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Original Article

Taste alterations in patients following hematopoietic stem cell transplantation: A qualitative study

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ABSTRACT

Objective: This study aims to explore the experiences and consequences of taste alterations in patients undergoing HSCT, how they respond to these changes, and the factors that influence their responses.
Methods: In this descriptive qualitative study, face-to-face semi-structured individual interviews were conducted with 31 patients undergoing HSCT in a comprehensive hospital in Hubei, China. The interview data were transcribed and analyzed using Colaizzi's seven-step analysis. The Symptom Management Theory was applied to design the study and identify key themes.
Results: Three key themes were identified from the theory: (1) the complexity and diversity of taste experiences; (2) coping strategies; and (3) the multifaceted challenges of coping. Taste alterations in HSCT patients were characterized by diversity and dynamism. Patients employed three distinct coping styles in response to taste alterations: active coping, reluctant submission, and passive coping. These coping styles were influenced by various factors, including the specific treatment modalities of HSCT, individual patient characteristics, and the healthcare environment.
Conclusions: The experience of taste alterations among HSCT patients is intricate and varied, and the importance of addressing this symptom can easily be underestimated. Management of taste alterations is influenced by multiple factors. Nursing staff should give careful attention to taste alterations in HSCT survivors, enhance their expertise in managing taste alterations, provide robust health education, conduct regular screening and assessments, and formulate individualized intervention plans to assist patients in actively and effectively managing taste alterations.

Introduction

Hematopoietic stem cell transplantation (HSCT) is a treatment involving mega-dose radiotherapy or chemotherapy to remove tumor cells from the patient's body while simultaneously destroying the patient's immune system. This simultaneous action is necessary to reduce or prevent the risk of the recipient's body rejecting the donor's hematopoietic stem cells. The treatment also infuses the recipient's (autologous) or donor's (allogeneic) hematopoietic stem cells for the reconstruction of normal hematopoietic and immune functions.[1] It is widely used in the treatment of malignant and benign hematological diseases. The number of HSCT patients in the Asia-Pacific region has exceeded 10,000 annually since 2008.[2] Meanwhile, from 2008 to 2020, the number of allogeneic transplants continued to increase in China at a rate of more than 800 %.[3] The number of HSCT survivors continues to increase as transplantation techniques and supportive care evolve.[4] Studies have revealed that the three-year survival rate of HSCT recipients is 44 %-85.7 %.[5,6] HSCT is a complex procedure that can result in reduced life quality and life expectancy. It can induce various short-term and long-term complications and unpleasant symptoms due to its toxic effects on the patient's organs and systems.[1,7,8] Whether they are home-based or hospitalized, patients undergoing HSCT reportedly experience various symptoms of varying degrees and frequencies throughout the different phases of the therapy. The symptoms include pain, nausea, vomiting, lack of appetite, weakness, insomnia, and taste alterations (TAs).[7,9,10]

Taste is the perception of food chemicals by taste buds that are present on the tongue, resulting in different flavors.[11] Taste is easily confused with flavor, which is a more integrated sensory experience that combines the sensations of taste and smell and the holistic characteristics of the food.[12] Taste alterations, known as dysgeusia, is an abnormality or

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impairment of taste perception resulting in a distorted sense of taste.[13] It can be caused by many factors, including age, infections, smoking, medications, and treatments[13–16]. Symptoms of taste alterations can vary significantly from one individual to another, which may be measured by quantitative and qualitative disorders of taste. Quantitative disorders may be presented as the absence of a sense of taste (ageusia), reduced taste sensitivity (hypogeusia), or increased taste sensitivity (hypergeusia). Meanwhile, qualitative disorders may be portrayed through the sense of taste without external stimulation (phantageusia) or an unpleasant perception of taste in response to an external stimulus (parageusia).[17] Taste alterations may cause agony and eating disturbances in patients.[18] Studies have shown that these alterations negatively affect the nutritional status and life quality of the patient.[17,19,20] The primary manifestations include decreased dietary intake, increased negative emotions, and diminished social activities.[21,22]

