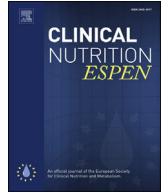




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Original article

Taste changes as a metaphor for biographical disruption: A qualitative study in patients undergoing haematopoietic stem cell transplantation

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SUMMARY

Purpose: and objective: The treatment side effects of patients undergoing haematopoietic stem cell transplantation can cause various eating difficulties. The objective of this study was to explore the significance of eating experiences and taste changes from the perspective of patients undergoing haematopoietic stem cell transplantation.

Method: This was a qualitative, exploratory study based on semi-structured interviews applied during hospitalisation for haematopoietic stem cell transplantation. Thematic content analysis and the biographical disruption concept were used as theoretical references to explore the results.

Results: Twenty patients were studied. The overarching theme identified from the results was deconstruction of the taste reference resulting from sensory taste change, loss of eating references and changes to the hedonic relationship with food caused by the treatment. In addition to this deconstruction, participants described the reformulation of eating habits as a way of coping with the disease, which affected the eating experience and motivated the dietary strategies adopted.

Conclusions: Taste changes during haematopoietic stem cell transplantation are related to both biological issues and metaphysical aspects. This study raises the meaning of loss of sensory references and their symbolic aspects. These results were important to expand our view to include other aspects that can contribute to improving the care given to these individuals.

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Introduction

The conditioning regimen of haematopoietic stem cell transplantation (HSCT), a treatment common to haematological diseases and malignancies, involves chemotherapy and/or total body irradiation. These treatments affect the patient profoundly due to their adverse effects. Nausea and vomiting, loss of appetite, mucositis, dry mouth, organ toxicity and taste changes, among other adverse effects, can cause physical, emotional, cognitive and social damage, resulting in changes to the patient's life trajectory [1–6]. The side effects of chemotherapy affect up to 80.0% of HSCT patients and are brought about by inflammatory processes that affect the gastrointestinal tract, making it difficult to eat and leading to appetite loss [6].

Abbreviation: HSCT, Haematopoietic stem cell transplantation; TBI, Total body irradiation; AML, Acute myeloid leukaemia; CML, Chronic myeloid leukaemia; ALL, Acute lymphoblastic leukaemia; BMT, Bone marrow transplantation; AA, Aplastic anemia.

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The sensory changes present in these patients are orchestrated by numerous factors such as the tumour itself, changes in the number of taste receptors, disruption to neural encoding, systemic chemotherapy neurotoxicity, the secretion of drugs via saliva and hyposalivation [3,5,7–10]. Despite the wide range of studies related to taste changes in patients undergoing chemotherapy, a pattern associated with these sensory changes has not been established [4,9,11–14]. Qualitative studies have shown that sensory disorders (taste and smell), changes in food preferences, loss of interest in food, impairment in social interactions and reduced quality of life are all consequences related to chemotherapy [13–16].

The subjectivity involved in eating relates to cultural identity, social status, religion, family memories [17,18] and other meanings and can be disrupted and transformed by taste changes. In terms of these considerations, it may be said that eating defines not only what is ingested but also the person who ingests it [19].

In the hospital environment, eating is affected by specific physiological conditions and the institution's norms and values relating to diet, involving changes to eating practises that can

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change patients' perception of their own identity [20–22]. The understanding of subjective aspects of eating and taste changes in HSCT can allow better management of the nutrition and treatment of these patients.

Theoretical background: disease as biographical disruption

The onset of a disease brings pain, fear, suffering and the possibility of death, experiences that, during the life trajectory, are viewed with detachment and even neglected as an avoidance strategy, which gives less realism to such facts. Studies by Michael Bury [23,24] seek to understand the process of falling ill and its consequences in terms of reorganising one's life. The concept of biographical disruption developed by the author suggests that chronic disease creates and modifies the life trajectory, expectations and very biography of the patient. Three stages are used to elucidate this concept: the discontinuity of assumptions and behaviours relating to what is happening, followed by a fundamental review of one's biography, with a changed body awareness, and, finally, the reaction, which involves the mobilisation of resources to confront the disease. The biographical disruption caused by disease depends not only on the physical impact but also on associated positive and negative meanings, including social and ideological relations [25].

