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Nursing Practices to Integrate Family Efforts for the Pediatric Cancer Patient Undergoing Hematopoietic Stem Cell Transplantation

Orie Koizumi* **and Reiko Inoue**

Department of Nursing, School of Medicine, Tokai University,143 Shimokasuya Isehara, Kanagawa, 259-1193, Japan

Abstract

Objective: To clarify support provided to a pediatric cancer patient and her family through the treatment process while undergoing hematopoietic stem cell transplantation.

Methods: This is a case study on the family of a pediatric cancer patient undergoing hematopoietic stem cell transplantation. An attending nurse collected data by extracting nursing practices provided for the patient and family from the patient's records, covering the period from hospitalization to transplantation, and organizing the information chronologically. Multiple nurses and researchers participated in reviewing the assessments and nursing approaches to enhance the authenticity of the study. Ethical considerations were addressed by obtaining approval from the institutional review board of the affiliated institution and ensuring the anonymity of the patient's family.

Results: The patient's family faced daunting challenges in caring for their sick child, while providing explanations and appropriate support for the donor brother. However, the parents struggled to work together due to an overwhelming fear of their child's life being in danger. Nurses intervened to help the family recover from psychological crisis, coordinate responsibilities and roles within the family, and support the fulfillment of parental duties, in order to strengthen family integration for hematopoietic stem cell transplantation.

Discussion: Transplantation medicine places multiple roles on a single family, including those of patient, donor and non-donor. Before transplantation, the family is constantly under tension due to an ongoing struggle with their child's developmental challenges and an exhausting fight against the disease. Such intensive pressure can severely impact the family, potentially leading to dysfunction as a consequence. The nurses in this study expressed empathy toward the family, who had experienced psychological shock and a sense of helplessness and supported them by clarifying their roles and creating a supportive environment. Additionally, with the same goal in mind, the nurses intervened to enhance family integration by coordinating their responsibilities within the household and educating the parents on how to parent a sick child. These approaches are presumed to have contributed to the family's own efforts.

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Introduction

In Japan, childhood cancer develops in approximately 0.2% of children (2,000 cases out of 15,000) and is one of the leading causes of childhood mortality [1]. Although advances in medical treatment have improved its cure rate, side effects continue to impact the lives of patients and their families. In response, the Cancer Control Act was established in 2006, leading to reorganization of the treatment and medical system with an emphasis on QOL [2]. Also, Hematopoietic Stem Cell Transplantation (HSCT), a treatment for refractory childhood cancer, poses a substantial impact on both patients and their families. When HSCT is required for pediatric cancer treatment, specialized approaches are essential for both patients and families to proceed with transplantation, donation and treatment concurrently. To address this, Core Hospitals for Hematopoietic Stem Cell Transplantation were established nationwide, each comprising a specialized outpatient department, general pediatric ward, and transplant unit tailored to the treatment process. Additionally, specialists, nurses, Hematopoietic Cell Transplant Coordinators (HCTC), clinical psychologists, child life specialists, medical social workers, and others are assigned to transplantation teams.

It is important to provide pediatric patients with holistic medical care that considers the characteristics of their growth phase and offers support according to their life stage. In order to do so, coordination among the patient, family and medical team is essential from the outset of the treatment. Especially in the case of HSCT, the family must select a donor, forcing them to make a decision about the patient's and donor's lives . Consequently, the family's role structure may change, potentially weakening their unity [3]. Furthermore, if a sibling is the potential donor, the impact on the heathy child becomes a significant concern. Therefore, the family requires specialized support, the family, as well as those caregivers who understand their vulnerabilitities and provide appropriate interventions, requires specialized support.

The family of the pediatric cancer patient receiving HSCT is expected to face many challenges, as they must manage both cancer treatment and bone marrow donation simultaneously. Hence, this paper will present a case study that illustrates nursing practices for the pediatric cancer patient undergoing HSCT and for the patient's family.

***Corresponding Author:** Orie Koizumi, Department of Nursing, School of Medicine, Tokai University,143 Shimokasuya Isehara, Kanagawa, 259-1193, Japan; Tel/Fax +81-463-90-2062.