Studies have demonstrated that 47 %–59.6 % of individuals who underwent HSCT suffered from altered taste sensations.[23,24] A systematic review highlighted that taste alterations are affected by therapy modality.[25] Compared to radiotherapy and chemotherapy, patients undergoing HSCT represent a unique population in which the taste is impaired by multiple factors, including severe conditioning regimen-related oral-gastrointestinal mucosal damage, preventative and supportive medications, and potential changes in the biodiversity of the oropharyngeal-gastrointestinal microbiome.[16,26] Thus, the experience of taste alterations may be different between patients treated with HSCT and radiochemotherapy. Although studies have deciphered the factors affecting the coping strategies in response to taste alterations in patients receiving chemotherapy,[27,28] it is still unclear for HSCT patients. Therefore, understanding the factors influencing the management of taste alterations in HSCT patients is vital for providing accurate assistance to the patients so they can cope with the taste alterations effectively. This study aimed to explore the experience of taste alterations in HSCT survivors, the strategies they used to alleviate the adverse effects of the symptom, and the factors that influence their response to the changes.

Methods

Study design

A qualitative descriptive study was conducted involving the HSCT survivors. The primary data were collected via face-to-face interviews featuring semi-structured interview guidelines. The theory of symptom management was adopted as a theoretical framework for research design and data analysis to gain an understanding of the true experience of taste alterations among HSCT patients.

Theoretical framework

Symptom Management Theory (SMT) provides useful guidance for oncology research and nursing practice.[29,30] SMT includes three core concepts: symptom experience, components of symptom management strategies, and outcomes, which are affected by the person, environment, health, and illness.[31] It emphasizes the importance of how individuals perceive, interpret, and respond to symptoms during their illness. In this study, the three constructs of this theory assisted the researchers in gaining an understanding of the real experiences of taste alterations in HSCT survivors: the patients' experience of taste alterations (perception, evaluation, and response), their management strategies (components of symptom management strategies), and factors influencing their management strategies (person, environment, and illness). The application of the theory is vital for researchers to focus on the study question and solve the problem.

Participants

The descriptive qualitative study applied in this research involved a phenomenological approach to explore the experience of taste changes in HSCT patients treated in a tertiary hospital in mainland China. From July to December 2022, patients with HSCT who were admitted to the hematology department were selected and recruited for semi-structured interviews, which were conducted using a purposive sampling strategy. Once data saturation was achieved, the data collection ceased.

The inclusion criteria were determined, which include patients undergoing HSCT before the interview, taste alterations with a total score of $\geq$4 points according to the Chinese version of the CiTAS (C-CiTAS),[32] being $\geq$18 years of age, Chinese-literate, not having cognition problems, voluntarily agreeing to participate in the study, and giving written informed consent. Individuals who were unable to eat by mouth (receiving tube feeding or total parenteral nutrition) and those who were treated with HSCT twice or more were excluded from the study.

Data collection

In-depth face-to-face interviews were conducted by nurses trained in qualitative methods to gather the data, and a semi-structured interview guide was applied in each interview. The semi-structured interview guide was developed by applying the theory of symptom management[31] as a framework and consulting the nurses working in hematology wards. Two pilot interviews were performed to test the guide, and the necessary changes were made. The two interviews were included in the analysis as they both provided interesting data.

The study questions about the experience of taste changes included: (1) Please tell us about the changes in your sense of taste since receiving the hematopoietic stem cell transplantation. (2) How did it affect you? (3) What did you do when you noticed taste changes? (4) What help have you sought? How did they do? (5) What are your suggestions for patients experiencing taste changes?

The interviews were conducted by the first author in the hematology ward and lasted from 10 to 60 minutes. All the interviews were audio-recorded and subjected to a verbatim transcription, which was then stored in the pre-set folders with the recordings.

Data analysis

All transcripts were organized using NVivo 12 software and analyzed using Colaizzi's seven-step analysis method.[33] Firstly, recordings of each interview were read repeatedly to understand the participants' meanings and feelings. Secondly, significant statements related to the experience of taste alterations were extracted from each transcript. Thirdly, meanings were formulated and coded based on these significant statements. Fourthly, the codes were grouped into categories, themes, and sub-themes. Next, transcriptions, themes, and sub-themes were compared multiple times to confirm findings and identify the differences. Then, the theme and intrinsic of the patients' experience were described using their own words in complete detail. Lastly, each transcript and result were returned to the participants to affirm the findings.

Ethical considerations

This study obtained approval from the Medical Ethics Committee of Union Hospital with a decision dated June 7, 2022. Information about the study was provided to the HSCT survivors who met the inclusion criteria and who had given written informed consent before the data collection. All identifying information about the participants was removed from the transcripts, with their names being replaced with numbers.

