



Understanding the symptom experience and self-management strategies of adult hematopoietic stem cell transplantation patients during hospitalization: findings from a qualitative longitudinal study

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Abstract

Purpose The aim of this study was to explore the symptom experience and self-management strategies of adult hematopoietic stem cell transplantation patients during hospitalization.

Methods This was a qualitative descriptive study. A heterogeneous sample of 19 patients who underwent hematopoietic stem cell transplantation from May to October 2021 were enrolled in the study. Semi-structured interviews were conducted at four time points during hospitalization, providing a total of 64 interview datasets.

Results Four themes and 11 subthemes reflecting the symptom experience and self-management strategies of adult hematopoietic stem cell transplantation patients during hospitalization were observed. The four themes were (1) unexpected symptom burden: dynamic, disturbing, co-occurring, and correlative; (2) emotional complexity at different periods; (3) internal predicament: ineffectiveness of symptom management; and (4) external strength: desire for support from multiple sources. Hematopoietic stem cell transplantation patients experienced a complex and dynamic array of symptoms from admission to discharge, and they experienced the dual forces of internal predicament and external strength in symptom self-management during hospitalization.

Conclusion The findings of this study emphasize the need for a deeper understanding and precise management of the symptom experience of adult hematopoietic stem cell transplantation patients during hospitalization. Hematopoietic stem cell transplantation nurses need to assess symptoms on an ongoing basis; educate patients on ways to perceive, express, and self-manage multiple symptoms; and develop patients' self-symptom management skills to enhance their symptom relief and quality of life.

Keywords Hematopoietic stem cell transplantation · Symptom experience · Self-management · Cancer patients · Qualitative research

Introduction

Hematopoietic stem cell transplantation (HSCT) is the use of healthy autologous (i.e., patient's own cells) or allogeneic (i.e., cells from a donor) hematopoietic stem cells (HSCs) to replace a patient's HSCs and thereby reconstruct the patient's hematopoietic and immune functions [1]. HSCT is the best and only effective treatment for hematological malignancies, severe aplastic anemia, metabolic disorders after disease relapse, and failure of conventional treatments [2]. More than 580,000 transplant patients were registered in the International Blood & Marrow Transplantation Research Center database in 2020 [3]. According to the latest data from the China Marrow Bank in 2021, a rapid growth trend was observed following 10,684 HSC donation cases [4].

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HSCT improves overall survival and progression-free survival for several malignant and non-malignant diseases. However, this benefit is associated with multiple symptoms and significant complications during and after transplantation [5]. Symptoms are subjective experiences that reflect changes in an individual's biopsychosocial functioning, sensations, or cognition [6]. Most HSCT patients experience several physical, emotional, and cognitive symptoms [7–12], especially during the acute recovery phase after transplantation. They often present with gastrointestinal symptoms, such as nausea, vomiting, lack of appetite, and taste changes, during the pre-transplant conditioning period and for a long time after transplantation [13, 14]. Gastrointestinal symptoms in the pretreatment period are considered chemotherapy-related adverse reactions, and those in the post-HSCT acute recovery period are caused mainly by acute graft versus host disease (aGVHD) or electrolyte disturbance [15, 16]. In addition, aGVHD also causes several other symptoms such as skin changes, oral ulcers, dry mouth, and pain. Asthenia and pain have the highest incidence, severity, and distress symptoms at almost every time point during the acute recovery phase [14]. Approximately 77% of patients undergoing HSCT report sleep problems during hospitalization [17], and 35% report less than 3 h of continuous sleep on ≥ 1 day [18]. Consequently, this physical distress can negatively affect HSCT patients' prognoses, quality of life, and even increase their suicidal ideation [19, 20]. Besides, HSCT patients present with several clinically significant emotional symptoms, such as anxiety, depression, or adjustment disorders during hospitalization, which may negatively affect the subjective symptom burden, treatment compliance, and length of hospital stay [21, 22]. Anxiety levels during isolation are associated with changes in physical symptoms such as pain, nausea, and loss of appetite [23]. Therefore, properly assessing and managing HSCT patients' symptoms and risks during hospitalization and minimizing the symptom burden deserve attention. The utilization of an array of self-management strategies by HSCT patients to cope with these symptoms during hospitalization plays an important role in this process [24]. Self-management can be defined as a dynamic and continuous process that refers to "the individual's ability to manage the symptoms, treatment, physical and psychological consequences, and lifestyle changes inherent in living with a chronic condition" [25].

