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ORIGINAL ARTICLE

The experience of dysgeusia in allogeneic haematopoietic cell transplantation survivors: a qualitative study

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Abstract

Background Taste disorders are one of the most common side effects of treatment in oncology patients and often occur after allogeneic haematopoietic cell transplantation (allo-HCT). Dysgeusia does not receive close medical attention, and information about this disorder is largely based on the clinician's own experience. However, taste disorders can have an impact on the quality of life and nutritional status of survivors of allo-HCT. The number of performed annual transplantations is growing, as the number of older long-term survivors increases, but only few research studies examine survivors of allo-HCT with taste disorders. We conducted a qualitative descriptive study to explore experiences of dysgeusia in patients undergoing allo-HCT and to examine what strategies they used to mitigate it.

Methods Using purposeful sampling, survivors of allo-HCT were recruited. Audiotape interviews were conducted until data saturation was achieved. Each interview was transcribed verbatim, and content analyses were performed to extract significant themes and subthemes.

Results Three major themes embracing various aspects of allo-HCT survivors' experiences were identified: (1) the shape of taste; (2) everything is irritating and it is arduous to eat; (3) finding new strategies to overcome the problems. Together, they highlight the experiences of survivors showing how the taste disorders can affect the physical, psychological and social dimensions of a person.

Conclusion A cumulative burden is the result of dysgeusia and its clinical course reinforced also by related symptoms. Healthcare professionals must focus their attention on the management of these symptoms and offer interventions to safeguard the patient's social, physical and psychological well-being.

Keywords Qualitative study · Dysgeusia · Taste disorders · Allogenic haematopoietic stem cell transplantation · Quality of life

Introduction

Taste disorders are one of the common treatment side effects in oncology patients and often occur also after allogeneic haematopoietic cell transplantation (allo-HCT) [1–3]. In these patients, reduction in taste sensation (ageusia), alteration of taste (dysgeusia) or presence of metallic taste or chronic bitter sensation [4, 5] affect their enjoyment of eating, food intake,

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weight and nutritional status [2, 6]. Often, dysgeusia is correlated with food aversion and an increased risk of weight loss, with possible consequent physical deterioration [7]. Disinterest in food also affects patient food choices and emotional status, causing frustration, distress and discouragement [2], significantly damaging their quality of life [3, 8]. Dysgeusia appears to be a longer-lasting and more complex problem, especially in patients undergoing allo-HCT, because of the intense conditioning regimens, total body irradiation linked with an important mucosal injury, high exposure to immunosuppressant and an increased frequency of infections [3]. In fact, high-dose chemotherapy with or without total body irradiation can cause taste dysfunction from days to months, and in many cases, taste is recovered more than 3 months after HCT [1, 2]. Moreover, drugs like cyclosporine and tacrolimus may induce changes in taste [8]. Onset of dysgeusia as a side effect of treatments depends on patients' disease, transplantation typology and treatment themselves; thus, its severity and durations vary [3]. Dysgeusia is rarely a life-threatening complication, and for this reason, it may not receive close medical attention, and information about this disorder is largely based on the clinician's experience [5]. However, when dysgeusia occurs, the risks of malnutrition and weight loss and lower caloric intake as well as the necessity to replace oral intake with parenteral nutrition increase [3, 6]. In the literature, there are many studies about taste disorders in oncology patients [2, 5, 9, 10], and one of the most studied populations is head and neck cancer patients, while allo-HCT patients are still unstudied [3]. Whereas the number of annual transplantations performed continues to grow, and the number of older long-term survivors increases, it is essential to bring attention to this complication [11, 12]. Starting from this assumption, we conducted a qualitative descriptive study to explore the taste disorder experiences in patients undergoing allo-HCT and to examine what strategies they use to mitigate it.

Methods

Study design

We performed a qualitative descriptive study using semi-structured interviews [13] and following qualitative content analysis [14, 15]. We followed the consolidated criteria for reporting qualitative research (COREQ) principles [16].

