



The parental involvement process regarding childhood cancer survivors becoming independent: Focus on balancing health management and social lives from adolescence to adulthood

メタデータ	言語: English 出版者: 日本看護科学学会 = Japan Academy of Nursing Science 公開日: 2025-09-22 キーワード (Ja): キーワード (En): adolescent development, parenting, self-management, survivors of childhood cancer, transition to adult care 作成者: Kyoko, Miyagishima, Kazuko, Ichie, Kimiyoshi, Sakaguchi, Yuka, Kato, 宮城島, 恭子, 市江, 和子, 坂口, 公祥, 加藤, 由香 メールアドレス: 所属: 浜松医科大学, 聖隷クリストファー大学, 静岡県立こども病院, 浜松医科大学
URL	http://hdl.handle.net/10271/0002000554

(i) Title

The parental involvement process regarding childhood cancer survivors becoming independent: Focus on balancing health management and social lives from adolescence to adulthood

(ii) Short running title

Parenting process of CCSs' independence

(iii) Author names and affiliations

Kyoko Miyagishima¹

Kazuko Ichie²

Kimiyoshi Sakaguchi³

Yuka Kato⁴

¹ Faculty of Nursing, Hamamatsu University School of Medicine, Hamamatsu, Japan

² Faculty of Nursing, Seirei Christopher University, Hamamatsu, Japan

³ Pediatrics, Hamamatsu University School of Medicine, Hamamatsu, Japan

⁴ Department of Nursing, Shizuoka Children's Hospital, Shizuoka, Japan

(iv) The postal and e-mail addresses and telephone number of the corresponding author

**Kyoko Miyagishima, Faculty of Nursing, Hamamatsu University School of Medicine,
1-20-1 Handayama, Chuo-ku, Hamamatsu, Shizuoka 431-3192, Japan**

E-mail: kyksk@hama-med.ac.jp

Abstract

Aim: This study aimed to elucidate the parental involvement process regarding childhood cancer survivors' (CCSs') independence while balancing their health management and social lives from adolescence to adulthood to obtain suggestions for long-term support for CCSs and their parents.

Methods: Semi-structured interviews were conducted with 19 parents of Japanese CCSs aged 16–25 years. The data were then qualitatively analyzed using the modified grounded theory approach.

Results: Three “categories” and 20 ‘concepts’ were generated. The connections among these categories and concepts revealed the parental involvement process regarding CCSs’ independence while balancing their health management and social lives. The first phase in this process is to “support careful behaviors,” mainly during CCSs’ treatment in the outpatient clinic or shortly after discharge. As CCSs recover after cancer treatment, parents “watch over, but feel conflicted,” with ‘conflicts between protecting their sons/daughters and giving them independence.’ Then, parents reach a phase in which they “acknowledge and entrust,” which includes ‘acknowledgment development and efforts’ of their sons/daughters, and develop an ‘attitude to entrust medical checkups to their sons/daughters, along with their preparation.’ The influencing factors of the three phases include ‘ongoing anxieties about the late effects of therapy and recurrence’ and an ‘expectation for their sons/daughters to acquire abilities for living independently.’

Conclusions: These findings suggest that nurses need to accept parents’ feelings and thoughts regarding conflicts with CCSs, recognition of CCSs’ development, and values. These processes may help nurses and health-care professionals support parents from a comprehensive perspective.

Keywords

adolescent development, parenting, self-management, survivors of childhood cancer,
transition to adult care

1 INTRODUCTION

As many patients with childhood-onset chronic diseases (CCDs) become adults owing to advances in medical care, they still tend to experience difficulties such as health complications and social issues involving education, employment, and income, even after childhood (Jin et al., 2017; Pinquart, 2018). To maintain the health of such patients, it is important to support independent and adult patient-centered health-care transition, which is a common issue both nationally and internationally, and to support adolescent and young adult (AYA) patients and their parents regarding self-determination and self-management (Got Transition, 2014–2023; Ministry of Health, Labour and Welfare, 2017; White et al., 2018). In addition, counseling services are needed for balancing treatment with schoolwork and employment (Ministry of Health, Labour and Welfare, 2017). Therefore, support for independence/autonomy that balances health care and social life is required.

As survival rates for patients with childhood cancer have improved to about 80% in developed countries (Allemani et al., 2018; Siegel et al., 2020), the number of childhood cancer survivors (CCSs) has been increasing every year. The number of CCSs in Japan is currently estimated to be more than 50,000 (Ishida et al., 2016). Many long-term survivors of childhood and adolescent cancer experience a wide range of late effects, such as endocrinopathy, organ dysfunction, secondary neoplasms, and reproductive and neurocognitive problems (Landier, 2018; National Cancer Institute, 2022; Tonorezos et al., 2022). Therefore, long-term follow-up (LTFU) care is provided based on relevant guidelines (Children Oncology Group, 2018), and a shift in the focus of health care from parents to CCSs is required. However, AYA CCSs are not always well prepared for the transition to adult health care, and developing health self-management skills, such as seeing a doctor without their parents and understanding their developmentally appropriate treatment history and late effects, remain an important challenge

(Frederick et al., 2017; Klassen et al., 2014; Syed et al., 2016). Many parents worry about CCSs' late effects (Greenzang et al., 2021), and mothers tend to accompany AYA CCSs to clinical follow-up visits to provide practical support out of concern for their health and well-being (Doshi et al., 2014). Thus, a transition in parental roles (Frederik et al., 2017) and mental support for parents are needed for CCSs' independence in terms of health management.

Treatment for childhood and adolescent cancer and late effects can affect normal developmental experiences and social independence, including mental health, education, employment, and financial aspects (Brinkman et al., 2018; Michel et al., 2020). Conversely, some studies have reported positive psychological and social conditions among CCSs and the support provided to them (Jervaeus et al., 2014; Tremolada et al., 2018). A qualitative study focusing on the process of AYA CCSs' independence says that CCSs' health management and social life change from the phase of coordination within inevitable physical and relational constraints into a phase of finding a way to live with oneself, which integrates health management and social life with their own will (Miyagishima et al., 2023). The process involves psychological development among CCSs, a social life release from constraints, continued hospital visits due to health concerns, and changes in parental involvement; however, this process is not uniform, and certain elements may be missing or unachieved, suggesting the need for individualized assessments (Miyagishima et al., 2023). Therefore, the key to independence is the autonomy and will of the individual. Additionally, a comprehensive perspective that includes balancing medical management and social life and the involvement of surrounding people is also necessary.

Parents of CCSs have expectations and anxiety about CCSs' independence in consideration of their age and complications (Rabelais et al., 2016), and CCSs' independence is a parental interest. However, cancer treatment can last several years and often affects family home-life

routines, parental roles, and mental health (Liu et al., 2023; Nakajima-Yamaguchi et al., 2016; SanGiacomo et al., 2019). Parenting styles in regard to CCSs have some positive aspects such as affection and care, but some concerns including a tendency toward overprotection have been raised about the impact of parenting styles on the independence of CCSs (Ernst et al., 2019; Sharkey et al., 2019). In addition, a positive correlation has been reported between CCSs' and healthy youths' perceived parental overprotection and their parents' perceived frustration in the parent–child relationship (Schepers et al., 2018). AYA CCSs receive more support and experience more conflict from family members compared with other types of relationships, and this has been shown to be associated with psychological health (Kay et al., 2019). These findings suggest that further research on the impact of parent–child relationships and parental involvement on CCSs' lives and independence is needed. On the other hand, Schepers et al. (2018) report findings of no significant differences in the perceptions of parental care and overprotection by healthy youths or CCSs more than 3 years after diagnosis. Regarding relationships with parents during the process of becoming independent, CCSs appreciate their parents and recognize that their overprotective parents have changed their encouragement for what they want to do (Miyagishima et al., 2023). Therefore, parental involvement with CCSs may change during the post-treatment course and growth of CCSs, so research from the parental perspective is also needed.

As described above, previous studies have identified the elements and processes of CCSs becoming independent, parental concern for CCSs' independence, and parenting styles for CCSs. However, few studies have been conducted on parental involvement in the independence of AYA CCS, and this process has not been clarified from the perspective of parents. Therefore, with a focus on parents' perspectives, the present study aimed to elucidate parental involvement process regarding CCSs' independence while balancing their health management and social

lives from adolescence to adulthood. The findings could be expected to provide suggestions for long-term support for CCSs and their parents. In this study, “independence in CCSs” refers to the process in which CCSs become the main managers of, and decision-makers for, their own health and social lives according to their own will, and balance them, through the use of various resources. Although the definition of AYA is broad and the typical age range is 15–39 years (Li et al., 2019; National Cancer Institute, 2020; Saloustros et al., 2017), the present study focused on the developmental process from adolescence in early AYA CCSs.

2 METHODS

2.1 Study design

This study employed a qualitative research design using a modified grounded theory approach (M-GTA) that was developed in Japan by Kinoshita in 1999 (Takeshita, 2019) based on the theoretical and content properties GTA described by Glaser and Strauss (1967/1995). GTA, which includes M-GTA, is a qualitative research method for generating substantive theory grounded on data to explain and predict social interactions among people in specific situations (Glaser & Strauss, 1967/1995; Takeshita, 2019). Among the various versions of GTA that have been developed, M-GTA is particularly suited for research in human services fields and data analysis of semi-structured interviews (Takeshita, 2019). Therefore, it was considered appropriate for the present study because the aim was to generate a theory of the parental involvement process to use for long-term support among parents of CCSs, with a focus on social interactions between parents and CCSs, spouses, medical staff, and school personnel.