The dynamic symptoms model [26] is the framework for the dynamic nature of symptoms. This model includes clear components such as antecedents, symptom experience, symptom trajectories, consequences, interventions, and symptom management strategies, which could address the complex nature of symptoms, co-occurring symptoms, symptom interactions, and the longitudinal trajectories of symptoms that change over time. We therefore inferred that time may influence the symptom experience of HSCT

patients. This model guided the longitudinal study design and served as the interview guide for this study. Although many studies have focused on measuring symptom burdens in HSCT patients, analyzing the incidence, intensity, and trajectory of symptoms over time, these studies have mostly used quantitative methodological approaches [8, 27–30]. Only few qualitative studies have exclusively explored the symptom experience of HSCT patients during hospitalization. Qualitative research may provide a unique perspective for understanding the mechanism of symptom occurrence and specific symptom prevention and management. Besides, to the best of our knowledge, only few qualitative studies have compared and analyzed changes in HSCT patients' symptoms over time during hospitalization. To fill these gaps, we conducted this longitudinal descriptive, phenomenological study, which aimed to explore the symptom experience and self-management strategies of adult HSCT patients during hospitalization.

Methods

Study design

This qualitative descriptive study used semi-structured interviews [31] and descriptive phenomenology [32]. Phenomenology is a method of discovering an individual's past experience or world of life [33]. A lived experience provides a meaning to how an individual perceives a particular phenomenon, presenting the reality of the experience in the individual's life [26]. HSCT patients may experience different symptoms and symptom strategies at different transplantation stages. The descriptive phenomenological approach is suitable for exploring the subject experience of HSCT patients during hospitalization. Semi-structured qualitative interviews were conducted at four time points, selected after clinical observation, literature review, and discussions with experts: at hospital admission (T1), during the pre-transplant conditioning period (T2), on the day of transplantation (T3), and the day before discharge (T4). The study was reported according to the consolidated criteria for reporting qualitative research [34].

Setting and participants

All the participants were recruited from the HSCT center of a large tertiary hospital in Fujian province, China. The HSCT center has 32 transplant single-bed wards, and the workload of the center includes 300 HSCTs per year, which ranks first in the province. The ward where HSCT patients are located is an air laminar flow asepsis room, which is an independent and fully enclosed ward that does not accept family members or caregiver. There were

no new COVID-19 cases in Fujian Province during the study period. The hospital stepped up measures to prevent COVID-19. Researchers were required to take their temperature and show their health code and negative nucleic acid report before entering the ward.

A purposive sampling strategy was used for participant selection and data collection during hospitalization from May to October 2021. The inclusion criteria were (a) 18–65 years old; (b) patients with hematological malignancies who were aware of their diagnosis and prognosis; (c) first HSCT session; (d) fluency in Mandarin; and (e) consent to participate. Patients with cognitive impairment (comprehension or expression problems) were excluded; this was measured using the mini-mental state examination.

We first consulted the patients' medical records to understand their sociodemographic and disease characteristics such as age, sex, education, marital status, diagnosis, type of transplant, and donor source. Then, we established a relationship with the patients, explained the study purpose and content, and obtained written consent.

Data collection

Audio-recorded in-depth interviews were conducted using a semi-structured interview guide (Table 1), which was developed based on a literature review and joint discussions with a panel of specialists (one HSCT specialist, two nursing specialists, one psychologist, and one specialist in qualitative research) and included three themes: symptom experience, correlation between symptoms, and assumptions and self-management of symptoms. Based on the dynamic symptoms model [26], the interview of symptom experience focused on the timing, distress, intensity, and nature and assessment of symptoms.

All interviews were conducted by one researcher (J.C.), a nursing doctoral researcher trained in conducting interviews. They were one-on-one in-depth interviews and conducted in a private transplant ward in the absence of other people. The interview time was at 3:00–4:30 pm or 6:30–8:00 pm to avoid the time of treatment, meals, and rest. Easy-to-understand expressions were used, and medical terms were avoided.

Table 1 Interview guide

Could you talk about any disease or transplant-related symptoms you've had recently (physical, emotional, cognitive, etc.)? Please tell me your experience with each symptom (perception, frequency, distress, intensity, quality, etc.)

What types of symptoms do you feel are co-occurring or interrelated?