Sampling and research setting

We used a purposive sampling strategy, which included the following eligibility criteria: patients who have undergone allo-HCT from 3 to 6 months before the interview and with a persistent taste alteration; aged 18 years or older; capable of having a fluent conversation in Italian; with no physical or cognitive impairments which affect participation.

Patients were recruited by two nurses at a haematological day care service of a university hospital in Northeast Italy. Patients were asked to participate during their clinic appointment between January and February 2016. The nurses suggested participants according to the mentioned criteria and assessment about his/her characteristics of having lived the experience and being willing to talk about it [17].

Data collection

The authors defined the main topics of the semi-structured interview which encompassed the following: (1) the kind and duration of the taste alteration; (2) the experience of taste and smell issues; (3) appetite and food enjoyment, the alteration's emotional aspects and the strategies to manage eating issues; (4) the impact of smell and taste alterations on daily life and social relationship, especially with family and loved ones. Interviews were conducted using a topic guide to ensure all relevant topics were addressed during the discussion. A general question was used to begin the interviews to establish a cordial relationship between the researcher and the patient; the interviews then dealt with more detailed issues following initial answers, inviting the patients to verbalise about the interview's topics [18]. Open-ended and follow-up questions are used to minimise the risk of predetermined answers and to guarantee a more in-depth understanding.

A trained researcher conducted the interviews with all the participants, in a private room at the haematological day service, a location convenient to both the participants and the researcher. The informed consent and the permission to audiotape were obtained from each participant before the interview. The duration of interviews ranged from 7′ 29″ to 38′ 51″. Researchers continued the participants' recruitment until no new concepts arose from data analysis, achieving data saturation [17, 19].

Data analysis

All interviews were audiotaped and transcribed verbatim by the first author. Two researchers analysed the data according to the qualitative content analysis as indicated by Graneheim and Lundman [15]. Firstly, they read repeatedly the transcripts to obtain the overall sense of the interview and to grasp the informants' perceptions [20]. Then, they independently selected the meaning units from the participants' statements. The meaning units were condensed in specific descriptions, grounded in the data, which have been discussed by all the authors. Subsequently, after discrepancies were solved, involving if necessary a third researcher, the meaning units and condensed descriptions have been interpreted under the

light of the research question, inductively grouping them into subthemes and main themes [20].

Ethical considerations

For this study, research ethics approval was obtained from the University and Academic Hospital of Udine Internal Review Board. Verbal and written consent from participants were obtained, as well as researchers guaranteed anonymity and confidentiality. Participants received information related to the study purpose in oral and written form prior to the actual involvement, and researchers made them very aware of the possibility to withdraw from the study at any time.

Results

Seventeen patients were asked to participate and 14 patients accepted the interview (Table 1).

Through the analysis of interview transcripts, it was possible to detect the patient's emotional experience related to taste alteration and its effects on nutrition and patients' daily life. Moreover, it was possible to identify the respondents' behaviours, adopted in an attempt to address the problem of dysgeusia, and some strategies to resolve it. Our analysis identified the following three major themes: (1) the shape of taste; (2) everything is irritating and it is arduous to eat; (3) finding new strategies to overcome the problems. Together, they highlight the lived experiences of patients undergoing HCT.

The shape of taste

This theme summarises how the patients described taste and how it is perceived in its alterations. It is composed of three subthemes: alteration of taste, absence of taste and, at last, modified and attenuated taste. Regarding the alteration of taste, the patients described it indicating the presence of unpleasant sensations during the feed, particularly while drinking water.

> *It feels like a layer of ... kind of plastic, it seems ... you do not feel anything ... not even the saliva... (Pz 1)*
> *The water, when I drink the normal water it seemed like drinking tinny water ... yes, I felt just tinny water and I could not drink it! (Pz 1)*

Other flavours are instead perceived altered to such an extent that foods seem to acquire strange texture, described as cardboard or plastic.

The second subtheme concerned the complete absence of taste. Some patients have reported that, unable to perceive any taste, the food has completely lost its flavour. In this case, everything seemed to be tasteless, uniform and without any notes or "nuances" that would allow them to perceive their characteristics. The sense of taste is completely lacking, generating dissatisfaction when the patients are not able to taste the foods that, before the transplant, they were able to eat.

