

Original Article

Problems in the Various Stages of Childhood Cancer Survivors' Lives and their Self-Care Processes

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Abstract

Background: Childhood cancers affect 2,500–3,000 children each year, and there are approximately 50,000 childhood cancer survivors who have completed therapy for their childhood cancer. The onset of childhood cancer most commonly occurs during the period of infancy to early childhood, and unlike adult-onset cancer, people who have cancer as children are expected to encounter many problems throughout their life. This study aimed to identify the kinds of problems that are faced by childhood cancer survivors on reaching adult age and the kinds of self-care that they perform.

Methods: Semi-structured interviews were conducted with nine adult childhood cancer survivors following an interview guide prepared in advance. The data obtained was analyzed using the modified grounded theory approach. Subjects were explained about the study prior to obtaining their consent.

Results: The analysis of their problems and self-care resulted in the development of four core categories, eight subcategories, and 39 concepts. The core categories were acceptance of and self-care for sequelae, secondary cancers, and late complications, Problematic situations during their growth and development, proactively obtaining information, and acceptance and appreciation of their own life.

Conclusion: Childhood cancer survivors were suffering from sequelae resulting from their treatments for long periods. Although they faced many other issues, they did not talk about them to their mothers or medical staff, leaving them unresolved. Furthermore, these issues evolved as the survivors grew. The amount of information for those who have experienced childhood cancer was small, and effective self-care was not achieved.

Key Word: Childhood cancer, childhood cancer survivors, problematic situations, self-care, secondary cancer and late complications

Background

Childhood cancer is a blanket term for all cancers that affect patients aged 0–14 years. The incidence of childhood cancer in Japan is said to be 2,000–2,500 per year (Ishida 2011). Although it is not a disease with a particularly high incidence among pediatric diseases, it remains the leading cause of disease-associated death among children. Moreover, Takimoto referred to this disease as “one of the diseases warranting national policies and strategies” (Takimoto 2015). In Japan, the total incidence of childhood

cancer from 2016 to 2017 according to the Main Classification of Table of the International Classification of Childhood Cancer, Third edition (ICCC-3) was 4,513. The most prevalent cancer is leukemia (31.1%), followed by brain tumor (21.9%) and lymphoma (9.4%). Leukemia is the most prevalent in children aged 1–4 years, brain tumor in children aged 5–9 years, neuroblastoma in infants, retinoblastoma in children aged 1–3 years, and renal and hepatic tumors in children aged 1–4 years, indicating that many develop the disease in infancy and early childhood (Center for Cancer Control and Information Services,

National Cancer Center Hospital).

Surgery, chemotherapy, and radiotherapy are treatments for childhood cancer. Although the disease is no longer incurable, it may leave patients with a variety of late physical post-treatment complications, such as developmental abnormalities (e.g., stunted growth and excessive weight gain or loss) and post-radiotherapy symptoms (neurological disorders, e.g., epilepsy, learning disability; impacts on reproductive function, e.g., problems with fertility and transgenerational effects on offspring; effects on organic function, e.g., decreased renal, cardiac, or auditory function). Furthermore, even when the childhood cancer is cured, various associated psychological issues, such as mental stress and dealing with whether or not they can explain the history of their illness to peers, acquaintances, and prospective schools and employers, may also affect the patient throughout their growth and development.

In a Japanese multicenter cross-sectional study of 50,000 patients with childhood cancer who have completed treatment and been cured, 50% of women and 64% of men experienced late complications, consisting of endocrine disorders (21%), stunted growth (14%), musculoskeletal disorders (10%), hepatic dysfunction (9%), and skin disorders and hair loss (7%) (Ishida 2010). The outcomes of the study showed that over half of Japanese childhood cancer survivors have late complications, highlighting the importance of improving their long-term follow-up.

Childhood cancer survivors must contemplate ways to improve quality of life after treatment in more situations than adult cancer survivors, suggesting the importance of providing new information and teaching self-care to childhood cancer survivors when they reach adulthood. A previous study reported a scarcity of nursing studies on long-term self-care among childhood cancer survivors and therefore, lack of long-term data about childhood cancer survivors.

This study thus aimed to elucidate the long-term issues that arise in various stages of Japanese childhood cancer survivors' lives after treatment and the coping methods and self-care that they practice.

