

The lived experience of dysphagia following non-surgical treatment for head and neck cancer

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Abstract

The prevalence and severity of dysphagia in people treated non-surgically for primary head and neck cancer (HNC) is well documented. However, few studies have looked beyond the physiological impairment to explore the lived experience of dysphagia in the post-treatment period of HNC. The current study adopted a person-centred, qualitative approach to describe the experiences of people living with dysphagia in the months and years following non-surgical treatment for HNC. Using maximum variation sampling, 24 participants who had undergone radiotherapy treatment for HNC were recruited. Individual interviews were conducted to explore the impact of dysphagia on participants' everyday lives. The themes identified included: (1) physical changes related to swallowing; (2) emotions evoked by living with dysphagia; (3) altered perceptions and changes in appreciation of food; and 4) personal and lifestyle impacts. The data revealed the breadth and significance of the impact of dysphagia on the lives of people treated curatively for HNC. Assessment and management in the post-treatment period must be sufficiently holistic to address both the changing physical states and the psychosocial needs of people with dysphagia following HNC. Rehabilitation services which focus only on impairment based management, will fail to fully meet the support needs of this clinical population.

Introduction

The medical complications of dysphagia following head and neck cancer (HNC), including aspiration, malnutrition, and dehydration are now well recognised (Agarwal et al., 2011; Buchmann, Conlee, Hunt, Agarwal, & White, 2013; Cartmill, Cornwell, Ward, Davidson, & Porceddu, 2011b, 2012; Hutcheson & Lewin, 2012; Nguyen et al., 2008). As a consequence, in more recent literature there has been increased consideration of the functional outcomes and changes to quality of life (QoL) associated with dysphagia in the HNC population (Llewellyn, Weinman, McGurk, & Humphris, 2008; Lovell, Wong, Loh, Ngo, & Wilson, 2005; Nguyen et al., 2005). Whilst such research has furthered our understanding of the impact of dysphagia following HNC management, the majority of studies to date have applied quantitative methods to measure the extent of functional change (Barringer, Hutcheson, Sturgis, Kies, & Lewin, 2009; Cartmill, Cornwell, Ward, Davidson, & Porceddu, 2011a; Cartmill et al., 2012; Jensen et al., 2007) or change in QoL (Lovell et al., 2005; Maurer et al., 2011; Nguyen et al., 2005). The value of taking a quantitative approach has been to confirm that a problem exists (Llewellyn et al., 2008; Lovell et al., 2005; Murry, Madasu, Martin, & Robbins, 1998; Nguyen et al., 2005). However, such studies have provided little understanding of the key factors that influence or impact on the daily life of people with dysphagia. As such, our understanding of the issues faced by people who live with dysphagia, and what is needed to help improve their ability to cope, adjust and optimise their QoL post-treatment, is not yet fully understood.

With the purpose of achieving a deeper understanding of the eating problems of people undergoing radiotherapy for HNC, the consequences on daily life and the strategies used to cope, Larsson, Hedlin, and Athlin (2003) used a qualitative methodology to explore the perspectives of 8 people while they were undergoing radiotherapy. The group were

interviewed after completing 2-3 weeks of radiotherapy, and again at 5 weeks of radiotherapy. At this early stage, the acute treatment effects were found to be significant and eating difficulties were having a considerable negative physical and psychosocial impact on the participants' daily lives. This initial study confirmed the need for specialist support for people with HNC whilst undergoing treatment and the authors called for more research, particularly further investigation of the impact of dysphagia in the period following treatment completion.

Since 2003, however, few studies have explored the impact of dysphagia in the post-treatment phase of HNC management. In 2011, McQuestion, Fitch, and Howell (2011) discussed the "changed meaning of food" (p. 147) revealed through in-depth interviews with 17 participants who were only 3 months post-radiotherapy. In the interviews, the authors noted that participants reflected on both the acute and early recovery period. As previously reported by Larsson et al. (2003), participants discussed significant losses experienced across the physical and emotional domains. However, social loss, relating to the impact of changes to meals and food choices on social interactions and mealtimes, emerged as an additional dominant theme. In light of the findings, the authors noted various ways current practice could be improved, including acknowledging the significance of eating problems post-treatment, and the need to adopt a person-centred approach to better prepare people with HNC for the post-treatment phase and to support them through the physical and the social/emotional challenges.