2.2 Participant recruitment

The participants, the parents of CCSs, were recruited from two hospitals in Japan (a children’s

hospital and a university hospital) where treatment and follow-up for CCSs are conducted. The inclusion criteria were as follows. The parents: (i) had physical and mental conditions suitable for participation in the study as assessed by a pediatrician or nurse; and (ii) were able to participate in an interview in Japanese and provide informed consent. The parents had sons/daughters (CCSs) who were: (i) age 16–25 years; (ii) had received cancer therapy for leukemia, malignant lymphoma, brain tumor, or osteosarcoma (these diseases are relatively frequent in teens and require LTFU) at age 10–19 years; (iii) had been informed of their diagnosis; (iv) had been hospitalized at a pediatric ward or were visiting a pediatric outpatient department; and (v) had experienced a social life after cancer therapy.

The physicians and a nurse referred parents of CCSs who met the inclusion criteria to the interviewer. Then, the interviewer informed these parents about the study and associated ethical considerations. In total, 19 parents of CCSs agreed to participate.

2.3 Data collection

The first author conducted face-to-face semi-structured interviews with all participants using an interview guide on parents' perceptions and involvement regarding CCSs' health management, social life, and independence. Information on the participants' characteristics was collected using a questionnaire. The guide and questionnaire were prepared after a discussion among the researchers, medical staff, and a representative of a family support group involved in pediatric care.

The interview questions were as follows: (i) What do you think about independence in your son/daughter with disease, and in general?; (ii) What do you think about your son's/daughter's health management, social life, balance between these, and independence?; (iii) How have you been involved in, supported, or talked with your son/daughter regarding their health

management, social life, balance between these, and independence?; (iv) What do you think or how do you feel about your son's/daughter's illness experience?; and (v) What kind of support have you and your son/daughter received and wanted from medical professionals regarding their health management, social life, balance between these, and independence? The questionnaire also asked about the son's/daughter's background characteristics, including age, gender, social status (education, employment, marital status, other), living situation, type of disease and therapy, age at diagnosis, and physical and life effects due to illness or treatment.

Each participant was interviewed once or twice. The interviews ranged in duration from 51 to 150 min (mean: 96.6 min) per participant. All data were collected from June 2016 to February 2018. The interviews (in Japanese) were recorded using a digital voice recorder and then transcribed verbatim.

2.4 Data analysis

Data were analyzed using M-GTA (Takeshita, 2019). In contrast to other versions of GTA, M-GTA has clear analysis procedures and sets the analytical theme and focus to generate an applicable theory within a limited range (Takeshita, 2019). M-GTA uses analytical worksheets to visualize the researcher's thoughts during the analysis process. The analytical worksheet for each concept includes the concept name and definition, data examples (variations), and theoretical notes on conceptualization. In addition, it uses coding without subdividing data to reflect human perceptions and behaviors accompanied by factors and conditions in context.

The analysis procedure was as follows: (i) the analytical theme was set as the parental involvement process regarding CCSs becoming the main managers of, and decision-makers for, their own health and social lives and balance them, and focus persons were set as parents of CCSs who underwent cancer therapy at age 10–19 years; (ii) data from transcripts focusing

on the analytical theme and after initial discharge were carefully selected; (iii) concepts were generated from the interpreted data with descriptive definitions; (iv) comparative analysis was repeated to examine similar or counterexamples; (v) relationships between concepts were examined and categories were generated; and (vi) a schematized diagram of the relationships among these concepts and categories was developed.

To ensure the credibility and trustworthiness of the data analysis, the principal author analyzed the data under constant discussion with the other authors and nursing researchers. Additionally, various researchers with experience conducting M-GTA provided advice regarding the analysis process. Two mothers whose children had cancer (one of whom was a participant in this study) also commented on the validity of the results. Theoretical saturation was determined by verifying that there was no new interpretability regarding the analytical themes and no omissions in the category relationships (Takeshita, 2019).

2.5 Ethical considerations

This study was approved by the ethics committee of two universities (approval No. 15-117; E16-043) and one hospital (No. 49). The authors informed each participant, both verbally and in writing, about the purpose of the study, disclosed that the interviews would be conducted in a private room without their sons/daughters, and ensured the anonymity and confidentiality of the data. The participants were also informed that their participation was voluntary and that they could refuse or withdraw at any time without penalization.

3 RESULTS

3.1 Participants' characteristics

Table 1 shows the characteristics of the 19 participants (17 mothers and two fathers, including

one couple) and their sons/daughters (CCSs). The CCSs ranged in age from 16 to 25 years (mean, 19.4 years), 12 of whom were in their teens and six in their 20s. Fourteen of the CCSs were students and two were employed full-time. Twelve of the CCSs had been diagnosed with leukemia. The treatment periods for six CCSs extended into high school.

3.2 Storyline

Qualitative analyses revealed three categories and 20 concepts. The relationships among these categories and concepts as the parental involvement process regarding CCSs becoming independent, that is, the main managers of, and decision-makers for, their own health and social lives and balancing them from adolescence to adulthood, are shown in Figure 1.

The process starts from “support careful behaviors” (category 1) during CCSs’ treatment in the outpatient clinic or shortly after discharge. As CCSs recover after cancer treatment, their parents reach a phase in which they “watch over, but feel conflicted” (category 2), with *conflicts between protecting their sons/daughters and letting them be independent*. Then, the parents reach a phase in which they “acknowledge and entrust” (category 3) their sons/daughters, including *acknowledgment of development and efforts, awareness of the positive effects of the illness experience, and attitude to entrust medical checkups to their sons/daughters, along with their preparation*.

The influencing factors of these three phases are *ongoing anxieties about the late effects of therapy and recurrence* and *expectation for their sons/daughters to acquire abilities for living independently*.

3.3 Categories and concepts

Tables 2–4 summarize the three categories and 20 concepts, including definitions of each

concept and supporting quotations.

Category 1. “Support careful behaviors” and influencing concepts

Parents are concerned about changes in CCSs’ physical condition and appearance associated with childhood cancer treatment and the impact on their social life. Hence, mainly during CCSs’ chemotherapy in the outpatient clinic or shortly after discharge, parents manage CCSs’ physical condition, provide direct and indirect support in daily life, as well as in living carefully in consideration of the impact of the disease.

Category 1 consisted of five concepts, as shown in Table 2. The parents had *worries about absence from school due to physical condition and appearance* of CCSs.

My daughter lost a lot of hair during her outpatient treatment. She didn't want to go to school, and she was absent for two months. She and I thought that hair loss was unavoidable during inpatient treatment, but even during outpatient treatment, she could see her skin, and I didn't know what was happening.
(Participant A)

Therefore, parents assisted CCSs by *helping with the physical condition and commuting to school, while sharing information regarding the disease with the school.*

My daughter hated to take the medicine very much because it made her feel more tired. I made her take it at different times of the day, because when she was very tired, she would get up late in the morning.
(Participant O)

I want my son to ride his bicycle to high school, but I'm worried about the hills, so I drive him there and back. When he is in a good condition, I let him take the school bus to school. (Participant C)

When my daughter was leaving the hospital, I attended a meeting with the teacher of the in-hospital classroom, her doctor, the nurse, and local elementary school teachers. I kept in close contact with her

homeroom teacher, including about treatment, taking over classes, the central venous catheter, prohibited raw foods, and colds and the flu among her classmates. I asked the teacher to tell her classmates all about her illness. (Participant K)

Parents also had *worries about overexertion and doing things busily* regarding CCSs, and gave *advice to be cautious in activities and career choices*, sometimes lasting for years after treatment or high school. Parents stated that:

After the onset of the disease, my son was very shocked mentally because he could not enjoy his junior high school life. When high school life started, it was amazing that he was over-paced, broke out of his previously suppressed life, and wanted to do this and that. He was very active at school, very tired after school, and slept most of the time at home. (Participant I)

I used to let my son do what he wanted before, but after his illness, I worry about everything he does and interfere. I tell him to stop so that he doesn't hit his head and I keep asking him if he's okay. My son forgets easily, and I worry about him choosing a job and if he'll be able to learn it. If his workplace is far away and he commutes by car, I worry about accidents. (Participant T)

Parents' involvement with CCSs in this phase interacted with *ongoing anxieties about the late effects of therapy and recurrence*, and sometimes lasted longer.

My daughter was on strong and various medications for a long period of time, so I am always worried about how it will affect her internal organs in the years to come. She also had liver damage during her treatment, so I still feel scared and anxious when she has a bloody nose. Her disease is always on my mind, and it never leaves me. (Participant O)

Category 2. "Watch over, but feel conflicted" and influencing concepts

In this phase, parents mainly watched over CCSs as they managed their physical condition and

adjusted their lives on their own, but were also conflicted between protecting their sons/daughters and letting them be independent. As factors that influenced these behaviors and feelings, two concepts were extracted: (i) *ongoing anxieties about the late effects of therapy and recurrence*; and (ii) *expectation for their sons/daughters to acquire abilities for living independently*.

