<Original Article>

Difficulties and Management of Oral Self-care in Patients with Physical Symptoms in the Early Period Following Hematopoietic Stem Cell Transplantation

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ABSTRACT

Objective: The purpose of this study was to identify the challenges patients experience with oral self-care during the early period following hematopoietic stem cell transplantation (HSCT) and to explore how they manage these challenges.

Methods: Semi-structured interviews were conducted with 12 patients (4 men, 8 women) who had undergone HSCT and were receiving outpatient care for physical symptoms. Data were analyzed qualitatively using an inductive approach to examine the difficulties and management strategies associated with oral self-care.

Results: Patients in the early post-transplant period reported three main difficulties: (1) managing oral self-care despite physical pain, (2) maintaining oral self-care routines, and (3) independently assessing and managing oral symptoms. Patients in the early post-transplant phase managed these difficulties using six methods, including "self-care tailored to multiple physical symptoms".

Conclusion: Physical pain was the most significant barrier to effective oral self-care. Nurses should provide individualized support tailored to the patient's condition and progress post-transplantation.

INTRODUCTION

Hematopoietic stem cell transplantation (HSCT) is employed for hematopoietic diseases that are unresponsive to conventional chemotherapy alone [1]. Advances in supportive care have contributed to improvements in transplant outcomes and enabled long-term survival for post-transplant patients [1, 2]. However, there is a continued risk of various post-transplant complications, including chronic graft-versus-host disease (GVHD) [3–6]. Post-transplant complications arise primarily through two main mechanisms: the conditioning regimen of total body irradiation and high-dose chemotherapy, and the development of chronic GVHD [7]. In addition, the destruction of normal bone marrow and immune cells due to pre-transplant treatments, along with the use of immunosuppressants to manage chronic GVHD, can impair cellular and humoral immunity, making it easier for infections to become seri-

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ous [8]. Patients in the post-transplant period typically discontinue immunosuppressants about one year after transplantation. However, due to the potential for multiple physical complications from the intensive pre-transplant procedures, which includes systemic radiation and high-dose chemotherapy, ongoing management of general symptoms is required. Nurses play a critical role in providing screening for post-transplant complications, implementing infection control measures, and offering both daily and social support at long-term follow-up (LTFU) outpatient clinics, tailored to the needs and condition of each patient.

In chronic GVHD, the most commonly affected sites are the eyes, skin, and mouth, with reported incidences of 31 %, 25 %, and 21 %, respectively, based on a cross-sectional survey of 1,140 allogeneic transplant survivors [9]. The oral mucosa, being particularly vulnerable to immunological disorders, is frequently affected by chronic GVHD [2, 10]. Common symptoms include hypersensitivity to food, oral pain, dry mouth, ulceration, increased susceptibility to tooth decay, difficulty speaking, and altered taste perception [10, 11]. In addition, oral complications can increase the risk of infection and secondary cancers [12, 13].

Since patients can independently care for their oral cavity, it is primary focus of outpatient guidance [1]. Oral bacteria significantly influence the frequency and severity of oral symptoms associated with cancer treatment [14]. Studies have shown a clear reduction in the incidence of oral mucositis following instruction in oral care for patients undergoing HSCT [15]. Furthermore, a comparative study reported a significant reduction in the incidence of ulcerative oral mucositis in patients receiving oral care intervention, suggesting that such care may mitigate oral mucositis in patients in the post-transplant period [16]. Therefore, monitoring oral care, and recognizing and managing symptoms independently can be beneficial for patients. For this reason, the Guidelines for the Oral Management of Patients undergoing Hematopoietic Cell Transplantation [17] recommend maintaining oral hygiene and scheduling regular dental check-ups. Prior to discharge, patients receive guidance on oral self-care and life after hospitalization. A new fee structure for the guidance and management of patients in the post-transplant period was introduced in 2012 to support appropriate interventions for the various conditions and challenges these patients encounter in the post-transplant period [18]. However, due to the anatomical complexity and limited visibility within the oral cavity, oral complications can be easily overlooked without sufficient anatomical knowledge and observation techniques [19]. In addition, a study by Nuernberg et al. [20] reported that patients with chronic oral GVHD often struggle to maintain oral hygiene, resulting in poor oral cleanliness. Therefore, to prevent the development and progression of oral complications, it is essential that patients with physical complications continue to manage their own oral health independently.

Prior to 2014, research on oral self-care following transplantation focused primarily on the perioperative period. The enactment of the Act to Promote the Appropriate Provision of Hematopoietic Stem Cells for Transplantation in 2014 led to an increase in research on oral self-care in the perioperative period after transplantation, including case reports on oral care for chronic oral GVHD [21] and research on standardizing oral care programs [22]. However, there have been no studies on oral self-care in the early post-transplant period (i.e., from discharge to 1–2 years after transplantation).

During the early post-transplant period, patients begin to reintegrate into daily life, but physical symptoms and emotional distress often disrupt their expected recovery, making it difficult to manage their symptoms effectively [1, 18]. In addition, as survival rates after transplantation have increased, patients' quality of life has become an important health outcome [1, 2]. However, little is known about the experiences of patients attending LTFU outpatient clinics during the early post-transplant period, or how they address challenges related to oral self-care. By clarifying the difficulties these patients face and their approaches to oral self-care, this study aims to identify strategies that highlight patients' self-care capabilities. These insights can guide the development of tailored oral self-care support, ultimately contributing to improved quality of life for patients in the early post-transplant period.

METHODS

Study design

This study employed a qualitative inductive research design.

Participants and setting

The selection criteria included adult patients receiving outpatient care who were within 10 years of their transplant and able to provide informed consent. Patients who had undergone autologous transplantation, those with dementia, and those experiencing a high physical or mental burden were excluded.

To conduct the survey, we asked the hospital and two patient organizations, which had agreed to cooperate, to introduce us to eligible patients. We also used snowball sampling to recruit participants. We provided written explanations of the study's purpose to the selected participants, arranged interview dates, and conducted interviews with potential participants who understood the research objectives and gave their consent.

Data collection period

This study was conducted from May 1, 2023 to June 30, 2024.

Data collection

To explore the difficulties and management of oral self-care in patients with physical symptoms during the early post-transplant period, we conducted semi-structured interviews using an interview guide. The interview covered topics including specific oral self-care behaviors and the reasons behind them in the early post-transplant period (approximately 1–2 years post-transplant), challenges and management of oral self-care, changes in self-care practices immediately after discharge to the early post-transplant period, healthcare provider interventions in oral self-care, participants' views on these interventions, and the kind of measures employed to maintain oral self-care. Interviews were conducted in private rooms to ensure confidentiality, after confirming that the participants were not unwell; the interviews were recorded with participants' consent. Each interview lasted approximately 60 minutes, with adjustments made if participants wished to continue beyond this time, taking fatigue into consideration.

Data analysis

Verbatim transcripts were prepared from the interview recordings, and qualitative inductive analysis was performed. In the individual analysis, the verbatim record was read over and over again, and the parts related to the verbal self-care difficulties and management of each participant were identified. Descriptions of the difficulties and management were separated and organized, with subjects and objects added to clarify the meaning of the verbatim transcript. The meaning of each participants narrative was expressed concisely, ensuring that the context before and after the statement was preserved. These refined statements were defined as primary codes. Analysis is an iterative process, and the researchers deepened their understanding of the data as they moved through the stages of analysis. First, one researcher read all the records and generated primary codes. Two researchers held a meeting to discuss the primary codes. In the overall analysis, primary codes from all participants were collected, and their similarities and differences were compared to capture the essential meaning, which was defined as the secondary code (hereafter referred to as the code). Before narrowing down the tentative themes and category analysis, the research team held a meeting to discuss the codes and generate codes. The generated codes were compared and analyzed, and those with similar meanings were grouped into categories, and themes in increasing levels of abstraction. The three researchers held a meeting to discuss the categories and themes that had been identified from the codes. When assigning categories and themes, we quoted the participants' words as much as possible in order to find terms that best expressed the patients' experiences. The data analysis in the qualitative descriptive study was conducted inductively, referring to an analytical method that describes the data as directly as possible without deviating from the participants' narratives and without making inferences [23]. The four researchers reviewed the themes and categories, returned to the entire data set, refined the analysis, and completed the coding.

Definition of terms

1) Oral self-care

In managing the patient's general condition, we decided not only to keep the mouth clean, but also to prevent, treat and manage oral complications to maintain oral function [24].

This study is based on Lazarus' stress coping theory [25], with the following definitions of difficulties and management:

2) Difficulties

The physical and psychosocial challenges and concerns encountered by patients during the post-transplant period.

