



Reframing eating during chemotherapy in cancer patients with chemosensory alterations

Britt-Marie Bernhardson^{a,b}, Karin Olson^c, Vickie E. Baracos^a, Wendy V. Wismer^{d,*}

^a Department of Oncology, University of Alberta, Canada

^b Department of LIME, Karolinska Institutet, Canada

^c Faculty of Nursing, University of Alberta, Canada

^d Department of Agricultural, Food and Nutritional Science, University of Alberta, Canada

A B S T R A C T

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Purpose: Our purpose was to describe how eating is reframed among cancer patients experiencing chemosensory alterations.

Methods: Using data collection and analysis strategies from a qualitative design called ethnoscience, we interviewed 12 patients experiencing taste and smell alterations during chemotherapy. We asked participants to provide a description of a meal and the process by which they decide what and how to eat. Each person was interviewed twice. We compared participants' descriptions of eating, and used this comparison to identify some core beliefs about eating. Participants also completed measures of dietary intake, symptom burden and quality of life.

Results: Based on the interviews, we identified specific constraints to eating, beliefs about the value of eating, and behaviours participants used to work around the constraints to eat during chemotherapy. Chemosensory complaints and other symptoms (i.e. pain, anorexia, tiredness), personal experiences and food preferences were the main constraints. Core beliefs about the value of eating included its social benefits, benefits of eating for health per se, and benefits related to preparing for the next chemotherapy cycle. These beliefs reframed the purpose of eating and were used by participants to develop specific strategies to work around the constraints to eating.

Conclusion: To date, interventions to promote eating among cancer patients have focused extensively on symptom management and on recommendations for macro/micronutrient intake. This study underscores the importance of understanding beliefs about eating. These beliefs may help clinicians develop patient-centered nutritional interventions.

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Introduction

Illness is a turning point often responsible for the reconstruction of food choice (Winkler et al., 2010; Sobal and Bisogni, 2009) and perceptions of food and eating habits typically change during cancer (Mroz et al., 2010; Bell et al., 2009) and its advanced stages (Hopkinson, 2007). A cluster of nutrition impact symptoms, such as anorexia, dysphagia and nausea, interfere with the ability of patients with cancer to eat (Kubrak et al., 2010). Each of these symptoms can alter, impede or even prevent oral intake. For example, chemosensory (taste and smell) alterations are a problem we have been studying and characterizing for several years (Hutton et al., 2007; Bernhardson

et al., 2007, 2008, 2009; Brisbois et al., 2011b). Chemosensory alterations are associated with decreases of energy intake of large magnitude (i.e. 900–1000 kcal/d) and thus have a consequential nutritional impact.

We hypothesized that physiological barriers to oral intake and psychosocial aspects of ingestive behaviour are interdependent. Specifically, we earlier showed that when advanced cancer patients lack appetite, conscious cognitive processes are employed to achieve sufficient food intake (Shragge et al., 2007). Thus, a balance must be struck between the symptoms which are a disincentive to eat, and the cognitive processes employed to overcome those disincentives. These cognitive processes are influenced by life experiences and personal beliefs, values, customs and behaviours (Sobal and Bisogni, 2009) and serve to reframe the eating experience (i.e. look at or think of in a new or different way).

While most researchers agree that cancer patients lack appetite and that a number of symptoms impair food intake (Mroz et al., 2010;

* Corresponding author. 4-10 AgFor Centre, University of Alberta, Edmonton, AB, Canada T6G 2P5. Tel.: +1 780 492 2923; fax: +1 780 492 4265.

E-mail address: wendy.wismer@ualberta.ca (W.V. Wismer).

Bernhardson et al., 2007; Shragge et al., 2007; Hopkinson et al., 2006; Strasser et al., 2008; Orrevall et al., 2005; McQuestion et al., 2010), understanding the influence of beliefs about eating on food intake is limited in the cancer setting. Despite the value of such information, research in this area to date has not used designs appropriate for studying beliefs about eating, nor have researchers provided sufficient demographic, nutritional, or medical detail about the sample (Currow et al., 2009). The purpose of the study presented in this article is to address this gap.

Methods

Study design

We selected cancer patients receiving cytotoxic chemotherapy and experiencing a defined primary nutrition impact symptom (chemosensory alterations of moderate to severe intensity), for an investigation of their reframing of the eating experience. We used a qualitative design called ethnoscience, accompanied by detailed information about participants' disease, treatment, and symptom burden.

