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Title

Experiences and consequences of altered taste, flavor and food hedonics during chemotherapy treatment

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Abstract

Purpose

Self-reported taste alterations are common in people receiving chemotherapy however it is usually unclear whether these reports refer to changes to the sense of taste itself or to problems related to the broader phenomenon of flavor, or the hedonic experience of eating and drinking. The purpose of this study was to explore patient and carer descriptions, experiences and consequences of taste and flavor changes associated with Oxaliplatin treatment.

Methods

This study utilised a grounded theory research design. Purposeful sampling was used to recruit eligible patients who had self-reported taste changes in relation to Oxaliplatin containing chemotherapy for colorectal cancer. Content analysis of interview data was performed using an analysis framework derived from previous sensory and nutritional sciences and supportive care research.

Results

Ten patients and four carers participated in semi-structured interviews. The overarching theme identified from the data was reduced food enjoyment. In addition to changes to taste, participants described sensory and hedonic changes which influence overall flavor perception and food enjoyment. Reduced food enjoyment had dietary, social and emotional consequences for patients and carers.

Conclusions

‘Taste’ problems during Oxaliplatin treatment mostly relate to the broader phenomena of flavor. This study has helped to unravel the major sensory determinants of the eating and drinking experience in the chemotherapy setting and has provided guidance regarding relevant and measurable endpoints of chemotherapy related flavor changes. There remains a gap in knowledge between the pattern of flavor changes associated with chemotherapy treatment and how this influences dietary intake and nutritional status.

Keywords

Cancer, chemotherapy, Oxaliplatin, taste, , hedonics, dietary intake

Introduction

Self-reported taste alterations are common in people receiving chemotherapy [1, 2] however it is usually unclear whether these reports refer to changes to the sense of taste itself or to problems related to the broader phenomenon of flavor [3] or to food hedonics [4]. Taste, flavor and food hedonics have clear and distinct definitions within the sensory fields but have not been well defined in the clinical literature. It is important to

understand these discrete but interrelated determinants of the overall eating and drinking experience if we are to improve supportive care strategies.

Taste refers specifically to the perception derived when chemical molecules stimulate specialized taste receptors located in the areas of the tongue, soft palette and oropharyngeal region of the oral cavity. The sense of taste is underpinned by five taste qualities: sweet, salty, sour, bitter and umami (savoury) [5]. The perception of flavor is complex and it is important to note that taste is only one component of flavor [6]. As well as involving the senses of taste and smell, flavor is influenced by physical properties (temperature and touch) as well as perceptual and cognitive interpretation [7, 8]. Food hedonics is an independent component of the eating and drinking experience and refers to a psychological determination of the extent to which eating and drinking provides affect of pleasure or displeasure [9]. Reduced food enjoyment during cancer treatment can have physical, emotional and social consequences [10]. Despite their distinct differences, health professionals and patients alike commonly use the words ‘taste’ and ‘flavor’ interchangeably or use the word ‘taste’ in reference to hedonic experiences [3]. For example, “I like the taste of chocolate”, which refers to the hedonic experience rather than any of the five taste qualities. Chemotherapy treatment is widely implicated in ‘taste changes’, however the changes may be more related to smell and hedonics rather than the sense of taste per se.

Some drug types, including platinum based regimens are more implicated than others, however there is no consensus around which drugs produce most severe taste, flavor or hedonic symptoms [11]. One recent study has shown that people receiving FOLFOX for the treatment of colorectal cancer were more likely to report subjective ‘taste’ alterations compared to six other chemotherapy regimens studied [2]. A study by Wickham and colleagues in 1999 found platinum based agents were related to greater distress from ‘taste’ changes, and this was associated with decreased quality of life, compared to other agents [12]. Although these studies describe *taste* changes, they investigated the hedonic component of eating and drinking rather than physiological taste function as such. Randomised controlled trials report conflicting findings of class of chemotherapy drug associated with worsening appetite scores [13-16]. Third generation platinum derivatives such as Oxaliplatin are understudied with regards to their influence upon taste function and other determinants of the eating and drinking experience.

