

Original Article

Rethinking Support for Pediatric Cancer Survivors Provided by Pediatric Specialty Hospital Outpatient Nurses

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Abstract

Background: In Japan, the number of pediatric cancer cases was approximately 2,200 in 2019. Notably, 15 hospitals are designated for pediatric cancer in Japan. This study focused on the outpatient nurses of a pediatric specialty hospital supporting these designated hospitals. The study aimed to clarify the support that these nurses provide to pediatric cancer survivors as well as their thoughts on supporting the patients at pediatric specialty hospitals.

Methods: This study used qualitative inductive research methods and conducted semi-structured free-response interviews with outpatient nurses working at a pediatric specialty hospital. Data analysis was performed using the Modified Grounded Theory Approach (M-GTA).

Results: Overall, 15 outpatient nurses were included in the study. Moreover, the M-GTA analysis generated four core categories. The thought process related to a long-term follow-up outpatient clinic for pediatric cancer survivors included considering factors that posed difficulty in the establishment of such a clinic, reconsidering the importance of establishing such a clinic, and contemplating about establishing a desirable clinic. This was based on the belief of the outpatient nurses regarding building a trusting relationship with the patients.

Conclusion: Owing to manpower issues, no guidance was provided for the pediatric cancer survivors at outpatient clinics, and follow-up care was provided only by physicians. Moreover, outpatient nurses recognized the problems faced by patients throughout their lives and understood the need to solve them, but they could not provide effective guidance. Because pediatric cancer survivors are at high risk of disease- and treatment-related outcomes, there is a need to develop a system that facilitates collaboration between different professional groups in order to improve their quality of life.

Keywords: Pediatric specialty hospital, outpatient nurse, pediatric cancer, pediatric cancer survivor, mother of a pediatric cancer survivor

Background

In Japan, the annual incidence of pediatric cancer has been estimated to be between 2,000 and 3,000 cases (Ishida, 2011), and in 2019, according to the National Cancer Registry in Japan, 2,200 children were diagnosed with cancer. At present, 80% of the children with cancer have been cured in Japan largely due to the standardized treatment protocols adopted throughout the country

(Pediatric Cancer Practice Guidelines 2016 Edition, Clinical Practice Guidelines for Pediatric Leukemia and Lymphoma 2016 Edition).

Although the lives of many children with cancer are currently being saved, the age of onset of pediatric malignant solid tumors is particularly low, which occurs during 2–4 years of age. This implies that even after completing treatment and returning to normal

life, patients with pediatric cancer face various challenges, including those related to preschool and back-to-school life, academic achievement, and friendships. In addition, with increasing age, they may face challenges related to school admission, employment, marriage, childbirth, and other aspects of their lives. Furthermore, they may need to cope with the anxiety of possible late-stage complications or secondary cancers following cancer treatment.

Currently, pediatric cancer treatment is performed at 15 designated hospitals across Japan that provide treatment as well as follow-up care. The present study aimed to examine the support provided by outpatient nurses to pediatric cancer survivors after discharge from pediatric specialty hospitals that act as collaborating hospitals to designated pediatric cancer hospitals. Ishida et al. (2017) investigated the utilization rate of long-term follow-up tools in Japan, and they found that the rate of using the follow-up notebook developed by the Japan Child Cancer Group was only 18%, and only 30% of the users fully understood the risk of late complications. In particular, our collaborating hospital is the only pediatric specialty hospital operated by Prefecture A. As the Ministry of Health, Labor and Welfare is considering to implement a support program to facilitate future transitions between designated pediatric cancer and collaborating hospitals, we expect that patients with pediatric cancers requiring treatment for hematological malignancies or malignant solid tumors will be admitted to such collaborating hospitals. Furthermore, we aimed to clarify the reality of support provided by outpatient nurses to pediatric cancer survivors at pediatric specialty hospitals after their discharge.

The significance of this research is that it describes the support provided by outpatient nurses at pediatric specialty hospitals during the long-term follow-up of pediatric cancer survivors as well as to document their thoughts on the provision of support.

Participants and Study Period

1. This participants of this study were outpatient nurses caring for pediatric cancer survivors at a pediatric specialty hospital.