This category consisted of six concepts, as shown in Table 3. As CCSs recovered from cancer treatment, their parents felt *relief about recovery of physical condition and daily life* and were *watching over physical management* and *watching over lifestyle* of their sons/daughters.

My daughter was in middle school, so from the beginning, I let her manage all of her growth hormone injections and nasal drops on her own. She also often had headaches, so I told her to tell the medical staff everything herself because it would then be easier to know what kind of pain she was having and whether the medication was working. (Participant Q)

As CCSs grew up, parents also had an *expectation for their sons/daughters to acquire abilities for living independently*, including making decisions and taking action, facing their illness, finding a job, and making a living on their own.

I think it would be better if my daughter could tell hospital staff about her condition. However, she doesn't. For example, I had told my daughter beforehand that she should ask the doctor whether she should continue or stop taking the medicine, but she didn't ask, so I did. I don't think my daughter can say she is independent unless she can make her own decisions, live a normal life on her own, and take care of her own health. (Participant E)

On the other hand, parents of CCSs had *ongoing anxieties about the late effects of therapy and recurrence* for years, even after CCSs' physical condition recovered. These anxieties influenced parents to have *concerns and advice about daily habits* of CCSs, with *conflicts*

between protecting their sons/daughters and letting them be independent. They also had worries about future marriage, fertility, and heredity. Parents commented as follows:

My son's blood pressure is high. I often tell my son that it's a matter of self-control and diet, because he says his diet mostly consists of ramen noodles. When my son lived with us, I used to tell him to eat vegetables and fish, but now that he lives alone, I doubt he eats them at all. I once told him to come home to eat at least once a week. (Participant F)

When I am strict, my son says that I don't understand him and protests. I wonder how much I should accept him. I wonder if I have been too assistive, if I spoiled him too much, or if I should have been stricter and let him go to school on his own. (Participant M)

My daughter's fertility problem was my main concern during her anticancer treatment. If my daughter would see a gynecologist and find out that she can't have a baby, there would be some obstacles to marriage. I think that would be awful and I wonder what I would say to her, especially because she loves children. My daughter's next visit to the gynecologist will be the biggest hurdle for both of us, and I want to be there with her at that time. (Participant Q)

Category 3. "Acknowledge and entrust" and influencing concepts

This category is the end point of the process in the present study. This phase is reached by changing from the "watch over, but feel conflicted" (category 2) or "support careful behaviors" phase (category 1). Parents of CCSs recognized their sons'/daughters' illness experience and age-appropriate developmental and behavioral abilities, and entrusted them to take charge of their own health management and lifestyle.

This category consisted of seven concepts, as shown in Table 4. Parents were *feeling the weight of living and shifting own values*, and some were influenced by *understanding their*

sons'/daughters' anxiety about recurrence and death. Therefore, parents experienced encouragement about what their sons/daughters want to do regarding CCSs' social and daily lives. Parents stated as follows:

Before my daughter got this disease, I used to nag her a lot. When she got ill, I wanted her to just live, so I began to think that her will came first. No matter what others may say, she is the one who thinks and acts. (Participant P)

The child who had been fighting the disease with my son had died, so he felt as if he might one day do the same. My son said the following. "Eventually, everyone around me will die from accidents or illnesses, and in my case, there might be a strong possibility of disease. It's better to do it now than to think I can't do it when my condition worsens. I don't want to feel regret." I fear his illness and don't want to think about it too much, but I am trying not to be a stopper so that my son can say that he did what he wanted to do in the end. (Participant B)

As CCSs grew, parents showed *acknowledgment of development and efforts* of CCSs and *awareness of positive effects of the illness experience* on CCSs:

My son suddenly started to tell his friends about his illness during his senior year of high school. I think my son finally accepted himself during his illness and thought he needed to tell everyone that he had it, so I am very happy. I definitely feel that my son has become stronger. (Participant I)

It was a very difficult illness, but now that I think about it, the illness experience has been positive for us both. My son probably realized that there are many children who have experienced the same kind of illness, and it also motivated him to want to work in a hospital in the future. (Participant R)

From the aspect of health management, parents were *recognizing the necessity to visit the hospital even into adulthood* and influenced by previous concerns regarding *ongoing anxieties about the late effects of therapy and recurrence* and *worries about CCSs' future marriage*,

fertility, and heredity. Hence, parents displayed an *attitude to entrust medical checkups to their sons/daughters, along with their preparation.* Parents also reinforced *acknowledgment of development and efforts* further when CCSs attended medical checkups on their own. Parents commented that:

My son has been going to every department to see the doctor by himself since he got his driver's license at the age of 18. His previous doctor told him to see the doctor alone because he would have to deal with his illness for the rest of his life and he needed to know what was going on himself. When I ask him how the visit went after he comes home, he answers me appropriately. (Participant M)

When my son went to see the doctor by himself for the first time, he said that he could ask many questions because his parents were not there. I thought that he couldn't question the medical staff before because he thought we (his parents) would worry about him. I felt that my son had become a little more mature. (Participant L)

4 DISCUSSION

In the present study, three categories were revealed in the parental involvement process regarding CCSs' independence while balancing their health management and social life from adolescence to adulthood. The results identify the following three characteristics: (i) in the “support careful behaviors” phase, parents provide more advice and have more involvement with health care and adjustments to social life; (ii) in the “watch over, but feel conflicted” phase, parents reduce help for their sons/daughters, but feel conflicted between protecting their sons/daughters and encouraging independence with complex feelings; and (iii) in the “acknowledge and entrust” phase, parents acknowledge their sons'/daughters' development and abilities, and CCSs are encouraged to be the primary managers of their own health care

and life coordination. In other words, the present study is unique in that it suggests a sequential process of change in the interaction between parents and early AYA CCSs, with gradual increases in the CCSs' independence and gradual decreases in parental assistance.

4.1 Why parents support careful behaviors of CCSs

In this phase, parents of CCSs are highly involved in helping CCSs manage their own physical condition and adjust to their social lives by providing advice and information. This is because parents have strong concerns about both the health and life of their sons/daughters, such as the possibility of late effects and recurrence in CCSs (Greenzang et al., 2021; Rabelais et al., 2016), as well as difficulty attending school, returning to school, and pursuing higher education because of their physical condition and changes in appearance (Inhestern et al., 2020; Iwai et al., 2017). This means that parents face difficulties in supporting CCSs in their attempts to balance treatment and schoolwork, which consists of repeated hospitalizations and outpatient visits for long-term childhood cancer treatment.

Due to these concerns, parents tend to recommend cautious behavior. At times, no parental prudence was seen before their sons/daughters became ill, similar to findings in previous research (Inhestern et al., 2020), and this lasted for years, extending beyond their education to employment. This indicates the magnitude of the impact that having a child with cancer has on parenting behavior. Furthermore, it could mean that parents continue to perceive their children as vulnerable even years after the completion of cancer therapy and independent of their current health status or past cancer history (Hogan et al., 2018). By contrast, CCSs feel overprotected by their parents and wish to be free from various restrictions (Miyagishima et al., 2023). These issues can create a gap between parents and children in balancing social life and health management.

For the appropriate development of adolescents, it is important to have age-appropriate school life experiences, such as gaining self-confidence and social skills (Newman & Newman, 2018), even if accompanied by parental help. Many children with cancer reintegrate into school well, but this process can also take a lot of effort from parents and children (Inhestern et al., 2020; Walker et al., 2019). Although CCSs have fewer years of education and lower perceptions of social support than healthy peers of the same age, school life is important because it provides opportunities to obtain social support from friends and romantic partners, among others (Tremolada et al., 2016). Therefore, nursing care is necessary for both parents and children, including working with the parents in coordinating with medical personnel and teachers to ensure that their child's wishes are reflected and that excessive restrictions are not imposed.

4.2 What it means that parents watch over CCSs, but feel conflicted

Parents capture their sons'/daughters' reactions by interacting with them, and then reflecting on and changing their own perceptions and ways of relating to them. Parenting attitudes in this phase shift to watching over CCSs' health and pace of life, with less help; however, parents feel conflicted between protecting CCSs and encouraging independence, and this is considered to be a transitional phase to the next step of CCSs' independence. This is influenced by parental complex feelings, including relief, ongoing anxieties, and consciousness of promoting CCSs' independence.

Parents felt reassured and began to watch over CCSs because they recovered their physical condition, resumed a normal life after treatment (Miyagishima et al., 2023), and established self-care in daily life. Their sons/daughters had been self-managing to some extent since starting to receive treatment, including the use of an intravenous catheter and medications at

home, and explaining their symptoms to medical staff during outpatient visits. The present study was conducted with parents of CCSs who were aged 10 years or older and had experienced treatment, which may have influenced the CCSs' willingness as well as the awareness of the medical staff and parents in regard to promoting their independence.

