

Title: Survivors' experiences of dysphagia-related services following head and neck cancer: implications for clinical practice

Running title: Experiences of dysphagia-related services in HNC

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Declaration of interest

The authors report no declarations of interest.

What this paper adds

What is already known on the subject: National and international service delivery research has highlighted limitations in speech and language therapy services for people with dysphagia following head and neck cancer (HNC). However, that research has been conducted solely from the clinicians' perspective. In order to accurately inform practice change we must also understand what people with dysphagia want regarding services in order to better assist them to live successfully with dysphagia.

What this paper adds: This paper used qualitative interviews to examine the perspective of people with dysphagia following HNC regarding dysphagia-related services and their service needs. These data highlight that support for the physical and practical changes is only one area of need and there are also emotional and psychosocial needs which are largely not addressed. People with dysphagia were seeking greater access to services, and ongoing holistic and targeted dysphagia management from the multidisciplinary team in the post-treatment survivorship period of HNC.

Abstract

Background: It is known that people with dysphagia experience a number of negative consequences as a result of their swallowing difficulties following head and neck cancer management (HNC). However their perceptions and experiences of adjusting to dysphagia in the post-treatment phase, and the services received to assist this process, has not been studied.

Aims: To explore the lived experience of people with dysphagia following non-surgical treatment for HNC and examine their perceptions of service needs.

Methods & Procedures: A demographically diverse group of 24 people who had received radiotherapy for HNC in the past five years, and experienced dysphagia as a result of treatment, were recruited using maximum variation sampling. Each participant took part in a semi-structured, in-depth interview, where they reflected on their adjustment to, and recovery from dysphagia following treatment for HNC, as well as the dysphagia-related services they received during their treatment. Thematic analysis was used to analyse the transcripts and to identify key themes that emerged from the data.

Results: The main integrative theme was the desire for ongoing access to dysphagia-related services in order to adequately manage dysphagia. Within this integrative theme were five additional themes including: (1) entering the unknown: life after treatment for HNC; (2) making practical adjustments to live with dysphagia; (3) making emotional adjustments to live with dysphagia; (4) accessing support outside the hospital services; and (5) perceptions of dysphagia-related services.

Conclusions & Implications: The interviews revealed the need for both greater access to services and a desire for services which address the multitude of issues faced by people with dysphagia following HNC in the post-treatment period. Speech and language therapists managing this caseload need to ensure post-treatment services are available and address not only the physical but also the emotional and psychosocial changes impacting people with

dysphagia in order to assist them to adjust to, and live successfully with dysphagia. Further research should be conducted to support the development of innovative services and to highlight dysphagia-related survivorship issues to governing bodies/policy makers.

Introduction

Head and neck cancer (HNC) is the sixth most common cancer worldwide with 635 000 people diagnosed each year globally (Ferlay *et al.* 2010). The incidence of HNC is expected to increase with the ageing population and with the recent surge in human papillomavirus (HPV) mediated tumours (Callaway 2011). This increase in incidence coupled with more targeted and aggressive treatment protocols, and the radio sensitivity of HPV-related tumours, has led to an increasing number of people living long-term with the side effects of their treatment (Lambert *et al.* 2011). For many, cancer is a chronic condition, yet a recent review of post-treatment care for cancer survivors noted that follow-up appointments frequently failed to identify and address the ongoing effects of treatment and the implications for lifestyle in the post-treatment period (Jefford *et al.* 2013).

Dysphagia, or difficulty swallowing, is a common acute and ongoing chronic effect of definitive, non-surgical treatment for HNC. It can lead to serious medical complications such as malnutrition, dehydration, and aspiration pneumonia, as well as decreased functioning, reduced participation in life activities, negative psychosocial consequences, and reduced quality of life (Cartmill *et al.* 2011, McQuestion *et al.* 2011, Nguyen *et al.* 2005, Nourissat *et al.* 2012, Ottosson *et al.* 2013). Speech and language therapists (SLTs) have an integral role in the diagnosis and management of dysphagia, and are core members of the multidisciplinary HNC team who provide services for people with dysphagia pre, during and post-treatment (Krisciunas *et al.* 2012, Roe *et al.* 2012).