> *Let's say that all the flavours are all the same ... does not taste like before, no? Not so ... strong, it's not like before ... it's more bland. (Pz 3)*
> *I found everything insipid ... for me it was all without salt. It's like that ... as if the food was always without salt ... (Pz 4)*

In the end, in the third subtheme, the taste was attenuated at the point that some patients presented a flattening of the taste alternated with an amplification of some flavours. This situation is determined by the loss of appetite, the alteration of food and their quality of life. The respondents declare, moreover, that they are no longer able to distinguish flavours, not even the simplest ones or those that they thought they knew well, losing all reference and no longer knowing what they are eating.

Everything is irritating and it is arduous to eat

For some patients, the act of eating is experienced as a sort of habit, an activity of daily life that must be performed but still perceived as something annoying, almost a burden. During the interviews, the most reported elements that seem to have more influence on nutrition were physical smells and sensations. The aversion, in fact, towards some smells perceived as intolerable made the feeding difficult, and in some cases, the association between the perceived smell and the food was so strong that it became unbearable.

> *Even other food just felt the smell annoying me ...! I felt them differently and they bothered me ... (Pz 12) In some cases, the smell of food is worse than eating it ... (Pz 10)*

Another significant aspect for patients is the simple perception of an odour that could cause a series of negative reactions such as nausea, aversion or complete refusal of food. Moreover, the flavours, associated with the smells, seemed almost to reinforce each other, causing a decrease in the stimulation of hunger, desire and pleasure of eating, to the point of provoking reactions of disgust and rejection. In association with the alteration of olfactory and gustatory perceptions, for some, the presence of stomatitis has also led to a worsening feed, as a source of pain and burning during intake.

> *The smells of eating, all amplified and disgusting enough! Sometimes it bothers me and I associate it with nausea. (Pz 2)*

Table 1 Participant's characteristics

Gender	*N*	%
Female	9	64.28
Male	5	35.72
Interview time	Mean	Median
Age (years)	51	46
Days after transplantation	231	201
Diagnosis	*N*	%
Acute myeloid leukaemia	8	57.14
Myelodysplastic syndrome	2	14.30
Chronic myelogenous leukaemia	1	7.14
Multiple myeloma	1	7.14
Non-Hodgkin's lymphoma	1	7.14
Chronic lymphocytic leukaemia	1	7.14
Type of transplant	*N*	%
Haematopoietic stem cell transplantation—MUD	8	57.14
Haematopoietic stem cell transplantation—HLA identical sibling	5	35.71
Haploidentic haematopoietic stem cell transplantation	1	7.15

HLA human leukocyte antigen, *MUD* matched unrelated donor

Even the texture, in relation to an altered perception of food and complications due to the transplantation of haematopoietic stem cells, is completely distorted and modified. Some patients report that they no longer perceive the taste of food, while others describe specific sensations, such as the feeling that what they were taking was flour.

> *The food sticks to me everywhere, to all the teeth, to the palate, everywhere. I do not feel anything ... The consistency is sticking all over… I just had all the food sticking to my teeth, under the palate and until you drink a little 'water and brush your teeth and ... you're left half ... It makes you feel like you have flour in your mouth, stuck to your mouth. (Pz 11)*

Finding new strategies to overcome the problems

Some patients, in order to be able to feed themselves, seek strategies to overcome the difficulties caused by the alteration of taste, even if, for many, dysgeusia is experienced with resignation, or as a condition linked to therapies and to which they cannot do anything. The choice and selection of foods for some respondents have proved to be a very useful strategy, even trying to select them by trial and error. The fact, however, to be able to discriminate those that were unpleasant from favourites or otherwise tolerated at that time, has helped them continue to feed. Analysing what was reported in the interviews, however, it was found that some patients also found strategies that went beyond the simple removal from the diet of a food or an unpleasant taste, such as the use of gel or the intake of food as an ice cream. These allowed them to be able to feed, without feeling repulsion towards a certain food or in some cases without even refusing the meal.