On the other hand, parents were concerned about and gave advice to the CCSs if they perceived their lifestyle as being unhealthy. Parents want to remain involved in the health care of CCSs (Viola et al., 2022), but they also expect them to be independent in consideration of their age and anxiety about the future of CCSs with a lack of independence (Rabelais et al., 2016). Both of these ambivalent feelings were observed in the present study, and may be attributed to the uncertainties of the disease outcome (Nurhidayah et al., 2023) and manifestations of the parents' sense of responsibility. CCSs' complications interfere with their schoolwork and employment and prolong parental protection (Rabelais et al., 2016; Sharkey et al., 2019), so parents are likely anxious about letting go of CCSs. Besides, parents express concern about fertility problems from the beginning of cancer treatment for their sons/daughters (Greenzang et al., 2021), which leads to new concerns such as marriage and heredity. Hence, the parents in the present study wanted to accompany CCSs on hospital visits and support them emotionally, especially during visits to new medical departments, similar to the findings of previous studies (Doshi et al., 2014). This derivation in the parents' concerns reflects the shift in the challenges after CCSs' cancer treatment and expanding social life.

Parents' expectations of CCSs' independence include aspects of medical examinations and health care, which may be a higher hurdle to independence than for AYAs without illness, and CCSs may need longer to do on their own. This can prolong parents' conflicts between protecting CCSs and encouraging independence, as well as providing help for CCSs. In such situations, parents are aware of their own conflicts and reflect on how they relate to their

sons/daughters while capturing their reactions, which is an important factor in taking the next step.

4.3 How parents acknowledge and entrust CCSs

This phase is characterized by parents encouraging their sons/daughters to do what they want and entrusting them to make medical visits, thereby letting them take the lead in health management and life arrangement. These parental attitudes are influenced by the shift in parents' values, a sense of son/daughter development, and parental motivation to promote health care for their sons/daughters themselves.

The uncertainty of the disease plays a role in changing the parents' values and their relationship with CCSs. Mothers of CCSs have been reported to take things one day at a time because their child does not know what the future holds (Rabelais et al., 2016). In the present study, parents understood that their sons/daughters perceived the threat posed to their life and felt uncertain about the future caused by cancer, and therefore, emphasized the irreplaceability of their sons'/daughters' lives and the value of living on their own volition. In other words, parents' concerns about recurrence, etc., have by no means disappeared, but can be understood as a change in priorities by overcoming the struggle with a potentially life-threatening disease together with CCSs.

Parents' realization that CCSs have developed according to their age, life, and illness experiences also influence how parents relate to CCSs. Cancer-related worries are higher among parents than among CCSs aged 14–25 years, but parents tend to recognize more cancer-related benefits than their children (Prikket et al., 2022). Parents' own self-acceptance and flexibility leads to their acceptance of their children (Friedman et al., 2003). These findings suggest that confronting their own sense of self-worth helps parents recognize their

sons/daughters and understand their feelings, words, and actions, and could encourage them to lead a life of their own choosing.

The results of this study also indicate that parental concerns can motivate parents to promote CCSs' health-care independence. In a previous study, compared with patients, parents of AYAs with CCDs were more likely to fear the transition to adult-oriented care and feel excluded from their adult child's medical decisions (Fernandes et al., 2014). However, due to parents' persistent worries about the disease, including the possibility of late effects, and the physician's explanations, they are aware that their sons'/daughters' disease will continue even into adulthood, which leads to an attitude of entrusting and preparing their sons/daughters to receive medical examinations by themselves. Furthermore, their sons'/daughters' health-care independence could lead to parental peace of mind and acknowledgment. AYA CCSs recognize that parents need to transition from a primary caregiver to a supporter (Frederik et al., 2017). From the foregoing, changes in parental roles during CCSs' transition from adolescence to adulthood are important for CCSs' autonomy, health care, and parent-child relationships.

4.4 Nursing implications

The results of the present study revealed a long-term perspective about the parental involvement process regarding CCSs becoming independent, including changes in parental perceptions and emotions. Clarifying this process could provide nurses and other health-care professionals involved with CCSs in various departments with more predictable and comprehensive perspectives for supporting parents. The present findings also suggest that it is important for parents to feel stable while promoting their sons'/daughters' independence and recognizing their reactions, development and effort. To do so, before CCSs transition to adult-oriented care, nurses should understand parental involvement with CCSs, appreciate the efforts

of the parents, and accept parents' feelings, including their conflicts in dealing with their adolescent sons/daughters. Nurses should also share and assume CCSs' physical condition and life and developmental changes with parents and provide them with opportunities to reflect on their own values and their relationship with their sons/daughters.

In addition, the present study revealed the characteristics present during the transition period, when the subject of health management, including medical examination behaviors, shifts from parents to CCSs. Parents are highly worried about their sons'/daughters' condition and support cautious behavior, but their sons/daughters may act and develop before the parents are fully aware of the situation. Nurses can take an approach that would link the parents' anxiety about CCSs' illnesses to their awareness and motivation to promote CCSs' health-care independence and the peace of mind that comes with it. In addition, nurses should promote mutual understanding between parents and CCSs regarding the shift to responsibility for CCSs' own health management and medical checkups while considering the preparation period. Furthermore, in the case that CCSs undergo cancer treatment past the age of 10 years, support for CCSs' accumulation of self-health management is needed from the treatment period. As described above, the results of this study could be expected to help provide support for parents and the transition of care regarding health management from parents to CCSs.

4.5 Limitations

This study did have some limitations. First, most of the children of the participants in the present study were students who had not yet achieved financial independence through employment, more than half were minors, and the parents were still the formal decision-makers in the medical setting. Therefore, the scope of the results is limited to the period when CCSs are progressing toward independence from their parents in terms of both their medical and

social life, although they are still valuable because they include content unique to the transition period. Second, the process identified in this study, which includes long-term change, is based on only one or two interviews in which the participants reflected on their experiences. Besides, medical histories were obtained only from the participants themselves, and the participants' children were limited to those with four types of cancer who had completed treatment at age 10 years or older. Therefore, the practical application of the results that reflect a wide range of individual characteristics may be limited, and thus should be validated in future studies.

5 CONCLUSIONS

The parental involvement process regarding CCSs becoming independent begins with the “support careful behaviors” phase, followed by “watch over, but feel conflicted”, and then shifts to “acknowledge and entrust”. These phases are influenced by *ongoing anxieties about the late effects of therapy and recurrence* and an *expectation for their sons/daughters to acquire abilities for living independently*. The clarification of this process suggests the possibility of providing predictive support to parents from a comprehensive perspective.

ACKNOWLEDGMENTS

The authors gratefully appreciate the study participants for sharing their valuable experiences in the interviews. We are also grateful to the hospital officials for their cooperation. Furthermore, we thank all those who advised us in regard to improving our data analysis. This study was supported by the Japan Society for the Promotion of Science KAKENHI Grant Nos. 16K12139 & 20K10933. We presented a part of this article at the 51st Congress of the International Society of Paediatric Oncology.

CONFLICT OF INTERESTS

The authors declare no conflicts of interest.

AUTHOR CONTRIBUTIONS

Kyoko Miyagishima designed the study, collected and analyzed the data, interpreted the findings, and drafted and submitted the manuscript. Kazuko Ichie advised the research project, study design, data analysis, and revisions to the draft. Kimiyoshi Sakaguchi and Yuka Kato made important contributions to the data collection and contributed to the interpretation of the data and revisions to the draft. All authors read and approved the final manuscript.

REFERENCES

- Allemani, C., Matsuda, T., Carlo, V. D., Harewood, R., Matz, M., Nikšić, M., ... CONCORD Working Group (2018). Global surveillance of trend in cancer survival 2000–14 (CONCORD-3): analysis of individual records for 37 513 025 patients diagnosis with one of 18 cancers from 322 population-based registries in 71 countries. *Lancet*; 391, 1023–1075. [http://doi.org/10.1016/S0140-6736\(17\)33326-3](http://doi.org/10.1016/S0140-6736(17)33326-3)
- Brinkman, T. M., Ness, K. K., Li, Z., Huang, I-C., Krull, K. R., Gajjar, A., ...Armstrong, G.T. (2018). Attainment of functional and social independence in adult survivors of pediatric CNS tumors: A report from the St Jude lifetime cohort study. *Journal of Clinical Oncology*, 36 (27), 2762-2769. <https://doi.org/10.1200/JCO.2018.77.9454>
- Children's Oncology Group (2018). Long-term follow-up guidelines for survivors of childhood, adolescent, and young adult cancers, version 5.0. Retrieved from: http://www-survivorshipguidelines.org/pdf/2018/COG_LTFU_Guidelines_v5.pdf
- Doshi, K., Kazak, A. E., Hocking, M. C., DeRosa, D. W., Schwartz, L., Wendy L. Hobbie, W. L., ...Deatrick, J. (2014). Why mothers accompany adolescent and young adult childhood cancer to follow-up clinic visits. *Journal of Pediatric Oncology Nursing*, 31(1) 51–57. <https://doi.org/10.1177/1043454213518111>
- Ernst M., Brahler, E., Klein, E. M., Junger, C., Wild, P. S., Faber, J., Schneider, A., & Beutell, M. E. (2019). Parenting in the face of serious illness: Childhood cancer survivors remember different rearing behavior than the general population. *Psychooncology*. 28(8), 1663-1670. <https://doi.org/10.1002/pon.5138>
- Fernandes, S. M., O'Sullivan-Oliveira, J., Landzberg, M. J., Khairy, P., Melvin, P., Sawicki, G. S., Fishman, L. F. (2014). Transitioning and transfer of adolescents and young adults with pediatric onset chronic disease: The patient and parent perspective. *Journal of Pediatric*

Rehabilitation Medicine. 7(1): 43–51. <https://doi.org/10.3233/PRM-140269>

Frederick, N.N., Bober, S.L., Lexie, B., Tower, M., & Kenney, L. (2017). Preparing childhood cancer survivors for transition to adult care: The young adult perspective. *Pediatric Blood & Cancer*, 64, e26544. <https://doi.org/10.1002/pbc.26544>

Friedman, M. M., Bowden, V. R., & Jones, E. G. (2003). Family developmental theory. In: Friedman, M. M., Bowden, V. R., & Jones, E. G. (Eds.), *Family nursing research, theory, & practice* (5th ed., pp. 103-150). New Jersey: Pearson Education.