Recent service delivery research in dysphagia management for HNC, however, has identified a number of limitations in current speech and language therapy services (Krisciunas *et al.* 2012, Roe *et al.* 2012, Ward *et al.* 2012). There is a recognised unmet need for proactive multidisciplinary management before, during, and following treatment (Roe *et*

al. 2012). Extensive variability also exists between clinicians and facilities internationally in regards to the nature of management of people with dysphagia undergoing HNC management (Krisciunas *et al.* 2012, Roe *et al.* 2012, Ward *et al.* 2012). SLTs have highlighted there is a lack of resources to meet the needs of people with dysphagia in the post-treatment period (Roe *et al.* 2012).

The exact nature of the services provided is also not well understood. Studies of speech and language therapy services to date have primarily concentrated on exploring clinician-reported interventions used to combat the physiological changes to swallowing (e.g., swallow manoeuvre exercises, compensatory techniques, oromotor exercises). Studies have reported that 50% (Roe *et al.* 2012) and 75% (Ward *et al.* 2012) of clinical teams routinely offer pre-treatment education for patients, with 97.6% (Roe *et al.* 2012) providing information on potential treatment effects on swallowing at initial assessment. However, exactly what information was given to patients and if this pertained to just to the expected physical changes to swallowing was not reported. In addition, whether or not this education also addressed issues of psychosocial adjustment was not provided. Similarly, although 9.5% of clinical teams reported assessing swallowing related quality of life (Roe *et al.* 2012), the nature and extent to which clinicians provide services to address psychological adjustment and enhance quality of life is unknown. A recent systematic review of swallowing intervention studies identified that there are currently no studies which specifically address the rehabilitation of psychological or/and social effects of dysphagia following HNC (Cousins *et al.* 2013).

In order to begin to address the service needs of people with dysphagia following HNC management, it is critical we explore not only the clinician perspective but also the consumer perspective, which is lacking in the current literature. The aim of the current study

is to explore the lived experience of people with dysphagia following non-surgical treatment for HNC and examine their perceptions of service needs. This study seeks to understand the perspective of the person with dysphagia to enhance health professionals' understanding of what skills are needed to adjust to living with dysphagia, the service expectations, and support needs of this group.

Methods

Participants

To explore the lived experience of adjusting to dysphagia and dysphagia-related services in the post-treatment survivorship period of HNC, a qualitative descriptive methodology with phenomenological aspects was adopted (Sandelowski 2000). To capture the heterogeneity of the HNC population, participants were recruited using purposive selection and maximum variation sampling (Patton 2002). Maximum variation sampling is used to select information-rich cases to capture and describe consistent themes across a broad range of participant demographics (Patton 2002). Specific selection criteria were used to achieve variation within the sample including: gender (male/female); age (<65 years/>65years); treatment modality (combined non-surgical modalities/radiation only); geographic location (metropolitan/regional, rural, or remote); months since treatment (<3 months/>3months); and mealtime situation (alone/shared). A minimum of one participant who met the criterion for each maximum variation category was recruited.

Twenty-four participants who had received radiotherapy (+/- systemic therapy) for a primary HNC between April 2007 and April 2012 were recruited through a large tertiary hospital in Brisbane, Australia. All participants had self-reported swallowing difficulties during and/or following their treatment with 14 requiring periods of alternative nutrition (11 nasogastric tube (NGT), 2 gastrostomy, 1 both NGT and gastrostomy). Ethical approval was

obtained from the relevant ethics committees and written informed consent was obtained from each participant. Participants were excluded from this study if they: a) had received primary surgery; b) had any pre-existing conditions that could be associated with dysphagia; c) were considered palliative; or d) had limited proficiency in English. Participant details with maximum variation sampling parameters and other demographic details are reported in Table 1.

[Insert Table 1 near here]

Data collection

Each participant took part in an individual, semi-structured, in-depth interview with the primary investigator. Interviews consisted primarily of open-ended conversational questions adapted to each individual context (Patton 2002). Interviews were conducted using a topic guide to ensure all relevant topics were addressed during the discussion. In order to gain insight into adjustment to dysphagia, participants were asked to comment on their expectations of eating difficulties following treatment, the strategies used to adjust to eating difficulties, and their experience of speech and language therapy services and other dysphagia-related services. In addition, participants were asked to comment on any other forms of support they had accessed as part of their recovery from dysphagia following HNC treatment. Each participant was sent a list of stimulus questions prior to their interview to encourage personal reflection. All interviews were audio-recorded and transcribed verbatim for analysis. Interview times ranged from 20 minutes to 2 hours duration.