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Objective

This paper reports on the nursing practices provided to a pediatric cancer patient who underwent hematopoietic stem cell transplantation for acute myelogenous leukemia, along with support given to the patient's family.

Methods

Data gathering

The target facility was a general pediatric ward at a Core Hospital for Hematopoietic Stem Cell Transplantation located in K prefecture. Data on the patient and family situation, as well as the nursing practices provided by a Primary Nurse (PN) and a Certified Nurse Specialist in Family Health Nursing (CNSF), were collected from the medical and nursing records, spanning from hospitalization to HSCT.

Data analysis

The PN and CNSF reviewed the observed patient's condition, the care provided to the patient, the family situation and its assessment, and the family nursing practices, and subsequently summarized the process in chronological order. They also confirmed the clinical course and discussed the assessments, practices, and evaluation in detail with the pediatric nursing researchers to ensure the appropriacy of the care.

Intervention period

6 months from May 201X to October 201X.

Ethical consideration

Before publication, approval was obtained from the institutional review board of the affiliated institution where the nursing practitioners worked, and the anonymity of the patient's family was ensured.

Case Study

Clinical process

The patient was a 3-year-old girl with no previous medical history. In May 201X, she was urgently hospitalized with suspected acute leukemia after the tests for persisting cold symptoms. Following further examination, she was diagnosed with acute myeloid leukemia, with genotypes indicating an adverse prognosis. In addition to chemotherapy, she underwent allogeneic hematopoietic stem cell transplantation with her older brother, who was an exact HLA match, as a donor. She was discharged 8 months after her admission.

Family structure (Figure 1)

The family consisted of four members: the patient, a father and a mother both in their thirties, and a 6-year-old brother.

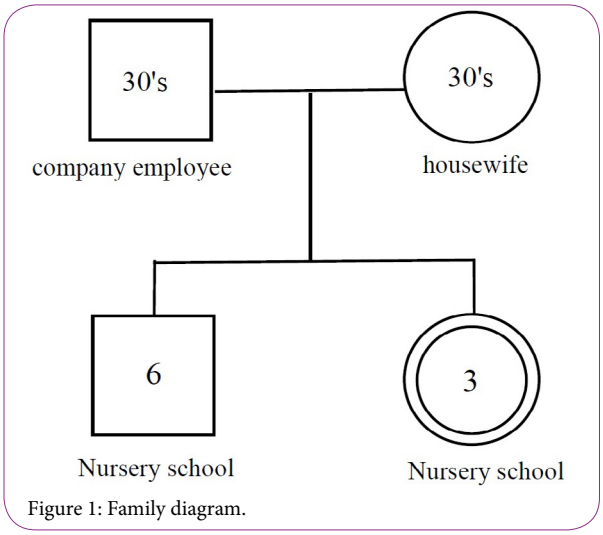

Figure 1: Family diagram.

Nursing Practices (Table 1)

Patient's condition and nursing interventions

Chemotherapy was initiated immediately after admission. The PN collaborated with a childcare worker and a nutritionist to address the patient's mental and physical health by alleviating symptoms and promoting her adaptation to the hospital environment. Once chemotherapy began, she became easily irritable; therefore, the PN carefully explained the situation to her and made efforts to provide a comfortable space. From the bone marrow suppression stage of chemotherapy to convalescence, the PN provided guidance on daily life activities and intervened to improve her self-coping skills. In the preparation period for transplantation, 6 months after admission, the PN focused on maintaining the patient's physical condition, while providing preparatory support for the transplantation, ensuring she was mentally well-prepared.

Family situation and nursing interventions

In the first week after admission, the parents were informed of the disease. The mother became overwhelmingly upset and broke down crying in front of the patient. The parents faced the dual challenges of selecting a donor within their family and adapting to the medical treatment and hospital environment simultaneously. The CNSF assessed the need for nursing interventions to help the parents work together to manage this situation and decided to provide step-by-step support leading up to the HSCT.

Supporting the family to recover from psychological shock

During the first week, the mother frequently sobbed in front of the patient, while the father expressed minimal emotions. Consequently, the PN and CNSF assessed that they were both experiencing psychological crisis. The PN demonstrated empathy for their feelings and intervened to create a space for them to share their concerns and emotions. The mother gradually regained her composure, and the father began expressing his feelings. The mother said, "I don't know what I can do." In response, the PN focused on educating her by providing necessary knowledge and skills for the cancer treatment. The mother visited the hospital daily and started actively participating in the patient's care. Furthermore, the CNSF decided to organize a team conference to propose multi-professional support for the parents, involving a clinical psychologist, a childcare worker, a social worker, and other specialists. Over time, both parents gradually became more stable.