Glaser, B.G., & Strauss, A.L. (1995). *The discovery of grounded theory: Strategies for qualitative research*. New Brunswick, NJ: Aldine Transaction. (Original work published 1967)

Got Transition (2014-2023). Six core elements of health care transition. Retrieved from: <https://www.gottransition.org/six-core-elements/>

Greenzang, K. A., Kelly, C. A., Al-Sayegh, H., Ma, C., & Mack, J. W. (2021). Thinking Ahead: Parents' Worries about Late Effects of Childhood Cancer Treatment. *Pediatric Blood & Cancer*. 68(12): e29335. <https://doi.org/10.1002/pbc.29335>

Hogan, M-J. S., Ross, W. L., Balsamo, L., Mitchell, H-R., & Kadan-Lottick, N. S. (2018). Parental perception of child vulnerability in childhood cancer survivors. *Pediatric Blood & Cancer*, 65(11):e27364. <https://doi.org/10.1002/pbc.27364>

Jin, M., An, Q., & Wang, L. (2017). Chronic conditions in adolescents (Review). *Experimental and Therapeutic Medicine*, 14, 478-482. <https://doi.org/10.3892/etm.2017.4526>

Inhestern, zl., Peikert, M. L., Krauth, K. A., Escherich, G., Rutkowski, S., Kandels, D., & Bergelt, C. (2020). Parents' perception of their children's process of reintegration after childhood cancer treatment. *PLoS One*. 15(10): e0239967. <https://doi.org/10.1371/journal.pone.0239967>

- Ishida, Y., Higaki, T., Hayashi, M., Inoue, F., & Ozawa, M. (2016). Factors associated with the specific worries of childhood cancer survivors: Cross-sectional survey in Japan. *Pediatrics International*, 58, 331-337. <https://doi.org/10.1111/ped.12940>
- Iwai, N., Shimada, A., Iwai, A., Yamaguchi, S., Tsukahara, H., & Oda, M. (2017). Childhood cancer survivors: Anxieties felt after treatment and the need for continued support. *Pediatric International*. 59(11), 1140-1150, <https://doi.org/10.1111/ped.13390>
- Jervaeus, A., Sandeberg, M., Johansson, E., & Wettergren, L. (2014). Survivors of childhood cancer report high levels of independence five years after diagnosis. *Journal of Pediatric Oncology Nursing*, 31(5), 245-51. <https://doi.org/10.1177/1043454214524026>
- Kay, J. S., Huth, V., Silver, R. C., & Sender, L. S. (2019). Support and conflict in relationships and psychological health in adolescents and young adults with cancer. *Journal of Health Psychology*. 24(4), 502–517. <https://doi.org/10.1177/1359105316676629>
- Klassen, A.F., Rosenberg-Yunger, Z.R.S., D'Agostino, N.M., Cano, S.J., Barr, R., Syed, I.A & Glanek, L. (2014). The development of scales to measure childhood cancer survivors' readiness for transition to long-term follow-up care as adults. *Health Expectations*, 18, 1941-1955. <https://doi.org/10.1111/hex.12241>
- Landier, W., Skinner, R., Wallace, H.W., Hjorth, L., Mulder, R.L., Wong, L.F., ... Hudson, M.M. (2018). Surveillance for late effects in childhood cancer survivors. *Journal of Clinical Oncology*, 36(21), 2216-2222.
- Li, C. K., Dalvi, R., Yonemori, K., Ariffin, H., Lyu, C. J., Farid, M., ... Mountzios, G. (2019). Care of adolescents and young adults with cancer in Asia: results of an ESMO/SIOPE/SIOP Asia survey, *European Society for Medical Oncology Open*, 4: e000467. <https://doi.org/10.1136/esmoopen-2018-000467>
- Liu, Y., Sundquist, J., Sundquist, K., Zheng, D., & Ji, J. (2023). Mental health outcomes in

- parents of children with a cancer diagnosis in Sweden: a nationwide cohort study. *eClinicalMedicine*, 55: 101734. <https://doi.org/10.1016/j.eclinm.2022.101734>
- Michel, G., Brinkman, T. M., Wakefield, C. E., & Grootenhuis, M. (2020). Psychological outcomes, health-related quality of life, and neurocognitive functioning in survivors of childhood cancer and their parents. *Pediatric Clinical of North America*, 67 (6), 1103-1134. <https://doi.org/10.1016/j.pcl.2020.07.005>
- Ministry of Health, Labour and Welfare (2017). Construction of transitional medical support system for patients with chronic specific diseases in children in prefectures. (In Japanese) Retrieved from: <https://www.mhlw.go.jp/file/05-Shingikai-10601000-Daijinkanboukouseikagakuka-Kouseikagakuka/0000191414.pdf>
- Miyagishima, K., Ichie, K., Sakaguchi, K., & Kato, Y. (2023). The process of becoming independent while balancing health management and social life in adolescent and young adult childhood cancer survivors. *Japan Journal of Nursing Science*, 20(3), e12527. <https://doi.org/10.1111/jjns.12527>
- Nakajima-Yamaguchi, R., Morita, N., Nakao, T., Shimizu, T., Ogai, Y., Takahashi, H., ...& Fukushima, T., (2016). Parental Post-Traumatic Stress Symptoms as Predictors of Psychosocial Problems in Children Treated for Cancer. *International Journal of Environmental Research and Public Health*, 13, 812. <https://doi.org/10.3390/ijerph13080812>
- National Cancer Institute (2020). Adolescents and Young Adults with Cancer. Retrieved from: <https://www.cancer.gov/types/aya>
- National Cancer Institute (2022). Late effects of treatment for childhood cancer (PDQ®)– Health professional version. Retrieved from: <https://www.cancer.gov/types/childhood-cancers/late-effects-hp-pdq>
- Newman, B.M., & Newman, P.R. (2018). Early adolescence. Later adolescence. In: Newman,

- B.M., & Newman, P.R. (Eds.), *Development through life: A psychological approach* (13th ed., pp. 317-466). Boston: Cengage.
- Nurhidayah, I., Nurhaeni, N., Allenidekania, A., Gayatri, D., & Rustina, Y. (2023). Uncertainty of parents due to having children with cancer: A concept analysis. *Belitung Nursing Journal*, 9(3), 218-226. <https://doi.org/10.33546/bnj.2612>
- Pinquart, M. (2018). Posttraumatic stress symptoms and disorders in children and adolescents with chronic physical illnesses: a meta-analysis, *Journal of Child & Adolescent Trauma*, 13, 1-10. <https://doi.org/10.1007/s40653-018-0222-z>
- Prikken, S., Raymaekers, K., Lemiere, J., Vercruyssen, T., Uytendaele, A., & Luyckx, K., (2022). Worries and Benefit Finding in Cancer Survivors and Parents: A Longitudinal Study. *Journal of Pediatric Psychology*, 47(6):641-651. <https://doi.org/10.1093/jpepsy/jsab130>
- Rabelais, E., Barakat, L. P., Ulrich, C. M., Jones, N. L., & Deatrick, J. A. (2016). Mother-caregiver expectations for function among survivors of childhood brain tumors. *Support Care Cancer*, 24(5), 2147–2154. <https://doi.org/10.1007/s00520-015-3013-1>
- Saloustros, E., Stark, D. P., Michailidou, K., Mountzios, G., Brugieres, L., Peccatori, F. A., . . . Bielack, S. (2017). The care of adolescents and young adults with cancer: results of the ESMO/SIOPE survey. *European Society for Medical Oncology Open*, 2: e000252. <https://doi.org/10.1136/esmoopen-2017-000252>
- SanGiacomo, N., Toth, J., Hobbie, W., Broden, E., Hoeve, E. V., Knafl, K. A., Deatrick, J. A. (2019). Challenges to family management for caregivers of adolescent and young adult survivors of childhood brain tumors. *Journal of Pediatric Oncology Nursing*, 36(6), 402–412. <https://doi.org/10.1177/1043454219844229>
- Schepers, S. A., Long, A. M., Russell, K., & Phipps S. (2018). Youth and parent perceptions of parenting in childhood cancer survivors and healthy peers. *Support Care Cancer*. 26(12),