Trustworthiness

To ensure the rigor of this study, several techniques were used. Data saturation was scrupulously followed to ensure the credibility of this study. Two authors analyzed the data independently and compared their findings, thus guaranteeing the triangulation of the investigators. The emerging themes were reviewed by all authors, and a consensus was reached. Additionally, the results were explained to two participants via

a face-to-face approach to ensure that the results are legible, understandable, and reflect their real experiences.

Results

Demographic characteristics

Thirty-one participants were interviewed in this study. All were allogeneic HSCT patients aged from 18 to 57 years, with 19 males and 12 females. The time since their HSCT varied between 0.5 and 48 months. Table 1 shows the general information of the participants.

Themes and subthemes

Three major themes emerged during the qualitative analysis: (1) the complexity and diversity of the taste experience; (2) the coping methods; and (3) the multifaceted constraints of coping.

Theme 1: the complexity and diversity of taste experience

There are four sub-themes under this theme. For HSCT survivors, the experience of altered taste is not fixed. It rather constantly changes over time, which is associated with disease progression and medical management. Taste alterations are manifested in four different dimensions, which include various symptoms and negative physical and psychological impacts on patients. The four sub-themes and their illustrative quotes are presented in Table 2.

Theme 2: coping styles

Active coping

The majority of respondents in this study were able to correctly perceive and evaluate taste changes and adopt individualized coping methods based on their own taste-change characteristics. The active coping methods and their illustrative quotes are shown in Table 3.

Reluctant submission

During the interviews, some patients were able to correctly perceive and evaluate taste changes and attempted to take appropriate measures according to their situation. However, they eventually gave up due to disease progression and the treatment's non-progressive outcomes.

> *Before, it was all about eating lots of soda crackers. But, with the recent skin drainage, I haven't been eating them.* (P3)

> *Soaking in sugar and salt water, still tastes the same as drinking plain water, and later I gave up*. (P12)

Passive coping

Some of the patients in this study experienced altered taste before undergoing HSCT. The patients believed that the taste changes would improve at the end of the treatment, thus choosing not to respond.

> *It (taste alterations) is caused by chemotherapy, and the taste will slowly get better after a period of time without medication.* (P1)

> *I've experienced this before, and then it (taste alterations) got better. Now the taste is gone from my mouth again. Certainly, it would be fine again after a while.* (P18)

Some patients also sought help from others, believing that the taste changes were unavoidable, thus failing to respond.

> *I talked to my mom, and she said that it (taste alterations) is normal, it is a post-transplant process, and it would get better slowly.* (P3)

> *They (the medical staffs) said it's normal. It heals itself when the body is well and it will recover.* (P25)

Table 1
Characteristics of the patients ($n = 31$).

Patient ID	Gender	Age (years)	Civil status	Education background	Conditioning regimens	Time after HSCT (months)	C-CiTAS scores
1	M	20	Single	Bachelor	Vp16 + BuCy2	1	8.43
2	F	51	Married	Junior high school	BuCy2	1.5	5.08
3	M	18	Single	High school	DAC + Ara-C + BuCy2	1	5.98
4	M	23	Single	Bachelor	DAC + Ara-C + BuCy2	11	5.92
5	F	18	Single	High school	BuCy2	1	5.66
6	M	47	Married	Junior high school	TMI + Vp16 + Cy	11	12.54
7	M	48	Married	Bachelor	DAC + Ara-C + BuCy2	6	10.71
8	M	28	Single	High school	Flu + BuCy + ATG	48	10.86
9	F	28	Single	Bachelor	IDA + BuCy2	0.5	4.87
10	F	51	Married	Bachelor	DAC + Ara-C+ BuCy + ATG	24	11.22
11	M	57	Married	Bachelor	IDA + BuCy2	0.5	9.35
12	M	27	Single	Bachelor	BuCy2	3	8.25
13	M	39	Married	Master	DAC + Ara-C + BuCy2	4	5.37
14	M	31	Married	Junior high school	BuCy2	2	11.16
15	F	40	Married	Junior high school	DAC + Ara-C + BuCy2	2	12.38
16	F	45	Married	Junior high school	DAC + Ara-C + BuCy2	11	11.57
17	F	46	Married	Junior high school	Vp16 + BuCy2	40	6.96
18	M	29	Single	Bachelor	BuCy2	5	6.16
19	M	46	Married	Bachelor	BuCy2	4	8.58
20	M	42	Married	Junior high school	FBA	2	8.75
21	F	35	Married	High school	Vp16 + BCNU + FBA	2	6.25
22	F	46	Married	Junior high school	Flu + Ara-C + BuCy2	1	8.58
23	F	18	Single	High school	Vp16 + BuCy2	1	10.59
24	M	43	Married	Master	Flu + Ara-C + BuCy2	1	10.83
25	M	18	Single	High school	Flu + Ara-C + BuCy2	3	11.74
26	M	30	Single	High school	BuCy2	3	6.09
27	M	23	Married	Bachelor	TMI + Cy	31	8.08
28	M	18	Single	High school	Vp16 + BuCy	2	8.10
29	F	18	Single	High school	Vp16 + BCNU + FBA	1.5	6.00
30	F	57	Married	Junior high school	Flu + Bu	19	5.87
31	F	51	Married	Bachelor	DAC + Ara-C + BuCy2	1	4.50

