

Original Article

Problems Faced by Mothers of whose Children have Survived Cancer that Appeared During the Life Stages of the Children and the Process and Guidance for Self-Care

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Abstract

Background: Childhood cancers affect 2,000–2,500 individuals per year in Japan, with onset at infancy. In Japan, there are ~50,000 childhood cancer survivors, and following recovery, the mother supports the child at home.

Aim: To elucidate how mothers confront problems following the discharge of childhood cancer survivors and the provision of guidance to the child regarding self-care.

Methodology: After creating an interview guide coinciding with the study objectives, semi-structured interviews of five mothers of childhood cancer survivors were conducted. The data obtained was analyzed using the modified grounded theory approach.

Results: The challenges faced by mothers of childhood cancer survivors who underwent surgery as children and the self-care guidance process comprised 5 core categories and nine categories from 34 concepts. The core categories included “formation of beliefs to confront the disease,” “promotion of understanding suitable to the child’s age at onset,” “individual actions against the lack of information,” “preparation of the environment by oneself when the child needs to be monitored,” and “reflection and acknowledgment of the process to date.”

Conclusions: The mothers of childhood cancer survivors with onset at infancy preferred for the child to understand their disease; however, the mothers experienced difficulty in explaining the disease owing to a lack of knowledge. To enhance their knowledge to facilitate the child’s self-care, mothers joined patient groups to gather information. Furthermore, following discharge, it was difficult for parents and their children to establish relationships with medical staff and no avenue was available for consultation in case of any concerns.

Key words: mothers, childhood cancer, childhood cancer survivors, problematic situations, self-care, secondary cancer, late complications

Introduction

In Japan, the incidence of childhood cancer is approximately 2,000–2,500 cases annually (Ishida, 2011). In the 2019 National Cancer Registry, the number of childhood cancer registries was about 2,200. (National Cancer Registry in Japan). Although not a frequently occurring pediatric disease,

childhood cancer remains the leading cause of disease-related mortality among children in Japan, described by Takimoto as “one of the diseases that should be addressed nationally” (Takimoto, 2015). Currently, a protocol for pediatric cancer treatment has been established in Japan. (Pediatric Cancer Practice Guidelines 2016 edition • Clinical Practice Guidelines for Pediatric Leukemia

and Lymphoma 2016 edition). The therapeutic outcomes of childhood cancer have improved to achieve a cure rate of 70%. Childhood cancers are classified into hematological malignancies, solid tumors, and brain tumors, with onset at infancy. Many children return to normal life as childhood cancer survivors and must face events during their life cycle with growth. Furthermore, when treatment-induced complications occur, these children are required to rebuild their lives alongside the complications while understanding the possibility that secondary cancer and late complications can develop years later. Hence, performing self-care for the maintenance of their health is of utmost importance (Ishida, 2011).

The psychological problems experienced by childhood cancer survivors following discharge include the dilemma of accepting their own body and the fact that it will not return to its original healthy state even after they return to school, overestimating oneself, contemplating explaining their disease to others, falling behind in studies, thinking about the need to explain their history of childhood cancer at the time of higher studies, when seeking employment, and to their marriage partners (Omata, 2018), and anxiety regarding the potential impact of anticancer drug use on their offsprings (Miyoshi, 2018), indicating that childhood cancer survivors have numerous psychological burdens.

Furthermore, the onset of cancer at childhood differs from that at adulthood as the patients go onto live long lives as childhood cancer survivors. The support required by childhood cancer survivors who experience numerous life events is provided by the family, particularly the mother who provides a great deal of support. Mothers also confront new problems that arise during the growth and development process of the childhood cancer survivors. Here we aimed to elucidate how mothers of childhood cancer survivors confront problems arising during the different life stages of the child and the provision of self-care guidance to enable the children to maintain their health. In Japan, the trend

toward nuclear families is progressing, and young couples are working together to raise children. When a sick child is at home, the mother takes the lead in caring for the child. Similarly, Molinaro (2018) and Kocaaslan (2021) state that the main people involved in the care of childhood cancer survivors are mothers. Cruz (2020) states that the primary caregiver at the time of admission is the mother at an 83.7% rate. The same is assumed for Japan. We believe that portraying these concepts can promote effective interventions by medical staff and improve the quality of life of childhood cancer survivors after treatment. I think it's very important to clarify the feelings of the mother. We believe that delineating these concepts will facilitate effective intervention by medical staff and to improve the quality of life (QOL) following the treatment of childhood cancer survivors.