Data analysis

Thematic analysis was conducted following the steps outlined by Braun and Clarke (2006). Themes were drawn from the interviews using an inductive approach (Braun and Clarke

2006, Patton 2002). Meanings and patterns were identified through thorough reading of the interview transcripts, and opening coding (Strauss and Corbin 1998) was used to identify statements relating to participants' expectations of eating difficulties, strategies used to adjust to eating difficulties, and experiences of support services. Coding was performed with the assistance of the NVivo9 software program. The number (n) of participants who commented on each category and the number of times each category was referred (ref) to was recorded. A list of categories was developed from the codes and further refined by an independent researcher until consensus was established. All interview transcripts were subsequently recoded using the revised list of categories.

Themes were developed by considering the potential relationships between categories and how they may form an overarching message regarding experiences of living with dysphagia (Braun and Clarke 2006). Themes were then reviewed by re-reading coded extracts and comparing with the entire data set. At each point in the analysis, codes, categories, and themes were reviewed by the co-investigators at research meetings, to ensure rigor and maintain consensus. All participants were sent a written summary of the main findings from the analysis and asked to confirm the investigators interpretation. Eleven of the 24 participants provided feedback, and all confirmed the investigators interpretation of their experiences.

Results

Five interrelated themes described the nature of participants' adjustment to dysphagia in the post-treatment period and their experiences and expectations of dysphagia-related services. Three of the themes highlighted key areas of support needs recognised by participants, whilst two themes reflected more on formal and informal supports accessed by participants. These themes included: (1) entering the unknown: life after treatment for HNC; (2) making practical

adjustments to live with dysphagia; (3) making emotional adjustments to live with dysphagia; (4) accessing support outside the hospital services; and (5) perceptions of dysphagia-related services. Serving as a link between and across all five themes was an overall integrative theme relating to the desire for ongoing access to dysphagia-related services.

Theme 1: Entering the unknown: Life after treatment for HNC

Entering the unknown was a key theme in this study with participants stating that they had not anticipated the severity and duration of the side effects of treatment on eating and swallowing *“I didn’t know it was going to be this hard. I just thought I would go home and have a normal meal ... have a normal life.”* The main categories and subcategories pertaining to this theme are summarised in Table 2. During treatment, some participants believed that their final fraction of radiation would signal the end of their struggles with dysphagia and that life would quickly return to normal *“after treatment it [swallowing] gets progressively worse ... just when you think you are going to get through it ... it all comes on full-bore”*. For these participants, treatment was just the beginning of their difficulties with dysphagia *“it’s bad during treatment but what you don’t know is that it’s going to get worse ... a lot worse before it gets any better.”*

Many participants reflected on the importance of/need for adequate education from health professionals regarding the potential side effects of dysphagia, including both the physical aspects, and its potential impact on other aspects of life *“I think if people were briefed a bit better in the first place about the whole process ... there is ... not enough of the right sort of briefing about how your life is going to change because of this”*. The end of treatment represented the beginning of a new and uncertain journey that many had not anticipated. Participants expressed feelings of doubt as to whether their life, and ability to eat, would ever return to normal. Though participants in this study reported improvements in their

swallowing throughout the recovery period, over half stated they were unaware and unprepared for the amount of time required for function to improve.

[Insert Table 2 near here]

Theme 2: Making practical adjustments to live with dysphagia

Participants discussed learning about “*what works*” and of the practical adjustments they had made in order to help them eat and drink during and following treatment. These strategies are summarised in Table 3. One of the dominant categories of this theme was centred on how “*food’s gotta be specially prepared.*” There was extensive discussion regarding learning about food preparation and ways to assist with the passage of solid food boluses (e.g., drinking fluids, naturally moist food, adding a gravy/sauce). The majority of participants also spoke about “*learning what I can and can’t eat.*” Many reported using trial and error methods to select suitable foods, and would consistently eat the same foods if they had success. Others discussed discovering food preparation strategies that helped them, including eating softer foods, eating smaller and more frequent meals, cutting food into small pieces, adding extra seasoning for flavour, and heating the plate to keep food warm due to the increased length required to consume a meal. Some participants noted they managed by simply avoiding all foods that were difficult to eat.