> *I go in search of food that I like, I am careful when cooking ... I recognized the taste of pasta with tomato sauce and ok: for three four days I ate pasta with tomato ... (Pz 6)*
> *The ice cream has helped me so much! Feeling the cold, as if the layer went away ... with ice cream I felt much better! (Pz 1)*

Furthermore, for a patient, even changing meal times proved to be useful. Do not eat at set times, but when you feel the stimulus of hunger, choosing the food that at that time seems more congenial has helped not to skip or avoid meals.

Finally, a further element that has helped patients overcome obstacles related to nutrition and taste alteration has been family support. All patients reported having received comfort and support from the presence of one or more caregivers. In fact, they have supported them in the most difficult moments in the recovery of everyday life, as well as stimulated them in the search for new foods or strategies to solve the problem of dysgeusia. Also, the fact of being able to return to your home after a long period of isolation turned out to be an important aspect. Being at home gave them a sense of protection and comfort.

My wife was the one who stimulated me to eat as much as possible. (Pz 12)
If my children hadn't been there, I would have died ... (Pz 5)
Feeling for someone ... for someone else and feeling important for someone else ... becomes important ... (Pz 10)

Discussion

Eating and food have a strong impact on the biological and social function of people, often taking on a strong symbolic meaning [21]. A symptom that impacts food intake in patients undergoing allo-HCT, but still little studied, is represented by the alteration of taste [2, 6]. By conducting semi-structured interviews, it has been possible to identify that for many patients the best way to describe the alteration of taste experienced by them is the use of metaphorical images. In some cases, in fact, the food has been described by referring to materials such as cardboard or plastic, as well as the consistencies of some foods have been compared, for example, with raw flour.

In agreement with Citron and Goldberg [22], the use of metaphor helps to conceptualise something abstract and to make a more easy-to-understand concept that is more closely connected to bodily experience. In the specific case of the interviewees, we can therefore deduce that these types of representations were used precisely to fully express the disgust felt towards food because of dysgeusia and its negative impact on their quality of life. A direct consequence of the total alteration of flavours was the complete loss of interest and refusal of meals, accompanied by a negative change in nutritional status. In agreement with the results of other studies [1, 2, 6, 8], numerous participants admitted to having lost weight and appetite precisely because of the alterations of flavours and for some also of smell.

An explanation of this phenomenon is linked to the fact that when other sources of gratification may be available in oncology patients, food sensory stimulation continues to be very important for them [23]. Consequently, food aversions, intake reduction and nutritional deficits are linked to patients' distress and taste alterations [24]. Moreover, it has been possible to notice the existence of a connection between dysgeusia and presence of other symptoms such as fatigue, appearance of nausea, vomiting, of changes in odours and in some cases also with mucositis. This condition could find its justification in the fact that the perception of taste does not work in isolation [7, 8, 25]. On the contrary, the symptoms seem to be mutually reinforcing by involving the gustatory, olfactory, tactile and thermosensory apparatus [8, 25]. Furthermore, in agreement with Larsson et al. [26], the close connection between physical problems related to food intake and foodstuffs highlights the presence of a complex phenomenon that requires intervention by specific and holistic health workers, considering both the psychosocial dimension of the patient and the physical one. This approach is also necessary according to the fact that patients tend to find the resolution of food problems autonomously, acting through trial and error, without asking for help from health professionals. The patient's way of acting indicates the need for health professionals to include, in their routines, patient care strategies for taste and smell, as well as changes in taste and smell. This would allow a more effective monitoring, capable of intercepting any problems early, implementing further evaluation and possible diet modification checks by expert professionals [7]. The autonomous action of the patient has however already been reported in the literature for other types of cancer patients, especially those suffering from head and neck tumours [21]. In cases of eating problems with a specific type of food, they would adjust their choices themselves if this resolved their problem [27, 28], thus learning the difference between what they could and what they could not eat. Strategies such as the use of spices, sauces and condiments to enhance or reinforce perceived flavours reported by respondents are also implemented by other cancer patients [7], as well as requests for help from family members [28–31]. This highlights how sometimes different patients, faced with the same problems, act and still find overlapping solutions, and this suggests to health professionals the possibility of adopting the same monitoring strategies and educational methods.