Methodology

Sample selection and survey period: Study samples include mothers of childhood cancer survivors who have undergone surgery for childhood cancer. In addition, mothers of childhood cancer survivors who have undergone surgery for leukemia stem cell transplantation and complications after treatment are included. I wanted to follow the life cycle after discharge from the hospital after cancer treatment, so I set the mothers of children over 13 years old, not the mother's age. Junior high school students in Japan are from the age of 13. The number of samples should be up to saturation.

The survey period was from December 2018 to November 2019.

Definition of terms

- Childhood cancer survivors: Patients who developed childhood cancer who are presently cured owing to treatment.
- Secondary cancer and late complications: Secondary cancer and health problems due to the treatment for childhood cancer.
- Self-care: "Self-care" refers to the care required by childhood cancer survivors as perceived by their mothers.

- Long-term follow-up outpatient clinic: Dedicated outpatient clinic for childhood cancer survivors who regularly visit after treatment for childhood cancer.

Study design: This is a qualitative study conducted via an inductive approach. We developed an interview guide based on which semi-structured interviews were conducted. Questions are open-ended. One interview is planned. The data obtained was analyzed to evaluate the challenging situations that appear during the numerous life stages of childhood cancer survivors as perceived by their mothers and to elucidate the process involved in self-care guidance provided by the mothers to the childhood cancer survivors.

Subject recruitment method: We requested pediatric hospitals performing long-term follow-up as well as patient groups comprising childhood survivors throughout Japan to recruit participants for the interviews. Referrals from the hospital were made to the child's mother, whose mother agreed to be interviewed and is following up with a long-term follow-up.

Interview method: On the day of the interviews, an explanation regarding the study was provided to the participants and a final informed consent was obtained. Semi-structured interviews were conducted based on the interview guide created by us. After permission was obtained, the interview content was recorded using an informed consent (IC) recorder. Visual information was recorded in the field notes.

Content of the interview guide

The interview guide included the following:

1. Timing and content explaining the disease, and the degree of understanding of the child of the disease
2. Problems faced and coping methods used during the child's life cycle
Life cycle is kindergarten, elementary school, junior high school, high school, university, current
3. Relationship between Living Conditions of Educational Institutions

and School Supporters

4. Self-care guidance content, state of implementation, and instructor
5. The hardest thing to do so far and how to deal with it
6. Thoughts and initiatives for child future health
7. Support required of healthcare professionals at each stage of growth and development
8. What do you think of the child who have overcome the disease?

Data analysis method: For data analysis, we employed a modified grounded theory approach (M-GTA). The M-GTA is a "theory for practical application," wherein Kinoshita (2013 · 2020) utilized the characteristics of the grounded theory approach proposed by Glaser and Strauss in the 1960s (1967) and modified it to into a practical method that can "be implemented in today's circumstances." Our analyses were conducted using this method. The analysis method was as follows:

1. Upon carefully reading the data of one case showing the greatest variation, we compared analysis data and focused on related data points. Thereafter, we generated concepts for the related points that were extracted. When generating concepts, we created an analysis worksheet containing the concept name, definition, and variation. Similar variations that fit the concept were sought from the rest of the data and encoded in the analysis workshop. After analyzing the first data, use the analysis worksheet and theoretical notes you are working on to analyze the second person in the same way.
2. Once several concepts were generated, the concepts comprising similar relationships were classified as categories, and the relationship between the categories was analyzed. Next, the categories with the same relationship were grouped to create core categories. From this stage, reliability was examined under the supervision of a qualitative researcher supervisor.