Vp16: Etoposide; Bu: Busulfex; Cy: cyclophosphamide; DAC: Decitabine.
Ara-C cytarabine; TMI: Temozolomide; Flu: Fludarabine; ATG: Anti-Thymocyte Globulin IDA: Demethoxydaunor Ubicin; FBA: Flu + Bu + ALG; BCNU: Carmustine. M: male; F: female.

Table 2
Four subthemes and participant quotes.

Sub-theme	Code	Participant	Example quote	*n* (%)
Different dimensions of taste alterations	A decline in basic taste	11	A lot of sugar was put in the porridge by my wife, but I still couldn't feel the sweetness.	19 (61.3)
		14	It was too salty to eat; noodles were boiled in water and washed with water, which were still very salty.	
		24	The salt taste was always bland to me, and I think it's because they (the family) put less salt in.	
	Discomfort	13	I lost my appetite when I couldn't taste it.	29 (93.5)
		17	At that time, there was no taste in my mouth, and I'd eat and then throw up and throw up and eat again.	
	Phantogeusia and parageusia	15	The mouth is always bitter.	25 (80.6)
		20	The stir-fry came out, just a clamped one, and it was particularly strange and abnormal in the mouth.	
		21	It was also bitter in my mouth; even if I don't eat anything, it was astringent and numb. I can't describe.	
		3	I'm in cutaneous graft-versus-host disease and chew like plastic when I eat.	
		29	In the transplant bin, it was like chewing straw when I ate.	
	General taste alterations	4	I had no taste for anything to eat when I was in the sterile warehouse.	29 (93.5)
		17	I didn't taste anything from the beginning of transplantation to three months after transplantation.	
Dynamic variability of taste experience	Worst in transplant bins	30	It (taste alterations) is worst in the transplant bin.	4 (12.9)
	Differing taste changes before and after HSCT	12	(When I was in the ward) receiving chemotherapy, everything I ate had a fixed taste: sour. Taste returns to normal in 2–3 days once the chemotherapy is over. In the transplant bin, I couldn't feel the salty taste when I ate, and now when I eat (something) without salt put in, I feel extra salty.	10 (32.3)
		27	Before the transplantation, it wasn't salty or anything but only bitter. Post-transplantation, it was mostly salty and sour.	
	Evolving	15	It (the sense of taste) comes in bursts; sweetness appears during this time, and after a few days, bitterness and saltiness appear.	3 (9.7)
Accompanying symptoms	Excessive drooling	21	I couldn't feel the sweetness; I just felt like my mouth was sticky and drooling all the time.	4 (12.9)
		22	My mouth turns bitter and keeps spitting.	
	Dry mouth	31	Then the mouth is dry, and anything I eat is tasteless.	4 (12.9)
	Vomiting	17	At that time, there was no taste in my mouth, and I'd eat and then throw up and throw up and eat again.	3 (9.7)
		25	It was that taste of eating that irritated me and made me want to throw up.	
	Olfactory changes	31	When there is no taste in my mouth, the smell can't be smelled and the sense of smell is not working either.	1 (3.2)
The impact of taste alterations	Changing eating behavior	11	Inability to eat food: one is the lack of taste response; the second is the inability to eat; and if you do you just throw up.	25 (80.6)
		19	Quite a big impact. I used to not like to eat noodles, but that has totally changed over, and there are noodles and steamed buns. I don't eat rice.	
		20	The greatest impact is the lack of desire to eat, the absence of taste, and the absence of desire to eat anything that I see.	
		21	As we all know, no salt is put into the bun skin, right? However, by the time I put the bun skin in my mouth, it was too salty to eat.	
	Increased suffering	11	Just painful, very painful. I feel sometimes that I'm quite hungry, yet I can't eat.	13 (41.9)
		19	The food you imagine should taste good, and it's beautiful when it's made. But once you put it in your mouth, you can't swallow it; everything tastes the same.	
		20	I have no sense of taste. Nothing that I see makes me want to eat. I drank porridge every day; oops, I got thrown up by the thin rice.	
		27	It affected the mood. Firstly, you have very little to eat. It's hard to have a new thing that you can eat, but when you get it in your mouth, it [the food] is actually tasteless; you feel salty, and you can't eat it. Then, again, you are limited to eating what you have eaten before.	
	Weakened importance	18	Taste changes are not a thing compared to disease and treatment, and the presence or absence of taste has little impact.	7 (22.6)
		24	In the barn (the transplant barn), the doctors also said that it does not matter if you do not eat; the nutrition can be satisfied with medication. Sustaining life. The doctors' exact words were, "Sustain life, not talk about taste."	
		27	The taste of something really doesn't matter. For this disease, taste is a secondary thing; the main thing is that it's good to live.	

