자는 2018년도 우송대학교 교내 학술연구비 지원사업을 통해 지원받았음을 밝힘. 본 연구는 2014년도 4월 International Society of Pediatric Oncology (SIOP) Asia Congress에서 구두 발표한 내용을 수정 및 보완한 것임.