3. The relationships between each concept were investigated.
4. Thereafter, the analysis results were summarized, and the storylines in the summary were concisely put into words.
5. A results diagram presenting the relationship between the concepts was created.

Ethical considerations: This study was approved by the ethical review board of the affiliated institution (Teikyo Heisei University Research Ethics Review Board; Approval no. 27-030-1). To include the mothers of childhood cancer survivors in this study, approval was received upon ethical review by the investigating institutions. The study details were explained to the patient groups verbally and in writing by their respective associations, and upon obtaining consent, they referred patients. On the day of the survey, the participants who provided their IC were provided a verbal and written explanation regarding the study details, voluntary participation, and consent withdrawal, following which their final consent to cooperate in the study was obtained.

Results

Study sample summary

The study sample included five mothers of childhood cancer survivors in their 40s and 50s. Overall, five children were included aged from 10s to 30s. All of whom had received long-term follow-up. The childhood treatment was received in infancy for two individuals, at school age in one individual, and at junior high school age in two individuals. The types of cancer included hepatoblastoma, nasopharyngeal cancer, osteosarcoma, acute lymphatic leukemia, and rhabdomyosarcoma. The interviews lasted for 60–70 min. Analysis results (see Table 1)

The core categories are denoted by **[]**, categories by **[]**, and concepts by **<>**. The challenges faced by the mothers of childhood cancer survivors during their children's life stages and the process of self-care guidance constituted 5 core categories, 9 categories,

and 34 concepts. The storyline formed by the concepts, categories, and core categories is presented below. Storyline (see Figure 1)

5 Core Categories

[Formation of beliefs to confront the disease]

[Promotion of disease understanding suitable to the child's age at onset]

[Individual actions against the lack of information]

[Preparation of the environment by oneself when the child needs to be monitored]

[Reflection and acknowledgment of the process to date] .

After leaving the hospital, the mother formed a belief to face her child's illness and began to gather information independently about the child's early childhood onset, which was difficult to explain due to the mother's lack of information. In parallel, she also took action to improve her child's living environment. And after overcoming many problems, she reflected on the different situations and acknowledged the whole process.

Core Categories **[Formation of beliefs to confront the disease]**

< Shock received by the mother at of diagnosis > was considerably strong; however, such feelings changed to the

< Formation of beliefs for confronting disease >, leading to the [Formation of beliefs to confront the disease despite the shock due to the onset of disease in children].

In the **[Promotion of disease understanding suitable to the child's age at onset]** , mothers adopted behaviors involving

<Acceptance of informed consent from the physician at the time of diagnosis for children in primary school or above>

and <Monitoring of the children who were in primary school or above after receiving informed consent from the physician>.

The mothers [Monitoring of the children after the informed consent request and explanation by the physician from the time of diagnosis]; the request involved monitoring of the child by

the physician as well as the mother after receiving the explanation.

Furthermore, the mothers developed a <Maternal sense of difficulty in explaining the disease of children who underwent surgery in infancy>

and a <Maternal sense of difficulty in explaining fertility to their child years later>.

They felt that the children with disease onset at infancy experienced

<Ambiguity of the children in understanding the disease as perceived by the mothers>.

Hence, the mothers experienced

[Difficulty and child ambiguity in understanding the mother's explanation regarding disease and fertility].

In **【Individual actions against the lack of information】** ,

<Confronting problems that appear due to a lack of information> was repeated and the mothers accepted

<Insufficient information regarding secondary cancer and late complications> and experienced

<Long-term progress while questions and anxiety persist> alongside the [Realization of insufficient information for childhood cancer survivors].

Moreover, after transferring to the outpatient clinic, the mothers experienced <Difficulty in building relationships with outpatient nurses>, understood that <Relationship with ward nurses that dissipates following discharge >, and that they were affected by the <The impact of attending physician transfers>, which [Medical staff with whom it became hard to build a relationship after discharge].

Furthermore, <Steps taken independently by the mother to obtain information about the child's future>, and the mothers adopted the behavior of <Complaints regarding the need for long-term outpatient follow-up for symptom management of late complications and the mental health of the children>.