Aim

The purpose of this study was two-fold:

1. To explore patient and carer descriptions, experiences and consequences of taste and flavor changes associated with Oxaliplatin chemotherapy treatment for colorectal cancer
2. To use the patient and carer experience to determine relevant patient centred endpoints of chemotherapy for subsequent measurement and analysis in a quantitative longitudinal study.

Methods

Study design

This study utilized a grounded theory qualitative research design[17] to explore patient and carer descriptions, experiences and consequences of chemotherapy induced taste and flavor changes. Qualitative, semi-structured interviews were used to gather data between October and December 2010.

Setting and sample

This study was set at Peter MacCallum Cancer Centre, a specialist oncology hospital in Melbourne, Australia. Ethical approval to conduct this study and publish the results was granted from the Peter MacCallum Cancer Centre Ethics Committee (project 10/91). Patient participants were eligible for inclusion in the study if they were currently or recently (within the last 18 months) receiving an Oxaliplatin containing chemotherapy regimen for a diagnosis of colorectal cancer, were aged 18 years or over, were able to read and converse in English and had self-reported taste changes in relation to the Oxaliplatin containing chemotherapy they had received. All patient-participants had received at least two cycles of the identified chemotherapy treatment regimen, had not received any other chemotherapy types within the preceding six months and had not received concurrent radiotherapy. Carers were eligible for inclusion in the study where both the patient and carer were agreeable to carer participation in the interview, carers were aged 18 years or over and were able to read and converse in English.

Procedures

Recipients of Oxaliplatin were identified via the chemotherapy prescribing database in use at Peter MacCallum Cancer Centre (CHARM). Nursing staff approached participants who met the treatment based inclusion criteria in the chemotherapy day unit (CDU) or at the gastrointestinal (GI) clinic during treatment or follow up appointments. These patients were screened for eligibility by asking “Have you experienced any taste changes or problems with taste since you started chemotherapy?”. If the patient answered yes to this question, the nurse explained the purpose of the study and obtained verbal consent for contact to be made by the researcher. If the patient was agreeable, the researcher made contact to confirm interest in participating in the study, answer any questions and arrange an interview date and location. Participants were given a choice of having the interview conducted in an interview room at the time of their next hospital appointment or at their own home. Written consent for study participation was obtained from patients and carers.

An interview guide (Table 1) was used to conduct semi-structured interviews. This guide was developed specifically for this study, based on a sensory science model of taste functioning and included elements of taste and flavor change frequently reported by patients receiving chemotherapy [3]. It was assessed for face validity by an oncology dietitian, oncology nurse researcher and sensory scientist. The interview guide was

piloted by the primary researcher in a mock interview situation with an oncology dietitian role playing a patient-participant. In addition to feedback received from the mock participant, the interview was audio-taped and played to a senior supportive care oncology research nurse. Reflections from the primary researcher, the mock participant and the research nurse were discussed. Minor revisions to content and moderate revisions to structure of the interview were made. A scripted introduction was incorporated into the interview guide which included an explanation of the difference between taste and flavor.

Interviews were audio-taped and later transcribed verbatim by the interviewer. Pseudonyms were assigned to all interviewees. Within four hours of completing each interview, the researcher documented reflective notes of the interview including events and processes observed, perceived personal relationship with the participant(s) and any concerns arising. Notes regarding emerging themes were also made at this time. As interviews were conducted and new themes and ideas emerged, the interview framework was adapted to include more specific prompts to further explore commonly reported patient and carer experiences.

Data analysis

Verbatim transcription of audio-taped interviews was purposefully undertaken by the interviewer herself in order to foster intimacy with the data and therefore facilitate data analysis [18]. NVivo software (version 8, QSR International, Melbourne, Australia) was used to facilitate the categorization of text with a set of codes. A content analysis of the qualitative interview data was performed by the primary researcher, using a preliminary theoretical theme list derived from the sensory science, nutritional and supportive care literature as an analysis framework. In addition, in vivo categories were established during analysis to categorize unanticipated themes and to drive further discovery and theory development beyond verification of pre-existing theory [19]. A final list of themes and assigned data was reviewed by all three authors resulting in absolute agreement after slight changes to two category labels to enhance the situation specific nature of these categories. No re-categorisation of data was required.