2. The number of study participants was planned to increase until data saturation.
3. The survey period was from March 2018 to September 2018.

Definitions

1. **Pediatric cancers:** Pediatric cancers refer to malignant solid tumors and hematological malignancies occurring in children.
2. **Secondary cancers:** Secondary cancers refer to the cancers that develop after pediatric cancer treatment.
3. **Late complications:** Late complications refer to health problems caused by chemotherapy, radiotherapy, and surgical therapy.
4. **Long-term follow-ups:** Long-term follow-ups refer to medical examinations and tests performed by a physician once a year.
5. **Long-term follow-up outpatient clinics:** Long-term follow-up outpatient clinics refer to clinics where nurses and other healthcare professionals provide guidance and support to pediatric cancer survivors and their families.

Study Methods

1. Study Design

This was qualitative inductive research performed using the modified grounded theory and semi-structured interview method. The study aimed to elucidate the process of self-care guidance provided by outpatient nurses in a pediatric specialty hospital and to report the changes in their thoughts and perspectives.

2. Data Collection Method

An interview guide was developed for outpatient nurses, and a free-response method was used for data collection. The interview guide was designed such that the questions focused on gathering participants' experiences, and the study was conducted using a semi-structured interview approach. Additionally, the researcher's visual information was recorded in field notes during the interview.

1) Interview Procedures

- (1) The interviews were conducted in a quiet private room to ensure privacy protection.
- (2) The researchers introduced themselves, explained the purpose of the study verbally and in writing and, and reconfirmed the consent of the participant.
- (3) The interview was semi-structured and based on the interview guide. Consent to use an IC recorder and prepare field notes was obtained from the participants.

2) Interview Guide for Outpatient Nurses

- (1) Determining the reasons and timing of the history of pediatric cancer as well as the content of the informed consent form.
- (2) Determining whether psychological support was provided after the patient had been informed about the illness at the outpatient department.
- (3) Reporting the content regarding the discussion between cancer survivors and their families and the nurse.
- (4) Examining the details of self-care education and guidance provided to the cancer survivors.
- (5) Examining the details of self-care education and guidance provided to the family.
- (6) Determining how information about secondary cancer and late complications was provided as well as gathering the details of the information.

3). Analysis Method

In the present study, we used the modified grounded theory approach (M-GTA) for qualitative inductive data analysis. In particular, the grounded theory approach was proposed by Glaser and Strauss in the 1960s as a research method for generating theories through the interpretation of data, and it has become an established research method in the field of nursing in the US. In the late 1990s, Kinoshita modified this approach and called it M-GTA; his method includes his own concept of methodological limitation. In addition, the characteristic of M-GTA is that it allows researchers to set clear research goals and develop compelling explanations for a

specific research area based on real-world data within the confines of the research. It is also a theory for practical activities, which clinicians can modify and apply while incorporating the characteristics of their own situation.

Analysis Procedure

(1) The contents of the recorded interviews were transcribed verbatim as data.

(2) The analysis theme and content were determined. The analysis theme was the reality of support provided by nurses to pediatric cancer survivors in pediatric specialty hospital outpatient departments, and the analysis focus was pediatric specialty hospital outpatient nurses.

(3) We carefully read through the data from a wide variety of examples and examined them in the context of the analysis theme, focusing on related areas of the data. Furthermore, we interpreted the participants' actions and perceptions, explained other similar concrete examples, and expressed the definition and concept name representing the meaning of the data.

(4) We created the analysis worksheet format while simultaneously creating concepts and entered the concept name, definition, and concrete examples with variations for each concept into a worksheet. At this point, we had discussions with our supervisor and checked the validity of the concepts.

(5) We recorded the ideas and questions that aroused when interpreting the data as well as the relationships between concepts as theoretical memos in the analysis worksheet.

(6) Starting from the second case, we analyzed each case from the viewpoint of opposite and similar comparisons. If, when creating new concept themes, we came across the cases that had already been conceptualized, we added a case to the corresponding analysis sheet as a variant.

(7) If no new specific similar cases were identified and data review for opposite cases was deemed sufficient, worksheet creation was completed.