Coordinating roles and responsibilities within the family

During the second and third weeks of hospitalization, the mother spent more time with the patient and the burden of household

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Treatment process	Patient's condition	Patient care	Family situation and assessment	Family nursing practices
From admission to **week 1**	Fatigue, fever	Focusing on symptomatic therapy	Mother was overwhelmingly upset and sobbed in front of the patient	Acknowledging the feelings of parents
Diagnosis and informing	Crying on the bed	Calming the patient down by holding her	Father seemed to understand the situation calmly	Creating a space for the parents to express their concerns and emotions
	Using diapers for excretion in bed	Taking care of her attentively	Parents were experiencing a severe psychological shock	Sharing information within the team and providing support
			Mother felt helpless	Providing education on key knowledge and skills for cancer treatment
From admission to **week 2**	Fatigue, nausea, vomiting	Focusing on symptomatic therapy	Mother visited every day; father visited once a week (on weekends)	Assessing the division of responsibilities within household
Start of induction therapy	Emotional outbursts during therapy and meals	Waiting a moment and explaining slowly and clearly	Mother's fatigue increased	Revealing the parents' recognition of family roles
	Crying frequently	Creating a calming environment for her	Father did not participate in the care, and mother said nothing about it	Demonstrating understanding toward the parents and listening attentively
			Mother did not seem to be working together with father	Encouraging the parents to grasp the current situation
			Mother was overloaded, lacking cooperation with father	Encouraging the parents to foster cooperation between them
From admission to **week 3**	Bone marrow suppression	Transfusion therapy, infection control	Mother simply responded to each demand from child	Observing the mother-child relationship
From the completion of therapy	Hair loss, fatigue, poor appetite	Providing guidance on daily activities, like washing hands	Lack of interactive communication between mother and child	Demonstrating understanding toward the mother's approaches
to the onset of side effects	More time to play on the bed	Consulting with a nutritionist to plan meals	Mother-child relationship was strained	Respecting the mother's childcare approaches
	Making unreasonable demands on her mother (Wanting candies and sweets, refusing to take oral medication,not wanting to take a shower, etc.)	Collaborating with a childcare worker to devise ways of playing		Explaining how to engage with a sick child
			Parents expressed their concerns and difficulties	Assessing changes in the family
			Mother calmly responded to her child; dynamics of the mother-child relationship changed	
			Father supported mother; dynamics of the husband-wife relationship changed	
From Admission to **week 4**	Recovery of bone marrow (remission confirmed)	Providing support to promote autonomous daily living	Brother said, "I don't want to lose my mom."	Encouraging brother to express his own experience and to empathize with his sister's experience
Start of consolidation therapy	Appetite regained; energy restored	Explaining what to be careful of when staying out of the hospital overnight (Preparation)	Brother felt isolated and anxious	Promoting mutual understanding within the family
Preparation period for the transplantation	Emotional outbursts and demands reduced		Need to support the entire family, including the brother	Enforcing cooperative system between medical staff and the family
				Sharing challenges toward the family goal and dividing roles among multi-professionals
				. Providing information to cleanroom nurses
				Coordinating the participation of all family members in treatment
				. Arranging for the donor brother to visit a cleanroom
				Support to improve the family's readiness
				. Preparing the patient for transplantation
				. Brother's hospitalization: Devising treatment procedures; making preparations
From admission to **week 24**	Remission maintenance		Brother was hospitalized	Devising treatment procedures, conducting tests, making preparations for the surgery
Transplantation	Entering the cleanroom		Mother stayed with the patient in the cleanroom	Explaining the hospitalization, surgery and transplantation process to the parents
	Radiation therapy		Father accompanied his son to the surgery	Arranging for brother to visit the cleanroom
	Pretreatment (myeloablative chemotherapy)		Maintaining consultative relationship with nurses and HCTC	