Results

Participant sample

Purposeful sampling was used to recruit 10 patient and four carer participants for this study. Forty-seven participants received Oxaliplatin containing chemotherapy for the treatment of colorectal cancer within the 20 month period before December 2010. Of these, twenty-seven patient participants met the eligibility criteria and were approached by nurses for further eligibility screening by asking whether they had experienced taste changes during the treatment period. Fourteen (52%) answered yes to this screening question. Of this group, two chose not to participate in the study and 12 agreed to be interviewed. Of these 12 patients, two changed their mind about participating on the day

of scheduled interviews. Ten remaining patients were interviewed for this study. Participant demographic and clinical characteristics are shown in Table 2. Four patient participants indicated they would like their carer to participate in the interview and these carers were agreeable. Three carers were wives of patients and one was a patient's sister. All patient and carers identified their cultural group as Australian. Recruitment ceased two months after the study commencement because data saturation had been reached and further interviews were unlikely to derive new findings.

Content analysis

The overarching theme reported by participants was that of altered eating and drinking experiences characterised by reduced food enjoyment occurring in association with or as a result of self identified 'taste changes'. Negative eating and drinking experiences had implications for gastronomical, social and emotional parameters (Table 3). In discussing taste, flavor and hedonic changes, interview data could be grouped into three main categories – *Experience*, *Consequences* and *Management*.

1. Experience of changes to taste, flavor and food hedonics

Participants used the word 'taste' when discussing their experiences of changes to taste, other components of flavor and food hedonics during Oxaliplatin treatment . (See Table 4 for examples of interview excerpts under the category of *Experience*).

Sensory

Sensory components discussed were categorised as taste, smell, touch, oral sensations, thermal sensations, intensity and food liking. In regards to basic taste qualities, participants most commonly described changes (either increased or decreased) in perceived intensity to sweet and salty tastes during Oxaliplatin treatment. Participants also described changes which do not relate to taste per se but to other sensory components which influence overall flavor perception and food enjoyment. Participants made reference to the sense of smell which was heightened in relation to certain foods and beverages, or to (usually unpleasant) olfactory properties of food which may influence perceived taste of food or food enjoyment overall eg the smell of hospital food being offputting. References to the sensory properties of touch and texture (such as dryness) were categorized as touch. This was a distinguishable sensory property from taste per se. Several participants talked about hypersensitivity to heat and cold in the days after receiving Oxaliplatin containing chemotherapy. Sometimes this affected the experience of eating or drinking. In particular, it was reported that chilli burn was significantly increased and so some participants found they could no longer tolerate chili in the amounts they previously consumed. Other participants referred to specific food items which were too cold to consume or enjoy (icecream and cold drinks such as beer). Participants described sensations experienced in the mouth which cannot be explained as taste, smell, touch or thermal sensation. The most common such oral sensations described were 'metallic' or a 'slick' or 'coating' in the mouth which affected food enjoyment. Participants who described a metallic oral sensation reported that this symptom was constantly present in the mouth as opposed to certain foods eliciting a metallic taste. To this end, patients would often seek out specific food or drink items or bring an eating event forward in attempt to mitigate this symptom.

In addition to discussing distinct components of flavor, participants also made general reference to the relative magnitude of a sensory element of flavor they experienced during Oxaliplatin treatment. Most commonly, an overall reduction in intensity of elements of flavor was expressed by participants through such descriptions as “food blanding out”, “flavor disappearing” and “no taste”.

Participants identified hedonic themes surrounding food liking. Decreases in food liking during Oxaliplatin containing chemotherapy treatment commonly manifested as ‘going off favorite foods’. In more extreme cases of reduced liking, especially in association with receiving chemotherapy in the hospital setting, certain foods became aversive and this led to long term avoidance of these foods for some people. Aversions to specific types of soup (pumpkin) and sandwich ingredients (bread, mayonnaise) were most commonly cited in association with hospital food consumed on the day of chemotherapy.