(8) For category generation, we validated the scope and level of concept explanation

and categorized it based on the coherence of the concept's meaning. Further, we collected compelling important concepts as categories. Additionally, we identified items that comprised multiple categories and defined them as core categories as well as clarified the relationships among core categories.

(9) We summarized and clarified the relationships between concepts and categories, created diagrams to explain the phenomena we wanted to clarify, and wrote concise explanations into a storyline.

2) Measures to Ensure the Reliability and Validity of Analysis

1) In order to increase the credibility and validity of this study, an expert in qualitative research supervised the concept generation process from the first cases as well as crosschecked the worksheets created.

2) Accuracy was improved through supervision by an experienced qualitative researcher during the process of establishing relationships and categorizing concepts.

Ethical Considerations

1. The study was approved after review by the ethical review board of the affiliated institution and the research institution.

2. A detailed explanation of the study was provided both verbally and in writing to the relevant department (nursing department) of the research institution, and their consent was obtained.

3. After obtaining ethical approval, the nursing department was requested to provide a list of outpatient nurses who met the criteria.

4. An explanation was provided both verbally and in writing to participants who met the inclusion criteria, and their consent to participate in the study were obtained.

5. The method of information management and handling was also clarified both verbally and in writing by identifying the person in

charge and providing relevant explanations to them.

6. Management and protection of personal information, materials, data, etc.

(1) The obtained data and interview content will not be used for any purposes other than the research.

(2) The recorded content and verbatim transcripts will be identified using symbols to ensure anonymity.

(3) The materials and data obtained in this study will be stored in a secure location accessible only to the principal investigator.

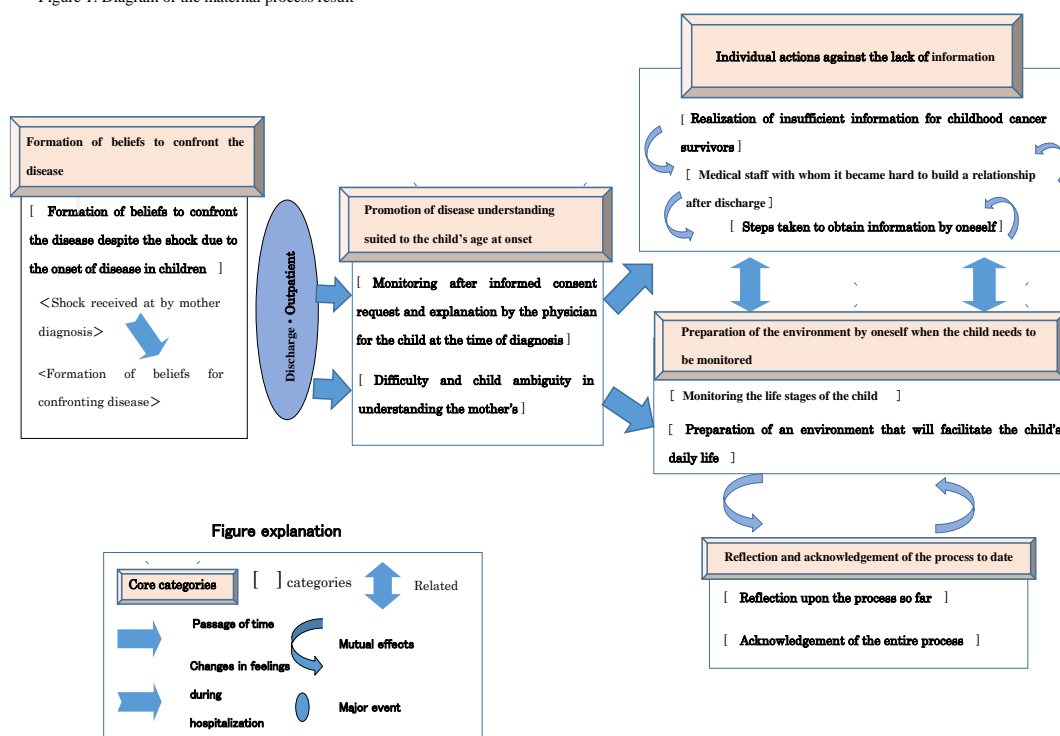
Results

1. Subject Overview

The participants of this study were 15 outpatient nurses working at a pediatric specialty hospital. Their mean age was 44.4 ± 11.5 (range, 30–70) years. Their length of stay at the outpatient department was 8.07 ± 7.13 years. The selection was not limited to nurses working at the hematology–oncology outpatient departments but included all nurses working at the internal medicine and surgical departments, considering possible transfers. The interview duration was approximately 30–60 minutes.