In the only study to take more of a long-term perspective Ottosson, Laurell, and Olsson (2013) interviewed 13 people with HNC at around 9 months post-radiotherapy. In addition to the complex mix of physical, social, and psychological effects of living with dysphagia, other important themes were identified. These included the emotional distress of the long and uncertain nature of the recovery journey for people with dysphagia, the process

of psychosocial re-adjustment, and the importance of ongoing information and support to help cope long-term with the impact of dysphagia. The study confirmed the need to recognise the significant impact of dysphagia and the importance of prolonged health care and professional support throughout the post-treatment period to help people treated for HNC to optimise their opportunity to live well with dysphagia.

From the limited qualitative research conducted to date, data support that the presence of dysphagia has a wide ranging impact on the person with dysphagia. However, there is a need for further investigation into the impact of living with dysphagia, particularly for those people beyond the early acute treatment phase. Hence it is the aim of the current study to use a qualitative method to explore how dysphagia impacts on the everyday lives of people treated non-surgically for primary HNC in the months and years following treatment. Through a more complete understanding of the everyday challenges that people with dysphagia face in the post-treatment period, health professionals will have the evidence to support practice change and develop services post-treatment to better address the information and support needs of this group.

Methods

Research strategy

A qualitative descriptive study using a phenomenological approach was used to explore the lived experience of the impact of dysphagia following HNC management (Sandelowski, 2000). Qualitative descriptive studies draw from naturalistic inquiry, and involve the study of real-world situations as they occur (Patton, 2002; Sandelowski, 2000). Qualitative descriptive studies are most suited to research in which descriptions of a particular experience are required (Sandelowski, 2000). A phenomenological perspective was also employed in this study, as the research question was aimed at exploring the *lived experiences* surrounding the

impact of dysphagia for people treated for HNC. Phenomenology aims to understand the meaning and experience of everyday existence from the perspective of the individual (Patton, 2002). This type of research methodology has been selected because of the subjective, individual, and exploratory nature of the research question.

Sampling

Due to the heterogeneous nature of HNC, its effects, and treatment, participants were selected using purposive and maximum variation sampling techniques. Maximum variation sampling is used when a broad range of participants is required and involves selecting information-rich cases to capture and describe consistent themes across a broad range of participants (Patton, 2002). In the current study, this involved identifying specific selection criteria that were considered of particular importance when constructing a sample of maximal variation (Patton, 2002). The following characteristics were sought to achieve variation within the sample: gender (male/female); age (<65 years/≥65 years); treatment modality (radiotherapy only/radiotherapy +/- systemic therapy); geographic location (major city/regional and remote); months since treatment (<3months/≥3 months); and mealtime situation (alone/shared). Recruitment continued until a minimum of one participant who met the criterion for each category was recruited. Participant details with maximum variation sampling parameters are presented in table 1.

[Insert table 1 near here]

Participants

A total of 24 participants who had completed curative non-surgical treatment for a mucosal HNC between April 2007 and April 2012, were recruited through the Radiation Oncology Department of a large tertiary hospital in Brisbane, Australia. All participants reported experiencing difficulty swallowing during and/or following their treatment. Ethical clearance

for this study was obtained from the relevant ethics committees and all participants provided written informed consent to participate in this study. Participants were excluded if they had received primary surgical treatment, had any pre-existing conditions that could be associated with swallowing disorders, were considered palliative, or had limited proficiency in English.

Participants were predominately male (20 male, 4 female) and ranged in age from 43-71 years, with a mean of 57.2 years (Standard Deviation [SD] = 8) (table 2). They presented with nasopharyngeal, oropharyngeal, and hypopharyngeal primaries and 23 participants received curative chemoradiation whilst one participant received radiation only. The majority of participants had completed their treatment more than three months prior to the interview with a mean of 18 months post-treatment (SD = 15.9 months, range = 1-60).