Appetite / wanting

Participants commonly described a reduction in desire for food. Sometimes this reduction was linked to perceived changes in taste (“*I knew it would taste bad so I didn’t want it*”) and on other occasions this association was not made clear or was attributed to something other than taste such as the smell of a particular item like coffee.

2. Consequences of changes to taste, flavor and food hedonics

Changes to taste, flavor and food hedonics had gastronomical, emotional and social consequences for both patients and carers. (See Table 5 for examples of interview excerpts under the category of *Impacts*).

Gastronomical consequences

Sub-themes of gastronomical consequences were identified as altered food selection; changed role of food; eating less; and altered food rituals for both patient and carer participants alike. This included changes in the social or domestic rituals linked to procuring, preparing and consuming food or drink. For example, participants spoke of avoiding certain shopping precincts well known and previously visited for specific cuisine types and exotic ingredients. One carer described altering her cooking patterns to bake less bread following her husband’s aversion to bread. Alterations to elements of flavor or food hedonics sometimes had knock on effects for other acts of daily living. One participant described how, after the enjoyment of coffee changed for her, it interrupted the planning of her whole day as she omitted her morning coffee normally taken whilst planning the day.

Emotional consequences

Some participants described bothersome consequences of sensory and hedonic changes in that they were troublesome, burdensome or annoying. These emotions manifested as frustration, guilt (at wasting food which could no longer be eaten) and disappointment. Changes in food enjoyment were a source of frustration for both patients and carers as they tried to regain pleasure from food for themselves or facilitate it for the patient.

Others acknowledged taste changes and just accepted their presence rather than considered the consequences to be bothersome, especially if they did not crave the foods they knew they could no longer tolerate (*"I didn't miss it because I no longer felt like [eating or drinking] it"*).

Social consequences

Changes to taste, flavor and food hedonics had social consequences when they interfered with usual social interactions centred around eating and drinking. For example participants and carers described how meal times, eating out, social occasions or even shopping for food were affected. If the patient experienced reduced food enjoyment, this sometimes impacted on the carers mealtime experience also. Changes to the enjoyment of wine reportedly impacted on the wine intake of carers as rituals such as 'wine and nibbles' or wine with dinner were less frequently engaged in as they were less enjoyable.

3. Management of taste, flavor and hedonic changes

Patients and carers discussed strategies they employed to manage taste changes and advice they received. See Table 6 for examples of interview excerpts under the category of *Management*).

Patient strategies

Patient-participants discussed a pragmatic approach to flavor related problems, choosing to 'just get on with things'. Participants were very practical in their approach to managing and thinking about changes they experienced which had affected their enjoyment of food. Strategies employed included seeking specific foods or ingredients such as ginger or high sodium condiments such as salt, soy sauce and Worcestershire sauce in an attempt to elicit more flavor from foods.

Carer strategies

Carers played an active or inactive role in strategies designed to ameliorate the experience or consequences of reduced food enjoyment. Carer strategies involved altering foods offered to patients depending on current preferences (*"I brought her what she felt like at the time"*). Two carers explained that they did not employ any supportive strategies to help with flavor related changes. Sometimes this was justified by reduced discernment of flavor on the patient's behalf. This is, if problems with flavor were apparent with all types of food, there was a belief that attempts to alter flavor or offer different foods would have little effect on food enjoyment (*"It didn't matter what I made, he wouldn't have liked it anyway"*).

Information given

Some patients received information (rather than advice) from health professionals regarding 'taste problems' either before or during chemotherapy treatment. Most patients received no information whatsoever. A general warning about 'taste changes' and a 'metallic taste' was most commonly provided to patients by nurses before chemotherapy commenced. Specific information regarding the nature, timing of onset and duration of the problem was not offered to patients by health professionals, nor were possible

consequences of changes or management strategies. Some participants sought out information either from friends or fellow patients who had experienced similar problems themselves.