Ethnoscience provides analytic strategies for identifying beliefs embedded in language (Graffigna et al., 2011). A growing number of research teams are using this approach to learn more about relationships between beliefs and behaviour. Recently, Porr et al. (2010) used ethnoscience to learn more about how patients' beliefs about tiredness, fatigue and exhaustion influenced their ability to manage depression. Hirst (2002) used ethnoscience to examine nurses' beliefs about resident abuse in long-term care facilities, and Bottorff et al. (1998) used ethnoscience to elucidate cultural beliefs related to breast health among south Asian women living in Canada.

In ethnoscience, the research team identifies words and phrases used by each participant to describe some experience. These words and phrases are placed on cards and participants are asked to organize the cards into groups, placing similar words and phrases together, and then label the groups. The participant is asked to "think aloud" during the sorting process and then talk about the similarities and differences among the groups. The research team compares the sorts completed by all study participants, and then prepares a written description of the patterns in beliefs they identified. This description is used as the basis for a flow-diagram that shows how the patterns in the data shaped participant behaviour.

Sample

The study was approved by the Research Ethics Board of the Alberta Cancer Board. All participants provided written informed consent. Outpatients at a local treatment center receiving systemic anti-neoplastic therapy from March 2009 to February 2010 were invited to participate in the study based on the presence of chemosensory alterations. Patients with tumours of the head and neck who were incapable of oral intake were excluded. The presence of chemosensory alterations was identified by a 16-item Taste and Smell survey that quantifies self-perceived chemosensory function (Heald et al., 1998). The tool yields a taste complaint score from 0 (no complaints) to 10 (severe complaints) and a smell complaint score, 0 (no complaints) to 6 (severe complaints). The total chemosensory complaint score (0–16) is the summed taste and smell complaint scores. Those who scored 2 or more on the Taste and Smell Survey were invited to participate in this study.

Qualitative data collection and analysis

Data were obtained through interviews conducted by the first author (BMB). In the interviews the participants were asked to recall

the eating experience throughout their chemotherapy treatment. The participants were prompted to begin their description by asking them to "tell their story" about a meal ("Can you please tell me a story that helps me understand how you decide what to eat?"). When participants mentioned beliefs about eating and behaviours related to food and eating, they were asked to expand on these points. Interviews were tape recorded and transcribed verbatim. Words or phrases used by participants related to beliefs about eating and behaviours related to food and eating were identified and written on cards by the first author in preparation for the second interview. Thirty-four to 77 cards were generated by each participant. Capture of each participant's own choice of words in describing their experience is essential in this design because language is the primary symbol system through which meaning is conveyed (Graffigna et al., 2011).

At the second interview, 14–30 days after the first, participants were asked to sort the words and phrases from their first interview into groups by placing similar cards together. They were then asked to describe the similarities and differences between the groups. This process was repeated three times, with participants first sorting their cards into as many groups as they wished. At the second sorting the participants were asked to re-sort their cards into three groups. In the final step, participants were asked to sort their cards into two groups. At each step participants labelled (i.e. gave a descriptive name) each group, and the researcher recorded the group number and label on the back of each card.

The researchers then constructed a table for each participant, with the labels for the first sort as the columns and the labels for the second sort as the rows. Each word or phrase that had been placed on a card was then placed within the appropriate cell of the table. Items sorted into the first group in the third sort were marked with red colour and items sorted into the second group of the third sort were marked with black colour. Following each second interview, the research team discussed the table and compared it to the tables prepared following the second interview with previous participants. Based on this comparison, the team began identifying possible beliefs that seemed to reframe eating during chemotherapy. At the end of the study, the research team compared the tables constructed from all participants' data, looking for common patterns. By comparing the labels used for the groups of cards across participants, the research team identified patterns in the data that seemed to influence participants' decisions about eating. We used this information to complete a componential analysis; a flow-diagram that integrates the patterns in beliefs and the behavioural pattern, which in this case was eating.

In accordance with sample size considerations in qualitative research (Richards and Morse, 2007), to ensure data saturation after the initial 10 participant interviews, two additional participants were recruited. All participants were interviewed twice. Quotations from the interviews are presented below, with pseudonyms used for all participants, to support our analysis. False starts, repeated phrases, and irrelevant information have been omitted, as indicated by three ellipses [...].

Rigor was maintained by including participants who had documented chemosensory alterations and by conducting at least two interviews so that participants had the opportunity to confirm that their statements and beliefs had been clearly and correctly captured. Data were collected and analyzed simultaneously so that information collected early in the study could inform later interviews, and emerging ideas were considered in light of published literature.

Quantitative data collection

To provide context about the participants and their symptom experience, clinical and demographic information were collected prior to the first interview. Diagnoses and treatment information

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