Studies that have used the concept of biographical disruption state that living with cancer can be a chaotic experience that requires the mobilisation of resources to respond to the disruption caused and efforts to maintain life [25,26], that the life disruption is associated with the feeling of fear and the ongoing process of renegotiation of identity and "normality" [27] and that the disease has positive and negative repercussions [28,29].

The purpose of this study is to explore eating experiences and taste changes during chemotherapy in patients undergoing HSCT in terms of the concept of biographical disruption [23,24].

Methods

This was a qualitative study of a descriptive and exploratory nature, using semi-structured interviews, which were analysed in terms of their thematic content [37] to explore nutritional experiences during the HSCT process. All patients admitted for HSCT at the Clinical Hospital of the Ribeirão Preto Medical School of the University of São Paulo, over a 12-month period were included. The project was approved by the Ethics Committee (566,879). The inclusion criteria were (1) an interest in voluntary participation in the study, (2) undergoing allogeneic HSCT up to 65 days prior to the interview, (3) use of a reduced-intensity or myeloablative chemotherapy protocol, with or without total body irradiation (TBI) and (4) being 18 years of age or older. Alcoholic patients and/or smokers were excluded.

A total of 30 patients were admitted in this period, of whom 26 were invited to participate (4 died and 2 declined to participate), leaving 20 subjects who participated in the study.

Data collection

An initial presentation was made to eligible patients as an introduction and to form bonds. The interview script, with

semi-structured questions, was based on the literature [3–5,8,11,12,14,16,30–36] and on a pilot study performed with six patients to test and adjust the instrument according to the research objective (Table 1). The following issues were addressed: history of discovering the disease, the eating experience during HSCT, dietary and taste changes, meanings of eating and dietary strategies adopted during treatment. Respondents were assigned pseudonyms. Sociodemographic and clinical information (illness, type of HSCT, conditioning regimen, symptoms and anthropometric data) was obtained from medical records or collected from the patients. Patients were interviewed between 15 and 65 days after their bone marrow graft.

Data analysis

The interviews were audio recorded, transcribed in full and imported into software (ATLAS.ti 7.0, Scientific Software Development GmbH, Berlin, Germany) for data analysis. Thematic content analysis [37] was used to identify, analyse and report patterns or themes present in the collected data. The coded data were read and reread and collectively discussed by four researchers (two authors and two external researchers) [38] until categories were defined that best covered the research question. The theoretical framework proposed by Michael Bury [23,24] on the subject of biographical disruption was used in conjunction with supplementary literature to inform the final analyses to identify patterns in regard to the experience of eating as a biographical disruption. The sociodemographic and clinical data characterising patients were tabulated with the aid of Microsoft Excel (Microsoft Corporation, USA), and the variables are presented as absolute and relative frequencies.

Results

A total of 20 subjects were interviewed (12 of whom were male). The mean age of the participants was 36 (19–58); 10 patients were over 40 years old, and 60.0% had completed high school education. Among the respondents, 65.0% had onco-haematological disease and 35.0% haematological disease. Acute myeloid leukaemia and sickle cell anaemia were the most commonly encountered diseases (Table 2). All symptoms were described by most patients: 95.0% reported dysgeusia, 85.0% mucositis, 70.0% changes in smell, 65.0% nausea and vomiting and 55.0% dry mouth. The mean body mass index (BMI) was 24.38 kg/m² (15.29–34.33 kg/m²). The mean interview duration was 57 min (minimum 20 - maximum 70). The results were organised into three categories, as shown below.

Diagnosis, disease and treatment: "the watershed"

The disease's signs and symptoms, investigation and diagnosis cause life changes at practical and subjective levels that represent a "watershed" between the periods before and after the disease. Changes to the patient's routine are permeated by feelings of anxiety and fear that surround the experience of the disease. Table 3 presents examples of excerpts that show how this period represents a milestone in the subject's life.

Table 1
Topics covered in the interview.

1. Tell me a little about your history and your diet.
2. Tell me how you found out about your disease.
3. Comment about your experience with food and eating during treatment.
4. Tell me about what you did when changes occurred to the taste of your food. Have you tried any strategies to manage it?
5. Tell me about the main changes you have had on the taste.

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