Methods

This study elucidates the processes associated with the problems experienced in various stages of life and self-care practiced by childhood cancer survivors who underwent surgery for the cancer as children. **Subjects and survey period**

Subject selection: Subjects of this study were childhood cancer survivors aged 18 years or older who underwent surgery for the cancer as

children. The sample included patients who underwent stem cell transplant for leukemia and those who underwent surgery for postoperative complications. A target sample size of 15 was determined. The survey period was December 2018 to November 2019.

Definitions of terms: Childhood cancer survivors: Patients who were treated for pediatric-onset cancer and are currently cured.

Secondary cancer/late complications: Cancers and other health problems secondary to the treatment for childhood cancer.

Self-care: Here, "self-care" refers to self-care as recognized by the childhood cancer survivors.

Long-term follow-up outpatient clinic: Outpatient clinic that childhood cancer survivors routinely visit after treatment for childhood cancer.

Adolescent and Young Adult (AYA) age group: Persons aged 15–39 years.

Ethical considerations: This study was approved by the ethics review boards of the affiliated research and surveyed institutions (Teikyo Heisei University Research Ethics Review Board Approval no. 27-030-1). The childhood cancer survivors who were eligible for this study were explained the details of the study verbally and in writing by a staff of the relevant department in the surveyed institutions (physicians or nurses) and were introduced to the researchers after the survivors provided informed consent.

Research methods:

Data collection methods

I. Study design: The present study was a qualitative inductive study that used the modified grounded theory approach (Kinoshita Y). Hereinafter, it is referred to as M-GTA. Interview guidelines that covered problematic situations and self-care at each stage of childhood cancer survivors' lives were created, and interviews were conducted using a semi-structured format.

II. Subject recruitment: Subjects were recruited by sending requests to childhood cancer survivor peer support groups within Japan. In addition, recruited subjects referred new subjects.

III. Interview methods: 1. After their referral by the peer support groups, the subjects were explained about the study. On the day of the interviews, meetings were held with subjects, the explanation was given again, and final consent was obtained.

2. A semi-structured interview was performed in accordance with the interview guidelines.

3. After permission was obtained, the interviews

were recorded with a voice recorder. Visual data were recorded in field notes.

IV. Interview guideline content: 1. Timing and content of explanations about the disease, and degree of subject understanding regarding the disease.

2. Self-care instruction, degree of self-care implementation, and self-care instructor.

V. Data analysis methods (M - GTA): 1. The recorded interviews were transcribed verbatim.

2. The analysis theme was “Problematic conditions arising in the life stages of childhood cancer survivors who underwent surgery for childhood cancer, and their self-care process.” The subjects of analysis were “Childhood cancer survivors who underwent treatment for childhood cancer.”

3. Focusing on areas relevant to the analysis theme, a single concrete example (variation) was sought, and a concept was generated to fit it. When creating the concept, an analysis worksheet containing the concept name, concept definition, and concrete example (variation) was prepared. Similar concrete examples (variations) that fit the concept were sought from the rest of the data and input into the analysis worksheet after encoding. New concepts were generated in a similar manner.

4. The relationships between each concept were investigated.

5. Categories were generated to group related faced [Problematic situations during their growth and development] and [Proactively obtaining information] related to potential problems that they might face. During these processes, they demonstrated [Acceptance and appreciation of their own life] .

Storyline (see Fig. 1 & table 1)

As part of [Acceptance of and self-care for sequelae, secondary cancers, and late complications] they experienced <acceptance of sequelae resulting from treatment> while also <seeking methods to overcome the sequelae through other treatments>. However, they had <positive feelings about the wound> from the operation, and rather than having negative thoughts about the sequelae or the wound, they [accepted the sequelae]. Furthermore, they <adhered with long-term follow-up>, <worked on self-care to maintain their own health>, and <managed late complications and cancers secondary to treatment> while experiencing <threats of suspected recurrences>. Nevertheless, they [worked on self-care despite the threats of suspected recurrences]. While facing [Problematic situations during their growth and

concepts, and the analysis results were summarized on the basis of intercategory relationships. The concepts were concisely put into words, and storylines were created.

