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Motivation for physical activity before and after allogeneic hematopoietic stem cell transplantation

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Abstract

Background and Purpose: This study aimed to identify patient motivation for physical activity before and after allogeneic hematopoietic stem cell transplantation (HSCT).
Methods: We conducted 14 semi-structured interviews of seven patients (two of each patient): one before starting a conditioning regimen and one after leaving the protected environment. All interviews were recorded and analyzed using the inductive content analysis method. The data collection period was May to December 2018.
Results: The participants comprised three men and four women aged 40-70 years. The patients underwent bone marrow, umbilical cord blood, or peripheral HSCT. The patients' motivation for physical activity before and after HSCT was classified into six categories and categorized into five themes including "to overcome HSCT," "to look after myself," "to respond to the donor," "the existence of supporters," and "encouragement from supporters."
Conclusions and implications for practice: The categories and themes developed here based on patient responses provide an important perspective that should be promoted among healthcare providers who care for patients undergoing HSCT.

Key words hematopoietic stem cell transplantation, motivation, physical activity, the desire for survival

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Introduction

Hematopoietic stem cell transplantation (HSCT) can cure several hematological diseases and hematopoietic malignancies, such as leukemia, malignant lymphoma, and aplastic anemia. As of 2020, the annual number of HSCT cases in Japan surpassed 5,000[1]. The survival curves for allogeneic HSCT at 1 and 10 years after HSCT in Japan are 64.9% and 44.7%, respectively, and half of all allogeneic HSCT procedures are performed in patients aged >50 years. Bone marrow transplantation has good therapeutic effects, and the number of patients undergoing HSCT is expected to increase.

While patients undergoing allogeneic HSCT benefit from advances in therapeutic technology, they also experience adverse events such as general fatigue, digestive symptoms, infections, and graft-versus-host disease (GVHD) after HSCT, which significantly limits their physical activity[2,3]. In this context, disuse syndrome often develops in a protective environment due to decreased cardiopulmonary and cognitive function, depression, declining muscle and physical strength due to long-term inactivity, and sarcopenia[4]. Sarcopenia reportedly contributes to higher nonrelapse and all-cause mortality rates after allogeneic HSCT[5]. Patients undergoing allogeneic HSCT must minimize loss of physical function to prevent disuse syndrome. However, physical activity decreases significantly because of mucosal damage from pre-transplant chemotherapy, fever caused by infection, acute GVHD, use of steroids for preventing GVHD, and persistent fatigue after transplantation[6,7]. As a result, physical function declines after HSCT and voluntary engagement in physical activity becomes extremely difficult. Therefore, patient motivation for reha-

bilitation gradually declines, and some patients cannot maintain their usual physical activity. Hence, motivation can play a key role in encouraging patients to engage in physical activity and continue rehabilitation[8,9]. However, few studies have specifically identified the motivation behind physical activity among patients before and after allogeneic HSCT[10,11]. Therefore, here we aimed to elucidate the importance of motivation for physical activity among patients before and after HSCT and how it can contribute to physical and psychological support for patients undergoing HSCT.

Patients and Methods

Study design

This study used a qualitative descriptive approach to determine what motivates patients undergoing HSCT to be physically active.

Definition of physical activity

The World Health Organization defines physical activity as any bodily movement produced by the skeletal muscles that requires energy expenditure[12]. Therefore, in this study, we included the activities performed during the rehabilitation of patients undergoing HSCT as well as their daily physical activities.

Setting and participants

Participants were recruited from a university hospital situated in a rural area of Japan. Participants were included in the study if they met the following eligibility criteria: age >20 years, scheduled for HSCT to treat hematological disease, Eastern Cooperative Oncology Group Performance Status Scale (ECOG PS)[13] 0-1 in the hospital, no serious complications, and participation approved by the primary care physician. Written informed consent was obtained from all patients. A hematologist identified the potentially eligible patients and explained the study outline. If the patient was interested in participating, the hematologist referred them to a nursing investigator, who explained the study contents to those who met the inclusion criteria using an explanatory document. Each participant provided written informed consent. On the day of the interview, the nursing investigator explained the purpose and outline of the study to the patients once again and re-confirmed that they could opt out at any time after the interview.