The thoughts of pediatric outpatient nurses at a specialized children's hospital regarding long-term follow-up clinics and self-care guidance for pediatric cancer survivors comprised 4 core categories denoted by (), 11 categories denoted by [], and 26 concepts denoted by < >. After (considering the difficulties in establishing long-term follow-up clinics), they (reconsidered the importance of opening long-term follow-up clinics for pediatric cancer survivors) and (contemplated about establishing an ideal clinic) based on the foundation of (belief in building a trusting relationship with patients as outpatient nurses).

Figure 1: Diagram of the maternal process result



1) Overview We conducted interviews with 15 outpatient nurses at a pediatric specialty hospital. The employment status of these nurses was both full- and part-time. The pediatric outpatient clinic was further divided into surgical and medical clinics, and long-term follow-up for pediatric cancer survivors was conducted at the hematology–oncology department of the surgical clinic.

2) Storyline (Factors posing difficulties in establishing long-term follow-up clinics): The participating nurses complained about <work-related limitations, such as the lack of opportunity for outpatient nurses to attend examinations> and the <difficulty in conducting follow-up examinations because of the system and manpower shortages>. Additionally, they talked about the <difficulty in communicating with parents of the patients>, which was a secondary problem caused by the busy nature of the work.

These situations created [apprehensions about the current shortage of manpower] among the nurses. Moreover, despite the current shortage of manpower, the nurses recognized the <difficulties of being a primary caregiver for long-term follow-up patients> as well as the

fact that they had <limited understanding of the child's illness and disease comprehension> as outpatient nurses. They also expressed [concerns regarding their own limitations in obtaining information] about patients as well as their <lack of knowledge in establishing a hematology–oncology follow-up outpatient clinic>. In contrast, they acknowledged <the idea that physicians are the mainstay in an outpatient setting> and recognized that the nurses play a [role mainly in assisting with examinations and tests].

(Re-evaluation of the importance of establishing a long-term follow-up outpatient clinic for pediatric cancer survivors): Nurses wanted to <continue the currently successful nursing care provided at their current outpatient settings> as well as <reflect on the well-established long-term follow-up system in the cardiology department>. Moreover, they had <positive opinions about the transitional care clinic that emerged as a result of the introduction of the cardiology transition outpatient clinic>, and they [affirmed the nursing intervention in the long-term follow-up outpatient clinic]. Furthermore, as outpatient nurses who monitor the growth

process of children undergoing treatment in infancy or early childhood, they recognized the <importance of explaining late complications to children while simultaneously considering their future>. They also contemplated about the <impact of pediatric solid tumors on adult survivors who underwent surgery in childhood; for example, on their ability to marry or conceive a child>. However, they also recognized the <inadequacy of self-care guidance for pediatric cancer survivors>, which led to a [renewed recognition of the importance of guidance for these individuals] among them. Moreover, they reconsidered the <importance of transitional care clinics for other medical specialties that specifically address pediatric patients>, which led to a greater <understanding of the importance of self-care guidance for pediatric illnesses>. They also contemplated the need for enabling children to implement self-care as well as the <need for follow-up at adult clinics> as nurses involved in long-term follow-up of pediatric patients. They then [reaffirmed the importance of guidance for pediatric diseases].