[Insert table 2 near here]

Procedure

Individual, in-depth, semi-structured interviews were conducted with each participant. The interviews consisted of mainly open-ended questions (Patton, 2002) with the assistance of an interview guide to ensure all relevant topics were covered. To gain more insight into the effects of dysphagia, participants were asked to speak freely and to describe their experiences of eating and swallowing difficulties during and following their treatment. Specifically participants were asked to comment on the impact of these eating difficulties on their everyday life and well-being, including their social activities and relationships. Prior to the interview, each participant was sent a list of stimulus questions to encourage personal reflection in preparation for the interview. Each interview was audio-recorded with the permission from the participant and transcribed verbatim for analysis. Interviews ranged in duration from 20 minutes to 2 hours. All interviews were conducted face-to-face with the primary investigator.

Data analysis

Thematic analysis was conducted using an inductive approach to analyse patterns and themes sourced from the interviews (Braun & Clarke, 2006). That is, common patterns relating to the experience of living with dysphagia and the associated lifestyle impacts were identified in the data. The inductive approach allowed for the coding of the data based on themes evident within that data, without any pre-existing coding frame (Patton, 2002). Using NVivo 9 software, participant statements were coded following the steps outlined by Braun and Clarke (2006). A record was kept regarding the number (n) of participants who commented on each category and the number of times each category was referred (ref) to. Initially, the principal investigator familiarised herself with the data as a whole, through repeated readings of each transcript. An open coding (Strauss & Corbin, 1998) approach was adopted and each transcript was searched for statements relating to the participants' lived experiences of dysphagia.

A list of categories was developed from the codes identified across the data set (Braun & Clarke, 2006). An independent researcher completed consensus coding by independently coding two interview transcripts using the list of categories. Following this step, some refinement of the list of categories took place and all interviews were re-coded using the revised categories. Related categories were then grouped into themes. The themes were reviewed in relation to each original transcript to note the extent to which each theme was representative across the data set. To ensure rigour and agreement, codes, categories, and themes were reviewed by the co-investigators throughout each stage of analysis and consensus established. Participants were sent a summary of the themes and categories identified from the analysis, and were asked to confirm the investigators interpretation of the

interviews as a whole. Eleven of the 24 participants provided written feedback and all confirmed the interpretation of their experiences.

Results

Thematic analysis revealed a rich description of the participants' experiences of dysphagia in the post-treatment period of HNC management. Four main themes relating to the impact of dysphagia emerged from the interview data. These were the extent and importance of: (1) physical changes related to swallowing; (2) emotions evoked by living with dysphagia; (3) altered perceptions and changes in appreciation of food; and (4) personal and lifestyle impacts.

Theme 1: Physical changes related to swallowing

Participants experienced a broad range of physical changes to their swallowing ability as a result of treatment. One participant summed up the extent of the changes by stating “the whole process ... it's all about the mouth. You wouldn't believe what happens when you can't function in the mouth”. Within this theme a number of categories and sub-categories were identified which are outlined in table 3. The most pervasive categories related to lack of saliva (xerostomia) and changes to taste (dysgeusia). For many, the importance of saliva had previously been underappreciated and many spoke of the food they could no longer eat because of the lack of saliva production “the biggest surprise out of the whole thing is I don't think you realise how much your saliva meant to you”. Participants also spoke about other physical changes such as oral and pharyngeal sensitivity, taking longer to chew food, food getting stuck, coughing on liquids, changes to sense of smell, changes to phlegm, and as a result of these physical changes to swallowing, participants also experienced a loss in appetite and weight loss.

The extent of the physical changes described by each individual highlights the multitude of the challenges faced by people with HNC, often at every meal, regardless of what stage post-treatment they are in. It was also observed that the extent to which the physical changes impacted each individual were reported to shift and change over time with some participants indicating that they had simply learnt to adapt to the physical challenges. This adaptation and acceptance of persistent difficulties is highlighted in the comment by one participant who was still on a minced and moist diet two years following treatment “[It’s not] eating and drinking difficulties. It’s something I’ve accepted”.