3) Management

A cognitive and behavioral effort to address the difficulties faced by patients with physical symptoms during the post-transplant period.

Stringency

We ensured the stringency of the research based on the criteria of truth value, applicability, consistency, and neutrality [26]. Firstly, to ensure truth value, participants were encouraged to speak freely about the difficulties and management of oral self-care. To ensure the accuracy of the recorded interviews, interviews were repeated as much as possible. Secondly, to ensure applicability, we provided background information on the participants. Thirdly, in order to maintain consistency, the difficulties and management of the story were frequently reviewed and critically examined. Finally, to ensure neutrality, we tried to eliminate any bias or prejudice on the part of the researchers when interpreting the data. In addition, a neutral stance was maintained to ensure that the researcher's reactions did not influence the interviews or the analysis. To increase the reliability of the analysis, the descriptions of the patients' oral self-care difficulties and management were verified by four nurse researchers.

Ethical considerations

This study was performed in accordance with the Declaration of Helsinki and the Ethical Guidelines for Medical and Health Research Involving Human Subjects, and was conducted with the approval of the Nursing Research Committee of Osaka University of Pharmaceutical Sciences and Health Sciences (NO: 2023-011). Research participants were provided with both written and verbal explanations of the study outline, purpose, survey methods, expected benefits and disadvantages, freedom to with-

draw from participation, handling of personal information, and data storage. Informed consent was obtained from all participants. The interviews were conducted in a setting that ensured privacy. Given that the participants were post-transplant patients, their physical and mental condition was carefully considered during the interviews. A support system was also prepared to address any physical and mental health concerns that might arise during the study.

RESULTS

Research participant summary

The study included 12 participants (4 men and 8 women) in their 20s to 60s (mean 53.7 years). The time since transplantation ranged from 4.5 months to 9 years (mean 3.5 years) (**Table 1**). Interviews lasted between 50 and 90 minutes (average 75 minutes) and all 12 participants gave their consent to be recorded. The interview was based on personal records, such as diaries, that the research participants had brought with them and they were asked to recall and talk about the period 1 to 2 years after transplantation. None of the participants complained of fatigue or poor physical condition during the interview.

The participants' primary diseases and symptoms are shown in **Table 2**. The most common symptoms affected the mouth, skin, and eyes. Symptoms that developed within a few months to a year after transplantation included diarrhea, compression fracture, fatigue and muscle weakness, and memory and concentration problems (**Table 2**). Symptoms that developed several months after transplantation and continued for years included dry eyes, skin symptoms, joint symptoms, and peripheral neuropathy. In addition, oral symptoms of dry mouth and gingivitis persisted for years.

Participants' oral self-care practices are shown in **Table 3**. All participants brushed their teeth, eight of them twice a day. Eleven participants gargled, and six of them used mouthwash or drank water to relieve dry mouth. Eight participants visited the dentist regularly.

Difficulties with oral self-care in early post-transplant patients with physical symptoms

Difficulties related to oral self-care in the early post-transplant period for patients with physical symptoms were categorized into 232 codes, 15 categories and three overarching themes: [After transplantation, physical symptoms are painful, making adequate oral self-care challenging], [It is difficult to maintain oral self-care routines when the benefits are not immediately noticeable], and [Assessing and managing oral symptoms independently is challenging due to inadequate environmental support] (**Table 4**). The theme is shown in **[ ]**, the category in **{ }**, the code in **< >**, and the participant's narrative in " ".

[After transplantation, physical symptoms are painful, making adequate oral self-care challenging]

This theme consisted of four categories. In the category {When you have strong physical symptoms or feel very tired, it's bothersome and difficult to move just to look after your oral health.}, the patient said: "I experienced regular compression fractures. Every month or so, I would feel pain again after about two weeks, followed by another fracture. I was afraid to move even a little. (Patient I) "The patient experienced strong physical symptoms and said: "When I went to the toilet, it felt like it would just rush out. If I relaxed, it would come out. Even when I was sleeping, it was like, "Is that just flatulence?" So, it was frightening, because whenever I sat down on the toilet, I felt I might have diarrhea". (Patient E). As a result, the patient said: "I found it inconvenient to get up and brush my teeth. It was difficult to muster the energy just to brush my teeth. (Patient I)" and "If my mouth hurts, I just go to sleep. When I'm done, I feel too lazy to do anything else. If I'm busy or my symptoms are strong, I just give up." (Patient H)

In the category {If the mucous membrane of the mouth is peeled off or the pain is too intense, it is not possible to carry out oral self-care.}, a patient with severe oral symptoms said: "If I have a mouth ulcer that is large, it hurts too much to continue. I know I have to do it, but I feel depressed and it seems overwhelming. (Patient I)" this patient was thus unable to perform oral self-care.

In the category {Inability to brush teeth effectively due to peripheral neuropathy or limited visibility within the oral cavity.}, the patient described their experience as follows: "My lower limbs have been numb for a long time, and I feel weak, making it difficult to move them, so standing for five minutes is challenging" (Patient C); "Sometimes, I have trouble brushing my teeth because they grow in an unusual way, and I'm not sure if the brush is reaching all of the surfaces or effectively cleaning them" (Patient D); "The cup I use for brushing my teeth is too small, and I can't reach it." (Patient D); "The cup keeps shaking. It shakes and spills ... (omitted). When I hold it with one hand it shakes so much that it's really amusing." (Patient L). The patient encountered significant difficulties with oral self-care due to a decline in physical function and movement limitations.

In the category {Susceptible to nausea, e.g., as a side effect of oral medications, with nausea triggered by placing a toothbrush in the mouth.}, a patient with severe nausea said: "When I am nauseous, I can hardly brush my teeth because if I put anything in my mouth, I vomit. (Patient D)" this patient was thus unable to perform oral self-care. Post-transplant patients had symptoms of nausea and vomiting due to medication side effects, among other factors, that interfered with oral care.

[It is difficult to maintain oral self-care routines when the benefits are not immediately noticeable]

This theme consisted of five categories. In the category {When oral symptoms are under control, the need and interest in oral self-care decreases, so oral self-care becomes

Table 1 Attributes of study participants

ID	Sex	Age	Name of disease	Number of years since transplant	Type of transplant	Radiation therapy	Immunosuppressant medication	Cohabiting family	Employment and school attendance status	Patient Association	Interview time (minutes)
A	Man	60s	Myelodysplastic syndrome	3 years	Umbilical cord blood	Not implemented	Without	With	Reinstatement	Non-participation	90
B	Woman	40s	Acute lymphocytic leukemia	2 years	Umbilical cord blood	Implementation	Without	With	Reinstatement	Participation	90
C	Woman	50s	Acute lymphocytic leukemia	1 year 9 months	Umbilical cord blood	Implementation	Without	With	Leave of absence	Non-participation	90
D	Woman	60s	Acute myeloid leukemia	8 years	Peripheral blood	Implementation	Without	With	Unemployed	Participation	90
E	Woman	50s	Acute myeloid leukemia	2 years	Umbilical cord blood	Not implemented	Without	With	Unemployed	Non-participation	50
F	Man	30s	Aplastic anemia	2 years	Bone marrow	Implementation	Without	With	Reinstatement	Non-participation	60
G	Woman	60s	Myelofibrosis	9 years	Bone marrow	Not implemented	Without	With	Unemployed	Participation	90
H	Man	20s	Acute lymphocytic leukemia	2 years	Bone marrow	Implementation	Without	With	Unemployed	Non-participation	50
I	Woman	40s	Acute myeloid leukemia	7 years	Bone marrow	Not implemented	Without	With	Reinstatement	Non-participation	90
J	Woman	60s	Acute lymphocytic leukemia	3 years	Bone marrow	Implementation	Without	With	Unemployed	Non-participation	50
K	Woman	60s	Myelodysplastic syndrome	1.5 years	Umbilical cord blood	Not implemented	With	Without	Unemployed	Non-participation	90
L	Man	50s	Myelodysplastic syndrome	4.5 months	Bone marrow	Not implemented	With	With	Reinstatement	Non-participation	60

Table 2 Main diseases and symptoms in transplant recipients in the early post-transplant period