Discussion

This study builds on previous research [3, 4, 20, 21] to reinforce that the word ‘taste’ as used by patients encompasses many components beyond the perception of the five basic tastes. Patients experience a range of symptoms which they identify as ‘taste’ problems during chemotherapy which in fact mostly relate to the broader phenomena of flavor and hedonics. This study has further classified these components, all of which can contribute to the eating and drinking experience. The extent to which food is enjoyed can drive dietary behaviour, food satisfaction and ultimately nutritional status during and beyond chemotherapy treatment. It is therefore important that patients are prepared for the development of taste, flavor and hedonic changes during chemotherapy treatment. although this support is currently challenging for clinicians to provide.

Reduced food enjoyment during chemotherapy is well documented in the literature [22-28] but there is limited characterization of its causes, specific manifestation (including nature, onset and resolution) and nutritional impact. In this study, the temporal pattern of taste, flavor and hedonic changes ebbed and flowed over the course of Oxaliplatin containing chemotherapy treatment and shaped what patients and carers chose to eat, drink, cook and purchase. Patients reported that changes in taste, flavour or hedonics were apparent by the third chemotherapy cycle. Symptoms were described as worse in the 5-7 days immediately post chemotherapy infusion and relief was identified toward the end of a chemotherapy cycle. Where symptoms had resolved for patients, participants described full resolution of bothersome symptoms by 6-8 weeks following the completion of Oxaliplatin containing chemotherapy treatment. Several participants described conditioned food aversions continuing well beyond this time point, however. Patients do not feel prepared for chemotherapy related taste, flavor and hedonic changes although they do develop their own strategies to manage these problems when they arise. These problems and their mitigating strategies also have implications for carers. Oncology clinicians do not feel well equipped to support patients with taste and flavour problems, partly because of the variation in symptomatology and because of an absence of classification of symptoms and a lack of evidence of what works to mitigate symptoms [3].

The word ‘taste’ is used in a colloquial rather than scientific way by patients and clinicians [3]. The broader, more encompassing meaning of the word ‘taste’ in this context (which includes smell, touch and food hedonics) needs to be understood by both clinician and researcher oriented health professionals as patient descriptions of how they experience particular dimensions or properties of a clinical condition, may provide the key to diagnosis of specific problems and perhaps suggest the course of therapy [29]. A systematic review of the influence of chemotherapy on taste function and food hedonics [11] concluded that there is insufficient published research to suggest taste is influenced

by chemotherapy and hypothesized that problems arise with regards to food liking and appetite independently of taste.

Most important is the link between 'taste changes', the overall food experience and the impact of these on nutritional status. Clinical responses will differ accordingly with priority given to those patients who experience negative impact on either eating and drinking experiences or nutritional status. Overall assessment of the specific changes to flavor and food hedonics will help guide the therapeutic response, suggesting that nutritional assessment requires a broad perspective as food enjoyment may be the greatest driver affecting dietary intake and nutritional status. There remains a gap in knowledge between the pattern of taste and flavor changes associated with chemotherapy treatment and how this influences dietary intake and nutritional status. It is unclear from this study whether changes in the eating and drinking experience had nutritional implications as dietary intake was not measured. To date few studies have been conducted investigating this link in the chemotherapy setting.

The current study has helped to unravel the major determinants of the eating and drinking experience in the chemotherapy setting. Insight has developed regarding relevant patient sensitive endpoints of chemotherapy related taste, flavor and hedonic changes and associated measurement procedure for these. Nutritional consequences of problems relating to taste, flavor and food hedonics need further investigation through appropriate quantitative studies, the design of which this study has informed. With more evidence surrounding patterns and consequences of taste, flavor and hedonic related problems, clinicians will be in a better position to match patient reported symptoms to advice regarding appropriate dietary and behavioral manipulation.