What are your assumptions about possible symptoms during HSCT? How you manage/take care of your symptoms?

HSCT Hematopoietic stem cell transplantation.

Data analysis

Data collection and initial analysis were performed simultaneously. The data were transcribed verbatim within 48 h of collection. The transcript was cross-checked with the audio to ensure information accuracy. We used Colaizzi's seven-step analysis method [35] to analyze symptom experience data using Nvivo (version 12.0). Field notes were kept to allow for later reflections. To reduce subjectiveness in the analysis, the data were analyzed by three researchers with experience in HSCT (J.C., J.Y., and M.X.): one doctoral nursing researcher and two master of nursing researchers. First, the transcripts were read several times for proper comprehension. Second, significant statements in the interview texts were identified. Third, meaningful concepts were formulated. Fourth, concepts were categorized into classes and similar conceptual "themes." Fifth, the findings were integrated into an exhaustive description of the phenomenon under study. Sixth, a comprehensive description of the fundamental structure of the phenomenon was presented. Finally, we validated the structure by comparing it to the patients' experiences. A theme was not accepted until a consensus was achieved among the three researchers. When no new code was extracted, the data were considered saturated, and another patient was interviewed to determine data collection saturation.

Ethical considerations

This study was approved by the Ethics Committee on Biomedical Research of Fujian Medical University (IRB Ref. No.: 2021/108). Written informed consent was obtained from all participants. They were aware of the possibility to withdraw from the study at any time. The participants' information was anonymized and confidential.

Rigor

Several strategies were employed to ensure scientific rigor of the findings by ensuring credibility, confirmability, dependability, and transferability [36]. To establish credibility, three researchers performed data analysis independently, and the senior researcher was continually engaged in the data analysis process. Besides, the researchers performed

“bracketing” before data collection by writing down their assumptions, understanding, and preconceptions about the symptoms of HSCT patients. To establish confirmability, an audit trail was used to ensure that findings were based on the participants’ perspectives without the authors’ bias. To establish dependability, the audio-recorded interviews were transcribed verbatim and verified with the participants to ensure accurate representation of their experiences. To establish transferability, we used a purposive sampling strategy to maximize participant diversity, considering age, sex, education level, marital status, diagnosis, and transplant type.

Results

Demographic profile of participants

Of 42 eligible patients, 23 refused to participate due to unwillingness to discuss the topic ($n=6$), lack of interest ($n=4$), and physical discomfort ($n=13$). Therefore, 19 patients were enrolled in the study and interviewed at T1. Seventeen participants were interviewed at T2; two patients had withdrawn due to physical discomfort. Fourteen participants were interviewed at T3 and T4; three had withdrawn (unwell, $n=2$; no reason, $n=1$). The final data corpus was made up of 64 interviews given at four distinct time points.

The mean age of the 19 participants was 46 (standard deviation, 14.5; range, 24–63) years. They comprised included workers, civil servants, teachers, salespeople, and farmers. The remaining patients’ characteristics are shown in Table 2. The interviews lasted between 26.0 to 58.0 min, with a mean of 36.6 min.

Thematic findings

Four themes and 11 subthemes reflecting the symptom experience and self-management strategies of the adult HSCT patients during hospitalization were observed (see Fig. 1). The four themes were (1) unexpected symptom burden: dynamic, disturbing, co-occurring, and correlative; (2) emotional complexity at different periods; (3) internal predicament: ineffectiveness of symptom management; and (4) external strength: desire for support from multiple sources.

Unexpected symptom burden: dynamic, disturbing, co-occurring, and correlative

Dynamic nature of symptoms

HSCT patients experienced a complex and dynamic array of symptoms over time from T1 to T4 (Fig. 2). They reported between 3 and 14 symptoms at four time points that included

Table 2 Demographic and clinical characteristics

Characteristics		Frequency (%) ($N=19$)
Sex	Male	9 (47.4)
	Female	10 (52.6)
Education level	Primary school	4 (21.1)
	Junior high school	5 (26.3)
	Senior high school	7 (36.8)
	Bachelor’s degree or above	3 (15.8)
Marital status	Married	13 (68.4)
	Single, divorced, or widowed	6 (31.6)
Diagnosis	Acute leukemia	12 (63.1)
	Lymphoma	1 (5.3)
	Multiple myeloma	2 (10.5)
	Myelodysplastic syndrome	4 (21.1)
Type of transplant	Autologous HSCT	5 (26.3)
	Allogeneic sibling HSCT	9 (47.4)
	Unrelated allogeneic HSCT (cord, peripheral blood)	5 (26.3)

HSCT, Hematopoietic stem cell transplantation.

physical, emotional, and cognitive symptoms. Patients reported mainly emotional symptoms of stress, anxiety, fear and uncertainty, as well as fatigue and sleep disturbances, even without receiving any transplant-related treatment at T1. Nearly all the participants reported multiple strong symptom responses at T2 and T3, with some symptoms persisting until T4.