4143–4149. <https://doi.org/10.1007/s00520-018-4285-z>

- Sharkey, C. M., Clawson, A. H., Mullins, L. L., Brinkman, T. M., Pui, C-H., Hudson, M. M., & Krull, K. R. (2019). The Relationship of Child Executive Functions to Parenting Capacities in Childhood Acute Lymphoblastic Leukemia Survivors. *Pediatric Blood & Cancer*, 66(8): e27761. <https://doi.org/10.1002/pbc.27761>
- Siegel, R.L., Miller, K.D., & Jemal, A. (2020). Cancer statistics, 2015. *A Cancer Journal for Clinicians*, 70, 7–30. <https://doi.org/10.3322/caac.21590>
- Syed, I.A., Klassen, A., Barr, R., Wang, R., Dix, D., Nelson, M., ... Nathan, P.C. (2016). Factors associated with childhood cancer survivors' knowledge about their diagnosis, treatment, and risk for late effects. *Journal of Cancer Survivors*, 10, 363–374. <https://doi.org/10.1007/s11764-015-0482-7>
- Takeshita, H. (2019). Thoughts on and methods used in M-GTA. In Ishiyama, N., Nakanishi, Y., Koyama, H., & Takeshita, H. (Eds.), *Mechanisms of cross-boundary learning: Communities of practice and job crafting* (pp. 59–89). Newcastle: Cambridge Scholars Publishing.
- Tremolada, M., Bonichini, S., Basso, G., & Pillon, M. (2016). Perceived social support and health-related quality of life in AYA cancer survivors and controls. *Psycho-Oncology*, 25, 1408-1417. <https://doi.org/10.1002/pon.4072>
- Tremolada, M., Bonichini, S., Basso, G., & Pillon, M. (2018). Adolescent and young adult cancer survivors narrate their stories: Predictive model of their personal growth and their follow-up acceptance. *European Journal of Oncology Nursing*, 36, 119-128. <https://doi.org/10.1016/j.ejon.2018.09.001>
- Tonorezos, E. S., Cohn, R. J., Glaser, A. W., Lewin, R. J., Poon, E., Wakefield, C. E., & Oeffinger, K. C. (2022). Long-term care for people treated for cancer during childhood and

adolescence. *Lancet*, 399, 1561-1572. [https://doi.org/10.1016/S0140-6736\(22\)00460-3](https://doi.org/10.1016/S0140-6736(22)00460-3)

Viola¹, A. S., Levonyan-Radloff, K., Masterson M., Manne, S. L., Hudson, S. V., Katie, A., & Devine, K. A. (2022). Development of a self-management and peer-mentoring intervention to improve transition readiness among young adult survivors of pediatric cancer: Formative qualitative research Study. *JMIR Formative Research*, 6 (8): e36323. <https://doi.org/10.2196/36323>

Walker, A.J., Lewis, F. M., Lin, Y., Zahlis, E., & Rosenberg, A. R. (2019), Trying to feel normal again: Early survivorship for adolescent cancer survivors. *Cancer Nursing*, 42(4): E11–E21. <https://doi.org/10.1097/NCC.0000000000000629>

White, P. H., Cooley, W. C., Transitions Clinical Report Authoring Group, American Academy of Pediatrics, American Academy of Family Physicians & American College of Physicians (2018). Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics*. 142(5), e20182587. <http://doi.org/10.1542/peds.2018-3610>

TABLE 1. Participants' background characteristics (N = 19)

Variable	n (%) or mean \pm standard deviation
Participants who are parents	
Gender	
Female (Mother)	17 (89.5)
Male (Father)	2 (10.5)
Age at interview (years)	47.9 \pm 5.7
Sons/daughters who are CCSs (n = 18)	
Gender	
Male	9 (50.0)
Female	9 (50.0)
Age at interview (years)	19.4 \pm 2.9
16–17	6 (33.3)
18–19	6 (33.3)
20–25	6 (33.3)
Occupation	8 (44.4)
High school student	(third year = 5; second year = 0; first year = 3)
University or college student	6 (33.3)
Full-time job	2 (11.1)
Other	2 (11.1)
Married	
No	17 (94.4)
Yes	1 (5.6)
With children	
No	18 (100)
Yes	0 (0)
Type of cancer	
Leukemia	12 (66.7)
Lymphoma	2 (11.1)
Brain tumor	4 (22.2)
Recurrence	
No	15 (83.3)
Yes	3 (16.7)
Type of treatment	
Chemotherapy	18 (100)
Surgery	5 (27.8)
Radiation therapy	6 (33.3)
Bone marrow transplant	2 (11.1)
Age at diagnosis or recurrence	12.5 \pm 2.1
School age at the end of cancer treatment	
Elementary school student	4 (22.2)
Junior school student	8 (44.4)
High school student	5 (27.8)
After graduation from high school	1 (5.6)
Any late effects	
No	12 (59.1)
Yes	6 (40.9)
Type of late effects: multiple responses possible (for "Yes" to the preceding question; multiple responses)	
Endocrine dysfunction (growth hormone deficiency, gonadal dysfunction)	3 (16.7)
Neurocognitive problems	2 (11.1)
Audiovisual problems	2 (11.1)
Hair loss that does not improve after treatment	2 (11.1)
Decrease in physical strength	2 (11.1)
Problems in the extremities	1 (5.6)
Metabolic abnormalities	1 (5.6)
Depression	1 (5.6)
Type of hospital participants mainly attend at interview	
Pediatrics at a university hospital	11 (61.1)
Children's hospital	4 (22.2)
Adult care department	2 (11.1)
None	1 (5.6)