Participants also spoke about discovering the importance of planning, being more prepared, and thinking ahead about meals. One participant would even take his own sauces and gravies when going out for a meal “*I usually go with a bag, and I take sauces with me and custard. I’m like a lady that has children, goes around with a nappy bag, now I’ve got a bag full of my stuff.*” Many participants reported learning the importance of oral hygiene and its broader implication on alleviating swallowing and chewing difficulties. Participants discussed the variety of strategies used to combat xerostomia, particularly the need to carry a

water bottle. Learning to use nutritional supplements and pain medication during treatment, and in the acute recovery period, to assist with oral intake and the maintenance of adequate nutritional status were further changes participants learned to incorporate into their lives.

[Insert Table 3 near here]

Theme 3: Making emotional adjustments to live with dysphagia

In addition to the practical adjustments adopted, participants in this study spoke extensively about the emotional adjustments, and changes in perceptions and attitudes required to live with dysphagia. These are listed in Table 4. The majority spoke about taking a positive attitude, while others spoke about not letting their difficulties with food become a barrier *“I’m still the same bloke. The only little problem I’ve got, and I treat it as little, is my eating problem.”* Quite often, foods that were previously enjoyed were now problematic, though approximately half of the participants talked about the importance of persisting and continuing to eat even though it was difficult *“even though you don’t want to eat ... you have to force it down.”* Ultimately most of the participants reached a point in their recovery where they had accepted the changes to their swallowing ability *“I don’t really worry about it anymore ... no point. If I can’t eat it I can’t eat it.”* This led to adapting and making adjustments *“you just learn to live with it, you don’t even think about it now it’s just a part of your diet.”* Other emotion-related strategies that participants talked about included: remaining hopeful that their eating abilities would return to normal, enjoying food vicariously through other people and what they could eat, shifting their focus from food and meals, and believing that there was always someone who was worse off than they were.

[Insert Table 4 near here]

Theme 4: Accessing support outside the hospital services

When exploring how participants learned to adjust and cope and live successfully with their dysphagia, participants talked about support received from family, friends, other patients, as well as their use of alternative therapies. These categories are summarised in Table 5. Family members were identified as a significant source of support for people with dysphagia, particularly regarding meal preparation and encouragement to keep eating “*I ate because ... [carer] insisted that I eat.*” Participants spoke about how important it was for their family/friends to understand their eating difficulties, noting supportive and accommodating attitudes regarding their mealtime needs “*[carer’s] been really understanding on the [eating] side of things, she says ‘take your time’.*” Some participants, though, felt their family members and friends had difficulty understanding their struggles at mealtimes “*the family’s not in your mouth, they don’t know what’s going on*” and “*some of your friends, if you’ve got a restricted diet, they won’t invite you to a meal because they ... don’t know what you’re going to be able to eat.*” Just under half of the participants spoke about the benefits of having the opportunity to talk with someone else who had been through a similar course of treatment. They noted the value of speaking with other people in the hospital waiting room “*sometimes when I’m sitting outside the clinic with other patients you might just start talking, sometimes you find that very helpful because he says ‘oh that happens to me too’.*”

[Insert Table 5 near here]

Theme 5: Perceptions of dysphagia-related services

Participants’ perceptions and experiences of dysphagia-related services during and following treatment are listed in Table 6. In order to manage oral intake issues during treatment, participants were seen by the SLT and the dietitian in joint sessions. For many participants, the differences between the role of the SLT and the dietitian in dysphagia management was

unclear *“I never quite understood the difference between the speech therapist and the nutritionist. They would both be in the room and they seemed to be covering the same ground ... it wasn't clear to me just what each one was supposed to be doing.”* Whilst some participants found the services helpful for swallowing difficulties, several participants were unaware of the scope of the SLT's role in the management of dysphagia. Half the participants reported that sessions with the SLT and dietitian largely focused on weight maintenance and tolerance of oral intake. Some participants felt that the information and advice was not personalised or practical to their situation but rather given in a general sense *“It's all general terms, in general terms of nutrition, and intake”*, and was therefore unhelpful to their situation. Other participants, however, reported that they had benefited from the service. The need for greater practical application and personalisation of information and services for people with dysphagia was an important issue identified by participants in this study.

