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Case Study

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

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Abstract

Objective: The study aims to clarify the supportive nursing practices for minor related donor candidates whose parents have confirmed disease recurrence after receiving hematopoietic stem-cell transplantation (HSCT).

Methods: The study employed a case study design, using a retrospective description of the support process in family nursing practice. Data collection and assessment of the participating family were conducted using the Four Topics Method by Albert R. Jonsen and Family Crisis Theory to clarify the challenges family members faced due to ethical confrontations and the crisis levels they experienced. Regarding ethical considerations, the facility director, the patient, and family members received oral explanations of the study to obtain their consent to participate.

Results: In the course of this study, ethical concerns for medical professionals were raised due to the fact that transplantation procedures were often moved forward without providing minor donor candidates with sufficient explanations or ascertaining their genuine consent. Conflicts in medical ethics were revealed in the process using Jonsen's Four Topics Method. The ABC-X model developed by Ruben Hill was also employed to clarify the family beliefs from existing family resources. Addressing these beliefs in perceiving their parents' disease recurrence incidents led to the expression of minor related donors' genuine intentions.

Discussion: Eliciting complex emotions hidden behind the related donor's sense of justice in saving their family from the assessment of intrafamilial conflicts using the Four Topic Method would lead to actual decision-making. Nurses played the role of advocates and accepted the donor unconditionally, as those allowed to be present alongside the donor. The supportive presence of the nurse probably helped the donor to confirm their will. Discussions regarding retransplantation among family members did not progress sufficiently, and the nurse organized a family meeting to discuss the patient's struggle against the disease. The nurse's act of voicing the patient's unexpressed emotions and wishes in this meeting restored the family's empowerment and led to a preventive intervention without escalating into a family crisis.

Conclusion: A case of a minor family member who became a donor candidate for their parent with post-HSCT recurrence was investigated in this study using the Four Topics Method and Family Crisis Theory, and the contents of effective nursing practice were revealed through visualization of relevant issues.

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Introduction

Allogeneic hematopoietic stem-cell transplantation (allogeneic HSCT) is a treatment method for diseases such as refractory hematologic tumors and hematopoietic failure syndromes. It is performed annually on approximately 3,000 to 3,100 patients in Japan, and 3,077 cases were reported in 2023 [1]. At the same time, this method cannot be performed without donors who have healthy hematopoietic stem cells (HSCs), and it always raises ethical conflicts. Stem cells for transplantation are usually obtained from three sources: non-related donors registered in the Japan Marrow Donor Program (JMDP), related donors, and umbilical cord blood units. The donor eligibility criteria include donors' willingness to donate HSCs and human leukocyte antigen (HLA) type compatibility. The HLA type is constituted by receiving half of the genetic material from each parent. Therefore, the patient's sibling has an approximately 25% chance of being a perfect HLA match. In the case of a patient's parent (or child), however, the probability of a perfect HLA match decreases to 1 in 30; they are typically considered haploidentical.

According to the 2023 report organized by transplantation types1), the number of related donors in allogeneic HSCT performed in Japan was 1,004, exceeding the number of non-related donors of 994 via the JMDP coordination. It is probably because, in addition to the impact of an aging society, various other treatment methods have been employed and become gradually dominant aside from HLA-haploidentical transplantation (haplo-HSCT). In the cases of donors registered in the JMDP (JMDP-registered donors), the necessary measures are taken to ensure that neither the donor nor the patient is identifiable to each other. In contrast, related donors are reported experiencing stress from having their family members being ill, pressure from a sense of duty of being a donor, and anxiety [2]. In these cases that involve related donors, the patients who receive the donation may also experience a sense of guilt or pressure, which

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might lead to undesirable changes in relationships among family members, thereby resulting in a family crisis. Therefore, stem-cell transplantation between a parent and a child in a dependent and hierarchical relationship is avoided as much as possible. Thus, it remains elusive how nurses address the minor-related donors' feelings of perplexity or wavering in accomplishing preventive intervention against a possible family crisis.

In light of the above situation, this paper examines the nursing practices of a Certified Nurse Specialist in Family Health Nursing (CNSF) in a case that could develop into a family crisis from a medical ethics perspective.

Objectives

This study aims to clarify the details of nursing practices performed for a minor family member who became a donor candidate for her parent with post-HSCT recurrence.

Methods

Research design

The study used a case study design, based on Nurse A's retrospective description of family nursing practice.