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Disclosures

None

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Table 1 Interview Guide

1	Thinking only about the five qualities (sweet, salty, sour, bitter and savory), can you describe what has happened to these tastes since starting chemotherapy?
2	Can you tell me anything about the timing at which this happened?
3	Can you tell me how these broader things, the flavor of food has changed for you since you started [name of] chemotherapy?
4	Can you tell me anything about the timing at which this happened?
5	Thinking of all these changes (whether they are what you would call taste or flavour), how did these changes affect you? Prompts: Did it affect how you felt? Did it affect what you did? Did it affect your food habits or social habits?
6	[Carer] How did this affect you? Prompts: As for patient participant
7	Have you received any advice from anyone about how to manage these problems? If yes, can you tell me about this? Prompts: Who? When? In what format? Was this helpful?
8	Have you tried any strategies to manage or improve the problems you describe? If yes, can you tell me about this (What did you try? How helpful was this?)
9	[Carer] Have you tried any strategies to manage or improve [participant name] taste or flavor problems? If yes, can you tell me about this (What did you try? How helpful was this?)
10	If there is one thing you could change or improve in relation to your experience of taste or flavour, what would it be?
11	[Carer] If there is one thing you could change or improve what would it be?

Table 2: Participant demographic and clinical characteristics (n=10)

Characteristic	N
Gender	
Male	7
Female	3
Age (years)	
46-50	1
51-55	3
56-60	2
61-65	3
65+	1
Stage of chemotherapy treatment	
Completed treatment (within last 6 months)	4
Currently receiving treatment (<6 cycles completed)	3
Currently receiving treatment (>6 cycles completed)	3

Table 3 Themes

Reduced food pleasure	
A	Nature and experience of changes to taste, flavor and food hedonics
1	Sensory <ul style="list-style-type: none"> • Taste • Smell • Touch • Oral sensations • Thermal sensations • Intensity • Liking
2	Appetite / wanting
3	Food doesn't taste like it used to
4	Timing of changes (transience)
B	Consequences of changes to taste, flavor and food hedonics
5	Gastronomical consequences <ul style="list-style-type: none"> • Altered food selection • Eating less • Changed role of foods • Altered food rituals
6	Emotional consequences <ul style="list-style-type: none"> • No bother • Acceptance • The joy of taste recovery • Frustration • Guilt • Disappointment
7	Social consequences
C	Management of taste, flavor and hedonic changes
8	Patient strategies <ul style="list-style-type: none"> • I just got on with things • Eating as a strategy • Pragmatism • Adding more seasoning to food
9	Carer strategies
10	Information given

Table 4: Examples of interview excerpts under the category *Experience*

Category	Sub-categories	Examples of interview excerpts
Nature and experience of changes to taste, flavor and food hedonics	Sensory Taste	<ul style="list-style-type: none"> I got a bit of that [increases intensity of sweet]. I did. You know what I had that with? I had that with soft drink[^]. But, I noticed that that varied a lot. I would not like ginger beer you know and I'd have to drink soda water. Yeah, intensely sweet yeah. (P2) I don't feel like enough salt in things... I keep on asking [others] is that salty enough [laughs], and they will say "yes" so I don't add anymore because obviously is enough [laughs]. (P3)
	Smell	<ul style="list-style-type: none"> Like I [would] smell the coffee and I already didn't want it. The sight of it or the smell of it, as soon as I smelled it I really didn't want it. (P3)
	Touch	<ul style="list-style-type: none"> But um, things that changed were, um, yeah, the sensitivity to sweet and salty, um, dryness in the mouth. That was a big issue, um the dryness. (P6)
	Oral sensations	<ul style="list-style-type: none"> But definitely the metallic taste, and that was a metallic taste in my mouth ALL the time. It wasn't when I ate something. In fact eating something gave me relief from it. (P3) Drinking anything cold as well sort of gives you that tingly, sort of pin and needly taste you know. (P9)
	Thermal sensations	
	Intensity	<ul style="list-style-type: none"> I don't think I've got the full range of tastes as good as what I used to. I think they're slightly masked - not as strong.... We would generally eat pretty well. Um, but yeah, look I really couldn't taste food very much. (P8) Food tasted really bland – it didn't taste 'bad', it just had no taste at all. (P10)
	Liking	<ul style="list-style-type: none"> Its like I eat the ginger biscuits, and I think, don't like the taste of them, the taste is nothing anymore, whereas before it was something I really looked forward to with a cup of tea, and it just went away. And that's the one I really remember 'cos I've always loved them so much. (P2) I went off tea, I went off coffee, um and the flavor of wine changed. So yeah, tea and coffee and wine, um yeah, they were the things that I did go off completely. (P6)
	Appetite / Wanting	<ul style="list-style-type: none"> Oh, before I had chemo I really enjoyed good food, and you know, say if I was going out to a good restaurant or something like that, I'd really look forward to it both for the food and the company and you know, I've always bought you know really good quality food and happily spent money on you know, better quality fruit and veg... now I just don't care about it as much. (P4)
	Food doesn't taste like it used to	<ul style="list-style-type: none"> Hot chips^{so} had no taste and so there was no point eating them – it was like eating cardboard. (P10)
	Transience	<ul style="list-style-type: none"> I think one of the things that helps with that sensation is within the cycle you see a return to normal. (P4)