Table 1: Chronological process from hospital admission to hematopoietic stem cell transplantation.

chores and caring for the son weighed heavily on her, leaving her increasingly exhausted. The PN and CNSF reviewed the division of responsibilities within the household and assessed that the mother might be unconsciously shouldering those duties on her own. Therefore, the PN held a meeting with the parents to discuss the family's challenges. During the meeting, the father acknowledged the need to actively support his wife rather than rely solely on her, while the mother could recognize the importance of not trying to manage everything by herself. Accordingly, the CNSF helped them gain a clearer understanding of their current family dynamics and guided them in reshaping their perceptions regarding the family roles. Through these efforts, the parents gradually developed a shared image of working together and sought to rebuild their relationship to support their child in fighting the disease.

Explaining how to engage with a sick child

In the third and fourth weeks of hospitalization, the bone marrow suppression phase began, following remission induction therapy. However, the patient's stress and emotional dependence on the mother led her to make repeated, escalating, unreasonable demands during the mother's visits. The PN and CNSF carefully observed the mother-daughter interactions and assessed that the mother tried to meet every demand out of sympathy for her daughter's poor condition, inadvertently straining their relationship. While respecting her parenting approaches, the PN educated her on how to engage with a sick child. Acknowledging her feelings, the PN explained the importance of teaching the child to distinguish between right and wrong, even though the child was a patient. Gradually, the mother regained the ability to interact calmly with her daughter.

Promoting family unity for hematopoietic stem cell transplantation

In the fourth week of hospitalization, the family's progress in preparing for the HSCT was reviewed. Her older brother, who was the donor, felt lonely and isolated as his mother spent much of her time with his sister. Additionally, the hospital visitation policy limited his visits, leaving him unable to fully grasp what it meant to fight against the disease. Therefore, to help the mother understand his sense of exclusion, the PN explained to her in detail the necessity of having conversations that would allow him to express his feelings. Gradually, she became aware of her son's emotions and acknowledged that he was also doing his best at home for his sister. This realization strengthened mutual understanding within the family and helped them recognize the need for cooperation for the HSCT. Meanwhile, the CNSF carefully listened to the parents about their guilt and burden due to their son's role as a donor. In transplantation, conflicts can easily arise between donor and non-donor family members. To mitigate this, the CNSF suggested the mother have an open conversation with her 6-year-old son to understand his perspectives, emphasizing the need to explain the situation to him as a donor. As a result, the parents and their son had time to talk together, enabling him to make his own decision to be a donor for his sister. The parents also shared his sister's situation with him to alleviate his feelings of isolation and fear. Strengthening the family bonds allowed them to unite in facing the critical situation of transplantation and donation.

Strengthening collaboration between the family and the transplantation team

Before HSTC, the CNSF organized a conference involving the specialists, nurses, transplant coordinator, clinical psychologist, childcare worker, and medical social worker. Those involved communicated closely, focusing on the family, to share the challenges for the HSCT. Additionally, a visit from the patient's older brother was arranged to facilitate communication between the siblings. The PN made preparations for the patient, including devising treatment procedures, to improve the family's readiness. Strengthening the collaborative system between the medical staff and the family for the HSCT allowed the patient and her family to approach the transplantation in a self-directed manner.

Discussion

The initial treatment for childhood cancer begins at the time of diagnosis and causes the patient severe side effects. Witnessing their child's suffering is unbearable for the family; therefore, nursing support is essential not only for the patient but also for the family. The case presented in this paper involved the shock of daughter's sudden onset of the disease and the harsh treatments, called HSCT, emphasizing important nursing perspectives on the donor brother. Faced with the potential danger to both of their children, the parents were overwhelmed, and the entire family was in turmoil. The nurses recognized the need to support the family, who were experiencing psychological crisis, and initiated necessary interventions from the early stage. Especially by carefully analyzing the information provided by the PN, the CNSF delivered appropriate interventions as an Advanced Practice Nurse (APN).