Data collection and analysis methods

Collection of family data and its assessment were conducted using methods widely employed in the field of clinical ethics: the Four Topics Method by Albert R. Jensen [3] and the ABC-X model by Ruben Hill4) presented in Family Crisis Theory. Intrafamilial ethical conflicts and crisis issues were extracted from the assessment results, and relevant nursing interventions for the family were organized chronologically. The validity of the ethics conference, in which the ward nurses attended to the patient and the donor, the outpatient nurses, and the doctor in charge participated was also examined.

Four topics method by Albert R. Jonsen

The Four Topics Method developed by Albert R. Jonsen is a medical ethics decision-making support tool that aims to organize and investigate the patient's status multidimensionally along four aspects: Medical Indications, Patient Preferences, Quality of Life (QOL), and Contextual Features. Medical Indications are evidence-based objective information, such as disease severity and test results, as well as advantages/disadvantages of treatment/care methods. Patient Preferences are based on the patients' objective opinions, including their personal information. QOL refers to information observed by patients themselves and others. Contextual Features indicate information regarding patients' social status, including their living environments, occupations, and relationships with the family.

ABC-X Model by Ruben Hill

It is a framework for understanding how family responds and adapts to a problematic situation, indicating that crisis response measures differ depending on how the family perceives stressors and its available resources. The model shows the process of crisis development in which A Factor (stressor events) interacts with B Factor (available resources) and C Factor (perception), leading to X Factor (family crisis).

Ethical Considerations

After receiving authorization from the facility director prior to the study implementation, the patient and family members received an oral explanation of the study, and their consent to participate was obtained in advance.

Case Study

Family structure (Figure 1)

Patient: A female in her 40s.

Family: The patient's husband in his 50s; the eldest daughter, attending high school; the second-eldest daughter, attending junior high school; and the eldest son, attending elementary school.

The patient's parents lived nearby, and the patient's two elder brothers also had their own families nearby.

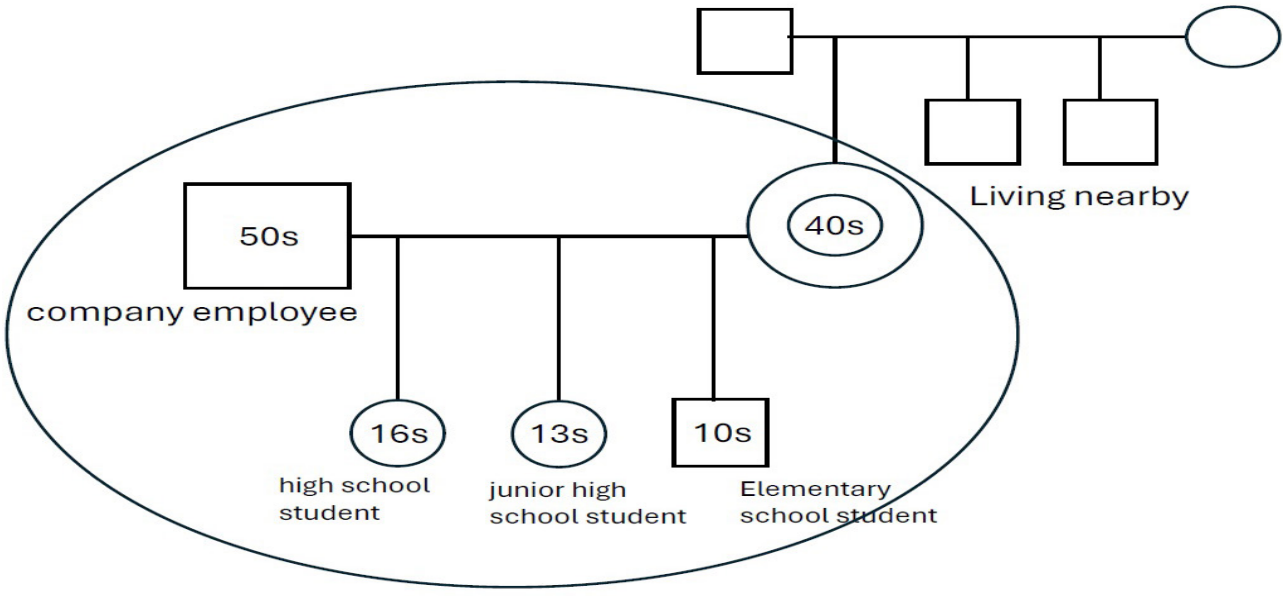

Figure 1: Genogram.