6. The relationship between concepts was illustrated in a results diagram.

Results

Summary of subjects: A total of 9 adults in their 20s and 30s who were childhood cancer survivors were included. Of these, three were women and six were men. Two underwent treatment for the cancer in infancy or early childhood; three at elementary school age, and four at junior high school age. Eight subjects continued to visit the long-term follow-up outpatient clinic, and one had completed follow-up at the clinic.

The subjects were treated for hepatoblastoma, neuroblastoma, nasopharyngeal cancer, Ewing's sarcoma, osteosarcoma, and acute lymphatic leukemia. Interviews lasted 45–159 minutes. Results of the analysis are provided in Table 1.

Hereafter, four core categories are denoted by [], nine subcategories by [], and 39 concepts by < >.

Among the childhood cancer survivors who underwent surgery as children, the problematic situations that arose in the various stages of these survivors' lives and their self-care processes were characterized by [Acceptance of and self-care for sequelae, secondary cancers, and late complications] as they [development] , survivors of childhood cancers began to wonder whether the <sequelae were a component of their personality development>. They <hid cancer history due to being seen as special> and experienced a <sense of alienation due to the illness> from other children. They acknowledged these experiences as the [effects of the cancer experience on their inner selves]. After completing the treatment phase, schools responded by providing <educational institution support after return to school>, and the childhood cancer survivors observed <a transformation of neutral peers into supportive friends after disclosing information about the illness to their peers>. <Support in the workplace> after entering the workforce and <parental support> ensured support that started immediately after treatment in various situations. In hindsight, the childhood cancer survivors <wished for in-hospital classes that could have prepared them for higher education admissions>, explained how <the impacts of the treatment period on higher education prospects> influenced their lives, and resorted to <choosing their paths based on their experiences>. The [length of the treatment period had an effect on the paths that the childhood

cancer survivors chose]. They had experienced being forced to <change their paths due to sequelae or the fact that they were childhood cancer survivors> and had become <independent in order to live as per their own wishes>. The childhood cancer survivors also experienced <uncertainty regarding whether or not to explain their history of cancer and sequelae in job interviews>. In adulthood, childhood cancer survivors began to <contemplate about love and marriage>, and along with it, <pondered on the topic of post-treatment fertility>. They also encountered [problems during the various stages of life]. While [Proactively obtaining information] , they not only lived with <distress that did not disappear despite continued outpatient visits> but also <accepted the change of attending physicians> even if their issues remained unsolved. These experiences led them to <wish for outpatient nurse clinics that establish effective relationships for childhood cancer survivors> so that they can be the ones to provide information, as well as <considered transferring to an adult department> when they reached adult age, or <accepted visiting the pediatric department after reaching adult age with a positive attitude>.

Furthermore, the <lack of understanding about the disease in childhood cancer survivors who underwent surgery in early childhood> compared to that in childhood cancer survivors who developed cancer after primary school age was revealed. Even when the onset of disease was during school years, they had <accepted the physicians' informed consent (IC) regarding the diagnosis despite having insufficient information>. In order to supplement their knowledge, they engaged in <research to collect information on the disease or treatment>; however, they were not seeking a large amount of information, but from their experience, <wished for accurate information for AYA childhood cancer survivors>. Childhood cancer survivors [were aware of the lack of understanding of their disease due to lack of information]. Furthermore, they joined patient groups and became keenly aware of the <significance of peer support> to help one another. Childhood cancer survivors also took actions to <express their thoughts to help establish an environment to make life easier for childhood cancer survivors>. They attempted to alleviate the distress of sick children in their treatment stage and their mothers by <providing information for people battling with the same problems that they had>. They also <expected educational and medical institutions to provide support to help childhood cancer survivors connect with one another>. Furthermore, they took actions to <consider strategies to expand

peer support> in the future. They actively participated in [Peer support for obtaining and transmitting information]. In terms of [Acceptance and appreciation of their own life] , childhood cancer survivors <reflected over and accepted the past and the paths that they had chosen> and <appreciated the relationship with the ward nurse who continued to provide post-discharge support>. They also had eternal <gratitude for their parents> who supported and protected them unconditionally and showed [acceptance of their own life and appreciation for those around them].