[Insert Table 6 near here]

Integrative Theme: Desire for ongoing access to dysphagia-related services

The five themes discussed above were all connected by an integrative theme that indicated the need for ongoing practical and personalised follow-up from health professionals in the assessment and management of eating difficulties. Participants in the current study described general support by health professionals across treatment. However a number of participants identified a lack of ongoing care in the period following the completion of treatment *“when you've had your radiation, you are told [to] come back in six weeks, you go home and that six weeks is the worst six weeks out of everything and you haven't got that support then.”* Once treatment was complete, participants felt ill prepared for the journey ahead, and desired ongoing contact with health professionals who could provide support and assistance regarding eating difficulties throughout the post-treatment period *“Follow ups ... we get oncology appointments ... I think we should have one for the eating ... on a regular basis.”*

Throughout the post-treatment period, participants made a significant number of physical and emotional adjustments in order to live successfully with dysphagia. These adjustments were often made independently or with their family, without access to information, guidance or support from health professionals. Largely because of the lack of professional services, participants commented on the importance of support from family, friends, other patients, and alternative therapies throughout the post-treatment period, highlighting the importance of supportive networks in order to live successfully with dysphagia.

Discussion

The use of a person-focused qualitative methodology in this study enabled insight into the adjustment and support needs of people with dysphagia following HNC. Five broad themes emerged from this study: the changing expectations of recovery, the substantial number of practical and emotional strategies required, the importance of external support, and reflections of the experiences of dysphagia-related services. The consistency between these themes was the greater need for practical and personalised care from healthcare professionals not only during but also throughout the post-treatment survivorship period.

The majority of participants in the current study noted they were unprepared for the degree and duration of the side effects on swallowing function following treatment. Many noted the challenges of living with dysphagia for months and years, often without the ongoing support of specialist health professionals. Participants reported reliance on family, friends, and alternative therapies in the post-treatment period, quite possibly due to the lack of services available to meet their psychological and supportive care needs at this time. Patterson and colleagues (2012) identified that up to one-third of people with dysphagia following HNC do not have carer support. The limited post-treatment services may further isolate these survivors. Their findings support that it is essential for health professionals to

recognise the end of radiation/chemoradiation treatment as a critical period for patients. Other research has similarly noted that the end of treatment often represents the commencement of a new and unfamiliar period of adjustment for many people (Larsson *et al.* 2007, McQuestion *et al.* 2011, Molassiotis and Rogers 2012, Ottosson *et al.* 2013, Wells 1998). People with HNC need to be prepared for this new phase through adequate counselling and education about the ongoing physical changes to swallowing throughout the trajectory of recovery, and the implications of these physical changes on everyday life, including emotional and psychosocial effects.

Whilst the focus of speech and language therapy services for people with dysphagia following HNC management has largely been on the rehabilitation of the swallow (Cousins *et al.* 2013), the current interviews highlighted the need to diversify the nature of rehabilitation. In parallel to interventions targeting the physiological changes to the swallow, specific support, training and education is needed to assist people with texture modification, meal preparation, food choices, and practical strategies. Whilst many clinicians may feel these are currently provided, the current interviews highlighted that people with dysphagia are needing/seeking more assistance and guidance in these matters and more individualised discussions of what may work for them.

The participants in this study revealed they had experienced a range of emotions relating to their swallowing impairments and had (largely) independently worked through an array of strategies to adjust to the physical, emotional, and lifestyle changes they had experienced. Previous literature has similarly noted the emotional impact of living with dysphagia and the need for significant personal adjustment (McQuestion *et al.* 2011, Molassiotis and Rogers 2012, Ottosson *et al.* 2013, Semple *et al.* 2008). Services need to be sought for people with dysphagia to assist them with the personal adjustments during the

post-treatment period. Exactly how this is best delivered requires greater understanding of this issue than is available from the current data. Whilst interventions exist for broader psychological and social effects of HNC and its treatment (e.g., fear of recurrence, distress, and depression) (de Leeuw *et al.* 2013, Howren *et al.* 2013, Luckett *et al.* 2011, Semple *et al.* 2004), there are currently no intervention studies which have specifically targeted the rehabilitation of the emotional, and psychosocial effects of dysphagia (Cousins *et al.* 2013). Locher *et al.* (2011) proposed counselling to reduce anxiety and psychosocial interventions which teach people with dysphagia how to communicate their distress associated with food and mealtimes. In addition, skill building programs that target activities such as meal preparation, food consumption, and food shopping have been suggested to promote physical and emotional wellbeing (Locher *et al.* 2011). Examining the benefits of such interventions for people with dysphagia following HNC is a potential area for future research.