[Insert table 3 near here]

Theme 2: Emotions evoked by living with dysphagia

Participants spoke about a range of emotions evoked in response to the multitude of physical changes to their swallowing ability. Specifically they expressed emotions around what they could no longer eat and their self-image; these categories are summarised in table 4. Many participants were no longer able to eat their favourite foods and the anticipated pleasure and satisfaction associated with eating was gone. In particular, changes in taste resulted in feelings of disappointment particularly for meals previously enjoyed by participants. However there was also a multitude of other emotions expressed such as frustration, anger, anxiety, depression, envy, loss, fear, and defeat.

The physical changes in swallowing also impacted on participants’ self-image. Participants described feelings of embarrassment when coughing on food in front of others, when taking longer to eat their meal than everyone around them, and when needing special modifications to their food to be able to eat. A few participants talked about feeling depressed with how their body now looked because of the weight they had lost during treatment. This

was noted to be a persistent issue for some, with one participant noting he was still trying to regain lost weight two years following completion of treatment.

[Insert table 4 near here]

Theme 3: Altered perceptions and changes in appreciation of food

The theme of altered perceptions and changes in appreciation of food was derived from statements about the how participants now felt about food, their eating, and mealtimes. The main categories and subcategories pertaining to this theme are summarised in table 5. The most common issue raised by participants was how eating was no longer an enjoyable or pleasurable experience, “the only satisfaction I get from food ... is that I won’t die from hunger”. Eating was simply seen as a task that had to be done as a means of nourishment, with some participants taking this one step further and fixating on food simply as a means to gain weight “the meaning of food was to try and keep my weight up ... that was the only reason I was eating ... if I didn’t have to keep my weight up I would just have said no”. Participants described changes to their eating routines, and many participants regularly skipped meals or no longer bothered to eat food they had previously enjoyed “I didn’t bother having anything to eat this morning and that happens often”. Several participants described enforced changes to their food and eating behaviours and how they now had food they previously had not liked. Participants also experienced a loss in social occasion, noting that the inability to share in meals at significant celebrations (e.g., Christmas) had separated them from those events. Some participants, who were long-term post-treatment and had regained their capacity to eat and enjoy food, expressed that they now felt a greater appreciation for food and mealtimes because it had been taken away.

[Insert table 5 near here]

Theme 4: Personal and lifestyles impacts

The fourth main theme to emerge from the interviews in this study was the magnitude of personal and lifestyle impacts created by the physical changes to swallowing, emotional responses to dysphagia, and the resultant altered perceptions of food and mealtimes. The categories and subcategories pertaining to this theme and supporting quotes are summarised in table 6. Many issues were raised by participants highlighting the enormous and diverse spread of effects that changes to eating and drinking can have on the lives of people with dysphagia following HNC management. The lack of understanding of dysphagia in the community and at restaurants resulted in an impact on participants' social lives and also their participation in other interests and hobbies "when people ring up, say for a barbeque, I tend to avoid that, knowing I can't, you know, eat".

These changes to lifestyle were not limited to the participant alone, and many spoke about how their difficulties with food had impacted on their family "it affects [my wife] as much as it affects me". Many participants described how their dysphagia had impacted on family members and recognised that partners were often cooking two meals or also going without their favourite foods "she doesn't want to eat in front of me knowing that I might want to eat that". Dysphagia had led to tension in some relationships and participants recognised that their family had often had to adapt to their needs. Many participants described a sense of loss of the family mealtime and no longer ate meals with their family. One participant even spoke of the impact on the type of holidays they now chose "cruise lines are good for us ... we can train the chef and waiters and the way the food should be prepared". Not only had dysphagia impacted on the family mealtime but also on the dynamics in the family and the roles the participant had in their family and relationships "it sort of becomes a bit like a child mother relationship ... a mother makes sure their kids are

eating the right type of thing ... I found it hard to move back to being an equal adult”.

Participants also talked about practical impacts such as the financial impact of dysphagia.

This was in relation to food wastage, “I used to see all the goodness being thrown out”, and the cost of necessary supplements and medications.