(Considering the establishment of a desirable long-term follow-up clinic): Based on the abovementioned considerations, instead of focusing on healthcare professionals, the nurses focused on <prioritizing the feelings of parents and children when explaining them about late complications>. They also aimed at centering the consideration on the child; for example, to <determine when and what information should be provided to the child> and explore the <content of the follow-up clinic for pediatric outpatients at pediatric specialty hospitals>. They also considered [ways to provide information aligning with the thoughts and feelings of the child and mother]. Moreover, they were [rethinking their own system for establishing a long-term follow-up clinic], such as <considering the hospital's system for establishing transitional support clinics as a pediatric specialist hospital> and <contemplating the need for a primary nurse in the clinic> who can be easily approached by pediatric cancer survivors for consultations. In addition, by <considering the coordination between ward and outpatient nurses, which is not currently well-established>, they reported that it may be possible to improve guidance on self-care and

share information. They also considered that <teamwork among healthcare professionals was necessary for long-term follow-up> when establishing the clinic, and they reported ways to achieve a [better multidisciplinary teamwork].

(The belief of the outpatient nurse in building a trusting relationship with patients): The nurses considered that it was their duty <to prioritize the best possible care and establish trust with patients>. They strived to [provide the best possible care] and believed that <providing a patient with accurate information was essential to maintain a trusting relationship with healthcare professionals>.

Therefore, they recognized that [providing accurate information to patients is a key element in building a trusting relationship].

Discussion

1. Difficulties in providing long-term follow-up at an outpatient department.

To the best of our knowledge, Hospital A—the collaborating facility for this study—is the only designated institution for pediatric treatment in Prefecture A. Currently, follow-up for pediatric cancer survivors by physicians is well-established, but to reveal more problems and improve self-care guidance for children, it is desirable to establish a long-term follow-up outpatient clinic through interdisciplinary collaboration. One of the factors considered challenging by outpatient nurses for long-term follow-up outpatient care is the prevalence of part-time nurses, which may increase manpower shortages in establishing the clinic. Moreover, outpatient nurses reported that it would be impossible to establish a long-term follow-up outpatient clinic with only outpatient nursing staff. In particular, the work of outpatient nurses is mainly focused on treatment, and they currently do not have sufficient information about long-term outpatient follow-up care because they cannot participate in doctor–patient conversations or do not know how much a child understands his/her illness, which prevents them from providing adequate self-care guidance. Hospital A is a public pediatric specialty hospital with a large number of experienced nurses as staff. By promoting collaboration between ward and outpatient nurses, it is

believed that more comprehensive guidance can be provided. Additionally, regular meetings with ward nurses who had provided support to the child during hospitalization may make it easier for the child to express more anxieties and questions. Muroka's (2019) needs assessment of collaboration between neonatal intensive care unit (NICU) and visiting nurses during the transition from NICU to home revealed that the needs of these nurses were knowing the mother's emotional changes and efforts, sharing information, understanding the condition, and strengthening health literacy.

Their assessment indicated the importance of information sharing between NICU and visiting nurses. Similarly, in the present study, we believed that through collaboration and information sharing between both parties, previously unknown information about pediatric cancer survivors will be gathered, which will further provide guidance for self-care to maintain the health of pediatric cancer survivors.

Communication between the mothers and outpatient nurses was another perceived difficulty during interventions. Takahashi et al. (2016) conducted a study on the relationship between mothers of children requiring care and outpatient nurses. According to the results of their study, the nurses reported that they had failed to ask the mothers about their thoughts and needs. In contrast, the mothers regretted not being able to have in-depth discussions with the nurses but accepted that the inability to have a discussion was inevitable. Although their study focused on mothers of children who required medical care, the results are likely to be similar for mothers whose children require long-term outpatient follow-up care. Although the outpatient nurses at the pediatric hospital recognized issues, such as those related to the child's life in terms of education, marriage, and childbirth, they agreed that more effort was needed to ensure that these issues were addressed in actual patient care.

Furthermore, the outpatient nurses expressed concerns about their own lack of knowledge. In addition, they acknowledged that they needed to expand their knowledge of pediatric cancers to effectively manage long-term

follow-up appointments, particularly for children with cancer receiving treatment at the hematology–oncology departments. Notably, Irwin et al. (2011) reported that in educational programs aimed at improving the knowledge and skills of nurses caring for patients at oncology departments in survival care, nurses with <5 years of experience exhibited a higher knowledge deficit than those with ≥5 years of experience (49% vs. 36%). The proportion of children in Japan's population is decreasing, whereas the cure rate for patients with pediatric cancer is increasing. This suggests that the number of children who require guidance will continue to increase. Further, to ensure consistent guidance for pediatric cancer survivors, it is important to develop educational programs that allow outpatient nurses to continuously expand their knowledge.