When I first entered the isolation ward, my feelings were more of nervousness, fear, and anxiety. Now I feel like time is getting longer and longer, and I feel very depressed and lonely. (T2, P11).

Before the transplant, I had severe sleep disturbances and I was often only able to sleep for about two hours straight, day or night. Since my blood levels have returned to normal recently, my sleep is much better, and I am hopeful that the transplant will be successful. (T4, P5).

Disturbances of the body’s normal rhythms due to symptoms

Patients indicated that the symptoms disrupted the body’s normal rhythms, including recurrent sleep disturbances, severe loss of appetite, and persistent fatigue.

Recurrent sleep disturbance was the most common symptom in the transplant unit. Sleep disturbances included difficulty falling asleep, disrupted sleep, and lack of recovery sleep.

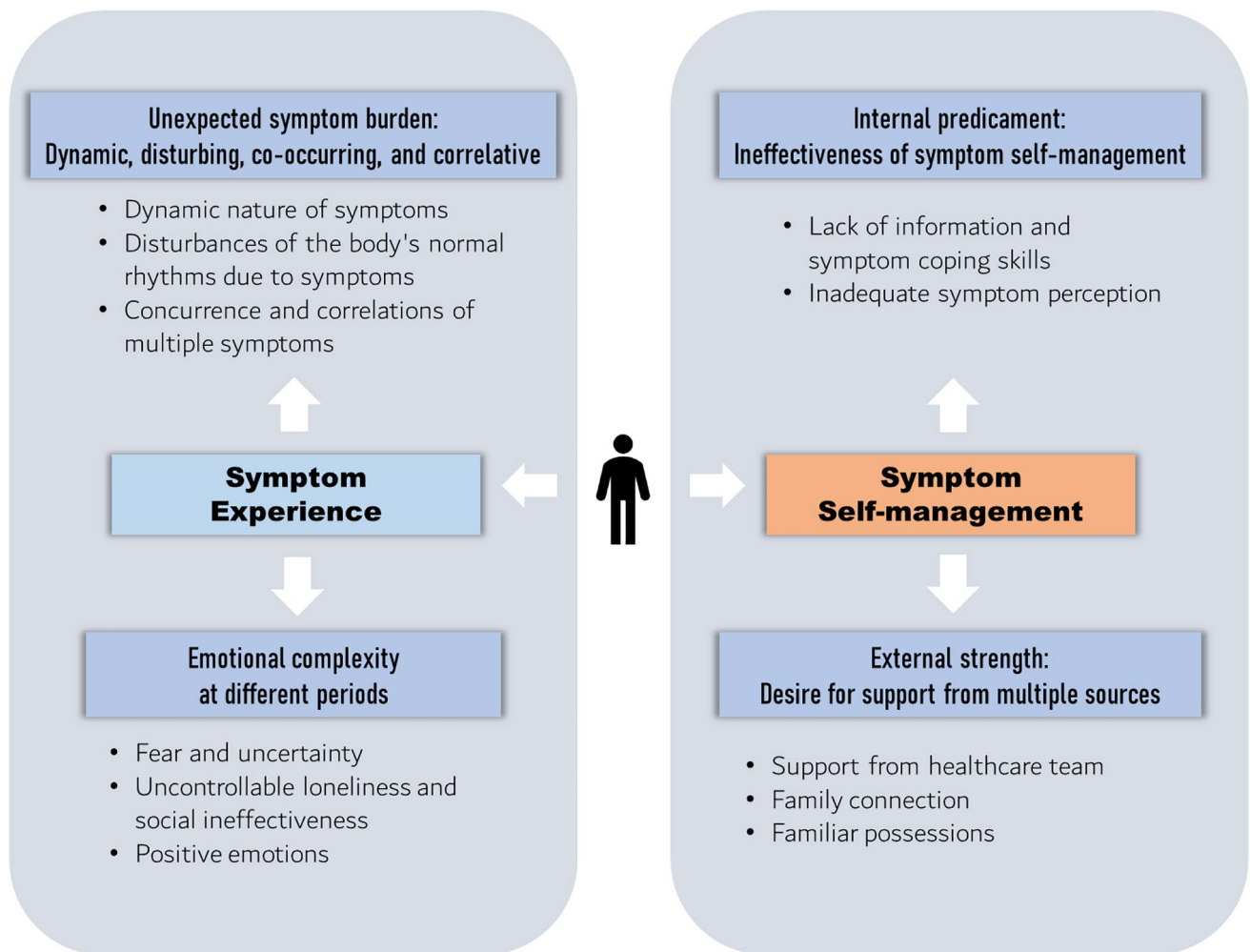


Fig. 1 Summary of themes and subthemes

I can't sleep well every day, and I am almost having a nervous breakdown. I would wake up after about an hour or two of sleep at night, and I am in a bad mood when I wake up. How I wish I could get a good night's sleep. (T3, P2).