[Insert table 6 near here]

Discussion

This study has provided an in-depth description of the complex effects of dysphagia on the lives of people treated non-surgically for primary HNC. The 24 participants in this study reported a wide range of physical changes impacting on their swallowing ability as well as their emotional response to living with dysphagia long-term. Key issues also included changes in the perception of food, how mealtimes had been altered, and impacts to the meaning and experience of food. These issues were found to culminate in a number of personal and lifestyle changes including considerable impact on the family unit. Through the exploration of personal perspectives, the current data provides an insight into the enormity of the impact of dysphagia on the lives of people in the post-treatment period of HNC management.

Consistent with previous research, participants reported living with an extensive range of physical changes to their swallowing ability (Larsson et al., 2003; McQuestion et al., 2011; Ottosson et al., 2013). However, whilst the physical changes to swallowing following non-surgical treatment were an important concern for participants in this study, the results also revealed a considerable, ongoing emotional response to dysphagia. Changes in the significance and meaning of food, and the personal and lifestyle impacts as a result of dysphagia were equally significant areas of concern for this group. This finding was consistent with earlier studies (Larsson et al., 2003; McQuestion et al., 2011; Ottosson et al.,

2013) and re-emphasises the complexity of living with dysphagia following HNC management.

The findings also confirm that support services need to take a broader approach. Services need to be sufficiently holistic to address not only the physical challenges of dysphagia but also the social and emotional challenges. Traditionally the assessment and management of dysphagia has been medically driven (Threats, 2007) with the majority of interventions for dysphagia focused on rehabilitation of the swallow (Cousins, MacAulay, Lang, MacGillivray, & Wells, 2013). However both the current data and prior evidence (Larsson et al., 2003; McQuestion et al., 2011; Ottosson et al., 2013) supports the need for active intervention for both the physical and psychosocial issues, and for services that extend beyond the acute recovery phase. In order to do this though, we need better processes for the detection and monitoring of psychological and social issues. This would require changing current practice to extend beyond simply swallowing or impairment based assessments, to consider each individual's perspective and how the presence of dysphagia may be impacting on various aspects of an individual's life.

Validated tools such as the M.D. Anderson Dysphagia Inventory (MDADI) (Chen et al., 2001) and The University of Washington Quality of Life Questionnaire – Version 4 (UW-QOL v4) (Rogers et al., 2002; Weymuller et al., 2000) are health-related QoL questionnaires which address the impact of dysphagia. The domains measured in these questionnaires (global, emotional, functional, physical on the MDADI and pain, appearance, activity, recreation, swallowing, chewing, speech, shoulder, taste, saliva, mood and anxiety on the UW-QOL v4) largely reflect the themes identified in the current study. Therefore adopting routine use of such tools that have the sensitivity to detect the broader impact of dysphagia would enable clinicians to identify those people who require additional education and support

to adjust to living with dysphagia in the post-treatment period. Once detected, there also needs to be effective interventions available to address the issues raised by participants. Unfortunately, there are currently no intervention studies which specifically address the psychological and/or social aspects of eating and drinking (Cousins et al., 2013). This requires immediate attention.

The current data also highlighted that the impact of living dysphagia is not confined to only the person with dysphagia. Individuals with dysphagia were not alone in their difficulties and both the individual with dysphagia and their family carer may experience effects as a result of the swallowing difficulties. McQuestion and colleagues (2011) have recognised the need to explore the experiences of family carers living with and supporting individuals with dysphagia following HNC. This is supported by the current findings in which participants commented on the impact of their dysphagia on family members and also on family life. Particular mention of the loss of family/shared mealtimes was a dominant theme in the current data set and previous research (Larsson et al., 2003), extending the impact of dysphagia beyond the family to friends and associates. Furthermore, as noted in previous studies (O'Brien, Roe, Low, Deyn, & Rogers, 2012) participants reported experiencing a shift in their roles within their family and relationships. Whilst participants generally recognised the value of the support of their family, some had difficulty adjusting back to their previous role as an equal partner once recovery commenced. Such changes also have the potential to have significant effects on the lives of family members. Future research is required to explore the experiences of family carers living with and caring for individuals with dysphagia following non-surgical treatment for HNC.