ID	Main diseases and symptoms	Oral symptoms
A	Mycobacterium avium complex pulmonary disease, nausea and vomiting caused by the treatment for pulmonary Mycobacterium avium complex disease, eye symptoms, peripheral neuropathy of the lower limbs, muscle weakness, fatigue, skin symptoms	Xerostomia, gingivitis, dental caries
B	Hydrocephalus, shingles, skin symptoms, nausea/vomiting, diarrhea, muscle weakness, fatigue	Xerostomia, gingivitis, dental fracture, dental caries
C	Compression fracture, herniated disc, joint symptoms, diarrhea, skin symptoms, muscle weakness, fatigue	Mild mouth ulcer
D	Pure red cell aplasia, pharyngeal cancer, skin symptoms, eye symptoms, tumors on the fingers, loss of concentration, muscle weakness, fatigue	Xerostomia, gingivitis, stomatitis, herpes labialis, changes in taste perception
E	Nausea and vomiting, eye symptoms, peripheral neuropathy of the lower limbs, muscle weakness, fatigue, skin symptoms	Dry mouth, dry lips, hypersensitivity
F	Diarrhea, chickenpox, difficulty sweating, regular fever, eye symptoms, skin symptoms, muscle weakness, memory loss, fatigue	Dry mouth, dry lips, swollen tonsils, hypersensitivity
G	Cellulitis, shingles, skin symptoms, joint symptoms, muscle weakness, fatigue	None
H	Nausea and vomiting, regular infections, skin symptoms, muscle weakness, fatigue	Dry mouth, mouth ulcers
I	Compression fracture, skin symptoms, septic, loss of concentration, muscle weakness, fatigue	Dry mouth, dry lips, mouth ulcers, impaired taste, tongue tumors, Dental pain due to neuroinflammation
J	Peripheral neuropathy, shingles, skin symptoms, eye symptoms, muscle weakness, fatigue	None
K	Diarrhea, loss of appetite, weight loss, fever, skin symptoms, eye symptoms, mood swings, insomnia, peripheral neuropathy, muscle weakness, fatigue	Xerostomia, taste disorder, dry lips, tongue coating, dental caries, tumors of the lips, oral discomfort
L	Trembling of the hands and fingers, skin symptoms, muscle weakness, fatigue	Dry lips

less of a priority and oral self-care is sometimes omitted.}, patients commented: “When the symptoms are under control, I think it’s OK to stop.” (Patient D), “I’m not interested because I don’t have any oral symptoms.” (Patient L). These responses indicate that when patients had few oral symptoms, the perceived need for oral self-care decreased.

In the category {Implementing multiple types of daily care is burdensome.}, one patient said: “There are many different types of care, so It’s not just one thing—there are six different types. (Patient A)”. This response showed that patients found it difficult to carry out oral self-care while also caring for and taking medication for multiple physical symptoms.

In the category {Continuing treatment is challenging if it does not appear effective for managing oral symptoms.}, a patient said: “My mouth hurt until about autumn, no matter what I did. I didn’t t really feel the effects of the treatment.” (Patient D). This highlights the difficulty of maintaining oral self-care when the benefits are not immediately apparent.

In the category {Forgetting to take medication or perform care when there is a change in the usual routine.}, a patient said: “I forget about medicines, care, if there is a slight change in the flow of the day.” (Patient J). This opinion indicated that changes in the patient’s care schedule make oral care more difficult.

In the category {Limited knowledge about oral self-care practices, including the use of specific self-care items and techniques like salivary gland massage.}, a patient said: “I’ve never heard of saliva massage or anything like that.” (Patient L). This was indicated by a lack of knowledge about oral care, including oral care products and coping strategies such as salivary massage for xerostomia.

[Assessing and managing oral symptoms independently is challenging due to inadequate environmental support]

This topic consisted of six categories. In the category

Table 3 Oral self-care and oral care items in early post-transplant patients

ID	Oral self-care	Oral care products
A	Brushing teeth twice a day, morning and evening, using mouthwash, regular dental visits, regular drinking of water.	Toothbrushes, one-tufted brushes, interdental brushes
B	Brushing teeth twice a day morning and evening, using mouthwash 2–3 times a day, regular dental visits, salivary gland massage, oral medication for dry mouth symptoms, application of lip balm.	Toothbrushes
C	Brushing teeth five times a day on waking, after meals and before bedtime, using mouthwash twice a day, use of mouthwash solution, regular dental visits, Regular drinking of water.	Toothbrushes, one-tufted brushes, interdental brushes
D	Brushing teeth twice a day, morning and evening, rinsing once or twice a day, using mouthwash, regular dental visits, Salivary gland massage, use of artificial saliva, application of ointments, regular observation of the mouth with a mirror	Toothbrushes, interdental brushes, tongue brushes, sponge brushes
E	Brushing teeth twice a day in the morning and evening, rinsing several times a day, use of mouthwash, application of ointment, observation of the oral cavity with a mirror, drinking water, Lip balm application, wearing a mask	Toothbrush, floss
F	Brushing teeth three times a day morning, noon and before bed, rinsing mouth several times a day, regular drinking of water, licking candy, Observing the oral cavity in a mirror (when symptoms are present), wearing a mask	Toothbrushes, interdental brushes
G	Brushing teeth twice a day in the morning and evening, rinsing once a day on waking, using mouthwash, regular dental visits.	Toothbrushes
H	Brushing twice a day, morning and evening, regular mouth washing, regular dental visits.	Toothbrushes, interdental brushes
I	Brushing teeth twice a day in the morning and evening, using mouthwash several times a day, using mouthwash, regular dental visits, application of ointments, drinking water, applying lip balm	Toothbrush, floss
J	Brushing teeth twice a day, morning and evening, regular dental visits	Toothbrushes, floss, interdental brushes
K	Brushing teeth four times a day after meals and before bedtime, using mouthwash, wearing a mask, applying gel, taking medication to improve dry mouth symptoms, drinking water, regular dental visits.	Toothbrushes, floss, interdental brushes
L	Brushing teeth once a day before bedtime, several times a day, including using mouthwash.	Toothbrushes

{It is difficult to make independent judgments because the symptoms are unpredictable, and the criteria for management are vague without specific guidance on how to address oral symptoms when they arise.}, one patient said the following: “I’m uncertain if I should just wait and see with mouth ulcers, or if there are any ointments I could use. I think about consulting another doctor if these symptoms reoccur. I’d like some standard guidelines for symptoms.” (Patient D); “Once I’m discharged, I’ll have to decide on my own when I need to see a doctor.” (Patient I). This illustrates the difficulty patients face in independently assessing unpredictable oral symptoms after transplantation.

In the category {The instructed care, such as brushing techniques and appropriate pressure to apply, is challenging to implement or there is too much information to remember.}, patients who received instructions during their dental check-up said the following: “I was taught how to brush my teeth, but I find it difficult to do. Brushing teeth is really challenging.” (Patient C); “I was recommended different oral self-care methods, but it felt overwhelming. I was repeatedly told how important oral care is, but I don’t remember most of the techniques I was shown.” (Patient H).

In the category {Brushing teeth at the workplace is challenging due to the time required, the risk of infection, and the desire for privacy during oral self-care.}, one patient said: “If I’m going to brush my teeth, I want to do it thoroughly, so I don’t want to do it short sessions at work. I also don’t like doing it in a way that feels messy or strange.”

Table 4-1 Difficulties of oral self-care in patients with physical symptoms in the early period after hematopoietic stem cell transplantation

Theme: After transplantation, physical symptoms are painful, making adequate oral self-care challenging.	
Category	Code
When you have strong physical symptoms or feel very tired, it's bothersome and difficult to move just to look after your oral health.	"When I go to the toilet, it feels like it just happens immediately; if I relax, it comes out." (Patient E) "When my mouth is sore, I go to bed, and when I'm busy or experiencing severe symptoms, I skip it." (Patient H) "I had regular compression fractures, about once a month. After two weeks, it would start hurting again and then break, which was difficult; even a small movement felt frightening." (Patient I)
If the mucous membrane of the mouth is peeled off or the pain is too intense, it is not possible to carry out oral self-care.	"Chapped lips make it difficult to eat and brush teeth." (Patient B) "I stopped taking care of my mucous membranes because my mouth got so bad, and I was scared." (Patient D) "If a mouth sore is too large, it's too painful to care for. You know you need to take care of it, but it feels overwhelming and discouraging." (Patient I) "I didn't want to brush my teeth because it hurt so much. The pain was prolonged, and I wondered for about six months if it would ever go away." (Patient I) "One day, I suddenly had severe pain while chewing—it hurt so much I couldn't eat. I went to the doctor, who said it wasn't a cavity but inflammation near a nerve in the back." (Patient I)
Inability to brush teeth effectively due to peripheral neuropathy or limited visibility within the oral cavity.	"The lower limbs are constantly numb, with weakness and difficulty moving them, making it hard to stand for five minutes." (Patient C) "The issue with brushing is that my teeth are misaligned, so the brush doesn't reach all areas effectively, and it may not fully remove the dirt." (Patient D) "The cup shakes—shakes a lot—causing water to spill." (Patient L)
Susceptible to nausea, e.g., as a side effect of oral medications, with nausea triggered by placing a toothbrush in the mouth.	"When I ate, I felt like I was going to vomit. In a way, it would have been better if I did vomit, but at the same time, vomiting would have been terrible." (Patient A) "When I am nauseous, I can hardly brush my teeth because if I put anything in my mouth, I vomit." (Patient D) "If I feel something is wrong with my stomach, it starts to feel unsettled, and I end up vomiting." (Patient E)

(continued)

(Patient I). This response reflects the difficulty of performing oral self-care in a work environment where conditions differ from those at home.