Recently, my sleep problems have become more serious, and I can't tell whether it's related to my nervousness or treatment. I feel physically exhausted, but I can't maintain my energy through effective sleep. I really can't stand it after staying in this ward for a long time. (T2, P6).

Loss of appetite was a common symptom during the pre-transplant conditioning period; it persisted during the graft reinfusion phase without the use of chemotherapeutic agents and co-occurred often with gastrointestinal symptoms, such as nausea, vomiting, and taste changes.

I've been nauseous a lot lately, and I don't want to eat at all when I see the food delivered. I can't appreciate the food's taste. (T2, P14).

I feel worse now than at the pre-transplant time. I keep throwing up and have no appetite, but I would try to eat as much as I can, as instructed by the nurse. (T3, P11).

Fatigue and tiredness were the most common symptoms experienced in the ward. At T4, the patient's state of fatigue had decreased, although it was persistent.

My energy seems to be drained completely, and I can only lie in bed most of the time. (T2, P9).

I feel better but still a little tired, and the lack of exercise has caused my legs to seem to be losing strength. (T4, P15).

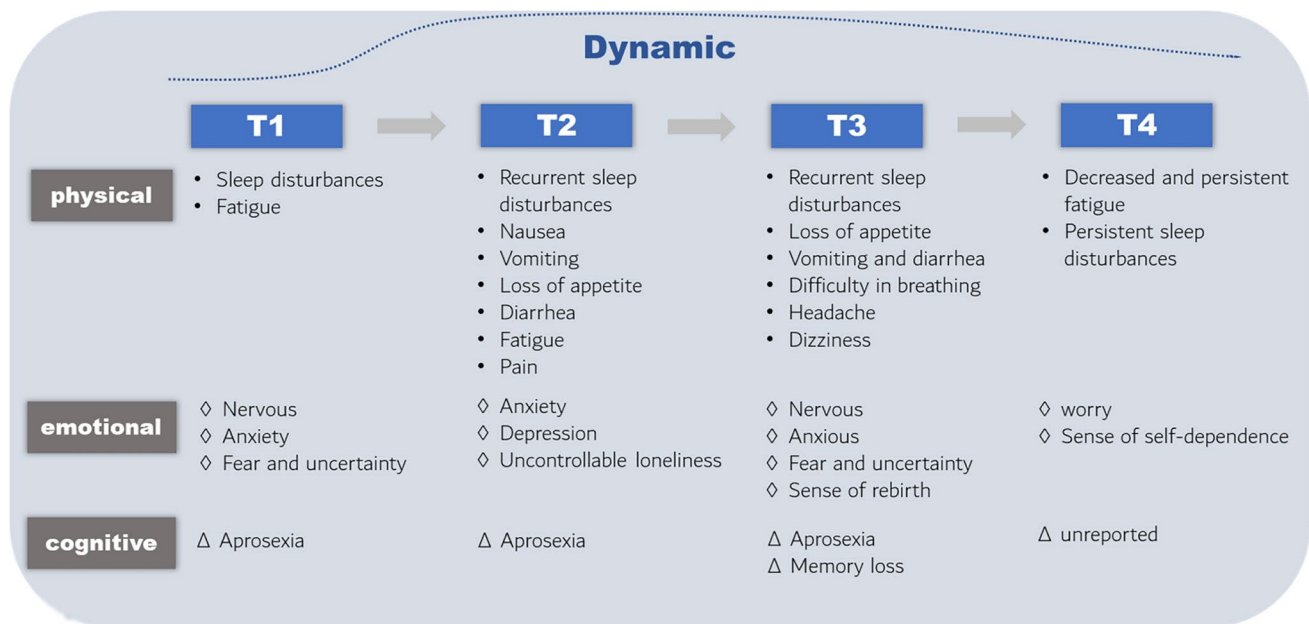


Fig. 2 Dynamic symptoms of hematopoietic stem cell transplantation patients at four time points