Whilst the current research has supported and extended the findings from previous studies, it is recognised that some limitations exist. The participant group spoke about their

experiences across both the early and long-term post-treatment period. There was no attempt made to separate the extent of the impact and individual adjustment at various time points in the recovery period. Future research which systematically explores the differences and similarities in the impact of dysphagia across various time points in the recovery phase may provide more specific information to guide the nature and timing of future interventions. The participant group also represented people with a range of dysphagia severity and tumour types, sites and stages. It is possible that limiting the group to people with similar demographic variables (including milder or more severe dysphagia, similar tumour types, sites and stages) may provide different insights into the impact of dysphagia. We also did not confirm whether or not participants experienced reduced QoL, therefore to what extent the issues they raised were directly impacting their QoL cannot be confirmed. Furthermore, although the study population represents the largest cohort studied to date in this area, and maximum variation sampling was used in an effort to capture the central themes across a great diversity of participant variables (Patton, 2002), all participants were recruited from the same clinical service. As such their experiences and perceptions of support needs may not be representative.

Conclusions

The current study has highlighted the complex and ongoing negative effects of dysphagia on people in the post-treatment period of HNC management. Individuals reported experiencing a wide-range of physical changes to swallowing as well as changes to their emotions, perceptions of food, and to their lifestyle. The current data confirms that there is a need for greater recognition of the wide ranging impacts of dysphagia on people receiving HNC management and that these impacts are not confined to early post-treatment and can continue throughout the post-treatment period. There is a need to change practice and develop services

which support holistic assessment and management of this population to address not only the physiological impairments but the associated emotional and psychosocial consequences of dysphagia.

Declaration of interest

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

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Table 1. Maximum variation sampling characteristics (n=24)

Demographic	Parameters	Number of Participants
Age	≤65 years	18
	> 65 years	6
Sex	Male	20
	Female	4
Treatment modality	Radiotherapy + Systemic therapy	23
	Radiotherapy only	1
Geographic location	Major city	21
	Regional/rural/remote	3
Months since treatment	<3 months	5
	>3 months	19
Mealtime situation	Alone	2
	Shared	22

Table 2. Demographic details (n=24)

Demographic	Parameters	Number of Participants
Primary site	Tonsil	11
	Base of tongue	7
	Hypopharynx	3
	Nasopharynx	2
	Unknown	1
T Stage	T0 – 2	14
	T3 – 4	10
N Stage	N0 – 1	6
	N2 – 3	18
HPV Status	Positive	14
	Negative	1
	Unknown/not tested	9
Smoking status	Never	5
	Ex	17
	Current	2
Alcohol consumption status	Never	3
	Ex	5
	Current	16

T = tumour; N= node; HPV = human papillomavirus

Table 3. Theme 1: Physical changes related to swallowing

Categories	Sub categories	n	ref	Example participant quotes
It's all about the dryness		21	80	"the lack of saliva ... the dry mouth ... it affects everything ... eating, swallowing, talking, everything"
Changes in taste		21	62	"I've had times where we've been eating ... the same thing ... and I've said to [my wife] ... does this taste nice? You know because I don't know"
Oral and pharyngeal sensitivity		18	44	"I had a lot of ulcers in my mouth ... it stopped me from eating ..." "my mouth and tongue is very sensitive"
Chewing takes a long time		16	47	"I would probably exceed the old adage of 32 chews to the bit ... I'm ... painfully slow in eating"
Food gets stuck		16	41	"I just couldn't get it [food] down ... it would sit there and I just couldn't, even if I took water it just wouldn't go down"
Change in smell		6	15	"The biggest thing for me was that sense of smell thing, just how that impacted on what I could eat, what I could stand the smell of"
Liquids make me cough		5	10	"every time I would drink water it would trigger off this coughing"
Phlegm		4	4	"I ... bring up dry fluffy phlegm ... it's so dry that when I try to spit it out it seems to stick on the tip of my tongue"
Physical impacts resulting from dysphagia	Weight loss Loss of appetite	13 4	18 5	"I lost a lot of weight" "it got to a point where you just lost interest, you lost your appetite, you lost your desire to eat"

