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Physical symptom burden of post-treatment head and neck cancer patients influences their characterization of food: Findings of a repertory grid study

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ABSTRACT

Background and aim: Dietary advice for post treatment head and neck cancer (HNC) patients emphasizes food characteristics of nutritional value and texture, and not patients' characterization of food. The aim of this study was to determine patients' characterization of food.
Methods: Repertory grid interviews were conducted with 19 orally-fed HNC patients between 4 and 10 months post-treatment to characterize foods commonly eaten, avoided and eaten sometimes. Patients compared and rated 12 foods using their own descriptors. Data were analyzed by General Procrustes Analysis (GPA). Socio-demographic status, taste and smell alterations, appetite and food intake data were also collected. Patient physical symptom burden was defined by University of Washington-Quality of Life Physical Function domain scores and used to stratify patients with "less physical symptom burden" ($n = 11$, score ≥ 61.7) or "greater physical symptom burden" ($n = 8$, score < 61.7).
Results: All patients used descriptors of taste, ease of eating, convenience, texture, potential to worsen symptoms and liking to characterize foods. Overall, avoided foods were characterized as having dry texture, while foods commonly eaten were characterized by their ease of eating and low potential to worsen symptoms. Descriptors of nutrition and smell were significant only for patients with greater physical symptom burden.
Conclusions: Physical symptom burden influenced the characterization of foods among post-treatment HNC patients. Nutrition counseling must consider patients' physical symptom burden and the subsequent characterization of food that drive food selection or avoidance to facilitate dietary advice for adequate, appropriate and enjoyable food intake.

1. Introduction

Illness has been identified as a turning point responsible for the reconstruction of food choice (Sobal and Bisogni, 2009; Winkler et al., 2010), and affects the negotiation and priority perception of food values (e.g. health vs. taste or convenience vs. cost) (Bernhardson et al., 2012; Sobal and Bisogni, 2009). An estimated 48–58% of cancer patients change their eating habits after diagnosis (Danhauer et al., 2009; Maskarinec et al., 2001) and head and neck cancer (HNC) patients are among those commonly compelled to make these changes as their symptoms and structures associated with the tumor often interfere with normal eating and drinking. During treatment, 72% of HNC patients experienced clinical conditions, symptoms or socioeconomic considerations that restricted their usual food intake (Cruz et al., 2012; Toporcov and Ferreira Antunes, 2006).

Many symptoms persist post-treatment, delaying the return to normal eating habits, reducing food enjoyment (McQuestion et al., 2011), nutritional status and quality of life (McLaughlin and Mahon, 2014). During the 4–10 months post-treatment, patients transition to pre-treatment food intake, making alterations to their lifestyle and food choices (Semple et al., 2008). Patients use a variety of

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coping strategies and eating behaviors evolve to deliberately avoid certain foods and preferentially consume others. Wilson et al. (1991) observed that HNC patients develop specific eating strategies in response to treatment problems and Larsson et al. (2003) revealed the coping methods used by patients to manage both the reduced physical capability and mental desire to eat. We previously observed that patients receiving chemotherapy reframe their eating experience based on new constraints and pre-treatment experiences to manage food choice and intake (Bernhardson et al., 2012).

Symptom clustering after HNC treatment impacts nutritional outcomes (Cousins et al., 2013) and the prevalence of malnutrition in this group has been estimated to be 13% (Jager-Wittenaar et al., 2011). While the restrictions of symptoms on dietary intake and nutritional status among HNC patients is well documented (Kubrak et al., 2012; Ganzer et al., 2013), little is known about the influence of symptoms on patient characterization of food, which in turn influences food preference and food choice, and subsequent dietary intake and nutritional outcomes.

Dietary advice for post treatment HNC patients emphasizes food characteristics of nutritional value and texture, and does not consider patients' characterization of food. Knowledge of how HNC patients perceive, describe and characterize foods post-treatment could aid nutrition education in all areas of eating behavior, including food acquisition, preparation and intake, and improve patients' QoL. Therefore, the aim of this study was to determine patients' characterization of food as influenced by physical symptom burden.

2. Methods

2.1. Participant recruitment

The study was conducted at the Cross Cancer Institute (CCI), in Edmonton, AB., between July 2012 and May 2014. Research procedures were approved by the University of Alberta Ethics Review Board and all participants completed informed consent. Outpatients who completed treatment for HNC (oral cavity, salivary glands, paranasal sinuses, oropharynx, nasopharynx, hypopharynx and larynx) with any histology and at any stage were invited to participate. Inclusion in the study required being at least 18 years-old, English-speaking, capable of oral intake and having completed treatment between 4 and 10 months prior to the interview. Recruitment continued until no new information emerged from the interviews indicating data saturation was reached (Tan and Hunter, 2002).