TABLE 2. Summary of category (1st) and influencing concepts

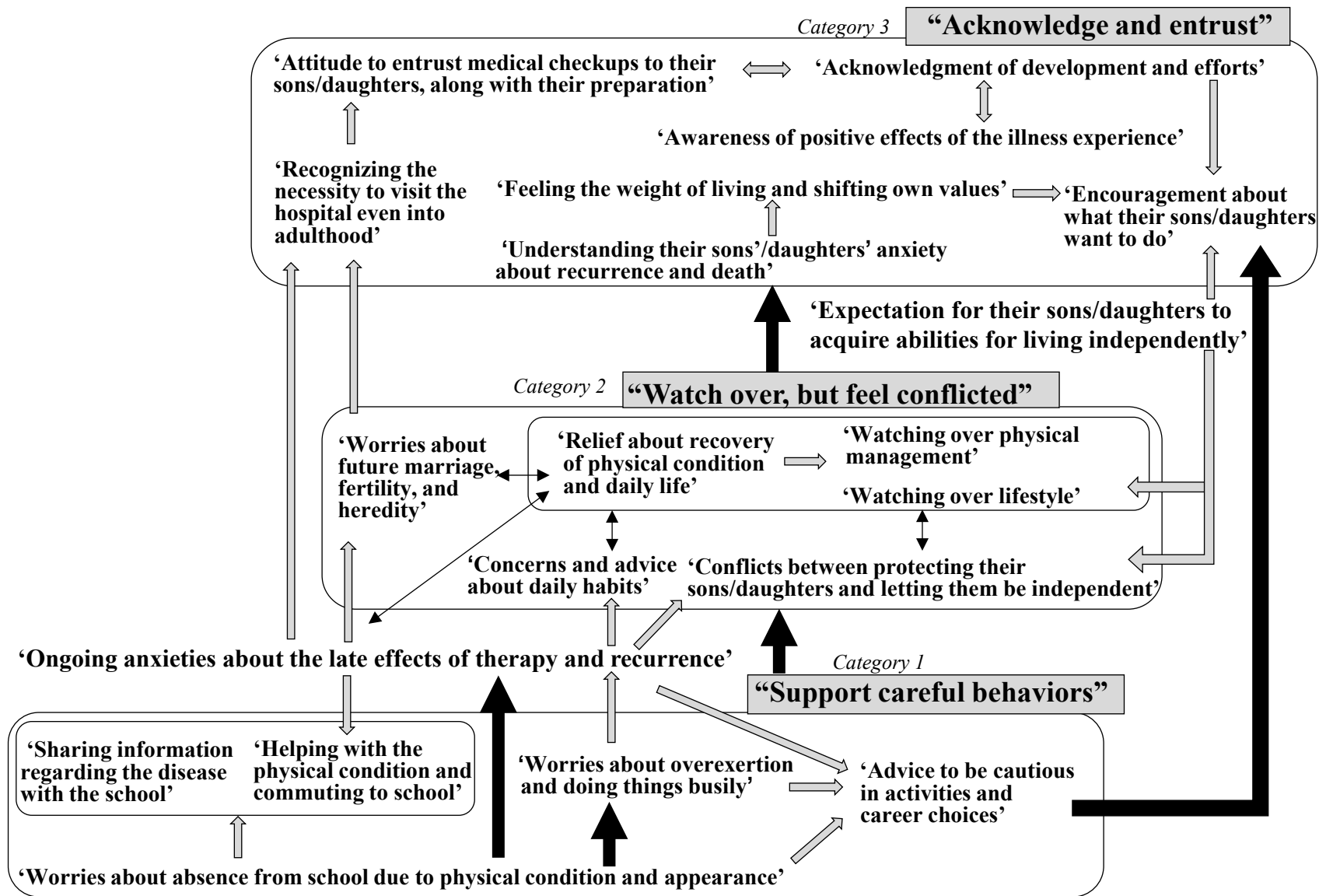
Category	Concept	Definition of each concept and supporting quotations
1. Support careful behaviors	Worries about absence from school due to physical condition and appearance	<p>Parents worry about the side effects of outpatient treatment, such as nausea, vomiting, fatigue, and hair loss, and that these side effects make it difficult for their sons/daughters to attend school.</p> <p><i>My son couldn't go to high school so many days because of fatigue after treatment. It was difficult to maintain attendance for each subject and earn each credit. If he misses a class in a subject that is offered only once a week, he must attend all classes in that subject in the following week. When the treatment was so severe and his attendance was inadequate, I told him he could consider quitting school. (Participant F)</i></p>
	Helping with the physical condition and commuting to school	<p>Parents are anxious about their sons'/daughters' condition worsening, complications appearing because of treatment, or recurrence, and provide practical help and advice regarding symptom monitoring, medication, medical visits, diet, and other physical conditions, as well as daily activities such as going to school.</p> <p><i>My son could not walk to middle school by himself after he was discharged from the hospital, so I had to pick him up and drop him off. I picked up my son after he entered high school in the hopes that he would graduate. I have always continued to assist him because of his illness. (Participant M)</i></p>
	Sharing information regarding the disease with the school	<p>Parents communicate with the school and discuss parents' and their sons'/daughters' intentions regarding daily activities and explanations to students based on their son's/daughter's illness and physical condition.</p> <p><i>We parents talked it over and decided that it would be best for our daughter's future if we didn't disclose her illness too much. We told my daughter about it and asked the teacher to inform everyone at the staff meeting. I asked the teacher not to tell the classmates the disease name, but to say that she would have to stay in the hospital for a long time, and that even after she left the hospital, her body would still be swollen from the medication and that she would be in a different state than before. (Participant H)</i></p> <p><i>I asked the teachers to let my daughter participate in everything she could do at school so that she would have no regrets, because I think that when something happens, it happens. I told the teacher that I hoped they would make a decision on the spot after discussing my daughter's condition. My daughter participated in both a school excursion and a marathon. (Participant Q)</i></p>
	Worries about overexertion and doing things busily	<p>Parents worry that their sons/daughters who are CCSs will do the activities they desire to do busily with over-exertion and a lack of control.</p> <p><i>When my son entered high school, he joined a club that did not put too much burden on his body, but one day, he suddenly came to me with a transfer form and said he was going to start strenuous exercise. Because he was still fighting the disease and taking anticancer drugs, I was worried that he would engage in strenuous exercise, that it would cause nausea, and that he would relapse because of the stress, so I consulted my husband and doctors. (Participant B)</i></p>
	Advice to be cautious in activities and career choices	<p>Parents advise their sons/daughters, who are CCSs, to act and make choices in a cautious direction regarding their life behaviors and career choices.</p> <p><i>I limited my son's exercise while he was taking anticancer drugs, and as a parent, I put the brakes on some of his challenging spirit. (Participant B)</i></p> <p><i>I wanted my daughter to go to college from home if possible, so I told her to choose a nearby college. She still has to go to the hospital regularly, so I am still worried about her going far away. After all, if she is close by, I will be able to notice immediately when she is not feeling well. (Participant O)</i></p>
	Ongoing anxieties about the late effects of therapy and recurrence	<p>Parents worry about the possibility of complications appearing, already appearing, or recurring in their sons/daughters who are CCSs.</p> <p><i>My son refused to take any medication, including for his leukemia, at home. He knew it was a medication for the cure, too. He slept in in the morning and didn't take his medicine. He only took two doses of the medicine that he should take three times a day, and one dose of the medicine he should take twice a day, once in the morning and once at night. I told my son to take it because it is for treatment. He told me he would throw up if he took it, and I said that it was OK to throw up, but I threw away quite a lot of the medicine. I thought about what to do, but I couldn't tell the doctor even if I went to the hospital, so I really felt worried every time I got the test results. (Participant F)</i></p> <p><i>My son still has a brain tumor, so I worry first about what will happen to the part that was not removed. He has a shunt tube inside his head because of the disease, so I worry what would happen if something happened to him when he moves. (Participant T)</i></p>

Table 3. Summary of category (2nd) and influencing concepts

Category	Concept	Definition of each concept and supporting quotations
2.		Parents feel joy and relief that their sons/daughters who are CCSs have completed treatment, survived and are living a normal life.
Watch over, but feel conflicted	Relief about recovery of physical condition and daily life	<i>It was really difficult at the beginning of her hospitalization, but when the doctor told me that my daughter's condition was okay and that she had avoided a very dangerous situation, I felt a sense of relief. As for the disease, she was really treated properly, so she has been living a normal life as before without any changes in her diet, exercise, or other aspects of her life. (Participant H)</i>
		<i>My son was irritated when he took the high school entrance exam. However, "You're not sick," was the family's motto, so I was happy that he was healthy and could take the exam. I was so glad that I burst into tears when my son departed for his high school exams, because I had not expected him to be able to go to high school at the time of his illness. (Participant L)</i>
Watching over physical management		<i>When I heard the name of my daughter's disease, I thought she was going to die. There are many people who really die, and as for my daughter, she had a very difficult time, but I think she was really lucky that her treatment went well. I was told she was super high risk for her disease, but she only received chemotherapy, not radiation or a hematopoietic stem cell transplant, and we got through the tough times. (Participant J)</i>
		Parents watch over their sons'/daughters' self-management of their own physical condition, such as taking actions that take into account their physical condition and informing the medical staff about their own physical condition when they go to see the doctor.
Watching over lifestyle		<i>The central venous catheter management was done by me as the mother at first, but later, my daughter did it properly for herself. After leaving the hospital, she disinfected the catheter insertion point, injected fresh heparin, and protected the catheter for bathing by herself. (Participant O)</i>
		<i>I feel that my son's walking has improved a lot since he started going to the pool once a week. He says that walking and swimming in the pool is easier on his hip joints and knees because he doesn't have to put as much weight on them. He swam about 400 meters the other day. (Participant C)</i>
Concerns and advice about daily habits		<i>My son is very particular about many things, saying he won't do anything that is not good for his health. For example, he doesn't eat instant food or drink coffee. He says that he will never smoke cigarettes. (Participant L)</i>
		Parents watch over their sons'/daughters' lifestyle or promote their own pace of life without restraint.
Conflicts between protecting their sons/daughters and letting them be independent		<i>We keep my son and his residence separate so that we can keep our hands off of him without too much interference. There is an apartment where my son lives just a few minutes' walk from our house, and he goes home to sleep. (Participant M)</i>
		<i>My daughter is now 19 years old and is making a lot of decisions on her own, so we are increasingly asking her about it. She has been influenced a lot by her friends, and even in deciding her career choice, she seems to have made some decisions with her teachers rather than us. After high school, her friends from outside our own neighborhood were added to the mix, making it difficult for us to keep track of her friendships. (Participant D)</i>
Worries about future marriage, fertility, and heredity		Parents concern and advice about their sons'/daughters' inadequate self-management of health-related lifestyle issues such as diet, water intake, and exercise.
		<i>My daughter got urticaria rather often when she didn't get enough sleep or when she was tired, so I was very worried about her. She was also prone to oral ulcers. These symptoms were still present in her high school years. As the body is the basic principle, I wanted my daughter to concentrate on her studies in a short time to get more sleep. I have been trying to nag her, but she can't correct the problem. I also told her to watch her food and to drink a lot of water, as she tends to get constipated. (Participant P)</i>
Expectation for their sons/daughters to acquire abilities for living independently		<i>My daughter has been driving to school because she has a lot of luggage, and I am very concerned that she is getting a little fat from a lack of exercise. She has not been moving much since her summer vacation, so when I call out to her, she stops eating. Her diet is unbalanced. She doesn't drink water when she goes out. She says she hates to go to the bathroom often. I worry so much about her getting dehydrated that I make her carry water with her, even though she says it is a burden. (Participant D)</i>
		Parents recognize their protective role toward their sons/daughters who are CCSs and reflect on the degree of protection they provide, their hesitation in determining when to leave them to their actions, and their overprotection.
		<i>Even though I think my daughter is cured of her illness, there is still no end to the effects of the disease, and once she crosses one, she will have to move on to the next, and I will have to support her no matter what happens. It doesn't mean that she will be okay and won't get hurt when she grows up, so whether she was 12 years old or now that she is 19, my feeling of wanting to protect her as a parent remains the same. I think my daughter's age now is probably the most emotionally conflicted and difficult. I think we are at a point where we have to go beyond that for our daughter to become independent. (Participant Q)</i>
		<i>I'm the kind of person who has a hard time keeping my hands off of my daughter and ends up taking care of her. I try not to interfere with my daughter as much as possible, but I tend to worry about her, so I have been asking her the same questions and telling her to do this and that. I repeated the same things over and over again until my daughter was in university and started living alone. I think she already knew what I said. (Participant J)</i>
		Parents concern about future marriage, fertility, and inheritance of the disease to a grandchild of their sons/daughters who are CCSs.
		<i>Before radiation and chemotherapy, the doctor explained that the treatment might make it impossible for my son to have children and to preserve sperm. I feel sorry that my son will not be able to have children in the future, but as a parent, I could not ask my junior high school-aged son, who was in a daze, to take on a huge burden and save his sperm, so we did not. When we were briefed before the start of treatment, we were shocked by our own son's medical condition, and because we prioritized the current situation at the time, I am worried about his fertility and the woman he may marry in the future. (Participant T)</i>
		<i>Lately, I have been thinking about the impact of my son's cancer treatment on his future children. Even though my son has received explanations from the doctors and believes that his child will not inherit the cancer, he still has to explain it to the person he is going to marry. I would like the medical staff to explain my son's illness to his future spouse and the fact that it will not directly affect a child he would have in the future. After the prospective spouse is reassured and convinced, her parents should understand and accept the situation. My son also understands that there are stages to getting married. (Participant F)</i>
		Parents expect their sons/daughters who are CCSs to develop abilities of independence, including making decisions and taking action on their own, facing illness on their own, and finding a job and making a living.
		<i>I want my son to grow up a little more mentally and not be so shaken. We are there to support him now, but we won't live forever. As he is now, I'm not sure if he will be able to go out to work, so I want him to be in a state of mind where he can live on his own, have the strength to live, and be able to work properly. (Participant M)</i>
		<i>I don't think my son has enough motivation to do things on his own and be independent. He relies on us for everything at home, and asks us to do this and that for him. He says, "I was in the hospital and worked very hard," and does nothing at home. (Participant S)</i>