Rehabilitation was performed before and after HSCT at the study facility. All participants were instructed by their physicians to undergo rehabilitation and did so throughout their hospital stay. The rehabilitation program included exercise instruction by a physical therapist that included stretching, strengthening exercises, and walking as well as pre- and post-transplant muscle strength assessments and a 6-minute walk test, all of which were tailored to the patient's condition.

Data collection

Two oncology nursing researchers (>5 years of experience in hematology nursing) developed an interview guide and ascertained at the first interview whether each participant could describe their personal perspectives. One of the nurses conducted semi-structured interviews using open-ended questions. Interviews were conducted twice: before (1-2 weeks from hospitalization to the start of the preparative transplant regimen) and after (1-2 weeks after leaving the protected environment room) HSCT. Fourteen interviews were conducted of the seven participants. None of the participants refused to be interviewed.

Motivation for physical activity is thought to differ before versus after HSCT, while physical activity is thought to decrease after HSCT. Therefore, it is beneficial to understand how HSCT patients balance their physical symptoms and physical activity before versus after HSCT. After leaving the protected environment room, the patients were interviewed within 1-2 weeks according to their physical condition. The main questions in the interview guide were as follows: 1) What is your motivation for physical activity? 2) What are your motivations for engaging in physical activity? The interviews were recorded digitally and transcribed. The mean interview duration was 42 minutes (range, 18-62 minutes) before starting the transplant preparative regimen and 22 minutes (range, 10-45 minutes) after leaving the protective environment. The interviews were conducted at a university hospital between May and December 2018.

Analysis

Interview data were analyzed using Graneheim and Lundman's content analysis[14] as follows: 1) All interviews were recorded and transcribed and their content analyzed verbatim; 2) The oncology nursing researcher listened to the recordings and reviewed the transcripts to identify meaningful units; 3) The oncology nursing researcher extracted the units associated with the study topics, such as motivation for physical activity, in the form of initial codes; 4) The oncology nursing researcher conceptualized and categorized the extracted types of motivation for direct physical activity based on similarities and differences in content under the supervision of a cancer nursing investigator. Pre-HSCT data were first analyzed, followed by post-HSCT data; 5) The oncology nursing researcher integrated all categories before and after HSCT and then categorized them based on their similarities; 6) All categories of motivation for physical activity were defined; 7) Themes were

Table 1. Patients' demographics

ID	1	2	3	4	5	6	7
Age	50s	50s	40s	40s	70s	40s	60s
Gender	F	F	F	M	F	M	M
Disease	ALL	AML	ALL	APL	AML	MDS	AML
Transplant	u-BMT	r-PBSCT	CBT	u-BMT	u-PBSCT	u-BMT	CBT
Conditioning regimen	CY+TBI	CY+BU+ATG+RT (spleen)	FLU+BU+MEL	FLU+BU+MEL	FLU+BU+TBI	FLU+BU+MEL	FLU+BU+MEL
Disease status	CR	PD	CR	CR	CR	CR	CR
Protective Environment days	27	48	31	32	30	39	28
PS before HSCT	1	1	1	1	1	1	1
PS After HSCT	2	3	3	3	3	1	1

AML, Acute myeloid leukemia; ALL, acute lymphoblastic leukemia; APL, acute promyelocytic leukemia; MDS, Myelodysplastic syndrome; BMT, bone marrow transplantation; CBT, umbilical cord blood transplantation; PBSCT, peripheral hematopoietic stem cell transplantation; CY, cyclophosphamide; TBI, total bodyirradiation; BU, busulfan; ATG, anti-thymocyte globulin; FLU, fludarabine; MEL, melphalan; CR, Complete remission; PD, Progressive disease

defined from all categories; and 8) Surface validation for all categories and themes were performed by nurses with at least 5 years of experience in hematology. All interviews were conducted in Japanese, and DeepL software was used to perform English-to-Japanese-to-English translation.

Ethics approval

The study protocol was approved by the ethics committee of the Tokushima University Hospital (no. 3143) and performed in accordance with the latest version of the Helsinki Declaration. Seven patients received information pamphlets and provided written informed consent before the interviews, which were conducted in a private room. The physical status of each patient was considered, and interviews were promptly conducted by the researcher.