Concurrence and correlations of multiple symptoms

Physical, cognitive, and emotional symptoms rarely occur solely. Most patients reported concurrence and correlations of multiple symptoms. Loss of appetite-vomit-diarrhea, pain-lack of energy-depression, nervous-anxious-difficulty breathing-dizziness, and difficulty concentrating-fatigue were the commonest symptom correlations/co-occurrences.

Not only did I experience a loss of appetite, I also had severe vomiting and diarrhea. (T3, P12).

When my muscles ache all over my body, I also feel low on energy and depressed. (T2, P6).

I felt very nervous and anxious before the graft was infused, and I also had difficulty breathing and dizziness. (T3, P15).

When I suffer from weakness and fatigue for some time, it makes it hard for me to concentrate and even think. (T2, P18).

Emotional complexity at different periods

Fear and uncertainty

At T1, patients felt unfamiliar with a completely different environment from the outside and had a sense of fear of the internal environment, regulations, and uncertainties of prognoses. At T3, patients had concerns and uncertainties about the possible reactions after graft reinfusion and the prognosis of transplantation.

When I came in, I was always afraid that I didn't get it right and didn't meet the requirements. The nurse has informed me about several requirements and precautions just now, but I still feel very nervous. (T1, p8). This room is so small, I feel like I'm going to jail. (T1, P14).

I don't know whether this transplant will be successful. My family's financial situation is not good, and I feel a lot of uncertainty. (T1, P16).

The graft reinfusion was the moment that gave me a second life. I feel both excited and uncertain about how I might react after graft reinfusion. (T3, P10).

Uncontrollable loneliness and social ineffectiveness

After being admitted to the isolation ward for a few days, many patients reported that they felt a huge sense of loneliness that could not be alleviated by socializing online. Quite a few patients expressed that mental distress and social ineffectiveness during isolation are more distressing than physical symptoms.

Although I can chat with others through social media, I rarely communicate with the outside world except I am informing my family about my treatment. I feel hopeless because I can't see a loved one standing in front of me and listening to me for almost one month. (T2, P4). I had chemotherapy before, so I felt that the physical pain was bearable. However, the mental pain and stress broke me down. I'm so lonely and so homesick

in the isolation room, and that's what hurts me the most. (T3, P6).

Positive emotions

During the graft reinfusion phase, some patients reported that they experienced positive emotions because they sensed that a new life had begun from that moment. At T4, when the hematology index recovered and the patient was to be discharged, they felt that they had recovered from the difficult time and developed strong positive emotions, which helped them achieve high levels of emotional well-being.

The graft reinfusion was the moment that gave me a second life. I was both excited and a little nervous about the moment. (T3, P10).

My husband has to work, my mother is getting older, and my sisters have their own housework. I have survived this difficult time, and I will be stronger in the future. (T4, P17).

Internal predicament: ineffectiveness of symptom self-management

Lack of information and symptom coping skills

Patients lacked different information at various periods. When first admitted to the transplant ward, patients had insufficient understanding of the ward environment, regulations, and cooperation. Patients expressed their need for continuous, updated information during hospitalization. After transplantation, the patients had insufficient information about possible symptoms and how to cope. Patients lacked the coping skills for self-care, early recognition of symptoms, and symptom management. They were almost entirely dependent on the medical staff.

I checked some information on the Internet, and also chatted with patients through WeChat. However, when I actually came in, I was still confused. I hope that the doctors or nurses will provide me with continuous information support. (T2, P8).

I know there may be rejection after transplant, but I don't know what symptoms I may have and how I can detect and deal with them. (T3, P2).

If I feel unwell, I will just tell the doctor and nurse in time. I certainly won't handle it myself. (T1, P10). Just leave it all to the doctors and nurses. (T3, P16).