In addition, in the category {Even if the people around you are medical professionals or other transplant patients, there is a difference in perception between you and the people around you because they don't fully understand transplant patients, so it feels like they don't relate.}, patients said the following: "There is a difference in perception between myself and other people. This gap exists with any illness; if you haven't experienced it, you can't fully understand it." (Patient D); "Even if the age or illness differs slightly, the main points of treatment are the same, yet no two people are exactly alike. This disease is unique, and I think everyone's experience is somewhat different." (Patient C). Patients felt that it was challenging to gain genuine understanding from those around them regarding their situation.

In the category {There are no nurses with transplant-specific knowledge who can provide timely advice on specific transplant-related issues}, one patient stated: "I can't ask about my symptoms as soon as they arise, so I still feel a lot of anxiety." (B). This indicates that the patient continued to feel anxious due to reduced access to medical staff intervention after discharge.

In the category {Challenges in using oral self-care products, such as an unpleasant mouthwash taste or an ill-fitting mouthpiece.}, a patient said: "The gargle solution tastes

Table 4-2 Difficulties of oral self-care in patients with physical symptoms in the early period after hematopoietic stem cell transplantation

Theme: It is difficult to maintain oral self-care routines when the benefits are not immediately noticeable.	
Category	Code
When oral symptoms are under control, the need and interest in oral self-care decreases, so oral self-care becomes less of a priority and oral self-care is sometimes omitted	"Oral care tends to become a lower priority when symptoms improve." (Patient B) "If the symptoms subside significantly, I feel ready to move on." (Patient D) "No preventative measures are taken for mouth problems when there are no symptoms." (Patient G) "I am not interested in oral self-care because I have no symptoms." (Patient L)
Implementing multiple types of daily care is burdensome.	"There are several types of care needed, not just one—there are six different types." (Patient A) "When I had to take a lot of medication, I experienced frequent vomiting and diarrhea, and because of my physical weakness, I had to alternate between moving a little and then resting." (Patient C) "I had to ask my family to apply the ointment daily, and they said it was becoming a hassle. It was really hard for me at that time, and there were moments when I cried and said, 'I would do it myself if I could manage it.' If I could do it on my own, I would, but I can't, so I rely on them, and that makes it difficult for me." (Patient I)
Continuing treatment is challenging if it does not appear effective for managing oral symptoms.	"My mouth was sore until about autumn, regardless of whether I performed the care or not, and I didn't feel much benefit from it." (Patient D) "It's hard to keep up with it. After a dental cleaning, it feels smooth, and I try hard to brush, but without any oral symptoms, I gradually stop caring for my mouth." (Patient G) "Salivary gland massage doesn't seem very effective, so I don't do it much anymore." (Patient H)
Forgetting to take medication or perform care when there is a change in the usual routine.	"I forget about medicines, care, if there is a slight change in the flow of the day." (Patient J)
Limited knowledge about oral self-care practices, including the use of specific self-care items and techniques like salivary gland massage.	"I don't understand the priorities in oral care—is brushing my teeth the best approach?" (Patient C) "(I have) xerostomia, but I didn't receive saliva massage—I didn't know about it." (Patient F) "I've never heard of saliva massage or anything like that." (Patient L)

(continued)

somewhat unpleasant." (Patient F). This revealed that there were difficulties in using oral self-care products.

Management of oral self-care difficulties in early post-transplant patients with physical symptoms

The management of difficulties related to oral self-care in patients with physical symptoms in the early post-transplant period were categorized into 296 codes, 17 categories and six overarching themes. The theme is shown in **[ ]**, the category in **{ }**, the code in **< >**, and the participant's narrative in " ". **Table 5** shows the management of the difficulties of oral care in patients who present with physical symptoms in the early period after hematopoietic stem cell transplantation.

These categories were organized under six overarching themes: [Self-care tailored to multiple physical symptoms and performed with creativity], [Adjusting oral self-care based on experience, in response to symptoms and environmental factors], [Establishing effective care habits based on guidance and experiences received during hospitalization], [Accepting and addressing new symptoms post-transplant with a sense of responsibility as a transplant recipient], [Independently assessing symptoms, accepting limitations, and enduring them when necessary], and [Seeking support from those around you to enable continued self-care of the mouth] (**Table 6**).

Table 4-3 Difficulties of oral self-care in patients with physical symptoms in the early period after hematopoietic stem cell transplantation

Theme: Assessing and managing oral symptoms independently is challenging due to inadequate environmental support.	
Category	Code
It is difficult to make independent judgments because the symptoms are unpredictable, and the criteria for management are vague without specific guidance on how to address oral symptoms when they arise.	"I would like to know whether I can monitor the mouth ulcers as they are or if I should consider seeing a specialist when these symptoms appear, or if there are other criteria to follow." (Patient D) "I'm not really sure where the line is drawn between what's concerning and what's acceptable after transplantation." (Patient H) "Once discharged from the hospital, they must also decide on their own when they need to see a doctor." (Patient I)
The instructed care, such as brushing techniques and appropriate pressure to apply, is challenging to implement or there is too much information to remember.	"I've used floss before, but I don't use it now, it was too difficult to manage." (Patient A) "I've been taught about tartar brushing, but I find it really difficult to brush teeth that are hard to reach." (Patient C) "They explained how to do oral self-care, but I was told so many things that I don't remember most of them now." (Patient H)
Brushing teeth at the workplace is challenging due to the time required, the risk of infection, and the desire for privacy during oral self-care.	"When work started, it became a bit more challenging to manage my care and take internal medications." (Patient B) "I used to bring my toothbrush and take care of my oral hygiene, but now, with COVID-19 being so widespread, it's harder for me to prioritize mouth care in the same way." (Patient C) "When I'm working, I don't have time to brush my teeth carefully. I tend to brush messily, and I don't like brushing my teeth outside of my home anymore." (Patient I)
Even if the people around you are medical professionals or other transplant patients, there is a difference in perception between you and the people around you because they don't fully understand transplant patients, so it feels like they don't relate	"I think it's remarkable that no two people experience the same disease in exactly the same way; everyone is different in some way." (Patient C) "There is a gap in understanding between yourself and others, a gap that only those who have been through it can fully comprehend, and that's significant." (Patient D) "When I went alone, I had to explain quite a lot about my treatment and symptoms, and it was challenging because the other doctors in the department didn't know much about transplantation." (Patient I)
There are no nurses with transplant-specific knowledge who can provide timely advice on specific transplant-related issues.	"The sudden onset of symptoms remains a concern, as it's not easy to seek immediate assistance." (Patient B) "I had a follow-up outpatient session where we discussed my symptoms briefly, but now it's over, and I've lost one place to talk about them." (Patient G) "I feel that if I could meet with the ward nurses, I could discuss more specific aspects of my life with them." (Patient I)
Challenges in using oral self-care products, such as an unpleasant mouthwash taste or an ill-fitting mouthpiece.	"The gargle solution tastes somewhat unpleasant." (Patient F) "They offered to make me a mouthpiece, which they did, but it's uncomfortable to sleep with and it makes my mouth feel uneasy." (Patient I) "My mouth seems to be sensitive, and the irritation from toothpaste is painful." (Patient K)

[Self-care tailored to multiple physical symptoms and performed with creativity]

This topic was divided into four categories. In the category {Use goods and medicines according to the physical symptoms that appear and cope with them in their own way.}, one patient said: "When I feel slightly nauseous, I pause my routine and take breaks in between". (Patient J).