Family members, and in particular family carers, were identified in this study as a significant source of support for people with dysphagia following HNC throughout the trajectory of care. Family members have been recognised as having an essential role in caring for people with HNC (Baghi *et al.* 2007, Penner *et al.* 2012), with two-thirds of people with dysphagia following HNC identifying a carer. Despite this there is an absence of research regarding the role of the carer for people with dysphagia following HNC. Mayre-Chilton and colleagues (2011) conducted the first known study to report on family carers of people with dysphagia following HNC treatment who were dependent on a gastrostomy. They found that family carers experience significant physical, emotional, and social burdens as a result of their family member's HNC, and thus also require strategies to cope with the caregiving role. Health professionals must support the role of the family carer. The importance of their role in supporting the patient highlights the need for specific targeted services for carers to help

prepare them for their role in dysphagia management (Patterson *et al.* 2012, Penner *et al.* 2012).

Overall the current participants expressed a desire for greater levels of ongoing care and support throughout the post-treatment period to assist them through the physical, social and emotional adjustments to their swallowing difficulties. This finding was not unexpected as Jefford and colleagues (2013) noted that unlike other health conditions (e.g., heart attack or stroke), cancer care does not have an emphasis on post-treatment rehabilitation. The challenge though, is how best to achieve such enhanced post-treatment support for people with dysphagia. Indeed, the insights obtained from the participant interviews revealed that not only is more contact with services required, but a greater diversity of services is needed to help people with swallowing difficulties meet the complex and multifactorial changes associated with living with dysphagia. Hence the issues cannot simply be solved with greater numbers of SLTs.

Changing services to better meet the needs of people with dysphagia will require the consideration of multiple new strategies, some of which could include: adopting new models of care for post-treatment monitoring (e.g., regular remote monitoring via technology to monitor status and provide more timely interventions); conducting more holistic assessments (e.g., monitoring distress to facilitate early referral to support services); engaging greater involvement of other members of the allied health team to address the adjustment and psychosocial issues of living with dysphagia (e.g., social work, psychology); greater use of allied health assistants to support delivery of services (e.g., running sessions on practical advice for food preparation); embracing the important role of the family by ensuring carers receive information and training (e.g., family-centred care approach); using opportunities to encourage peer support (e.g., group therapy); and encouraging links to community and social

networks. Further research is required to evaluate these and other novel strategies so that clinicians can better meet the needs of people with dysphagia to enhance post-treatment care and support.

Conclusion

This qualitative study has provided an in-depth description of the experiences of adjusting to dysphagia and dysphagia-related services following treatment for HNC. Participants in this study provided a detailed account of their expectations and experiences of swallowing difficulties following treatment, and the substantial number of physical and emotional adjustments required to cope with the multifaceted effects of dysphagia. The study also provided insights into participants' perception of services and support, specifically relating to their dysphagia, both during and following treatment. Future studies are required to develop and evaluate new models of care which increase access to support and not only address the physical changes but also the psychological effects and social impacts of dysphagia following HNC. Greater understanding of how the expectations of, and need for services, changes over the course of treatment and the post-treatment phase is also needed to give greater insight into when such interventions may be most beneficial.

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Table 1. Participant characteristics (n=24)

Demographic	Parameters	Number of Participants
Age	≤65 years	18
	> 65 years	6
Gender	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
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 2. Theme 1: Entering the unknown: Life after treatment for HNC

Categories	n	ref	Example participant quotes
Need for adequate preparation of side effects	20	43	<i>“More an awareness of the sorts of things you can expect ... in written form you get so much information ... you don’t always take everything in ... in a written form at least you have got something to refer back to”</i>
Survivors underestimate the extent of side effects on swallowing	18	34	<i>“You don’t know if you are going to get over it. You don’t know if you are going to be able to eat”</i>
Recovery is a slow process	15	58	<i>“My diet is still very limited ... I’m still struggling with the weight ... it’s taking a long time”</i>
Post-treatment is probably the worst part	6	16	<i>“During treatment it is probably not that much of a trouble but it is after treatment... when it sort of catches up, it is a real problem”</i>