Discussion

Acceptance of sequelae and self-care with second cancer or late complications

Even after reaching adulthood, childhood cancer survivors confronted treatment-related sequelae and accepted them through long-term experience. Comparing themselves with others, they experienced dilemmas when they were unable to do various things and so struggled repeatedly. Miyagishima (2017) indicated that teenage childhood cancer survivors had “awareness regarding their own bodies after hospital discharge” and a “goal to be the same as everyone else.” When childhood cancer survivors found that they had no control over the struggles, they accepted this fact and conveyed their feelings to their outpatient nurses for support. The results of the present study showed that although childhood cancer survivors similarly tended to focus on their inabilities, they took action to accept their sequelae by focusing on the activities they were able to do with their friends and recognizing how they were enjoying themselves. Accordingly, it was our understanding that it would be effective in supporting childhood cancer survivors by understanding their propensity to experience sadness regarding their inabilities, directing their attention to what they can do, and trying to boost their self-confidence by affirming their abilities. Miyagishima (2017) reported that adult survivors of childhood cancer cited the shock of changes in appearance as one of the bodily changes that occurred due to treatment. Hatae (2013) also observed the shock of changes in physical appearance as one of the experiences of adolescent childhood cancer survivors who had completed treatment. The present study clarified the situation of childhood cancer survivors who continued to experience delayed complications even after reaching adulthood. Although one might expect that childhood cancer survivors would need to come to terms with themselves and accept their sequelae over time, we believe that constantly having to answer questions about their appearance worsens their emotional

distress. We think that they repeatedly brood on the effects of treatment on their appearance and that these thoughts become a factor that decreases their self-esteem. In the future, it will be necessary to gather more data related to the acceptance of sequelae even after reaching adulthood, strengthen psychological support systems for sequelae, and provide support to improve post-treatment quality of life.

In the present study, it is evident that childhood cancer survivors were not engaging in self-care with an understanding of their disease and late complications, but were engaging in it as a general activity. Although many studies investigated second primary cancer or late complications (Ishida 2008, Ishida 2018, Kiyotani 2019), few focused on the effectiveness of guidance. It is our understanding that it is necessary to clarify the contents of the health education provided to childhood cancer survivors. Furthermore, providing new information to childhood cancer survivors may consolidate self-care behavior and enable them to anticipate and make decisions about their future.

Effect of childhood cancer experience on subjects

The present study revealed that cancer sequelae contributed to a survivor's personality development and influenced his/her personality. Hyeran An (2019) reported that adolescent leukemia survivors were emotionally distressed upon returning to school because they attracted attention owing to their post-treatment appearance and outward changes. We think that similar emotions were experienced by the subjects in the present study.

In particular, having a short stature was a matter of particular concern for male childhood cancer survivors. Even after reaching adulthood, the effects of this condition seemed to persist. Cameron (2019) investigated that the psychosocial interactions of adolescent and young adult cancer survivors and the effects of cancer on their development. In a 1-year follow-up interview, 50% of the participants acknowledged that the effects of their cancer experiences had diminished by half. The effectiveness of the follow-up interview alone shown by Cameron (2019) suggests that even if situations do not improve, it will be possible for survivors to deal with the emotions arising owing to their medical condition as long as they can speak with someone who understands their emotions. Axline VM (1993) stated that, through counseling, children learn how to overcome the hardships they face and develop a positive outlook on the future. We think that the childhood cancer survivors in the present study should also have had counseling at appropriate

stages.

Some hallmarks of post-treatment childhood cancer survivors are their lifespans after recovery and the prevalence of life events during the process of becoming an adult. With each new life event, survivors are impelled to confront their sequelae. We think that perhaps medical professionals should aid childhood cancer survivors in facing the problems that occur together with their sequelae during their lives.

Unsolved problems of childhood cancer survivors

The present study revealed that although childhood cancer survivors had concerns, they lacked a place to discuss them, and they also had anxieties that persisted even during outpatient visits, which could not be discussed with anyone. Mori (2008) observed that one emotion felt by adolescent cancer patients as part of their disease experience was a feeling of concern about burdening their parents; a similar finding was observed in the present study. We think that the desire of survivors not to stress their mothers combined with their immature verbal ability made it even more difficult for them to express their concerns. Additionally, it is our understanding that repeatedly changing the consulting doctor made it more difficult for children to communicate. Therefore, an environment should be created wherein children can converse with medical professionals in the long-term follow-up examinations conducted once or twice yearly and where they can freely express their anxieties.