In the category {Taking measures to ensure that

Table 5 Management of the difficulties of oral care in patients who present with physical symptoms in the early period after hematopoietic stem cell transplantation

Theme: After transplantation, physical symptoms are painful, making adequate oral self-care challenging.		
Category	Management	Patients
When you have strong physical symptoms or feel very tired, it's bothersome and difficult to move just to look after your oral health.	Management (1–6)	Patients A, B, C, D, E, F, G, H, I, J, K and L
If the mucous membrane of the mouth is peeled off or the pain is too intense, it is not possible to carry out oral self-care.	Management (1, 2, 4–6)	Patients B, D, E, F, I and K
Inability to brush teeth effectively due to peripheral neuropathy or limited visibility within the oral cavity.	Management (1–6)	Patients A, C, D, E, G, I, J, K and L
Susceptible to nausea, e.g., as a side effect of oral medications, with nausea triggered by placing a toothbrush in the mouth.	Management (1–6)	Patients A, B, D, E and H
Theme: It is difficult to maintain oral self-care routines when the benefits are not immediately noticeable.		
Category	management	Patients
When oral symptoms are under control, the need and interest in oral self-care decreases, so oral self-care becomes less of a priority and oral self-care is sometimes omitted	Management (2–5)	Patients A, B, C, D, G, J and L
Implementing multiple types of daily care is burdensome.	Management (1–4, 6)	Patients A, B, C, D, E, F, G, H, I, J, K and L
Continuing treatment is challenging if it does not appear effective for managing oral symptoms.	Management (2–4, 6)	Patients D, G, H, J, K and L
Forgetting to take medication or perform care when there is a change in the usual routine.	Management (2–6)	Patients D, H and J
Limited knowledge about oral self-care practices, including the use of specific self-care items and techniques like salivary gland massage.	Management (5, 6)	Patients C, D, E, F, G, J and L
Theme: Assessing and managing oral symptoms independently is challenging due to inadequate environmental support.		
Category	management	Patients
It is difficult to make independent judgments because the symptoms are unpredictable, and the criteria for management are vague without specific guidance on how to address oral symptoms when they arise.	Management (5, 6)	Patients A, B, C, D, E, F, G, H, I, J, K and L
The instructed care, such as brushing techniques and appropriate pressure to apply, is challenging to implement or there is too much information to remember.	Management (1–6)	Patients A, C, H, I, and L
Brushing teeth at the workplace is challenging due to the time required, the risk of infection, and the desire for privacy during oral self-care.	Management (2–5)	Patients A, B, C, F and I
Even if the people around you are medical professionals or other transplant patients, there is a difference in perception between you and the people around you because they don't fully understand transplant patients, so it feels like they don't relate	Management (5, 6)	Patients A, B, C, D, I, J and K
There are no nurses with transplant-specific knowledge who can provide timely advice on specific transplant-related issues.	Management (5, 6)	Patients A, B, D, F, G, I, J, K and L
Challenges in using oral self-care products, such as an unpleasant mouthwash taste or an ill-fitting mouthpiece.	Management (2, 3, 5, 6)	Patients B, D, E, F, I and K

Table 6-1 Management of the difficulties of oral self-care in patients who present with physical symptoms in the early period after hematopoietic stem cell transplant

Theme1: Self-care tailored to multiple physical symptoms and performed with creativity	
Category	Code
Use goods and medicines according to the physical symptoms that appear and cope with them in their own way.	"I was using anti-diarrhea and anti-nausea medications, and even with vomiting and diarrhea, I practiced oral care whenever possible." (Patient B) "Eyes were treated with eye drops, and I pulled back the eyelids by hand." (Patient F) "I had numbness in my fingers and toes, so I'm doing exercises to manage it." (Patient J)
Taking measures to ensure that immunosuppressant medication, which is the highest priority, is administered consistently using tools such as an alarm or pill box.	"The medicine chest is helpful because it confirms if I've taken the medication, and it keeps both me and my family informed." (Patient A) "I had to set a timer on my mobile phone to track my medication, as I sometimes forgot after being discharged from the hospital." (Patient E) "I was determined to manage my immunosuppressive drugs properly, and I made sure to do so." (Patient F)
Immediately after discharge from hospital, the patient is significantly underweight and fatigued due to a prolonged hospital stay, so the activity level is increased step by step with breaks in between.	"I started my rehabilitation by going out and walking a little in parks or places with no people, and then gradually added more activity." (Patient B) "I feel like it's hard to do anything, so I move around a bit at home and then rest." (Patient C) "It was hard to even brush my teeth; I had to increase my activity level very gradually." (Patient I)
Taking infection prevention measures when going out to prevent infection, and implementing precautions at home, such as not sharing toothpaste with family members.	"I'm still very careful, but I'm definitely the most diligent about bathing." (Patient B) "Before I had leukemia, we shared toothpaste, but after the transplant, we stopped because it's risky." (Patient H) "To prevent infection, wash your hands when you go outside and wear a mask when taking out the trash." (Patient K)
Theme2: Adjusting oral self-care based on experience, in response to symptoms and environmental factors	
Category	Code
Not performing oral self-care poses a risk of infection, so I make my own judgement based on my own experience and respond to symptoms.	"It's like using a gargle solution or something similar, depending on the symptoms." (Patient C) "I continue with oral care because I am afraid of getting sick. I perform oral care as a preventive measure to reduce the likelihood of worsening conditions." (Patient D) "The decision to see a doctor is based on personal experience, without the influence of being in the hospital." (Patient J) "I look in the mirror at the inside of my mouth. It's not a perfect pink color, there's a slight ochre diagonal line, but I think it's okay." (Patient K)
Adapting oral self-care products to the condition of the mouth and adjusting practices according to the environment and symptoms.	"I had to adjust to the symptoms in my mouth; today, I just gargled a little. Some days I skip oral care." (Patient B) "I gargle when I'm out and about." (Patient C) "I keep doing oral care because I'm afraid of getting sick. I also have a job, so if I need further treatment, it would negate all the effort I've put into taking care of myself." (Patient D)

(continued)

Table 6-2 Management of the difficulties of oral self-care in patients who present with physical symptoms in the early period after hematopoietic stem cell transplant

Theme3: Establishing effective care habits based on guidance and experiences received during hospitalization	
Category	Code
Performing care that gives a sense of accomplishment and using methods deemed effective based on experience.	"If I brush my teeth too hard, my gums get damaged easily, so I brush gently." (Patient D) "I like to floss myself, so when I see a lot of plaque on the floss, I feel accomplished." (Patient I) "I use a toothbrush with soft, thin bristles that can reach into the nooks and crannies easily, and after trying many different brushes, I feel this one works best—it's based on experience." (Patient L)
Planning daily oral self-care with a structured order of care and making oral self-care a habit.	"I have a schedule for care. I know when to apply the ointment myself to a certain extent. I brush my teeth after eating and apply the eye ointment before bedtime—there's an order to it." (Patient D) "Brushing teeth is part of my daily life and has become a habit." (Patient I) "He is diligent, so he schedules and follows the instructions given to him." (Patient C)
Implement oral care using the guidance on oral self-care received during hospitalization and information on oral care from television.	"During my hospital stay, they taught me so much about oral care that I didn't have any issues with my mouth afterward. I didn't encounter any problems after discharge because they guided me and helped with my care while I was in the hospital." (Patient G) "(Regarding floss use) I think I learned from watching TV." (Patient J) "When I was in the hospital, the nurses emphasized the importance of gargling, and I really understood its benefits, so I used a gargle solution regularly." (Patient K)
Theme4: Accepting and addressing new symptoms post-transplant with a sense of responsibility as a transplant recipient	
Category	Code
They are grateful for the transplant and feel they have been given a second life, which motivates them to do their best in self-care. They set goals and care for themselves to find the positive and enjoyable aspects of life by viewing their symptoms positively, not because they are unwell and unable to do things.	"It is a second life that I was given, so I have to take care of it. I am very aware of the fact that I've been given a second chance." (Patient B) "I think it's important to look at symptoms positively and focus on the good things, like being able to do certain activities." (Patient C) "I'm looking forward to seeing my daughter on stage, and that's why I want to be healthy, so I'll do my best." (Patient G)
Using well-known transplant recipients as examples to talk about your own symptoms and circumstances, thereby fostering understanding from others, and drawing on their experiences as role models.	"I wanted to improve like the swimmer who had a transplant—that man is amazing. I see him as a role model." (Patient A) "Talking about a famous person who had a transplant gives you the chance to know there are others with the same condition." (Patient B) "When I see a celebrity who has had a transplant, I feel I can go this far too, and that feeling is significant; it motivates me to work hard as well." (Patient C)

(continued)

immunosuppressant medication, which is the highest priority, is administered consistently using tools such as an alarm or pill box.}, the patient said: "I was determined to manage my immunosuppressant medication properly. I was committed to doing this, said (Patient F). For this patient, taking medications such as immunosuppressants were the most important part of self-care.