In addition, for some patients, there was no way to mediate their altered sense of taste.

> *Many people experience changes in taste after transplantation, but there is no specific protocol to improve.* (P8)

> *No way; I can't do anything.* (P24)

Theme 3: multifaceted constraints of coping

Specificity of the treatment

Hematological disorders are treated with HSCT due to its specificity, which influences the way patients manage their altered taste sensations.

Patients with HSCT are pre-treated with high doses of radiotherapy or/and chemotherapy before the transplantation. After the transplantation, infection prevention is often achieved with antibiotics, antifungal drugs, and immunosuppressive drugs to avoid graft rejection. Notably, a wide variety of medications affect the management of taste alterations.

The intake of animal products and fresh fruits and vegetables is restricted in HSCT patients 30 days after the transplantation or during neutrophil deficiency to reduce the risk of infection. The food is minimally oily, light, easily digestible, and cooked well, with the spices and condiments used sparingly or not used at all to avoid food-induced inflammatory reactions. Furthermore, patients with special dietary requirements have fewer options for coping.

The secondary heating and sterilization of food in the transplant barn may affect the sense of taste in some patients. However, there are concerns about transplant complications caused by a poor diet. Treatment modality factors and their illustrative quotes are presented in Table 4.

Table 3
Active coping methods for taste alterations.

Response	Participant	Example quote	*n* (%)
Oral care	14	Clean your mouth before you go and eat.	4 (12.9)
Adjusting the diet	7	Change this stew one day, and that one the next. Slowly season the tract, and it will recover.	6 (19.4)
	11	Keep adjusting what you usually like to eat and eat as much as you can.	
The use of condiments or other food	4	When you add sugar and you have a sweet taste to your food, your appetite is a little better and you may eat a little more.	4 (12.9)
	15	Try a little bit of sweet, or improve that bitter taste in your mouth with another flavor, like sour, sweet. Sugar, yoghurt–tried them all.	
Tongue-scraping	20	There will be a thick layer of stuff on top of the tongue; scrape it off, and it will be better.	1 (3.2)
Ice-cube application	22	After I take the medicine, I take the ice into my mouth, and it's comfortable inside my mouth.	1 (3.2)

Patients themselves

Patients' perception and evaluation of taste alterations, taste alteration symptoms, and personal eating habits influence how they manage taste alterations.

As I am in the hospital, so it is too much trouble for me to do something with it. (P3)

I'm from a rural area, so there won't be much impact. (P6)

I still prefer sweets. Firstly, I like sweet things, and secondly, only sweet things still appeal to me. (P11)

Nothing could be done, and I'm not a fan of sweets or sugar, so I didn't add any either. (P24)

As a heavy eater, I have to eat light, so it doesn't matter to me. (P26)

Medical environment

People have social attributes, and the management of taste changes in HSCT patients is influenced by the environment they are in such as the physical environment, the dietary requirements, the attitudes of health care professionals, and the attitudes and behaviors of fellow patients toward taste changes.