Abbreviations: P = Participant; [^] = soda / pop; [∞] = French fries

Table 5: Examples of interview excerpts under the category *ImpactsConsequences*

Category	Sub-categories	Examples of interview excerpts
Impacts of changes to taste, flavor and food hedonics	Gastronomical impactsconsequences	<ul style="list-style-type: none"> I used to have this er, Uncle Toby thing, cereal with apples and sultanas* whatever, I couldn't eat that, I had to go to plain cornflakes...it was too sweet, I just couldn't have that (P3)
	Altered food selection	<ul style="list-style-type: none"> Well my taste normally, I like salty, strong flavours... olives, anchovies, capers, curries, you know, ah, can't face anything like that at all. (P4)
	Eating less	<ul style="list-style-type: none"> The quantities of what he ate reduced a lot as well. Before he started chemotherapy Heath's serving sizes would have been double everybody elses but once he started chemo, his serving sizes would be no bigger than mine and our son would have the biggest serving size. (C3)
	Changed role of foods	<ul style="list-style-type: none"> You just sort of start eating for the sake of eating. Like I'm a big one for a harvester's platter. Sort of bread and cheese and olives and bits and pieces and that was just, nothing. It was just sort of eating for the sake of eating. (P8)
	Altered food rituals	<ul style="list-style-type: none"> I would wake up in the morning and have a cup of coffee and I [would] sit down, figuring [out] in my head what I'm gonna do all day. I mean I [I would think that I] have to go to work and what's my schedule gonna be and I have to go and do this and this so I figure it all in my head while I was having this coffee [laughs]. All of a sudden I didn't have the coffee, I didn't have it [so] I didn't work out anything... it was missing something, yeah. (P3)
	Emotional consequencesimpacts	<ul style="list-style-type: none"> I didn't sort of feel left out [for no longer feeling like drinking wine]. No, the desire wasn't there... it wasn't as though I sort of felt isolated because I wasn't drinking, no. (P8)
	No bother	
	Acceptance	<ul style="list-style-type: none"> It didn't worry me as such because there was no taste. I accepted it as a fact that you know the chemo itself causes that, when you've finished chemo it will come back. And that was the end of it. (P1)
	The joy of taste recovery	<ul style="list-style-type: none"> I go and have a slice of bread and see what it tastes like and I go, oh that tastes good, I'll have another slice, whatever. Yeah that's it. I go, "oh OK, my taste is OK". Once I taste the bread, I'm quite pleased that my taste is alright. That's my tester [laughs] (P3)
	Frustration	<ul style="list-style-type: none"> Its always been, there's always been a social aspect to food with our family and then yeah, you know you sit down for cheese and wine and nibbles and then you just can't, can't eat that ... I found it frustrating. (P6) The only thing I found frustrating was that I would cook what she wanted and then she would turn her nose up... She'd taste it and then it would sit there and you'd think [rolls eyes]. It's frustrating. (C1)
	Guilt	<ul style="list-style-type: none"> When I was in hospital...I felt terrible even leaving food on the plate and being so wasteful but there was no way I could get it in [laughs]. (P6)
	Disappointment	<ul style="list-style-type: none"> Coffees were rubbish, right... Just didn't like the coffees anymore, some of the coffees were terrible. I'm normally a very big coffee drinker, but then being in Melbourne with lots of good coffees, good coffees weren't good [laughs]. So it was extremely disappointing. (P8)