2.2. Study design

Individual repertory grid interviews were performed to determine the characteristics of foods perceived by patients post-treatment. The repertory grid method (RGM) is based on the Personal Construct Theory of psychology developed by Kelly (1955) that seeks to understand individuals' perception of the world as defined by their constructs of it (Fransella et al., 2004). In research settings, constructs that describe similarities and differences among items are elicited from individuals in the one-on-one presentation of items as successive triads. The constructs are then used by the individual to rate each item. The combined matrices of item ratings generated by each individual are mathematically transformed using Generalized Procrustes Analysis (GPA) to generate a consensus map of ratings that highlights commonalities in perception and item characterization among individuals. RGM has been used in health care research to explore beliefs about heart failure treatment (Cottrell et al., 2013), the meaning and impact of their disease among HNC outpatients (Turpin et al., 2009), and to assess patient preferences for angina treatments (Rowe et al., 2005). RGM is also used to reveal consumer perceptions of foods and their appropriateness for use (Monteleone, 1997).

Twelve foods were selected from a previous study with post-treatment HNC patients (Kubrak et al., 2012) for use in the RGM interviews. These foods represented three categories: foods commonly avoided (rice, cheese, fresh vegetables and citrus fruits), foods commonly eaten (milk, fish, eggs, and cooked vegetables) and foods eaten sometimes (bread, meat, chicken and pulp fruits). The name of each food was written on a white card, one food name per card. Cards were presented to patients in six triads. Three cards were selected from the initial pool of 12 (triad 1). The second triad was constructed by randomly selecting one of the cards from the first triad and including two more from the remaining nine cards. This procedure was repeated until all cards were included in a triad (Thomson and McEwan, 1988).

Triads were presented one at a time and participants were asked to think about "something that two foods had in common that the third did not have" in regards to their current food intake and then "how the third food differed from the other two", which prompted participants to elicit bi-polar descriptors known as constructs. When all possible constructs within a set of cards had been elicited, a new triad was shown and the same procedure was followed. To conclude the interview, each participant used their own constructs to rate each of the 12 foods on a 5-point scale, where 1 represented the first elicited construct (e.g. cheap) and 5 represented the opposite of that construct (e.g. expensive). Details of this methodology have been reported elsewhere (Jancowicz, 2004). The interviews (approximately 1–1.5 h) took place in meeting rooms at the CCI.

2.3. Socio-demographic status, taste and smell, appetite, food intake and quality of life

A questionnaire on socio-demographic status was used to collect data on education, housing, income, ethnic group and dietary restrictions. Self-reported taste and smell alterations (TSA) and associated factors were evaluated through the Taste and Smell Survey (TSS) (Heald et al., 1998) and a supplementary questionnaire on potential triggers and symptoms that are known to affect the ability to eat (Gollub and Weddle, 2004). The TSS quantifies the nature and severity of TSA through a final score, the Chemosensory Complaint Score (CCS) that ranges from 0 to 16 (Insignificant/Mild (1–4), Moderate (5–9) and Severe (10–16) (Hutton et al., 2007). Appetite, hunger and satiety were assessed using the Council of Nutrition Appetite Questionnaire (CNAQ) (Wilson et al., 2005). Energy and protein intake were estimated from three-day food records (three consecutive days including one weekend day) using the Food Processor II Nutrient Analysis Program™ (Esha Research, Salem, OR).

Quality of Life was assessed using the University of Washington Quality of Life Questionnaire (UW-QoL) version 4 (Rogers and Lowe, 2010), a tool that evaluates overall QoL and severity of 12 common symptoms (i.e., chewing, swallowing, speech, taste, saliva, appearance, anxiety, mood, pain, activity, recreation and shoulder) in scores from 0 to 100, where higher scores indicate better QoL. The Social-Emotional Function domain is calculated as the average of anxiety, mood, pain, activity, recreation and shoulder scores, while the Physical-Function domain is calculated as the average of taste, chewing, swallowing, speech, saliva and appearance. Patient scores were stratified as "less physical symptom burden" (i.e., $\geq$61.7) or "greater physical symptom burden" (i.e. $<$ 61.7) according to the overall median PF domain score, reflecting less or more PF impairment, respectively. The RGM characterization of food