I am also in the hospital, so it is too much trouble for me to do it. (P3)

In the transplant warehouse, you can't see what it's like outside for a month, and there's no one to talk to, and you have to suffer the pain of chemotherapy and the pain of having that hypodermic needle in your body every day, so you're really depressed and you can't eat. (P4)

No one discussed taste alterations when many patients were together. (P18)

Only eat those things and don't talk about the taste, as stressed by the doctor. (P24)

Discussion

The findings of this study reveal that the experience of taste alterations in HSCT survivors is complicated and dynamic. Additionally, the coping styles of patients are diverse and constrained by multiple factors. Based on the symptom experience model (SEM), the symptoms experienced by HSCT patients in this study are multidimensional, interdependent, and constantly changing.[34] Lazarus' transactional theory of coping[35] suggests that coping changes with the situation. Patients' perception and behavior toward taste alterations are related to the symptoms in the patients and other circumstantial factors such as the medical setting, treatment regimen, and transplant-related complications.

Patients in this study believed that taste alterations were trivial compared to the treatment benefits and chance of living. This perception could be due to the fact that graft-versus-host disease, infection, and hemorrhage are the major complications and leading causes of mortality. Furthermore, enteral and parenteral nutrition are generally applied to offer nutritional support for patients in clinical work. Taste alterations are easily discounted by both patients and health care professionals. However, in Maslow's Hierarchy of Needs, all needs are rooted in physiological needs such as food, water, and air, and taste is a key aspect of food intake. Taste alterations are also strongly correlated with the energy intake of the patients.[36] Previous studies have indicated that taste alterations affect eating and increase pain. Some patients reportedly suffer from anorexia due to a reduction in appetite, hunger, and the hedonism of eating.[18] These results are consistent with the findings in this current study. Therefore, it is imperative for health care workers and patients to emphasize taste alterations. Health care providers should also encourage patients to report any symptoms of altered taste and other related symptoms and to attend regular screenings and health evaluations. This initiative is particularly important for HSCT patients in transplant bays and with transplant-related complications and symptoms. Although there

Table 4
Treatment modality factors.

Special factors	Participant	Example quote
Drugs	7	Breathe ah, sweat ah, eat all (is the taste of drugs), take drugs, put brown sugar together, not sweet at all.
	14	Seafood, mangoes, and other foods may affect a drug's efficacy, and doctors told us not to eat those things, so I did not eat.
	31	In the post-transplant period, tacrolimus and cyclosporine are used to treat rejection. These two drugs have many food interactions, some compatibility issues, and many side effects.
Dietary requirements	3	This disease is treated by avoiding foods such as greasy food, milk, and what you want to eat.
	9	I can't eat just anything, nor too much oil or salt.
	11	In the six months after you get out of the barn (the transplant barn), there are some things that aren't edible.
	22	There's no taboo about eating when you're undergoing chemotherapy. But it is contraindicated to eat in the transplant barn."
Eating procedures	21	Then the second course is heated, sent in, then left for a long time, cool and warm, before it can be eaten, a process that must have produced a change in that flavor.
	30	It [the food] would use that high pressure, press it, and everything tasted different.
Worry	21	Those are the few things that we eat often, because a little carelessness can lead to intestinal drainage.
	24	Milder cases will have some bad changes, while more severe cases will have persistent diarrhea, which will eventually become life-threatening.
	27	I'm worried that eating indiscriminately may cause other complications.

is no standardized tool to assess and characterize distortions in taste sense[37], CiTAS has been used for an immediate and easy assessment of taste alterations in patients with different treatment modalities, cultural backgrounds, and types of tumors.[38] The application of CiTAS is especially recommended for an assessment of taste alterations in cancer patients. Studies have also suggested incorporating taste assessment into the patient's follow-up and providing targeted guidance based on the assessment results.