In addition, insufficient sources of information engendered the <Acquisition of information through peer support by mothers

of childhood cancer supporters> and performing [Steps taken to obtain information by oneself].

In the **【Preparation of the environment by oneself when the child needs to be monitored】** , feelings emerged such as <Following discharge, mothers must look after their children> and despite being <Concern regarding the physical burden of the children>, the mothers were determined in <Wanting to raise one's child normally>. Furthermore, <Monitoring the dilemma of the child not being understood by their peers> and <Acceptance of the impact of the disease onset on the child's learning> were included. Moreover, <Monitoring the employment options of the child>, <Monitoring children who decide to relinquish their goals owing to renal impairment>, and <Monitoring the desire of the children to be independent> were performed. The monitoring of the children also included <Approval of marriage to a fellow childhood cancer survivor>, and the mothers adopted a behavior wherein they always [Monitoring the life stages of the child], which included the <Provision of information to educational institutions by the mother to facilitate the daily life of the child> and <Repeating the disease explanation to the homeroom teacher at each change of school year>. The mothers also <Building a close relationship with the homeroom teacher for problem solving>. The categories included the <Collection of information that the presence of renal impairment in sequelae would limit entering high school> and <Knowing that teaching staff have little knowledge of childhood cancer, and accordingly, providing a detailed explanation>. Moreover, for children, <Self-care instructions provided to children when the mothers possessed little information>. In addition, the mothers adopted the behavior of [Preparation of an environment that will facilitate the child's daily life].

<In **【Reflection and acknowledgment of the process to date】** , the mothers adopted the behavior of [Reflection upon the process so far], including <Reflecting upon and

regretting the impact on siblings during treatment>, <Asking oneself whether or not one could have done more for the child during treatment>, and <Reflecting upon and expressing gratitude for support from friends and acquaintances> who helped over the

years. Furthermore, by observing their child at present, the mothers <Reflecting on the struggle with the disease and acknowledging of the entire process>, thereby [Acknowledgement of the entire process].

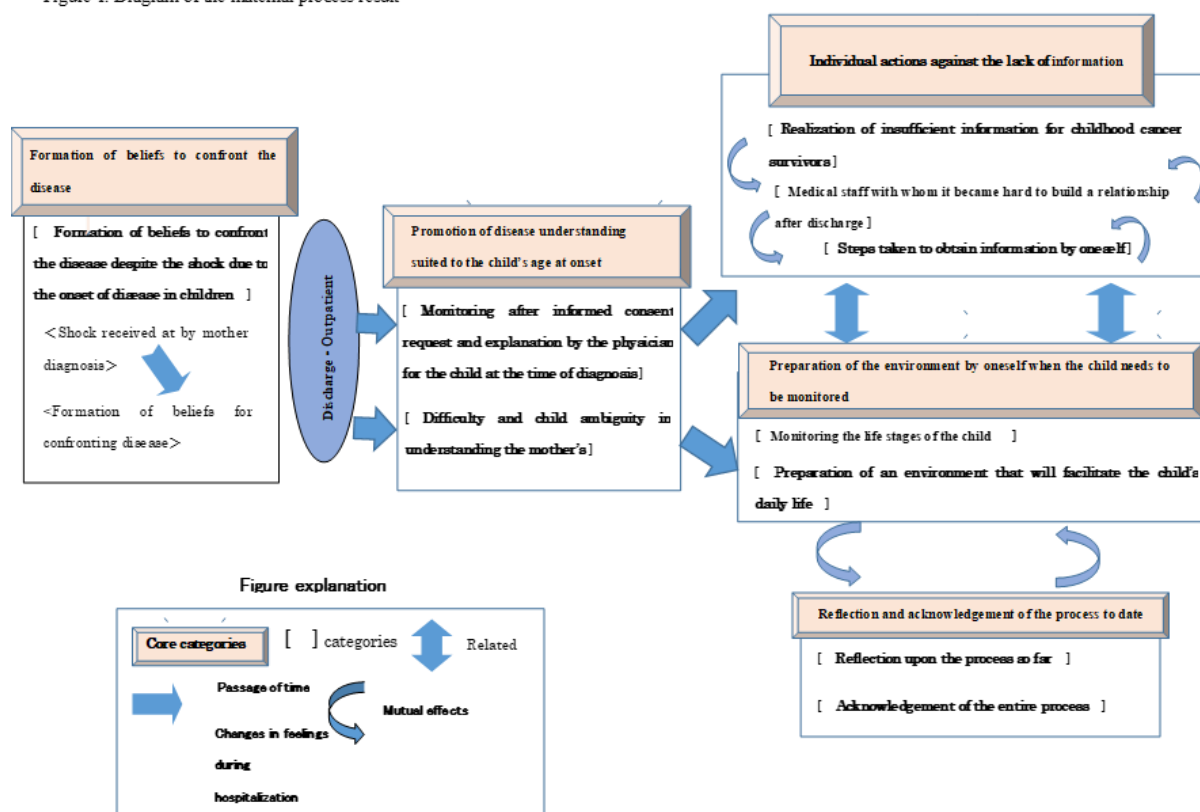
Table 1: Maternal concepts, categories, and core categories