The preparation period is of great importance for successful HSCT. The focus of nursing practices varies depending on the phases, including the physical preparation of the patient, mental preparation of the family, and management of long-term complications. This case involved the family struggling to accept their daughter's cancer diagnosis and to understand HSCT. The distinct yet collaborative roles of the PN and CNSF, particularly in understanding the parents' feelings and focusing on their psychological well-being, are presumed to have enabled simultaneous nursing interventions for both the patient and her family. The PN clarified the division of their responsibilities and created a space for them, gradually alleviating their pessimism. As a result, they regained a sense of control as parents and became able to deal with their child's illness more positively. Additionally, the CNSF established the multi-professional team system to exchange information and provide interventions to support the parents for the HSCT. This approach is considered to have allowed the parents to receive the specialized necessary support, helping them recover from the psychological shock. For recovery from psychological crisis, the process of meaning-making of support experience received from those close to them is considered crucial [4], and the interventions in this case were deemed effective due to the CNSF's timely and appropriate actions.

Features of the nursing interventions in this case included coordinating the roles and responsibilities within the household upon the onset of the child's disease and educating the parents on how to engage with their sick child. Each family has their own history, as well as unique roles and values. Generally, when a child becomes ill, family members seek to adjust their roles and responsibilities to fight the illness [5]. However, childhood cancer is a life-threatening disease requiring long-term treatment, and the family must endure hardship in fighting against the disease. As a result, the functional roles of the family can easily be disrupted. This type of situation was observed in this case study, when the mother lost herself in taking care of her sick daughter, thereby undermining the family's function. In contrast, the

father avoided communicating with his wife, seemingly escaping from reality. The PN and CNSF recognized this situation and discussed the issues with the parents, emphasizing the necessity of confronting reality, reshaping the family's perspectives to adapt to the situation and working together. This effort is considered to have shifted their perspectives. Both parents have a common goal of saving their child. With this in mind, it is essential for nurses such as PNs and CNSFs to assess and understand the parents' psychological shock objectively and interact with the family accordingly. The mother-child relationship, characterized by mental and physical closeness, can sometimes blind the two family members and cause confusion in their interactions. In this case also, the mother felt deeply sorry for her sick daughter and tried to accommodate her every demand. However, this approach made it difficult for her to grasp the child's true needs, resulting in a vicious cycle that intensified the child's unreasonable behavior . With this in mind, it is crucial for nurses to carefully assess a mother-child relationship and provide tailored support to improve interactions between the two. At the same time, this support should respect the mother's childrearing approach without pressuring her to overexert herself. This study underscores the importance of fostering changes aimed at the common goal, cultivated through their shared history, as such efforts can lead to the construction of a new evolving relationship.

HSCT requires interventions involving changes in family structure. One concern of HSCT is a complication called Graft Versus Host Disease (GVHD), in which the recipient's immune cells reject the donor's graft as foreign matter and attack various organs, causing organ failure. Therefore, accurate Human Leukocyte Antigen (HLA) matching is of vital importance. Since half of the HLA is inherited from each parent, there is a once-in-four chance of finding a donor within siblings [6]. Thus, upon the onset of the illness, the family begins the process of selecting a donor, creating diverse roles such as a patient, donor and non-donor [3]. In the tense early stage of pediatric cancer treatment, the family must not only care for the patient but also make a life-changing decision about selecting a donor, shaping diverse experiences among its members. This significantly impacts the entire family and can even strain their bonds. In this case study, the older brother had never imagined that his younger sister would develop such a severe disease. For him, it was all about the absence of his mother and sister, who had always been by his side. Thus, it was essential to intervene to foster mutual understanding within the family, since each member experienced this situation in their own way. Eventually, the family came together to communicate, united around the shared goal, and were able to overcome this critical situation as a cohesive unit.

This study suggests that interventions addressing the changes in family dynamics due to HSCT are crucial for enhancing family integration as each member undergoes their own unique experience.

Conclusion

Support was provided to all family members of the pediatric cancer patient undergoing HSCT. HSCT requires support for the entire family. Through the interventions of family nurses, the treatment phase successfully transitioned to HSCT by helping the family recover from the psychological crisis, coordinating the division of roles and responsibilities within the household, educating the parents on how to engage with their sick child, enhancing family bonds in preparation for HSCT, and improving collaboration between the family and the transplantation team.

Competing Interests

There are no parties with conflicts of interest related to this medical research that need to be disclosed, including companies,.

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Prof. Reiko Inoue
Department of Nursing
Tokai University
Japan