Social
impactsconsequences

- The thing I enjoyed about coming down here was the [Vietnamese] restaurants and sort of hitting all of the different markets for those tastes and things but um yeah [when I was getting chemo] I just went there for ginger teas and ginger lollies⁺ [laughs]. (P8)
- It's not quite the same, you know, if you're just, for myself, you know to sit there and eat a plate of food and Heath might as well have a plate of chaff or something like that. It's not really the same is it. (C3)

Abbreviations: C=Carer; P = Participant; ^{*} = dried grapes; ⁺ = sweets / candy

Table 6: Examples of interview excerpts under the category *Management*

Category	Sub-categories	Examples of interview excerpts
Management of taste, flavor and hedonic changes	Patient strategies	
	I just got on with things	<ul style="list-style-type: none"> • Even when I had the PICC line in and I'd meet my brother and we'd go out on a Saturday night to go out for tea somewhere and have a glass of wine and things like that. Um, although you sort of, the taste wasn't as strong as what it is now, um, you just carried on and you just had your meal and you just had your drink, you talked and you bypassed everything. (P1)
	Eating as a strategy	<ul style="list-style-type: none"> • The other thing that I noticed was that things that were quite pleasant in my mouth, um, you know and things that are always pleasant to eat, like blueberries or something. I'd eat them and they'd taste perfectly nice and then afterwards I felt like I had a sort of slick coating in my mouth that didn't taste nice... so I was kind of continuously looking for something that would take that taste away (P3) • I started looking for very strong flavors in food to just sort of cut through that [metallic sensation] ... like having lots of salt, [trying to get a] bit more flavour. (P8)
	Pragmatism	<ul style="list-style-type: none"> • I love um prosciutto and I get the Spanish one now because its got less salt whereas if you get the normal pale one its actually very salty and you sort of go off that, yeah. Its like anchovies, now I've found Spanish white anchovies [are] beautiful so I get those (P9)
	Adding more seasoning to food	<ul style="list-style-type: none"> • I would sort of deliberately change my diet from spicy food, sort of Asian food to tacos and things like that and put chilis and just put things in there just basically just give my taste buds a kick (P2) • So I'd cook myself a piece of steak and force myself to eat it and then you know have lots of hot mustard or something [laughs] you know (P5) • I probably do um have a little bit extra salt the first coupla days [after chemo] coz' you can't taste nothin'. (P7)
	Carer strategies	<ul style="list-style-type: none"> • Well we havn't changed any of our eating habits. I havn't. I just cook and if he doesn't eat it he doesn't eat it [laughs]. (C2) • Heath would eat it regardless of whether it was, and to be honest he'd um tuck into a frozen meat pie as easily as he would tuck into um Thai chicken or something like that, it didn't really make much difference so it, it made more of a difference to me what the flavours were, he would really just eat what was put in front of him. (C3)
	Advice given	<ul style="list-style-type: none"> • I didn't ask about it [taste problems]. I mean the second dietitian came along, she didn't ask. I asked for her – I thought I better see somebody to see if I'm on the right track. So, but no, nothing about taste [laughs]. Wasn't interested in taste. I mean I didn't bring it up. She didn't talk about it either (P2) • I was aware that there would be changes but nothing further (P4)

- It varies, you know. Is what they tell you. It varies and they can't be precise, yeah. (P8)
- You know they said your taste buds will be very metallic. (P9)

Abbreviations: C=Carer; P = Participant

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