n = number of participants who commented on a category/subcategory

ref = number of times category/subcategory was mentioned

Table 4. Theme 2: Emotions evoked by living with dysphagia

Categories	Sub categories	n	ref	Example participant quotes
I can't eat what I used to eat	Frustration	11	26	"the frustrating thing out of the whole lot is ... what you can eat and what you can't eat"
	Fear	7	12	"you dread it, you dread having something to eat it hurts so much"
	Defeated	6	8	"I tried to eat some chocolate the other day and it just got glagged in my mouth ... I just say I can't be bothered with it, and threw it in the bin"
	Loss	6	6	"I would like to be able to really have a sit down and have a nice meal ... it has been so long"
	Depression	5	9	"I just get depressed with it all when you just keep eating the same stuff nearly every day"
	Disappointment	5	8	"If I feel any disappointment out of the whole end result ... it's the fact that I can't taste some foods that I have previously"
	Anger	4	5	"my diet has changed a lot now and that really ***** me off"
	Anxiety	4	4	"every time they'd bring a meal to me I'd freak out"
	Envy	2	3	"she might have a steak and I always want a steak but I can't have it"
Self-image	Embarrassment	6	12	"it's not very nice sitting at a table ... coughing it up"
	It makes me feel down	2	2	"I've lost heaps [weight] that makes me feel ... down ... before I used to look good"

n = number of participants who commented on a category/subcategory

ref = number of times category/subcategory was mentioned

Table 5. Theme 3: Altered perceptions and changes in appreciation of food

Categories	Sub categories	n	ref	Example participant quotes
How participants feel about food has changed	Eating is not enjoyable	15	38	“I don’t enjoy food like before” “A lot of the food I used to like eating ... I don’t eat now because eating is not an enjoyable thing for me”
	Food is just a fuel	14	23	“I only see food as a fuel. It’s only fuel to keep me... going”
	A fixation on food to gain weight	6	8	“I spend a lot of time near the kitchen... I’ll move into the fridge move into the kitchen...I should be having to put weight on ... what can I have”
Participants changed the way they engage with food	Eating is a task	4	4	“We had a weekend away recently and we went out for a meal and it was just too much hard work looking at the menu and thinking what can I have”
	Forced changes to eating lifestyle	5	11	“Sometimes if the family’s having a roast or something ... I’ll go and have my WeetBix [cereal] ... I never liked WeetBix at all”
	Change in eating patterns	5	7	“getting up at 3’oclock in the morning to have noodles ... you know because you’re just starving because you couldn’t ... eat a lot for dinner”
Changed appreciation of	A loss in social occasion	4	4	“[At] Christmas the family was around and they had Christmas turkey ... I was sitting on the lounge with my milkshake”
		3	10	“I have got more of an appreciation... I appreciate food more now than I ever did,

food

because I got it taken away”

n = number of participants who commented on a category/subcategory

ref = number of times category/subcategory was mentioned

Table 6. Theme 4: Personal and lifestyles impacts

Categories	Sub categories	n	ref	Example participant quotes
Changes to social life and interests		16	35	“I used to like going out ...I don’t do that anymore. So far as my social life goes, I don’t have any.”
		9	24	“we do have problems with restaurants trying to explain to people my problem ... most people don’t understand”
		8	15	“It has affected me a lot”
Impact on family life	Family rituals	18	32	“I won’t be at the table a lot of times. We always used to have tea together, lunch together, breakfast together, but most of the time I have mine separate”
	Family dynamics	4	12	“I used to do most of the cooking, but I don’t go near the kitchen at the moment because I couldn’t cook, I couldn’t taste or prepare it properly”
Impact on family members	Perceived impact	18	32	“This is a we thing not a me thing because it affects [carer] ... it affects [carer] as much as it affects me, ... how I am”
	Family adapts	8	16	“She doesn’t eat as much either now ... she skips dinner all the time now, ‘cause she doesn’t cook for one person”
	Relationships	3	9	“It created a fair bit of tension in our relationship ... I’d lost my independence ... I felt that reflected in the meal situation”
A financial impact		5	9	“Try and get a meal in front of me that isn’t going to be wasted” “That [supplement] was very expensive and I

couldn't believe it"

n = number of participants who commented on a category/subcategory
ref = number of times category/subcategory was mentioned