Conclusions: 1. Even after reaching adulthood, childhood cancer survivors continued to confront sequelae of treatment for childhood cancer.

2. The long-term treatment of childhood cancer affected the education and career choices of survivors, forcing them to abandon their goals.

3. Lack of information did not lead to effective self-care.

4. The results of the present study are difficult to generalize because they were based on the experiences of a small number of childhood cancer survivors. Future studies with a larger sample size to clarify the actual situation with regard to problematic situations and self-care during the process of growth. Furthermore, it is imperative to clarify the effects on education and career choices, strengthen collaborative ties between medical and educational institutions, and provide support so that childhood cancer treatment does not burden patient lives.

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Table 1. Concepts, categories, and subcategories of the interviewed childhood cancer survivors

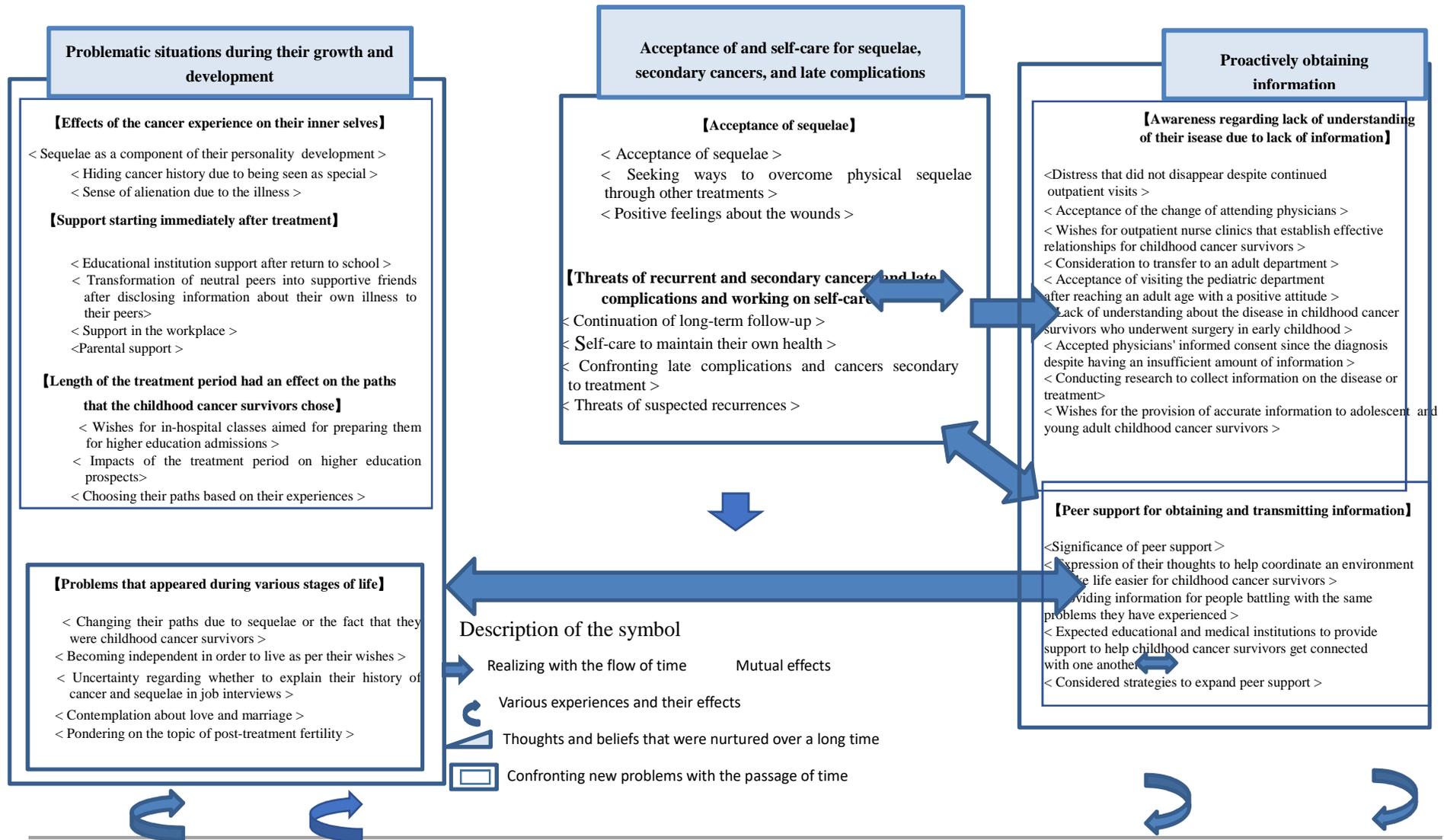
Concepts	Subcategories	Core categories
Acceptance of sequelae	Acceptance of sequelae	Acceptance of and self-care for sequelae, secondary cancers, and late complications
Seeking for ways to overcome physical sequelae using other treatment		
Positive feelings about the wound		
Continuation of long-term follow-up	Threats of recurrent and secondary cancers and late complications and working on self-care	
Self-care to maintain their own health		
Encountering late complications and cancers secondary to treatment		
Threats of suspected recurrences		
Sequelae as a component of their personality development	Effects of the cancer experience on their internal selves	Problematic situations during their growth and development
Hiding cancer history due to being seen as special		
Sense of alienation due to the illness		
Educational institution support after return to school	Support starting after treatment	
Transformation of neutral peers into supportive		