Case development

The patient was diagnosed with myelodysplastic syndrome (MDS) in 2022. She received administration of a carcinostatic agent at the facility's outpatient department and underwent bone marrow transplantation (BMT) in 2023 using HSC provided by a JMDP-registered donor. After two months of hospitalization, she was discharged. However, the disease recurrence was confirmed from the detection of blast cell increase in the bone marrow biopsy at the one-month follow-up; she was diagnosed with acute myeloid leukemia. The doctor in charge recommended a treatment option more powerful than BMT, haplo-HSCT, to the patient, her husband, her eldest daughter (16 years old at the time of disease recurrence), and the patient's mother. The patient's ADL level was stable at the moment, but she was re-hospitalized immediately due to the blood test results that indicated an emergency, requiring immediate carcinostatic agent administration. The doctor in charge explained to the patient, her husband, and the eldest daughter that the retransplantation success rate was approximately 10% or less and that the eldest daughter was the donor candidate, as both of the patient's elder brothers had medical histories that prevented them from serving as donors. The husband coerced the eldest daughter into becoming the donor, and she subsequently underwent HLA testing. The patient suffered from severe distress, torn between her feelings of guilt for her daughter's sacrifice and the pangs of conscience she felt as a mother, and expressed it to the CNSF.

Nursing practice

An entry was made to the doctor's chart on the day of the patient's second admission, indicating that "Confirmation of 16-year-old eldest daughter's consent to donation. HLA testing to be scheduled." The CNSF asked the doctor how the "eldest daughter's consent of donation" was obtained in such a short period, and by whom and where the proper explanation of the donation process was made. The CNSF learned that no one was involved in the daughter's decision-making process regarding the donation. Therefore, the CNSF determined that the issue had not been sufficiently discussed among family members and considered a preventive intervention necessary to avoid a possible family crisis. Specifically, the CNSF determined that the eldest daughter had not received sufficient explanation regarding donation, and that moving the donation process forward without confirming the donor candidate's genuine intentions would lead to ethical challenges; she proposed medical professionals to call for an ethics conference. The matter was discussed in accordance with the four principles of biomedical ethics, using the Four Topics Method by Albert R. Jonsen (Figure 2) and taking the JMDP-registered donor eligibility criteria and the Convention on the Rights of the Child into account. As a result, it was revealed that the patient was aware of her eldest daughter's distress, though the transplantation was the best option to save the patient's life. Various issues were also identified in moving the donation process forward without confirming the eldest daughter's intention. In line with the conference results, the CNSF collaborated with other professionals to engage in a series of multidisciplinary discussions on the best way to facilitate the eldest daughter's awareness of the meaning of being a related donor and of the transplantation itself. The CNSF also collaborated with a medical social worker (MSW) to ensure that the donor could receive donor protection insurance without any disadvantages. As a part of the promotion of intrafamilial communication, the CNSF encouraged family members, using the pediatric donor information booklet, to arrange family meetings to discuss the matter.

CNSF also set up an interview session with the eldest daughter when she was admitted to the hospital for a stem-cell biopsy. In the interview, the CNSF assessed the family situation using the ABC-X model (Figure 3) by Ruben Hill and learned that the family was firmly united by a strong bond, described as "a family that supports each

Medical Indications	**Patient Preferences**
1. The success rate of haplo-HSCT using HSCs from a minor donor was 10%. 2. It was a critical situation that required immediate transplantation. 3. An option using an umbilical cord blood unit was also available, and administration of a carcinostatic agent alone could prolong survival. 4. It was a retransplantation due to disease recurrence, and a more intensive transplantation option was required for a potential complete recovery. 5. Invasive procedures were necessary for collecting cells from the healthy eldest daughter.	1. The patient would decline transplantation if it risked her daughter's safety. She also worried the daughter might later regret declining to be a donor. She wished to live until her children reached adulthood. 2. The patient wished to receive transplantation after fully understanding all haplo-HSCT risks and benefits. 3. The patient requested details on donor insurance coverage for her eldest minor daughter. 4. The eldest daughter was willing to donate HSCs and had undergone the HLA test.
QOL	**Contextual Features**
1. The prognosis was estimated as poor even after receiving haplo-HSCT, and the patient felt anxious about fulfilling her role as a mother in the family. 2. The prognosis could deteriorate suddenly during the post-HSCT follow-up period. 3. Since post-transplantation side effects were unavoidable, administration of a carcinostatic agent alone to maintain the patient's current ADL level was also a treatment option. 4. Invasive procedures that would cause pain to the healthy eldest daughter were required. 5. A decline in the patient's QOL would result in a decline in the eldest daughter's QOL as a donor.	1. The eldest daughter knew her HSCs were necessary to save the patient. 2. The family knew that the eldest daughter must be the donor to save the patient. 3. The family had a strong cohesion based on mutual support, which the eldest daughter shared. 4. JMDP and facility-based donor criteria had conflicts/issues. 5. The eldest daughter's true feelings were not expressed.