Maternal concepts	Categories	Core categories
Shock received by mother at diagnosis	Formation of beliefs to confront the disease despite the shock due to the onset of disease in children	Formation of beliefs to confront the disease
Formation of beliefs for confronting disease		
Acceptance of informed consent from the physician at the time of diagnosis for children in primary school or above	Monitoring of the children after the informed consent request and explanation by the physician from the time of diagnosis	Promotion of disease understanding suitable to the child's age at onset
Monitoring of the children who were in primary school or above after receiving informed consent from the physician		
Maternal sense of difficulty in explaining the disease of children who underwent surgery in infancy	Difficulty and child ambiguity in understanding the mother's explanation regarding disease and fertility	
Maternal sense of difficulty in explaining fertility to their children years later		
Ambiguity of the children in understanding the disease as perceived by the mothers		
Confronting problems that appear due to a lack of information	Realization of insufficient information for childhood cancer survivors	
Insufficient information regarding secondary cancer and late complications		
Long-term progress while questions and anxiety persist		
Difficulty in building relationship with outpatient nurses	Medical staff with whom it became hard to build a relationship after discharge	
Relationship with ward nurses that dissipates following discharge		
The impact of attending physician transfers		
Steps taken independently by the mother to obtain information about the child's future	Steps taken to obtain information by oneself	
Complaints regarding the need for long-term outpatient follow-up for symptom management		

of late complications and the mental health of the children		
Acquisition of information through peer support by mothers of childhood cancer supporters		
Following discharge, mothers must look after their children	Monitoring the life stages of the child	Preparation of the environment by oneself when the child needs to be monitored
Concern regarding the physical burden of the children		
Wanting to raise one’s child normally		
Monitoring the dilemma of the child not being understood by their peers		
Acceptance of the impact of disease onset on the child’s learning		
Monitoring the employment options of the child		
Monitoring children who decide to relinquish their goals owing to renal impairment		
Monitoring the desire of the children to be independent		
Approval of marriage to a fellow childhood cancer survivor		
Provision of information to educational institutions by the mother to facilitate the daily life of the child		
Repeating the disease explanation to the homeroom teacher at each change of school year		
Building a close relationship with the homeroom teacher for problem solving		
Collection of information that the presence of renal impairment in sequelae would limit entering high school		
Knowing that teaching staff have little knowledge of childhood cancer, and accordingly, providing a detailed explanation		
Self-care instructions provided to children when the mothers possessed little information		
Reflecting upon and regretting the impact on siblings during treatment	Reflection upon the process so far	

Asking oneself whether or not one could have done more for the child during treatment		Reflection and acknowledgement of the process to date
Reflecting upon and expressing gratitude for support from friends and acquaintances		
Reflecting on the struggle with the disease and acknowledging of the entire process	Acknowledgement of the entire process	

Figure 1: Diagram of the maternal process result



Discussion

Relationship between the discrepancy in the amount of information that childhood cancer survivors had according to their age at disease onset and self-care

Maternal responses were greatly divided according to the child's age at the onset of cancer.