Results

The participating patients comprised three men and four women aged 40-70 years (**Table 1**). The mean (± standard deviation) duration in the protected environment room was 33.5 ± 7.4 days. The mean ECOG PS of all patients before starting the preparative transplant regimen was 1. After leaving the protected environment room, two patients maintained a PS of 1; the performance status of one patient was lowered to a PS of 2 and four patients had a PS of 3. After HSCT, Patient 2 had complications of sinusoidal obstruction syndrome/veno-occlusive disease. Patient 3 had grade 2 intestinal GVHD and gastrointestinal bleeding. Patient 4 continued to have a high fever due to the infection. Patient 5 had a fall.

Motivation for physical activity

The motivation for physical activity among patients before versus after HSCT was classified into six categories, from which five themes were derived. The categories are described below for each of the five themes: "to overcome HSCT," "to look after myself," "to respond to the donor," "the existence of supporters," and "encouragement from supporters."

"To overcome HSCT"

"To overcome HSCT" indicated that the patient was motivated by a desire to live, survive, and reestablish a normal daily routine. HSCT patients found reasons for physical activity that got them closer to their goals.

Before HSCT

"I want to live and return home" indicated a desire to live and return home after completely recovering from the disease. The reasons why patients decided to undergo transplantation differed. For example, some wanted to live longer to spend more time with their children and care for their parents. Transplantation is done for oneself, but wanting to live for the family, especially children, was a key motivator for participating in physical activity.

"*It is over when I die. I do not want my children to cry. I think this is a source of motivation for physical activity. For the sake of my children, I want to return home alive.*" *(Patient 3)*

"I want to survive my transplantation" indicated that patients wanted to engage in physical activity to ensure that the transplantation was successful. They had reasons for being physically active before transplantation, such as weight loss and age.

"*I have heard that transplantation is a very rigorous treatment option. There is a high possibility of becoming bedridden because of old age. I am old and have no physical strength, so I have to move my body. I will do my best to prepare for the transplantation. I have to move myself. This is the difficulty of the treatment.*"

(Patient 5)
After HSCT

"I want to return to daily life" indicated a desire to escape from the current situation and be discharged early. Patients had various reasons for wanting to return to their daily lives as soon as possible, including functioning as parents or returning to work. They wanted to be discharged early so that they could fulfill their social roles.

"*I want to return to work after being discharged from the hospital. I want to gain more strength than I had before hospitalization because my work requires physical strength.*" *(Patient 6)*

"I want to be able to move again" Due to fatigue and other physical symptoms, it takes time to resume physical movement post-transplant; however, patients undergoing HSCT recognized the importance of physical movement as well as treatment.

"*I was unable to exercise when the preparative transplant regimen began. I felt heavy. My liver and spleen swelled up after the transplantation, and I could not move. I want to move again now that the symptoms have subsided.*" *(Patient 2)*

"To look after myself"

Indicated that the patient was motivated by the desire to perform personal activities independently, particularly the desire to use the bathroom or take a shower on their own.

Before HSCT

"I want to look after myself" indicated a need for independence in everyday routine behavior.

"*After chemotherapy (complete introduction therapy), I could not move at all except when going to the bathroom. I could not bring myself to move. However, I would like to go to the bathroom by myself.*" *(Patient 1)*
After HSCT

"I want to look after myself as much as I can" refers to reduced post-transplant physical status causing difficulty using the bathroom. However, the need to do so, at least independently, is a factor that motivated the patients.

"*I could not consciously think about it, but I knew that I only wanted to go to the bathroom by myself. I knew that I had to do everything I could.*" *(Patient 1)*

"*I tried my best to shower. From the beginning, I thought I had to move as much as possible.*" *(Patient 4)*

"To respond to the donor"

Indicated that the donor's presence was the reason behind the patients' hopes and desires to perform physical tasks as before HSCT. Their willingness to respond to the donor's feelings motivated them to perform physical activity.

Before HSCT

"I want to respond to the donor's feelings" indicated that the patient was grateful for receiving the bone marrow donation. They recognized the donor's existence as the only hope for a complete cure of the disease, which provided them with the energy to proceed with treatment.