Figure 2: Four Principles of Biomedical Ethics by Jonsen's Four Topics Method Chart

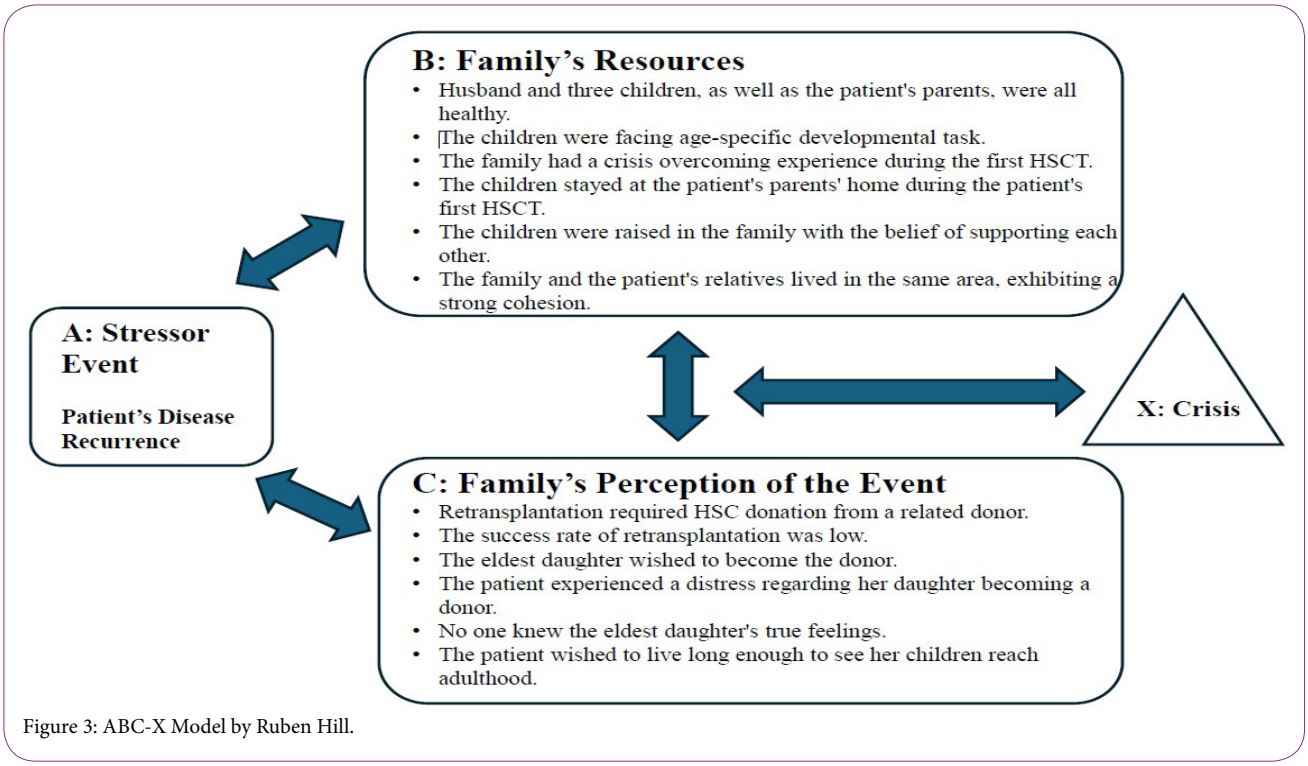

Figure 3: ABC-X Model by Ruben Hill.

other." The intervention was attempted based on a hypothesis that the belief in "supporting each other" shared in this family was passed on to the eldest daughter. First, the CNSF expressed her admiration for the belief of helping each other as a family, and at the same time, she explained to the eldest daughter that becoming a donor and helping her mother as a family member were completely different matters. The CNSF continued that she was on the eldest daughter's side and asked the daughter to reveal her true feelings so that she could pass it on to the patient. The daughter replied with tears, "I'm terrified, but I will do anything for my mom... But why ME?" The CNSF commended the daughter, who had been unable to share her feelings with anyone, and showed her respect, offering further support.

The CNSF shared these developments with medical professionals to ensure that the eldest daughter would be treated with respect as a donor.

