



Difficulties faced by long-term childhood cancer survivors: A qualitative study

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ABSTRACT

Purpose: Due to improved survival rates of childhood cancer, there has been growing attention to survivors. In addition, experiences of illness in youth, during growth and development, affect the lives of these individuals in numerous ways. With a sample of long-term survivors of childhood cancer, this study investigated their difficult experiences after treatment completion and provided fundamental data for intervention programs that can assist growth.

Methods: Data from 15 survivors aged 15–28 years old were collected through face-to-face interviews; analysis used Giorgi's phenomenological method.

Results: The long-term survivors' lives involved a process of struggle to overcome the difficulties. Survivors had physical vestiges of cancer treatments, such as physical strength limitations, appearance changes, and sexual problems. Additionally, they experienced social withdrawal and awkwardness due to adaptation difficulties caused by social life interruption, family issues, social prejudice, and discrimination. These physical and social struggles led to experiences of mental stress and psychological withdrawal, but were followed by rebound.

Conclusions: Long-term survivors of childhood cancer experienced physical, social, and emotional struggles following treatment completion. These results can yield improved understanding of this population, facilitate attention to their challenges, and contribute to their more effective integration into society, helping them live healthy and positive lives.

1. Introduction

Illness experiences during development affect individuals' lives in various ways, such as the disruption of schooling, delayed growth, and difficulty in forming relationships with peers (Arpawong et al., 2013; Bitsko et al., 2016; Cantrell and Conte, 2016; Jervaeus et al., 2016). Survival rates of patients with childhood cancer have rapidly increased due to treatment advances; in the United States, 5-year survival rates of childhood cancer exceed 80% (Howlader et al., 2013), while the rate in South Korea is 79.9% (Korean Central Cancer Registry, 2012). As a result of this increase, survivors of childhood cancer have received increased attention.

Childhood cancer differs from adult cancer in patterns of types, treatment methods, and intensity (Ganz, 2009; Kim and Kwon, 2010). Additionally, since children and adolescents are still developing, cancer treatments can significantly affect physical, mental, social, and

economic areas of their lives even after completion; common effects include anxiety about sexual functioning, relapse, and fertility, all of which can persist long-term (Brown et al., 2015; Ganz, 2009; Jervaeus et al., 2016; Wang et al., 2015).

Social isolation during treatment, along with the physical and emotional sequelae, create difficulties in coping with graduation, job, marriage, and childbirth; hence, individuals with childhood cancer tend to have long-lasting difficulties with social adaptation (Gurney et al., 2009; Kirchhoff et al., 2011; Pivetta et al., 2011; Wakimizu et al., 2011). Additionally, survivors' often low physical self-image, affected by childhood cancer treatments and related experiences, can have negative effects on self-esteem, social functioning, and quality of life (Evan et al., 2006; Robert et al., 2010).

Some studies have reported no significant differences in anxiety, depression, and quality of life between childhood cancer survivors and control groups (Chung et al., 2012; Kim et al., 2008; Kwon et al., 2009;

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Table 1
Participants' demographic data (N = 15).

Participant	Sex	Cancer type	Treatment type	CurrentAge (years)	Occupation	Time since last treatment (years)
1	M	Malignant lymphoma	CTX	20	Temporary absence from school	6
2	M	Leukemia	CTX, RT	24	University student	12
3	M	Leukemia	CTX	23	University student	7
4	F	Neuroblastoma	OP, CTX	17	High school student	15
5	M	Leukemia	CTX	15	Middle school student	8
6	M	Leukemia	CTX	21	Unemployed	9
7	F	Wilms tumors	OP, CTX, RT	23	Employed	19
8	M	Malignant lymphoma	OP, CTX	20	University student	12
9	M	Germ cell tumor	OP, CTX	25	Employed	11
10	M	Malignant lymphoma	CTX	19	College student	10
11 ^R	M	Leukemia	CTX	16	High school student	9
12	F	Leukemia	CTX	18	High school student	14
13 ^R	F	Malignant lymphoma	CTX, RT	16	High school student	6
14	M	Leukemia	CTX	25	University student	11
15	M	Germinoma	OP, RT, CTX	28	Employed	12

CTX, chemotherapy; OP, operation; R, relapse; RT, radiation therapy.