Findings from this study have demonstrated that most of the interviewed individuals have adopted strategies such as oral care, diet modification, and condiment addition to cope with the altered taste. A previous study conducted in Italy highlighted the coping strategies adopted by patients experiencing distorted taste sense, which include choosing and selecting foods, changing meal times, and seeking family support.[18] However, this current study also found that some patients coped negatively due to a lack of knowledge about taste distortions. HSCT patients usually experience more than one symptom during the treatment, and their lack of knowledge and poor perception of the symptoms hinder them from effectively coping with the changes.[10] The inability to properly acknowledge the distortion in taste sense and a poor knowledge of appropriate treatments have hindered patients from seeking help to manage the symptoms.[39] To improve awareness and management of taste alteration, nursing managers should systematically equip nurses with knowledge related to taste alterations which includes the appropriate assessment and diagnosis, influencing factors, and management strategies. Furthermore, health education for patients should be enhanced to help them identify taste alterations, adopt an appropriate coping method according to their situation, and improve their symptom management skills.

This current study reveals that the health care environment, treatment modality, and patients themselves have a significant impact on the coping strategies adopted by patients to manage the distortions in their taste sense. The three core concepts of symptom outcomes, environment, and health and illness are incorporated into the symptom management theory. Additionally, health care professionals and patients are extremely cautious about diets during HSCT treatment due to their unique and potentially life-threatening complications. Currently, the majority of transplant centers worldwide use a low-microbial diet to prevent enteric-derived infections.[40,41] This study noted that patients' perceptions toward taste alterations, their experience of symptoms, and their eating habits affect their management strategies. Taste alterations are impacted by multiple factors, including aging, drugs, malnutrition, radiotherapy, chemotherapy, pre-conditioning, graft-versus-host disease, and oral health.[16] The findings also suggest that preventing and managing taste alteration alone is insufficient. Therefore, nurses, as the primary practitioners and instructors in managing taste alterations, should be proactive in understanding patients' eating habits and experiences with taste alterations to better formulate proper interventions. For patients who associate pasta with nausea, it is recommended that they opt for wontons and noodles. Patients who prefer rice can choose from a variety of porridges. The patients with dry mouths are advised to drink more water and to consume fresh fruits and vegetables. Patients who like a sour taste may choose sour foods such as oranges and yogurt. Meanwhile, patients are encouraged to report symptoms of taste alterations voluntarily. Furthermore, primary caregivers should be involved in their management to increase caregiver awareness and provide appropriate support to help patients manage taste alterations effectively.

Limitations

This study has some limitations. Firstly, all participants were recruited from hematology wards in a tertiary hospital in mainland China. Thus, some bias in the selection of the HSCT sites involved in this study might have been introduced. Secondly, all individuals are allogeneic HSCT survivors. Thus, it is unknown how taste alterations are experienced by autologous HSCT patients and whether there is a difference between allogeneic and autologous HSCT survivors. Finally, none of the participants were in the transplantation bins. Therefore, little is known about their experience of taste alterations in the bins. In the future, it is recommended that a multicenter study be conducted to enroll patients with diverse types and timelines of HSCT.

Conclusions

In conclusion, the experiences of taste alterations in HSCT survivors are complex and diverse, negatively impacting their lives. Some patients are unable to cope with taste changes due to a lack of knowledge, and their management is limited by multiple factors. In addition to paying attention to taste alterations, the collaboration between nurses, patients, and caregivers needs strengthening to assist patients in actively and effectively coping with taste alterations.

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CrediT author statement

Yuanyuan Chen: Investigation, Methodology, Data curation, Formal analysis, Writing-Original draft. **Yun Fang**: Writing - Original and Revised draft preparation, Supervision, Project administration. **Minjie Liu**: Conceptualization, Methodology, Investigation, Data Curation. **Ruishan Yao**: Methodology, Software. **Jia Wan**: Visualization. All authors had full access to all the data in the study, and the corresponding author had final responsibility for the decision to submit for publication. The corresponding author attests that all listed authors meet authorship criteria and that no others meeting the criteria have been omitted.

Declaration of competing interest

The authors declare no conflict of interest.

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Ethics statement

The study was approved by the Medical Ethics Committee of Union Hospital, Tongji Medical College, Huazhong University of Science and Technology (IRB No. [2022] Review No. 0439). All participants provided written informed consent.

Data availability statement

The data that support the findings of this study are available from the corresponding author, [Fang Y], upon reasonable request. These data cannot be made public as they involve information about the privacy of the participants.

Declaration of Generative AI and AI-assisted technologies in the writing process

No AI tools/services were used during the preparation of this work.

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