Discussions

Ethical challenges identified by the four principles of biomedical ethics

The eligibility criteria differ between JMDP-registered donors and related donors in Japan. In the case of a related donor, each facility has its own set of standards to some extent, and the ethics committee's approval is mandatory for minor related donor cases like the one investigated in this study. However, the candidate in this study was a minor and at the same time, she was old enough to express her own will: it took time before she was selected as the donor. As for the matter of donor insurance, several setbacks were observed in the decision-making process, including the fact that the recipient was the donor's own mother, as well as hesitations of medical professionals and other family members to proceed with the treatment unless the eldest daughter's security was ensured. Fatal cases or severe complication cases have been reported worldwide, such as six cases in bone marrow biopsy and 12 cases in peripheral blood stem cell collection [5]. Therefore, the CNSF invited the MSW with expertise in donor protection insurance to explain the matter to the candidate and successfully connected the donor to an appropriate accident insurance policy.

The Four Topics Method by Albert R. Jonsen [3] is often employed to assess specific cases with ethical challenges objectively and to clarify conflicts among four values. In this case, the patient's respect for autonomy, expressed as her wish "to live," was also the whole family's wish. However, the justice of the eldest daughter, who was well aware of the necessity to donate her stem cells for her mother, but incredibly lonely under the invisible pressure and unspoken expectations from other family members, must be considered. In addition, performing invasive tests and cell collection procedures on a healthy donor in response to the respect for autonomy of the patient in preparation for haplo-HSCT could lead to a conflict against the principle of non-maleficence, as well as another ethical conflict between the abovementioned doctor's principle and risks of haplo-HSCT, leading to the decrease of both patient and family members' QOL. Therefore, eliciting complex emotions underlying the eldest daughter's sense of justice through the assessment of intrafamilial conflicts using the Four Topic Method would lead to actual decision-making.

In cases outside of the related donor eligibility criteria, the final decision regarding the donor candidate's eligibility is entrusted to each facility judgment. Conflicts in values will arise in such treatments; therefore, it is essential for medical professionals to organize multidisciplinary discussions to reframe their practices as well as to reflect on their standpoint comprehensively.

Nursing practices and preventive interventions for related donor using family crisis theory

ABC-X model by Ruben Hill [4] from Family Crisis Theory was used in this study. In this model, stressor events do not directly

cause the crisis; it is designed to evaluate the results of stressors' interactions with available resources and perceptions of stressor events in presence/absence of a crisis. In this sense, confirming information regarding available resources and perceptions of stressor events with the family was considered essential in order to understand the family, leading to effective care practices for them and the patient. Since ABC-X model is based on the interactions among four factors, perception-related C factor was considered (based on the information from the B Factor) an obstacle for the eldest daughter, preventing her from expressing her true feelings by making her aware of the family belief as shown in this study. Kobayashi [6] argued that young adults in their adolescence are in the process of developing their decision-making ability and recommended a dedicated advocacy approach when interacting with patients in this age group. The NSCF in this study accepted the donor candidate unconditionally, continuously stood by her side, and supported her throughout the process: the NSCF's dedication to the donor candidate was one of the decisive factors that encouraged her to express her true feelings.

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.

Implications for nursing practice for minor-related donors

In nursing practice, targeting minor donors requires a sufficient level of ethical considerations, taking their rights to self-determination or possible impact on their physical and mental health into account. A medical professional's appropriate support is crucial to ensure that family reaches consensus and makes a decision accordingly, while respecting the child's wishes. Thorough discussion and forming consensus among family members are essential to this end, and confirmation that the decision reflects the wishes of the whole family is crucial. Medical professionals are required to be mindful of the family's emotional state and respect the child's will while providing necessary explanations; persuading tone or language aiming to force their consent must strictly be avoided. Providing accurate information, establishing a comfortable environment for the family to resolve any questions or concerns, and building a trusting relationship with the family to prepare enough time for them to reach a decision are all essential. Specifically, psychological support from experts such as clinical psychologists and psychiatrists should be considered to help the family make a decision calmly. Lastly, support practice that can ensure the family will not regret the decision later, providing them with a sense of assurance that the option of donation will lead to the child's best interests should be used.

Conclusion

A case of a minor family member who became a donor candidate for her parent with post-HSCT recurrence was assessed using the Four Topics Method and Family Crisis Theory, and a multidisciplinary ethics conference was organized, leading to successful consensus among medical professionals and the family.

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Competing Interests

The authors declare no competing interests relevant to this article.

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