"*I thought only about dying until a donor was found. I told my family that I did not want to undergo further treatment. When a donor was found, I thought that I should really do my best. I wanted treatment. I have a chance to thank the donor for remaining alive, so I want to try everything that I can.*" *(Patient 1)*

Having a family member as a donor was a significant source of emotional support. "*My sister became a donor and generously supported me.*" *(Patient 2)*

"The existence of supporters"

Indicates that patients were motivated by the presence of trusted medical professionals as well as people with the same disease who could share their transplant experience. This encouraged them to move independently. The presence of a supporter had a significant influence on patients' willingness to engage in physical activity.

Before HSCT

"The existence of reliable healthcare professionals" encouraged physical activity; when patients believed that the healthcare professionals involved in their treatment and care were reliable, they were more likely to engage in physical activity.

"*Doctors work hard to eliminate these illnesses. Nurses are at the bedside and provide peace of mind for us. I decided to undergo this transplant with the doctor I trust. The doctor advised me to commit to engaging in physical movement before the transplant, so I tried to move.*" *(Patient 4)*
After HSCT

"Being around people with the same disease with whom I can share the experience of transplantation" indicated that talking to people who suffered from the same disease made the patients feel more connected to them.

"*I was glad that I could help patients about to undergo a transplant by discussing my experiences and listening to them.*" *(Patient 5)*

"Encouragement from supporters"

Family members, health care providers, survivors, and other supporters of patients undergoing HSCT encouraged them to continue performing physical activity. The approval of healthcare professionals who understood the patients, as well as letters and photographs of the patients' children, gave them the strength they

needed to stay motivated.

Before HSCT

"I was encouraged by a patient who underwent HSCT" indicated that, by feeling closer to the patients who underwent HSCT and encouraging each other, the patients in this study could further motivate themselves to give their best effort to engage in physical activity.

"I go to the dayroom because it is fun to talk to other patients. I used to talk to people after transplantation. I was encouraged to do my best, and when I looked at other patients who received transplants and were discharged shortly thereafter, I thought I would do my best." (Patient 4)

After HSCT

"Encouragement and support from healthcare professionals who understand me" indicated that encouragement and approval from healthcare professionals who made the patient feel understood empowered the patient to perform physical activity.

"The physical therapist praised me for getting up from the bed. It was simple, but I was motivated by such praise." (Patient 6)

"A message expressing a wish for me to live" was the driving force. In particular, messages from children wanting to live with their parents were a powerful motivator for patients.

"My son said to me, 'Do not die. That is all. If you need bone marrow again,' he said, 'I will take care of it.'" (Patient 7)

"I placed pictures and letters written by my child on the wall, which gave me the strength to move." (Patient 4)

Discussion

Desire to survive

One motivation for patients undergoing HSCT was "wanting to live"[15]. In this study, "the desire to survive," a fundamental human desire, was the motivation for physical activity. Sometimes, transplantation is not only for oneself but also for one's family. In this study, most patients discussed their families before transplantation and were eager to return home alive to them.

Another patient stated, "I want to go back to work," indicating that returning to his social role was what motivated him. This can be as a way for patients to motivate themselves by setting the goals of living with their families and fulfilling their social roles after surviving the transplantation. After HSCT, several patients experience physical and emotional barriers[11], and overcoming them will help them maintain their hope to survive the transplantation. By identifying the meaning behind an individual's motivation for physical activity, the patient will be able to engage more proactively, increasing their chances of survival during and after transplantation.

Self-esteem

The theme "To look after myself" was observed, indicating the desire for self-discipline in adults. Patients undergoing HSCT wanted to care for themselves and be as self-sufficient as possible. In particular, patients undergoing HSCT wanted to perform activities of daily living by themselves, such as using the bathroom and taking showers. Many patients experience severe fatigue and self-management difficulties after HSCT. Tonosaki reported that post-HSCT fatigue was affected by diminished muscle strength[16]. Despite this, patients are motivated by a sense of self-reliance and self-esteem as mature adults, both physically and mentally, who want to do as much as possible on their own. Many patients with cancer report the need to be independent in daily activities[17], such as going to the bathroom and getting out of bed by themselves. This indicates that patients are motivated not only by physiological needs but also by a desire to be themselves and maintain their dignity as human beings. In Maslow's Hierarchy of Needs, esteem needs are placed at the fourth level and are described as those that motivate people toward self-actualization[18]. A survey conducted among college students reported a correlation between self-esteem and motivation[19]. Thus, it can be inferred that self-esteem is an important factor that motivates physical activity among transplant recipients.