friends by disclosing information about the cancer survivors' own illnesses to them		
Support in the workplace		
Parental support		
Wishes for in-hospital classes that could have prepared them for higher education admissions	Length of the treatment period had an effect on their paths	
Impacts of the treatment period on higher education prospects		
Choosing their paths based on their experiences		
Changing their paths due to sequelae or the fact that they were childhood cancer survivors	Problems that appeared with life stages	
Becoming independent in order to live as per their wishes		
Uncertainty regarding whether to explain their history of cancer and sequelae in job interviews		
Contemplation about love and marriage		
Pondering on the topic of post-treatment fertility		
Distress that did not disappear despite continued outpatient visits	Understanding their lack of information	Proactively obtaining information
Acceptance of the change of attending physicians		
Wishes for outpatient nurse clinics that establish effective relationships for childhood cancer survivors		

Consideration to transfer to an adult department		
Acceptance of visiting the pediatric department after reaching adult age with a positive attitude		
Lack of understanding about the disease among childhood cancer survivors who underwent surgery in early childhood		
Accepted physicians' informed consent since the diagnosis despite having insufficient amounts of information		
Conducting research to collect information on the disease or treatment		
Wishes for accurate information for adolescent and young adult childhood cancer survivors		
Significance of peer support	Peer support for obtaining and transmitting information	
Expression of their thoughts to help coordinate an environment to make life easier for childhood cancer survivors		
Providing information for people battling with the same problems they have experienced		
Expected educational and medical institutions to provide support to help childhood cancer survivors get connected with one another		
Considered strategies to expand peer support		

Reflection over and acceptance of the past and the paths that they have chosen	Acceptance of their own life and appreciation for those around them	Acceptance and appreciation of their own life
Appreciation for the relationship with the ward nurse who continued to provide post-discharge support		
Gratitude for their parents		

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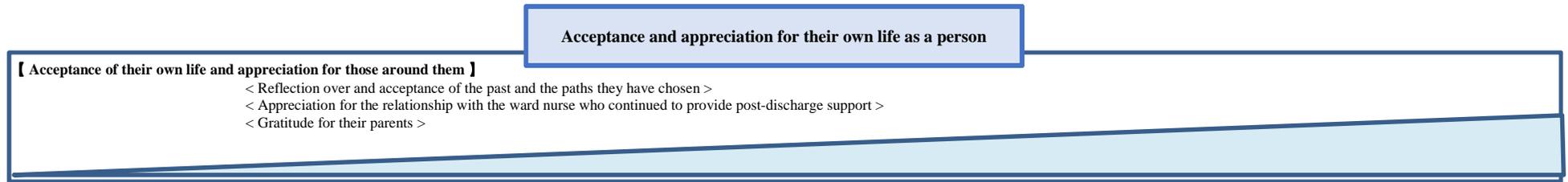


Figure 1. Study results