In the category {Immediately after discharge from hospital, the patient is significantly underweight and fatigued due to a prolonged hospital stay, so the activity level is

Table 6-3 Management of the difficulties of oral self-care in patients who present with physical symptoms in the early period after hematopoietic stem cell transplant

Theme5: Independently assessing symptoms, accepting limitations, and enduring them when necessary	
Category	Code
I assess symptoms myself and monitor their progression until the next outpatient visit.	"(The pain from the shingles) is totally manageable at the moment, so I'm fine." (Patient B) "I'll wait and see how things progress until one month after the scheduled outpatient visit, and if it worsens, I'll reconsider my options." (Patient C) "The numbness in my fingers has decreased since initially, and it doesn't interfere with brushing my teeth, so I'll monitor it." (Patient K)
Accepting that the sudden appearance of symptoms after a transplant is beyond control.	"After leaving the hospital, symptoms might suddenly appear, but that's just the way it is." (Patient H)
When mentally overwhelmed by poor concentration or the prolonged recovery process, shift focus to improve mood and allow time to pass and acclimate.	"When I go out, I feel a change in my heart. It feels like I can't keep worrying about my illness constantly." (Patient D) "When my mind doesn't work, it's like I'm just letting time pass and getting accustomed to it." (Patient E) "I play the guitar, play games, watch videos, and do other activities to shift my mood." (Patient L)
Theme6: Seeking support from those around you to enable continued self-care of the mouth	
Category	Code
If a patient experiences a physical symptom that they cannot manage alone, they should consult a specialist or discuss the timing of their return to work when they visit the hospital.	"If I experience symptoms, I consult with the nurse." (Patient C) "Initially, I thought it was just a sore throat and difficulty eating, similar to my usual mouth ulcer, but I realized it was beyond my control, so I went to see the doctor." (Patient D) "I spoke to the doctor about my symptoms." (Patient F)
Receiving help from friends and family with daily tasks and discussing symptoms.	"Once symptoms appear, my family takes care of me and then contacts the doctor." (Patient E) "I consult with my family about my symptoms." (Patient H) "My family assists with meals, toileting, bathing, and doctor visits. They help with various needs, buy necessary items, cook for me, and apply ointment after my bath." (Patient I)
Patients can discuss and share experiences with other transplant patients in support groups, exchanging information, such as criteria for deciding when to seek medical attention.	"It's really important to access diverse information at the patient association." (Patient D) "We exchange information with other transplant patients and use this as a reference for deciding when to go to the hospital." (Patient G) "The people I talk to are fellow patients I met during my hospital stay for the transplant. There's a strong sense of understanding among patient friends." (Patient I)

increased step by step with breaks in between.}, a patient who had lost muscle strength due to extended hospitalization said: "I felt like even small tasks were difficult, so I would move around a bit, then rest, and repeat. At home, I move around a little and take frequent breaks." (Patient C).

In the category {Taking infection prevention measures when going out to prevent infection, and implementing precautions at home, such as not sharing toothpaste with family member.}, patients who remained at risk of infection after transplantation shared experiences such as: "Until I had leukemia, my family and I used to share toothpaste. After the transplant, we began using separate toothpaste because it was safer." (Patient H). This patient practiced oral self-care with an awareness of infection prevention after being discharged from hospital.

[Adjusting oral self-care based on experience, in response to symptoms and environmental factors]

This topic was divided into two categories. In the cate-

gory {Not performing oral self-care poses a risk of infection, so I make my own judgement based on my own experience and respond to symptoms.}, one patient said: "I continue to perform oral self-care because I fear becoming ill. I also see it as a preventive measure to prevent further deterioration of my condition." (Patient A). This patient made self-care decisions based on personal experience and an awareness of infection risk.

In the category {Adapting oral self-care products to the condition of the mouth and adjusting practices according to the environment and symptoms.}, the patient said: "I would adapt my oral self-care based on my mouth symptoms, sometimes choosing just to gargle that day. It wasn't really skipping care, but there were times when I couldn't do more." (Patient B). This patient adjusted their oral self-care practices after the transplant, tailoring them to current symptoms as they changed.

[Establishing effective care habits based on guidance and experiences received during hospitalization]

This theme comprised three categories. In the category {Performing care that gives a sense of accomplishment and using methods deemed effective based on experience.}, participants developed a sense of self-efficacy and performed oral self-care based on prior successful experiences. For example, one participant stated: "I like to floss, and when I get a lot of debris out, I feel that I've done a good job." (Patient I).

In the category of {Planning daily oral self-care with a structured order of care and making oral self-care a habit}, one patient said: "I follow a schedule. I have a good idea of when to use the mouthwash and such, so I always use the eye ointment last thing before I go to bed. I always brush my teeth after meals, and I always finish cleaning around my mouth first." (Patient D). This patient organized and managed her oral self-care in a way that reinforced consistency.

In the category of {Planning daily oral self-care with a structured order of care and making oral self-care a habit}, one patient said: "During my hospital stay, they taught me so much about oral care that I didn't have any issues with my mouth afterward. I didn't encounter any problems after discharge because they guided me and helped with my care while I was in the hospital." (Patient G). This indicates that they are practicing oral care after leaving hospital, referring to the oral care advice they received in hospital and the oral care information they saw on TV.

[Accepting and addressing new symptoms post-transplant with a sense of responsibility as a transplant recipient]

This theme consisted of two categories. In the category {They are grateful for the transplant and feel they have been given a second life, which motivates them to do their best in self-care. They set goals and care for themselves to find the positive and enjoyable aspects of life by viewing their symptoms positively, not because they are unwell and unable to do things.} One patient expressed: "After all, it's a life I was given, so I have to take good care of it. It's a second life. I truly feel like I was given a second life." (Patient B). This patient managed her condition positively, driven by a sense of mission as a transplant recipient.

In the category {Using well-known transplant recipients as examples to talk about your own symptoms and circumstances, thereby fostering understanding from others, and drawing on their experiences as role models.}, one patient shared: "I wanted to recover like that swimmer who had a transplant. He's amazing, isn't he? He returned to competition right after his transplant. I think of him as a role model." (Patient A). To help people around him understand his condition after the transplant, he added: "When the topic of famous people who have had transplants is mentioned, it gives me a chance to let people know that there are people with the same disease around them." (Patient B).

[Independently assessing symptoms, accepting limitations, and enduring them when necessary]

This theme was divided into three categories. In the category {I assess symptoms myself and monitor their progression until the next outpatient visit.}, patients shared the following: "I wait to see how things progress for about a month until my next outpatient visit. If they get worse, I'll think about what to do." (Patient C); "If I think about it briefly, the pain of shingles is bearable, so it's manageable." (Patient B). Since visiting the hospital is a physical and emotional burden for patients, they often manage their symptoms by waiting until their next appointment.

In the category {Accepting that the sudden appearance of symptoms after a transplant is beyond control.}, patients who face prolonged recovery or who experience symptoms all over their body after a transplant said: "After I leave the hospital, symptoms might appear suddenly, but there's nothing to be done about it. You just can't control it." (Patient H).

In the category of {When mentally overwhelmed by poor concentration or the prolonged recovery process, shift focus to improve mood and allow time to pass and acclimate.}, one patient said: "When my mind doesn't work, it's like I'm just letting time pass and getting accustomed to it." (Patient E). This suggests that patients cope with the decline in concentration by waiting for it to improve. From this, we can see that patients are coping with the decline in concentration by waiting for it to get better.

[Seeking support from those around you to enable continued self-care of the mouth]

This theme was divided into three categories. In the category {If a patient experiences a physical symptom that they cannot manage alone, they should consult a specialist or discuss the timing of their return to work when they visit the hospital.}, one patient shared: "At first I thought it was just a sore throat, and I couldn't eat. I assumed it was just

my usual mouth ulcer, but I realized that it was something I couldn't manage on my own, so I went to see a doctor." (Patient D). Since post-transplant symptoms may sometimes require the medical intervention, patients managed these symptoms independently and went to hospital when necessary.

In the category {Receiving help from friends and family with daily tasks and discussing symptoms.}, a patient said the following: "My family helped me with meals, going to the toilet, bathing, and going to the doctor. They supported me with many things. They bought the things I needed, cooked for me, and even applied ointment on me after bathing." (Patient I). After the transplant, weakness and physical symptoms made it difficult for the patient to do all the housework and care for herself, so she received support from her family and friends.