The mothers of children who developed cancer in junior high school allowed the child to ask the physician regarding recurrence and

fertility as well as medical record disclosure in the long-term follow-up clinics. Nakamura (2015) also noted that children who developed cancer in the 10–19 years of age group tended to be more proactive during their medical treatment, which was similar to the behavior displayed by the children in this study. The mothers respected the feelings of the child even if the child developed certain emotions upon questioning the physician but did not express them. Although the mothers monitored their children, they did not become

overprotective. It is conceivable that in the conversation between the doctor and the child, there was something that the mother did not want the child to hear, such as childbirth. However, although the mother is worried about the child, she respected the child's right to know and accept the facts. This may be because the mothers recognized that knowing the facts was important to enable the children to have a healthy future life. Furthermore, questioning the physician increased the amount of correct information obtained as well as amended and reinforced information that had been ambiguous. We believe that this affords self-care to maintain health, and the more frequently children receive information from medical staff at hospitalization, the more accurate their understanding of their disease. Moreover, we found that increasing the frequency of explanations provided the opportunity for children to gain a better understanding of their condition and exhibited a good effect on future self-care.

Conversely, among the mothers of children with disease onset at infancy, some said that the only information they could provide to their children was that they had childhood cancer and that they were treated with anticancer drugs. Such mothers stated that they wanted their children to receive a formal explanation regarding the disease from a health care provider, and it seemed to have become difficult for the mothers who are not medical professionals to explain the disease to their children after a long period. Similar results were obtained in the study by Shimoyama (2018), and we believe that it is very important to add and modify the information that mothers have regarding their children's diseases, especially those with onset at infancy.

Furthermore, medical staff also appeared to have the impression that only mothers should provide explanations to their children in case of disease onset at infancy; we believe that the insubstantial information provided from both sides yields poor disease understanding by the children who develop childhood cancer at infancy. Moreover, we think that explanations provided by mothers might not be proactive

for self-care as it might create an atmosphere as though the condition of another person is being described. Similarly, the mothers expressed that they only vaguely understood the extent to which their child comprehended the disease and this made the mothers feel uneasy regarding the level of their child's understanding of the disease. We believe that understanding one's disease is the first step in protecting one's health. In particular, we believe that effective self-care for childhood cancer survivors will not be achieved unless explanations are improved and education is provided to those who have experienced childhood cancer in infancy.

State of self-care guidance by mothers for secondary cancer and late complications

The mothers were perpetually anxious regarding the appearance of symptoms of secondary cancer and late complications, which require a high level of self-care, and they could not eliminate such anxieties even as the child grew older. During the treatment period, mothers received an explanation regarding secondary cancer and late complications by the physician; however, they were not sure how to communicate this information to their child due to uncertainty about whether or not their child might develop these complications. Furthermore, even after asking questions to the medical staff, certain mothers still had anxiety and questions as they did not personally understand the concepts owing to them not being experts, and certain explanations that it confused the mothers more. Despite receiving long-term follow-up, the concerns of the mothers were not resolved. The explanations included highly specialized content, which warrants the establishment of an expert desk where mothers can receive answers to their questions regarding childhood cancer. During the treatment period, although physicians obtained IC from mothers several times, after discharge, during the limited short period of outpatient visits, guidance received by mothers from physicians regarding their child's self-care is considered difficult. The effects of anticancer drugs used during childhood might produce problems in adulthood, such as in marriage

and fertility. During the different stages of development, the challenges faced change greatly, and it becomes necessary for mothers and childhood cancer survivors to develop the knowledge and skills to address such problems. In the short consultations during the long-term follow-up at outpatient clinics, the provision of education to foster such skills is limited, and hence, we believe that long-term and ongoing guidance should be performed in accordance with a program. Furthermore, it is preferable for guidance to be provided not only by the physician but in collaboration with medical staff. Moreover, in the early childhood years, parents and children should be educated together, switching to child-centered education when the health care provider and mother determine that the child has a better understanding and can be taught independently. This ensures the provision of knowledge in early childhood by the mother. We also believe that after switching to child-centered education, the child's awareness regarding the early detection of secondary cancer and late complications increases, thereby improving their self-care. Miyagijima(2017)revealed that childhood cancer survivors are rebuilding their normal lives while worrying about late complications. Also, childhood cancer survivors who have reached adulthood want to know the state of their bodies (Shimoyama 2021). It is not easy to live knowing that there is an element of anxiety. However, we believe that it is possible to enhance self-care and maintain a healthy life through information.