2. Importance of long-term follow-up clinics, as perceived by pediatric outpatient nurses

Hospital A offers transitional outpatient care for children with heart disease in the cardiology department. In the present study, the assigned nurse personally experienced the effectiveness of the guidance as they witnessed changes in the children; for example, previously silent children began to ask questions, and children began to perceive their illness as their own. In addition, by observing these changes, other nurses became more aware of the need for guidance for children in the outpatient setting. Sakurai et al. (2019) explained the process of acquiring self-care skills among children and care abilities among their parents during long-term hospitalization as well as the nursing support involved. The stages during hospitalization were categorized as follows: establishment of the foundation for self-care and parental care abilities by nurses, understanding of the treatment by the child and parents, implementation of appropriate care by the child and parents, and evaluation of the effectiveness of care by child and parents. Particular emphasis was placed on establishing the foundation for self-care and parental care abilities. Hase et al. (2019) classified children's self-care into three stages: the stage in which parents take the lead in the transition to self-care, the stage in which parent and child engage in self-care

together, and the stage in which the child takes the lead in self-care. Moreover, they reported that the process of enhancing children's self-care involves a step-by-step transition of the main agent in self-care. When an illness occurs at a young age, the focus is on the mother's knowledge. However, there comes a time when leadership passes from the mother to the growing child. Healthcare professionals believe that it is important to intervene during this transition period and provide the child with the right knowledge. The changes observed in children receiving guidance about their illness in the transitional outpatient care setting at Hospital A suggested that guidance previously provided by mothers was not effective and that guidance from outpatient nurses resulted in behavioral change that strengthened knowledge and understanding of the children. This change in behavior is considered the first step toward establishing self-care autonomy for the children.

Furthermore, outpatient nurses monitor the growth of children and are happy to see them grow. However, as children approach adulthood, the nurses become concerned about the need to provide information about late complications for effective understanding among children who develop cancer at a young age. Additionally, although they had various concerns regarding pediatric cancer survivors, they also acknowledged that they provided no guidance regarding self-care. Maru et al. (2013) reported that the nursing contents of follow-up outpatient care for pediatric cancer mainly include assisting with medical treatment, measuring physical changes, and conducting examinations, and in few cases, long-term nursing care is carried out with a long-term perspective. Moreover, they suggested the need to strengthen health education. Knighting et al. (2020) conducted questionnaire and interview surveys for pediatric cancer survivors undergoing long-term follow-up at a UK cancer center. Based on their findings, some pediatric cancer survivors indicated that they were not provided with sufficient information about their own cancer treatment, the purpose of the clinic visit, and the possibility of late complications. Therefore, despite long-term follow-up care, a review of the content of the consultation is necessary because it is not an

effective nursing outpatient service. Moreover, it is important to provide information for future health maintenance and health education for self-care in long-term outpatient follow-up. In addition, given that the content of the guide may change with changes in the target audience, the same content is unlikely to have a good impact on all target audiences. To determine whether healthcare professional counseling is effective, the responses and behavior of each pediatric cancer survivor must be analyzed. Furthermore, it is necessary to develop a careful step-by-step guide, repeatedly assess the level of understanding of pediatric cancer survivors, and check whether the content of the guide matches the patient expectations.

Conclusion: Amidst the busy outpatient work, the outpatient care nurses found it difficult to set up a long-term follow-up nursing outpatient clinic. They recognized the effectiveness of long-term follow-up outpatient care for pediatric cardiovascular diseases and understood the need for such care for pediatric cancer survivors. In particular, nurses in pediatric specialty hospitals considered that such a clinic was particularly important for children who grew up with diseases. However, the outpatient nurses found it difficult to set up a long-term follow-up clinic with only outpatient nurses, indicating their own lack of information and knowledge.

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