Inadequate symptom perception

Patients lacked the ability to perceive symptoms. When physical discomfort occurred, many patients could not perceive and identify symptoms in time. Some patients

detected somatic sensations but did not know how to describe and interpret them based on their experience. The lack of symptom perception made patients unable to self-manage effectively.

Sometimes I feel really bad, but I can't tell what's wrong. (T2, P7).

I often have headaches, but if you ask me where and how it hurts, I don't know how to describe them. It may not be a headache; it may be that the environment makes me feel depressed. (T2, P10).

I felt that my body was getting weaker and weaker, and there was pain in many places. However, I couldn't tell the exact location of it, and the location of the pain often changed. (T3, P14).

External strength: desire for support from multiple sources

Support from the healthcare team

When patients entered the isolation areas alone, it was difficult to obtain help from other sources. At this point, the care and guidance of medical staff was a good start and confidence guarantee for the patient's treatment. Patients had full trust in doctors and nurses and were eager to receive support from them.

Now my family can't come in and be with me. I hope the doctors and nurses can give me more guidance, which will make me more confident to face treatment. (T1, P5).

I totally trusted the doctors and nurses during the transplant, and if they had given me further information, I might have done better. (T1, P9).

Family connection

The patients could not get company from their family, but they wanted to be able to get support from family members in other ways, such as calls, video chats, or looking at family photos. Family support was an important source of good social functioning for the patients.

My family is connected to me in another way, which is very important to me, especially when I feel unwell. The words of my family gave me the motivation to persevere. (T2, P1).

I miss my son very much, but he is very busy with his high school studies. I look at his pictures every day for comfort and support. (T3, P11).

Familiar possessions

Some patients emphasized that some familiar and meaningful possessions from their past life made them comfortable and secure in unfamiliar and risky environments. They were able to get support from familiar objects to help them overcome fear and loneliness and get better sleep.

I brought a sterilized doll with me, the only thing I was familiar with in this isolation ward. It accompanies me like family and helps me sleep better. (T2, P4).

I brought a water cup with a picture of my family on it. I like it very much, and it makes me calm. (T4, P12).

Discussion

Although the individual experiences of adult patients with HSCT were unique, the individual accounts revolved around four themes (unexpected symptom burden: dynamic, disturbing, co-occurring and correlative; emotional complexity at different periods; internal predicament: ineffectiveness of symptom management; and external strength: desire for support from multiple sources) illustrating symptom complexity and dynamicity.

Of interest were the characteristics of symptoms experienced by HSCT patients during hospitalization. Our analysis revealed that HSCT inpatients experienced an array of unexpected symptoms associated with the treatment and its side effects, characterized as dynamic, disturbing, co-occurring, and correlative. At T2, the patients experienced several severe symptoms, some of which continued until discharge. These symptoms disrupted normal body rhythms, such as recurrent sleep disturbances, inefficient eating, and persistent fatigue. Notably, the patients still had obvious symptom burden at T3 and T4 when chemotherapeutic agents were not used. The symptom experiences of HSCT patients were dynamic and changed over time. Healthcare providers should continue to strengthen the daily assessment and management of symptoms after graft reinfusion. In addition, physical, emotional, and cognitive symptoms may co-occur and interact with one another. For example, fatigue may co-occur with sleep disturbance and chronic pain [37, 38]. Patients' anxiety levels were associated with changes in physical symptoms such as pain, nausea, and decreased appetite during isolation [39]. This suggests that healthcare providers should not only focus on one symptom of HSCT patients, but also analyze the correlation and interaction mechanism between symptoms.

Importantly, the emotional symptoms of HSCT patients during hospitalization changed as the situation and treatment stage changed, with distinguished features of complexity and

dynamics. Capturing the characteristics of emotional symptoms of HSCT patients at different hospitalization periods is important for individualized management of emotional symptoms. Faced with a completely unfamiliar isolation ward, strict regulations, and uncertain prognosis, patients reported fear and uncertainty at admission. In particular, the small isolation space caused patients to have a great emotional response, and some patients reported that they had a sense of fear and guilt as if they had been jailed. The perceived fear of HSCT patients changed as the situation changed. The HSCT procedure increased hope, and their fear increased immediately before HSCT and decreased afterwards [40]. In addition, as the length of stay in the isolation ward increased, patients experienced uncontrollable loneliness and difficulty to self-relief at T2 and T3. A study showed that the severity of anxiety and depressive symptoms of HSCT patients in the transplant ward increased over time, peaked on day 7, and declined on day 14 [39], which was similar to our findings. However, it was difficult for patients to interact effectively through online chats, telephone calls, or video chats, which led to emotional symptoms that are more troublesome than physical symptoms. Apart from negative emotions, HSCT patients had positive emotional experiences during graft reinfusion. The patients believed that the HSCT experience was analogous to being reborn. They had a strong tendency to survive and return to a normal life beginning from transplantation [40]. The patients experienced another positive emotion before discharge: the patients felt happy to recover from a difficult situation. These helped the patients to achieve high levels of emotional well-being and facilitated recovery post-discharge [41].