In the category {Patients can discuss and share experiences with other transplant patients in support groups, exchanging information, such as criteria for deciding when to seek medical attention.}, patients said: "I talk to patient friends I met when I was in hospital for my transplant. There's a lot we understand about each other's experiences. Sometimes, I ask them about symptoms I don't have, and I realize how challenging those symptoms might be. Transplant symptoms are really different for everyone, so even if I don't have certain symptoms now, I think I might in the future." (Patient I). By interacting with other patients, this patient improved her ability to assess her own symptoms and find the strength to carry on with the encouragement of her transplant peers.

DISCUSSION

This study identified specific challenges and management strategies for oral self-care in patients experiencing physical symptoms in the early post-transplant period, which have not been previously documented. There have been studies on difficulties and coping of post-hematopoietic stem cell transplant patients one year after discharge from hospital, and physical pain and dissatisfaction with others were reported as post-discharge difficulties [18], and the same trend was observed in this study. However, previous studies focused on difficulties related to limitations of life after transplantation and did not mention difficulties caused by multiple physical symptoms.

Patients in the early post-transplant period often felt unable to fully engage in oral self-care due to painful physical symptoms. In addition, patients found it difficult to continue oral self-care when they did not perceive the benefits of oral self-care, especially as they had to manage oral medications while manifesting multiple physical symptoms. In addition, patients experienced difficulties related to limited knowledge of oral health and self-care; inadequate environments for oral self-care, especially after returning to work; and, in assessing and managing their own oral symptoms. Patients in this early post-transplant period were found to employ six distinct management strategies to address these three main difficulties.

Difficulties and management of oral self-care in patients with physical symptoms in the early post-transplant period

Difficulties experienced by patients in the post-transplant period have been reported to include physical pain, anxiety about the effects of treatment, and dissatisfaction with family and environment [27, 28]. These difficulties were also observed in this study, with physical pain emerging as the most significant barrier to oral self-care for patients in the early post-transplant period. The timing of the onset of physical symptoms experienced by post-transplant patients varied depending on the course of the post-transplant period. In this study, patients managed severe physical symptoms, such as muscle weakness, loss of strength, fatigue, vomiting, and diarrhea, none of which could be predicted before the transplant, immediately after discharge from hospital until six months post-transplant. In addition, patients generally discontinued immunosuppressants between six months and two years after the transplant. By the time these medications were stopped, most physical symptoms had subsided, and patients often began to consider returning to work or school. However, new challenges emerged, including the management of long-term physical symptoms affecting the mouth and skin. We examined the difficulties and management strategies for oral self-care faced in the early post-transplant period, which we divided into two periods: the period from immediately after hospital discharge to six months after transplantation, and the period from six months to two years after transplantation.

Period from immediately after hospital discharge to six months after transplantation

The period from hospital discharge up to approximately six months post-transplant is typically characterized by a decline in physical strength and activity levels [1, 29–31]. Consistent with previous studies, all patients experienced muscle weakness, loss of strength and fatigue that could not be anticipated before the transplant. Lower gastrointestinal symptoms, reported to affect around 13 % of post-transplant patients [8], were also common among the participants in this study, who continued to experience diarrhea that would occur immediately after they relaxed, leaving them unable to move from their rooms to the sink to perform oral self-care. Thus, during this period, it is likely that post-transplant patients experienced physical changes that exceeded their expectations, including significant weight loss due to prolonged hospitalization, loss of strength and muscle mass pre- and post-transplant, and recurring compression fractures. In addition, patients faced urgent urination needs and found it difficult to prioritize oral self-care. Despite these

varied physical symptoms, patients maintained a sense of mission as transplant recipients, engaging in oral self-care through self-directed management strategies based on their own experiences.

In addition, patients in the early post-transplant period, while experiencing a decline in memory and concentration, felt burdened by the need to manage multiple care tasks required for oral medication and other aspects of self-care. This is likely due to the unique stressors experienced post-transplant [32], which differ from those faced during hospitalization, such as managing regular medication schedules, preventing infections, and dealing with the impact of GVHD on daily life. Patients said: "I was determined to take my immunosuppressant medication. I was committed to this routine". (Patient F), and there were numerous comments about the need to take life-sustaining immunosuppressant medication consistently. Thus, for patients in the post-transplant period, taking life-sustaining medication is their highest priority in their self-care. The results also showed that patients in the early post-transplant period employed a structured approach to plan their daily care activities. This included setting alarms on mobile phones to remind them to take their medication, or to apply eye ointment just before going to bed due to difficulty with opening their eyes. In other words, they made oral self-care a regular habit. This proactive approach likely reflects patients' understanding of their vulnerable condition and the need to self-care while experiencing strong physical symptoms resulting from post-transplant complications, which enabled them to act independently in managing their health.

Period from six months to two years after transplantation

For patients who have been on immunosuppressants for six months to two years post-transplant, the prospect of returning to work or school often arises as they no longer require immunosuppressants. Currently, 38 % of patients resume work one year post-transplant, and 57 % return to work within two years [33]. While hospitalized, patients prioritize medication adherence and treatment care. However, as they return to their daily lives and work, their priorities shift, often making it difficult to maintain their medication regimen or receive consistent care. In addition, patients find it difficult to brush their teeth at work due to time constraints, infection risks, and a desire for privacy, which complicates regular tooth brushing. The work environment presents new obstacles for oral self-care that were not present during hospitalization. There are also large individual differences in the physical condition and symptoms of patients after transplantation, which sometimes result in a lack of understanding from those around them. For instance, one participant noted: "There is a difference in perception between me and the people around me, and I feel that they don't understand me." This gap in understanding can further hinder the patient's ability to maintain oral self-care routines. To address these challenges, transplant patients found it helpful to communicate their symptoms to others to foster understanding. By discussing their symptoms openly and using famous transplant patients as role models, patients are better able to adapt their work and symptom management.

When the immunosuppressants are discontinued, patients' physical symptoms tend to stabilize to some extent; however, new symptoms may arise, and chronic diseases such as GVHD and other long-term effects may persist. Previous studies reported that many patients experience prolonged pain [30, 34–36] and peripheral neuropathy [8, 37] that lasted for years and interfered with their ability to perform oral self-care. Consistent with these findings, this study identified physical pain as a primary obstacle to oral self-care for post-transplant patients. Post-transplant pain and peripheral neuropathy are often associated with total body irradiation, high-dose chemotherapy, and chronic GVHD [38]. Studies have shown that 26–58 % of post-transplant patients experience pain in areas such as the joints, bones, mouth, and digestive organs [3, 32, 33, 39]. As a result, patients in the post-transplant period patients often adopt an attitude of acceptance, recognizing that certain symptoms may be beyond their control. For example, when tremors caused them to spill water from a glass, patients adapted by reducing the amount of water in the glass, or placing a chair at the washbasin when standing was difficult. Such adjustments illustrate how patients modify oral care practices to align with their physical condition and environment. Therefore, patients' physical conditions tend to stabilize after discontinuing immunosuppressive drugs. However, consistent with previous studies, 92 % of patients in the early post-transplant period continued to experience physical symptoms, such as oral and skin symptoms, with a median duration of six years [40]. This suggests that patients may struggle to maintain oral self-care if they do not perceive immediate benefits from these efforts.

Additionally, patients reported feeling burdened when visiting doctors outside the transplant hospital, as they often needed to explain their treatment history and symptoms due to the limited transplant knowledge among these doctors. Patients noted that within the first year post-hospitalization, numerous symptoms could emerge, potentially with considerable individual variation. Consequently, even if they talked to other transplant patients, the possibility existed that their experiences would not be fully appreciated. In addition, patients felt a disconnect between their own perceptions and those of the people around them. This communication gap stemmed from the lack of transplant-specific knowledge among healthcare professionals and other transplant patients, making it difficult for patients to convey their needs effectively. These findings therefore highlight the importance of creating a supportive environment for continued oral self-care, as the lack of understanding of those around them presents a clear barrier to patient well-

being.

On the other hand, several patients took management actions, such as engaging in conversations with other transplant patients in support groups, sharing information about when to see a doctor, and providing each other with emotional support. Consistent with previous studies [1, 8, 41], these interactions allowed transplant patients to interact with each other and realize that they were not alone in experiencing distressing symptoms. Such support groups provided a place patients could learn ways to reduce emotional distress and manage complications, including GVHD.