Another element noted with the interviews is the fact that some participants said they benefited from the intake of cold food and substances such as ice cream and ice lollies. In this regard also, Okada et al. [6] underlined the importance of the implementation of oral cryotherapy into the regimen of supportive care management in patients undergoing autologous haematopoietic stem cell transplantation. The data on the benefits of oral cryotherapy are still rather limited, however, as reported by our interviewees and those of Okada et al. [6], suggest the need to conduct a larger prospective study on the effectiveness of this strategy, involving large samples of the population. Another element that has been highlighted in all the participants is represented by the fact that, after the transplant, the difficulties related to intervention, added to those experienced for the feeding, were sources of strong emotional stress and discomfort even in social relationships. The presence of the family and the protective environment of the house, however, had a positive impact on the patients, who felt supported by their loved ones. In fact, for those interviewed, for example, taking food with company and not

in solitude, as happened during the period of isolation during hospitalisation, was identified as a source of great comfort. This element reinforces what has been reported in other studies that have highlighted the important role of family members providing assistance in the preparation of patients' food, helping with food selection, cooking and providing encouragement to keep on eating [26, 28, 31, 32].

In the end, the interviews revealed the lack of any search for information in order to improve the response and the possible reactions with respect to this disorder. In the present study, all the subjects faced the problem of dysgeusia on their own very often, "living day by day", finding the solution to problems when they appeared and not trying to implement behaviours or preventive strategies. In addition to this, the interviewees, even when the question was asked in a direct way, have always stated that they did not seek support or external opinions from professionals, not even nurses or dieticians, preferring to use methods tested on themselves or acting by trial and error. An explanation of this attitude can be given by the fact that all the interviewees reported that they did not ask for the origin of the disorder, assuming that it was a consequence of the transplant and the therapies, without even addressing the problem of the duration of this disorder. This behaviour seems to be in line with what is also reported by Zabernigg et al. [33] that patients rarely address taste alterations, and therefore the problem is not addressed together. This data highlights the need for health professionals to work more on these aspects with the aim of building a strong partnership between a patient and a structured approach. Healthcare professionals should ensure that the patients are aware of effective dysgeusia. Specifically, suggestions for patients should include the following: carefully maintaining oral hygiene; adding more or less seasoning; eating food at room temperature or frozen food; adopting plastic utensils and glass baking pans [4, 34]. The use of spices and herbs as well as sugarless hard candies, gums with strong flavour and mints has been also recommended [4, 34]. Furthermore, avoiding food with strong smell, eating small meals several times during the day, adopting sweet and sour food and adding sweetener or acidic fruit (like lemons, limes or oranges) to food were other helpful strategies for patients [34]. All these strategies should be tailored for motivating and monitoring of patients when they perform self-care activities, according to their specific taste changes and needs. Lastly, assessment and monitoring of patients during follow-up controls, dietary educations and detecting adverse patient outcomes such as malnutrition and quality of life alteration are strongly recommended.

Study limitations

In this study, all participants were selected from a single Italian university hospital, and the findings are limited by the small sample. For these reasons, the selected sample is not representative of the patients undergoing allo-HCT, and it may limit the generalizability. Furthermore, the time taken for data collection was very short, and this may have influenced the selection of participants in the study.

Conclusions

The interpretation of the patients' taste alteration lived experiences showed how this symptom can affect the physical, psychological and social dimensions of the person and may help healthcare professionals understand more on patients' experience. A cumulative burden is the result of dysgeusia and its clinical course reinforced also by related symptoms. Healthcare professionals are called to focus their attention on the management of this burdensome symptom, offering interventions to safeguard of the patient's social, physical and psychological well-being. Dysgeusia can be an extended side effect; therefore, the interventions on behalf of the healthcare professionals need to continue long after the completion of the treatment through frequent follow-ups.

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Compliance with ethical standards The study was exempt from formal ethical approval by the Internal Review Board composed by Academic Hospital and University members.

Conflict of interest The authors declare that they have no conflict of interest.

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