Maurice-Stam et al., 2008; Nayiager et al., 2017; Oh, 2016). Studies exploring the positive effects of childhood cancer on survivors have found that most survivors report post-traumatic growth (Arpawong et al., 2013; Kim, 2017; Kim et al., 2014; Zebrack et al., 2012). This may reflect their human ability to overcome extreme hardships, and these experiences may foster maturity (Barakat et al., 2006; Duran, 2013; Jim and Jacobsen, 2008).

Thus, the findings from previous studies have suggested that survivors of childhood cancer have both negative and positive experiences. Life-threatening illnesses may provide an opportunity for self-renewal as well as spiritual and personal growth (Duran, 2013). Therefore, the current study analyzed the difficult experiences of childhood cancer survivors, which could lead to the development of strategies and interventions that help survivors of childhood cancer overcome these difficulties. Through the development of such strategies and interventions, survivors of childhood cancer may be better able to experience more positive growth.

“Long-term survivors” of childhood cancer are those who are more than five years from the end of treatment (Cantrell and Conte, 2016). They are regarded clinically as “cancer survivors” in Korea. Some studies exist addressing in the short-term childhood cancer survivors' recovery experiences (Cantrell and Conte, 2016; Doukkali et al., 2013); however, only a few studies in Korea have examined the experiences of long-term survivors who are more than five years beyond the end of their treatment (Kim, 2017; Kim et al., 2014). Also, the few studies conducted in Korea have only focused on the positives or stigma experiences. Further, the bulk of research on experiences of childhood cancer survivors has been conducted in the United States, with little attention paid to diverse national and ethnocultural groups (Kim and Yi, 2013). Therefore, research that carefully observes only long-term survivors and focuses on negative post-treatment experiences is needed. The present research is expected to help us understand the experiences and needs of the growing number of survivors of childhood cancer in Korea, and to expand the body of literature on the quality of life of long-term survivors of childhood cancer by examining their difficult or negative life experiences, with a focus on a cultural group that has been largely unstudied.

This qualitative study takes a phenomenological approach, following Giorgi (1985), who attempted to be faithful to or “return [...] to the incident itself” (in the spirit of Husserl's phenomenology). Phenomenological studies investigate the structure of common experiences related to real-world phenomena; for example, this study investigated difficult experiences from the perspective of long-term survivors of childhood cancer who were at least 5 years post-treatment.

2. Methods

2.1. Design

Giorgi's phenomenological research method was used, as noted above (Giorgi, 2009). This method focuses on descriptions of experiences of a given phenomenon to comprehend the meaning of those experiences from participants' perspectives.

2.2. Participants

Participants were South Korean survivors of childhood cancer aged 12 years and older. To be eligible, they had to have received treatment at least 5 years earlier, to remember being treated after cancer diagnosis, and to be able to communicate verbally without substantial impairment. Participants were excluded if they had stem cell transplants (because stem cell transplantation is a more aggressive and stressful treatment than others, changing the nature of patients' experience both directly and through its effects on long-term sequelae, complications, and psychological responses, given which separate research necessary for this population; Kim et al., 2010; Riva et al., 2014) or if they declined to participate. A purposeful sample of participants provided information-rich cases for in-depth study, ensuring a broad range of childhood cancer survivors. Further recruitment halted when data saturation was reached. In other words, while collecting and analyzing data, participants were recruited until new meaning units no longer appeared. During data collection and analysis, there were no dropouts.

Ultimately, fifteen long-term survivors of childhood and adolescent cancer (11 males) participated; the age range was 15–28 years. Among the participants, 7 had been diagnosed with leukemia, 4 with malignant lymphoma, and 4 with solid tumors. All participants had received anticancer treatments, and 2 had experienced relapse before subsequently reaching 5 years post-treatment. Three survivors were employed, 1 was jobless, and the rest were students. The range of time since their last treatment was 6–19 years (Table 1).

2.3. Data collection

Participants were gathered from among people with a reservation to the outpatient department of a complete cure clinic for childhood cancer and were screened for eligibility by their physicians and a clinical nurse specialist. A research assistant called each participant to explain the study's objectives and methods before visiting them at one of their outpatient appointments. After participation was agreed upon, and the participant had voluntarily signed the informed consent form, the interviews were conducted in a hospital counselling room at the

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