Oral self-care "Management"

In this study, the rates of brushing at least twice daily and using dental aids were higher than the national average [41]. This suggests that patients in the early post-transplant period, who are aware of their elevated risk of oral infection, may have adopted rigorous oral self-care measures to prevent oral pain, swelling, and infection.

Patients in the early post-transplant period are more likely to experience long-term salivary gland dysfunction due to the side effects of pre-transplant treatments, including total body irradiation, chronic GVHD, and the use of antihistamines and other medications [1]. Many patients in this study reported symptoms of dry mouth and engaged in oral self-care practices to mitigate discomfort, including frequent water drinking, wearing masks, applying lip balm, and moisturizers.

Conversely, patients reported difficulties with certain oral self-care activities, such as applying moisturizers and massaging the salivary glands. Selecting a suitable moisturizer proved challenging, as patients noted issues such as ointments coming off during the day, dissatisfaction with the taste, and a need for gel recommendations for preventing dry mouth. Additionally, salivary gland massage tended to be underutilized due to a lack of knowledge. Patients stated: "I didn't do salivary gland massage because I didn't know about it" (Patient F) and "Salivary gland massage doesn't seem to have much of an effect, so I don't do it much now" (Patient H). These difficulties may stem from the fact that patients in the early post-transplant period are responsible for self-care amidst infrequent outpatient visits and limited access to medical staff [18]. Upon discharge, patients may also misinterpret, become confused by, or forget the extensive information provided to them [1].

Suggestions for Nursing

After transplantation, patients often experience prolonged physical complications due to complications arising from high-dose chemotherapy, radiotherapy, and other treatments [42–44]. In addition, the risk of infection remains elevated beyond 100 days post-transplant, particularly within the first two years, with some cases experiencing delayed immune recovery that extends this risk further [29]. Oral lesions are particularly common in chronic GVHD, causing symptoms such as mucosal inflammation, pain, and ulceration, which affect approximately 80 % of patients and significantly impact their quality of life [2, 11, 45]. In this study, patients in the early post-transplant period adapted their oral self-care practices in responses to oral symptoms. However, when symptoms became severe, such as when patients developed mucosal peeling or extensive stomatitis, they were often unable to perform oral self-care. Patients in the post-transplant period were generally more aware of the importance of oral self-care than the general population and could manage oral symptoms as they arose.

On the other hand, studies have shown that when patients experience an increase in oral mucosal symptoms, they often cannot perform oral self-care. During such episodes, it is crucial for nurses to provide specific guidance, such as recommending a dentist visit rather than attempting to self-manage symptoms, or promote the use of methods that do not irritate the mucosa [17]. Symptom onset and changes in the environment at different times after transplantation affected the maintenance and difficulty of oral self-care. Firstly, during the period of strong physical symptoms, i.e., from immediately after discharge from hospital to six months after transplantation, it is important for nurses to provide patients with the minimum necessary care. This includes suggesting gentler alternatives, such as gargling or drinking water, instead of brushing. Furthermore, nurses should play an active role in adapting oral self-care practices to support patients in managing their oral health as a priority. Secondly, during the period from six months to two years post-transplantation, patients often experience physical symptoms throughout the body while considering reintegration into the community. Previous studies have shown that the unpredictability of chronic GVHD symptoms can lower patients' sense of self-efficacy and complicate self-care [42]. Similarly, in this study, post-transplant patients reported difficulty in making independent decisions about managing symptoms without timely access to nurses. Consequently, patients often had to tolerate their symptoms, which interfered with their ability to maintain oral self-care. To address this, nurses should discuss with patients the specific situations in which they should use their moisturizer. Providing specific advice tailored to the patient's lifestyle can be valuable; for example, recommending the use of a gel-type moisturizer with a high hydrating effect for bedtime use, or a fast-acting spray-type moisturizer that is easy to apply when outside or at work.

Even when the patient's oral symptoms have subsided, the risk of oral complications remains high. Nurses should emphasize the importance for sustained oral self-care, provide feedback on current practices, and intervene to help the patient integrate oral care into other aspects of their self-care routine. In addition, during periods of physical and mental stability, nurses should educate patients about

oral conditions to be aware of, such as leukoplakia, erythroplakia, and lichen planus, as the risk of secondary cancers continues to rise even five years after transplantation.

Post-transplant patients must continue oral self-care while managing numerous physical complications and resuming social life. Learning from the experiences of other post-transplant patients has been shown to benefit patients' treatment and recovery, as well as facilitate communication with medical staff by highlighting potential issues and management strategies that may not have been addressed by medical staff [41, 46]. Consequently, many post-transplant patients seek information based on the experiences of other post-transplant patients [41, 47]. However, because information provided by patients in the post-transplant period is not always dependable, it can sometimes lead to misunderstanding, confusion, or distress [46, 48–50]. Consistent with previous research, providing a supportive environment where post-transplant patients can interact with one another can reduce psychological burden and help them learn strategies to manage complications, such as GVHD. At the same time, it is also important to understand that the information they receive from other patients in the post-transplant period may not always be accurate, as symptoms and experiences vary widely among individuals [46]. Nurses should verify the accuracy that patients receive from their peers in the post-transplant period, ensuring that interactions among patients does not induce stress. This approach helps patients continue with essential oral self-care practices.

Two thirds of patients in the post-transplant period develop chronic diseases such as chronic GVHD, neuropathy, cardiac disease, endocrine disease, and secondary cancers, requiring lifelong symptom management [51, 52]. For those with severe systemic symptoms, oral self-care becomes a lower priority, and the importance of oral self-care, including dental interventions, has been demonstrated due to bring about a decline in quality of life. Similar findings were observed in this study, where patients with severe physical symptoms were unable to perform oral self-care. A meta-analysis of self-management programs for individuals with chronic conditions demonstrated personalized self-care approaches are essential, and that support from healthcare professionals, such as providing information and guidance tailored to the individual patient, along with the patients' own efforts, promotes the continuation of self-care practices [53]. Since nurses cannot anticipate the full extent of symptoms that may arise in the post-transplant period, it is important that they consider the timing of the transplant and assess the impact of physical symptoms on oral self-care in terms of each patient's work and living conditions, providing tailor-made support accordingly.

Limitations and strengths

The participants in this study comprised 12 post-transplant patients who had lived with their transplants for periods ranging from less than a year to nine years. Consequently, it is possible that the participants recalled and organized their past experiences of difficulties before being interviewed, as they used notebooks and other materials that they had maintained during the post-transplant period. Also, since some participants had only recently undergone transplantation, the results may not be broadly generalizable. Despite these limitations, the results of this study highlight the reality of oral self-care among patients in the early post-transplant period. It enhances understanding of the challenges and management strategies associated with oral self-care in patients facing multiple physical symptoms in the post-transplant period. This understanding could inform nursing practices, helping nurses gain a deeper appreciation of the oral self-care difficulties encountered by patients in the early post-transplant period.

Conclusion

Patients in the early post-transplant period often faced limitations in engaging in adequate oral self-care due to the physical symptoms they experienced post-transplant. Many found it challenging to maintain oral self-care when they did not perceive the benefits. In addition, after being discharged from hospital or returning to work, patients had to adapt their oral self-care practices to their new environment. They found it difficult to manage their oral symptoms themselves because they were unable to assess their oral health.

To address these challenges, patients adapted their oral self-care practices based on personal experiences, adjusting routines to match their symptoms and environments, and incorporating oral self-care methods that accounted for multiple physical symptoms. In addition, patients obtained support from those around them to continue their oral self-care, making effective care a habit based on the guidance and training they received during their hospital stay. In addition, patients accepted the new post-transplant symptoms and approached oral self-care with a sense of mission as transplant recipients. Patients in the early post-transplant period were unable to predict the symptoms that would occur and were in an environment where they could not immediately consult with medical staff, so they assessed their symptoms independently, managing their oral self-care while enduring and tolerating ongoing discomfort.

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DECLARATION OF COMPETING INTERESTS

The authors declare no conflicts of interest associated with this manuscript.

ETHICS STATEMENT

This study was approved by the Research Ethics Committee of Osaka Medical and Pharmaceutical University (Approval No.: 2023-011). Participants were provided with information regarding the research purpose, methods, and the freedom to withdraw consent, and were asked to sign an informed consent form before participating in the interviews. The interviews were voice-recorded with participants' consent. To ensure anonymity, participants' personal information was coded. Participants received compensation after each interview.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

DECLARATION OF GENERATIVE AI AND AI- ASSISTED TECHNOLOGIES IN THE WRITING PROCESS

No AI tools/services were used in the creation of this work.

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