Existence of supporters

"To respond to the donor," "the existence of support," and "encouragement from supporters" all indicated that different aspects were involved in motivating patients to perform physical activity.

Patients are unable to move after transplantation despite their desire due to various symptoms. At that time, as parents, the words of their child, "I want you to live," were a strong motivational force for patients undergoing HSCT. Family support for patients is important because the stronger the bond between the patient and their family, the less painful the patient's symptoms are[20]. Through their experience with HSCT, patients recognized that their families were irreplaceable and wished them to return alive, which encouraged them to be physically active. Family support motivates patients to engage in physical activity[11].

The presence of family members, healthcare providers, and peers can empower patients to continue engaging in painful physical activity. In particular, nurses should actively seek cooperation from the hematologist, as explanations from them will facilitate physical activity[10].

Positive feedback from other HSCT survivors also

promotes physical activity, and it is important to provide a place where people with the disease can communicate with each other[10,11]. Sharing the transplant experience with peers can help create a positive perception of one's own existence and aid the overcoming of transplant-related challenges. As it is difficult to maintain motivation for physical activity, encouragement from family members and medical personnel is essential.

Relevance for clinical practice

Physical activity effectively improves fatigue after HSCT, and various programs have been proposed[21,22]. Previous studies reported that before transplantation is the optimal time to begin exercise in preparation for HSCT[23]. However, few patients voluntarily exercise before HSCT in anticipation of their post-transplantation physical condition. Healthcare providers should clarify the purpose of pre- and post-transplant physical activity for HSCT patients and work with them accordingly. We recommend the following three nursing perspectives to promote physical activity motivation among transplant patients:

1) The physical activity of HSCT patients is strongly motivated by "the desire to survive," but beyond this, the desire to achieve this goal motivates the patients toward survival. It is important to share this information with the patients while providing support.

2) The principle of nursing is to help patients maintain their self-esteem in all circumstances. Self-esteem motivates transplant patients to be physically active; however, it is also true that self-care ability declines significantly before and after transplantation. Therefore, supporting the patient's motivation to perform physical activity while providing appropriate support for their self-care ability is important.

3) For transplant patients, the presence of supporters motivates physical activity. During the transplant treatment process, direct infection control visits and contact with medical professionals are limited because maintaining minimal human interaction is an important aspect of care. In particular, the presence of family members was significant in this study; therefore, it is important to provide support in cooperation with family members.

Limitations

This study had several limitations. First, it was an interview-based survey conducted at one institution and included only seven subjects. Therefore, more cases require study in a similar manner. Second, all patients in this study talked about their motivation for physical activity, and it is possible that the study was biased toward those who were highly interested. Third, the results of this study do not clarify how to motivate patients to perform or maintain physical activity. Fourth, complications after transplantation occur frequently, and many patients in this study developed complications. Since the presence of physical symptoms influences the motivation for physical activity, further studies that consider complications are needed of the motivation for physical activity.

Conclusion

Motivations for physical activity were identified as follows: "To overcome HSCT," "to look after myself," "to respond to the donor," "the existence of supporters," and "encouragement from supporters." Although transplant patients are in a highly invasive environment, the existence of factors that motivate them to be physically active is evident both internally and externally. Interventions from diverse perspectives are necessary to evaluate these motivations and link them to specific physical activities. In the future, it is important to develop intervention programs that involve the collaboration of multiple professionals.

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Author Contributions

K.N., S.F., R.Y., and C.O designed the study. K.N. collected the data. K.N. and C.O. analyzed the data. K.N., S.F., R.Y., and C.O. wrote the manuscript.

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Ethics Approval

The study protocol was approved by the ethics committee of the Tokushima University Hospital (No.3143) and was performed in accordance with the latest version of the Helsinki Declaration.

Consent for Publication

Seven patients received information pamphlets and provided written informed consent before the interviews, which were conducted in a private room. The physical status of each patient was considered, and interviews were promptly conducted by the researcher.

Conflicts of Interest

The authors declare no conflict of interest. Disclosure forms provided by the authors are available on the website.

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