TABLE 4. Summary of category (3rd) and influencing concepts

Category	Concept	Definition of each concept and supporting quotations
3. Acknowledge and entrust sons'/daughters' anxiety about recurrence and death	Understanding their sons'/daughters' anxiety about recurrence and death	<p>Parents understand that their sons/daughters, who are CCSs, continue to have some anxiety about cancer recurrence and the associated fear of death through their illness and the death of fellow patients.</p> <p><i>My daughter doesn't like to make long-term plans. It's okay to think about the very long term, like what she wants to be in the future, but if she makes plans for a trip in three or six months, she's worried that she won't be able to go. She can't always sleep at the place she is staying because she thinks that she might not be able to come here anymore. My daughter's hair is very long now, and when I tell her that it will grow soon and she should cut it a little, she says, "But before it grows..." She makes these comments from time to time and seems to have anxiety about the future in the back of her mind. (Participant E)</i></p> <p><i>My son doesn't go to the hospital very often. I tell him to go to the hospital for a physical checkup, but he says he won't go. My son once said, "Do you know how scared I am?" Even though he knows he is healthy, he is still very scared to see the results of the blood test. I think he is worried about both the recurrence of the disease and the development of a new disease. (Participant F)</i></p>
	Feeling the weight of living and shifting own values	<p>Parents feel the weight of their sons/daughters being alive and shifted their values, such as placing importance on the will of the living sons/daughters.</p> <p><i>I think it's good that my daughter is healthy now, but I still feel a little uneasy because it's a disease for which no one can tell me it's cured. For now, all I can say to my daughter is that she should go to college or wherever she wants. I hope my daughter thinks and does what she wants. (Participant E)</i></p>
Encouragement about what their sons/daughters want to do	Parents show a supportive and encouraging attitude toward the school life and career path desired by their sons/daughters who are CCSs.	<p><i>My daughter was not enjoying her school life because of her illness. She missed six months of her final year of her junior high life and ten months of her high school life due to hospitalization, so I want her to go to college. Because she wanted to go to college and I told her she should go, she has studied hard. (Participant A)</i></p> <p><i>My son has sacrificed a lot of things that he could not do because of his illness. For this reason, I hope he will do what he wants as much as possible from now on. (Participant C)</i></p> <p><i>From the time my children were very healthy, I often said in ordinary conversations that we wanted to live without regret because we might die tomorrow. I also told my children that they should do everything they wanted to do without regret. I have been involved with children with the attitude that their minds are important, and that if they try something and fail, there is nothing they can do about it. Even when my daughter got ill, I didn't change my attitude. (Participant Q)</i></p> <p><i>My daughter wants to become a cancer care nurse. I hope she will be able to do it, if she is going to use her own painful experiences to pursue a career in nursing. I want her to fulfill it in a way that suits her lifestyle and physical condition. (Participant D)</i></p>
	Acknowledgment of development and efforts	<p>Parents acknowledge their sons'/daughters' development and efforts in dealing with illness, health care, mental health, interpersonal relationships, and achieving social goals such as school life and employment.</p> <p><i>As a parent, I recognize that my son is a very hard-working child, and that he has worked hard against his illness, both athletically and in his studies. As a parent, I have always told my son that it is great that he works so hard and that it is more important to work hard than to be able to do things. I also tell him that it's great to see the results of his efforts. But I always tell him that even if his hard work doesn't pay off on the spot, his efforts in life will definitely lead somewhere. (Participant S)</i></p> <p><i>Since experiencing the illness, my son has talked more, been more proactive, and doesn't care about being seen. I was surprised to hear him say that he enjoys talking to various people more after he got ill, and I think he is amazing. Though he still has some lingering effects from the illness, he is pushing himself to go to school more than before. He wants to go to college, so he studies on his own when he feels well without me having to tell him. (Participant C)</i></p>
Awareness of positive effects of the illness experience	Parents perceive positive changes in their sons'/daughters' statements and behaviors that occurred after experiencing the illness, such as career choices and compassion for others, in relation to the illness experience.	<p><i>My daughter had always been a kind-hearted girl, but after she left the hospital, people around her often told me that she became even kinder. I think that my daughter's gentle feelings probably became deeper because she went through some hard times herself, and she actually saw that there were other children who were going through the same hard times, and that the doctors and nurses were trying their best to help her in some way. (Participant J)</i></p> <p><i>The nurses who were involved with my son when he was sick had a huge impact on him. When the treatment was the hardest and we couldn't even think about tomorrow, my son said he would be a nurse when he grew up. I was surprised when my son described the hospital ward he was staying in as friendly. To me, the hospital ward was a place that felt like nothing but hell. When my son said it was very friendly, I think the nurses and doctors must have created such an atmosphere during the time I didn't know. (Participant L)</i></p>
	Recognizing the necessity to visit the hospital even into adulthood	<p>Parents recognize the necessity and reasons for continued medical care for their sons/daughters who are CCSs even into adulthood.</p> <p><i>My daughter needs to visit many departments, such as neurosurgery, endocrinology, and gynecology. Even though my daughter's condition is improving, she will have to see a doctor for the rest of her life, especially in the endocrine department. In some hospitals, the neurosurgeon comes once a month, or the endocrinologist is a part-time doctor on certain days of the week, so she has to go to the hospital many days a month. (Participant Q)</i></p> <p><i>The neurosurgeon told me from the beginning that he would have to deal with the neurosurgeon for the rest of his life, until the day he passes away, and that is how I think of it. The radiology department will also be monitoring his progress. My son's future visits to the ophthalmologist will probably be regular visits only. (Participant T)</i></p> <p><i>She's currently getting her medication from a pediatrician, but I'm sure that will change to a gynecologist at some point. I wonder how she moves to the adult department. She was told that she would need to take medication until menopause, so I am wondering if she will have to be in the hospital for the rest of her life. My daughter also said that she might have to go to the hospital for the rest of her life. (Participant E)</i></p>
Attitude to entrust medical checkups to their sons/daughters, along with their preparation	Parents entrust their sons/daughters, who are CCSs, with medical checkups, or discuss with and prepare them to attend hospital visits on their own in the near future.	<p><i>My son said that after he gets a job in the future, he will probably have a weekday off, so he can just drive back from his place of employment every time he needs to see the doctor. My son has never come to see the doctor by himself, and I always ride with him in the car when he drives to the hospital. Because he will be an adult soon, I think he will come by car by himself after he gets a job, even if I don't come with him. However, I think I'll come with him to the ophthalmologist because he can't drive home when his pupils are dilated for the examination. (Participant R)</i></p> <p><i>After graduating from high school, it will be time for him to graduate from the pediatric specialty hospital he is currently attending. We have been discussing the adjustment and follow-up outpatient visits with the medical staff. After he graduates from high school and is transferred to a new hospital, I will accompany him when it is important, but I will gradually let him go see the doctor by himself. I think my son will tell me if he has any concerns or abnormalities and will give me the results of his hospital tests. I think I need to tell my son exactly what the procedure is for a series of medical visits. My son has already learned to listen to and understand the explanations much better. (Participant I)</i></p> <p><i>When my daughter was in high school, I summarized the progress of her treatment in a single file that I wanted her to have when she moved out to go to college. I wrote down the medications used, when she started her current oral medication, and when she had her first menstruation, blood transfusions, complications, vaccinations she had been re-vaccinated with or will be vaccinated with, and the intervals between tests. Parents typically don't live longer than their children and my daughter won't remember what her treatment was as a child, so she will need a record of her treatment when she lives on her own. (Participant E)</i></p>



“ ” Concept Category ➔ Direction of change ➞ Direction of influence ↔ Interaction ↔ Opposite

FIGURE 1 Parental involvement process regarding childhood cancer survivors becoming independent while balancing their health management and social lives from adolescence to adulthood