Difficulty building relationships with medical staff following discharge

It was difficult for the mothers to build relationships with the busy outpatient nurses. Although there were numerous opportunities to meet ward nurses during the outpatient visits to the hospital wards, the distance with the ward gradually grew over time. Because there was no longer a reason to go there. Similar to the findings of Yamaji (2015), following discharge from the hospital, mothers are unable to easily consult medical personnel, and hence, this warrants improvement in the provision of support to

such mother. Following discharge, contact with medical staff diminishes. We believe that continued contact with hospital and outpatient clinic nurses who provided support to the mothers will enable them to express their feelings, such as the presence of anxieties and the requirement of any information, which might allow them to perform more effective self-care guidance for the child. Nurses who provide outpatient nursing care in long-term follow-ups are extremely important for monitoring the growth of the child as well as arranging interventions for the mothers. Unlike mothers who raise healthy children, chronic anxiety is predicted to persist in mothers raising childhood cancer survivors who are likely to face challenges following discharge from the hospital during different life events. Presently, in Japan, owing to the increase in the aging population and declining birth rate as well as nuclearization of families, many mothers do not have a support system wherein they can easily share their troubles and finding patients group may be difficult as well. In a previous study, Mori (2007) reported that there is currently little social support for parents during hospitalization of their children; however, following discharge, the parents became even more isolated without a support system. Moreover, the mothers became very discouraged following the transfer of the physician who they met at the time of the annual long-term follow-up, suggesting that they had a very high level of trust in the physician. Building a relationship with a new attending physician from the start constituted a burden for the mothers, and conveying the child's information accurately to the next physician might have become a new source of anxiety. While all childhood cancer survivors consider transitioning into adult outpatients desirable, the provision of detailed explanations and information by medical staff can enable individuals to establish self-care and prevent the development of intense anxiety even if the original physician changes. Numerous previous studies have reported the onset of depression in childhood cancer survivors (FDK;2010,M Bruce;2006,Lisa

Schwartz;2006), and in Japan as well, the rate of childhood cancer survivors with depression is considered to increase with a high cure rate. We believe that careful explanations and accumulating knowledge from childhood might make it easier for children to accept their disease and help relieve fear owing to excessive anxiety.

The explanations and guidance provided to childhood cancer survivors from childhood onward constitute the cornerstones for maintaining their health. We believe that, in due time, explanations received during childhood will produce the desire to confront their own health in adulthood, and self-care for health maintenance will take root. Therefore, providing help to mothers who support their children during their early years should be emphasized and information provided to the mothers should be improved. The medical professional must understand the problems that appear in the mother after the treatment of the disease is completed. And it is necessary to support mothers who are suffering from problems that appear at the stage of development of the child. For this we need to learn a lot about motherhood. Tracking mothers of childhood cancer survivors can be very challenging. In addition, it may be difficult to obtain consent even if there is a target person. However, we will continue our research to improve the environment for mothers to support childhood cancer survivors.

Conclusion: Mothers of childhood cancer survivors who developed the disease in infancy considered it desirable for their children to understand the disease; however, they faced difficulty in explaining the disease due to a lack of knowledge. To reinforce information that facilitates child self-care, mothers joined patient groups and collected information. Furthermore, following discharge, the parents and children experienced difficulties in building relationships with medical staff, and there was no place where they could consult in case of any concerns. Not enough information was provided to maintain the health of the future child. Mothers' lack of information increases

with the age of their children. One of the challenges for mothers is support after the child's illness. Health care providers need to recognize the difficulties of mothers and cooperate with them.

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