However, how did HSCT patients manage themselves while experiencing symptom distress? Unfortunately, HSCT patients experienced internal predicament in self-management in response to the onset of symptoms for two reasons: lack of information and coping skills, and inadequate symptom perception. During transplantation, the patients placed themselves in the role of the "weak" subconsciously and lost their autonomy. Nurses play a key role in helping patients acquire self-management strategies by providing information about symptom management, helping them manage their emotions, and encouraging them to be actively involved in their care [24]. Studies have demonstrated the feasibility and effectiveness of this self-management modality in HSCT patients during hospitalization [24, 42]. The acquisition of self-management expertise is gradual. Over time, patients develop interoception and body awareness related to their symptoms, which is one of the factors that affects their ability to manage themselves [43].

To seek more channels for self-management, HSCT patients required multiple sources of support as an external strength to relieve their physical and emotional distress. First, healthcare providers are the main source of multiple

supports for HSCT patients in the closed isolation wards. HSCT in-patients have a high level of reliance on health-care providers for symptom management. Second, family support and closed connection with family are important sources of positive psychological experience for HSCT patients [41]. Family support is one of the coping strategies for HSCT patients to relieve anxiety [44]. Family cohesion may be helpful in dealing with their symptom distress, which in turn will contribute to a faster resolution of their health problems [45]. In particular, under the influence of Confucianism, Chinese families emphasize unity and harmony in the face of illness [46]. Third, some familiar and meaningful possessions can give patients a sense of security and alleviate their anxiety and sleep disturbance. Medical providers may allow patients bring some personally meaningful things into the isolation ward while ensuring safety and asepsis.

Limitations

This study has some limitations. First, all the participants were selected from a single hospital in southeast China; therefore, the interpretation of the results is limited due to the small sample size and single source, which may affect transferability to other regions, nationalities, and ethnicities. Second, participant selection was subject to age restrictions; thus, the results of this study are not generalizable to children, adolescents, and the elderly. Third, the interview could have been interrupted by patients' physical conditions. However, the interviewers conducted an in-depth interview while protecting the rights of the patients.

Conclusion

In conclusion, this study emphasizes the need for a deeper understanding of the symptom experience and self-management strategies of adult HSCT patients during hospitalization. The HSCT patients experienced complex and dynamic symptoms at multiple points during their hospitalization. Healthcare providers should strengthen the daily assessment of symptoms; educate patients on ways to perceive, express, and self-manage multiple symptoms; and develop patients' self-symptom management skills to alleviate HSCT-associated physical and psychological symptom distress, and thus improve their quality of life. In addition, HSCT patients often suffer from distressing symptoms over the course of transplant. Established support pathways from multiple sources are important to promote person-centered symptom management and improve general health for HSCT inpatients. Further studies combining longitudinal quantitative and qualitative methods to explore the characteristics of symptoms during HSCT are needed, which may provide

a unique perspective for understanding the mechanism of symptom occurrence and better prevention and management of symptoms.

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Authors' contributions All authors contributed to the study's conception and design. Jingyi Chen, Jiejie Yu, and Mengting Xie performed material preparation, data collection, and audio file transcription and analysis. Yong Wu and Rong Hu performed project administration and supervision. Jingyi Chen wrote the first draft of the manuscript, and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

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Data availability The data sets used and/or analyzed during this study are included in this published article.

Code availability Not applicable.

Declarations

Ethics approval This study was approved by the Ethics Committee on Biomedical Research of Fujian Medical University (IRB Ref. No.: 2021/108).

Consent to participate Written informed consent was signed by all participants.

Consent to publication The patients provided informed consent to publish their data with anonymous names.

Conflict of interest The authors declare no competing interests.

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