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

ref = number of times category/subcategory was mentioned

Table 3. Theme 2: Making practical adjustments to live with dysphagia

Categories	Sub categories	n	ref	Example participant quotes
Food's gotta be specially prepared	Drinks help	20	48	<i>"I have water before I eat, while I'm eating, ... and when I swallow"</i>
	food go down			
	Moist food	19	54	<i>"Moist food, I can cope with"</i>
	Food must be soft	13	30	<i>"Most things ... have ... to be very soft"</i>
	Eat frequent and smaller meals	13	20	<i>"I have so many little meals a day and ... snacks"</i>
	Food cut small	7	20	<i>"Everything that I have I chop it up"</i>
	Add extra flavour	2	4	<i>"I need more seasoning in food"</i>
Learning what works	Heat the plate	1	1	<i>"I heat the plate ... then I have that extra time"</i>
		19	52	<i>"In terms of how I managed my eating ... it's a learned exercise"</i>
Oral hygiene	Products for dry mouth	10	18	<i>"I have a mouth spray that I use"</i> <i>"I tried all of the gels"</i>
	I carry water all the time	7	11	<i>"You can't leave anywhere without a bottle of water"</i>
	I rinse my mouth regularly	4	6	<i>"I have to ... of a morning ... and regularly throughout the day ... have a rinse of bicarb and ... salt together"</i>
	Dental care	6	8	<i>"I clean my teeth after meals"</i>
Supplements		9	18	<i>"You kind of live on [supplements] a bit, that sort of keeps you going"</i>
I'm more prepared		8	17	<i>"I'm always trying to think ahead with meals"</i>
Avoid problem foods		5	10	<i>"The texture of some foods doesn't agree with me ... so ... I avoid it"</i>
Pain medication		2	2	<i>"It was painful swallowing I had to ...take some ... medication ... so I can eat"</i>

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

ref = number of times category/subcategory was mentioned

Table 4. Theme 3: Making emotional adjustments to live with dysphagia

Categories	n	ref	Example participant quotes
Attitude	18	45	<i>“The food side of things hasn’t really changed me too much, just the eating habits has that’s the only thing that that’s changed”</i> <i>“I’ve always looked for something positive”</i>
Acceptance	17	36	<i>“I know that my life now is part of the compromise because it can’t be the same as it used to be because of my eating”</i>
Adapting	12	19	<i>“You just learn to live with it, you don’t even think about it now it’s just a part of your diet”</i>
Persistence	10	19	<i>“It was like a competition for me ... two years after treatment you are still trying to cope with your eating. You got to be a champion to do that”</i>
There’s always someone worse	8	8	<i>“I think there were people worse off than me, they ended up on liquids for much longer than I did”</i>
Remain hopeful	7	11	<i>“I just hope soon I’m able to sit down and have a nice meal”</i>
Living vicariously through others	2	8	<i>“I had to distract myself ... [I’d] start preparing a dish, even if you can’t eat it, give it to someone. Sit down, look at them, how they eat it. I enjoy that”</i>
I focus on things other than eating	2	4	<i>“I focus on things that are more ... important and more pleasurable for me”</i>

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

ref = number of times category/subcategory was mentioned

Table 5. Theme 4: Accessing support outside the hospital services

Categories	Sub categories	n	ref	Example participant quotes
Family	Meal preparation	10	15	<i>“I’ve got a good wife that prepares it all for me and goes to a lot of trouble preparing it [meals] it all”</i>
	Need family to understand	7	12	<i>“I’ve needed someone to understand about this [eating difficulties]”</i>
	Encourage me to keep eating	5	6	<i>“My wife tried endlessly to try and get me to eat but I was resistant”</i>
Friends	Supportive and accommodating	7	11	<i>“They just understood, you told them what you could do or what you couldn’t do and they would just go oh ok”</i>
	Lack of understanding	5	5	<i>“People come up and they’ll ask you but they don’t really understand”</i>
Waiting room		10	26	<i>“I used to ... listen to people when I waiting before treatment ... you get to meet people going through the same stuff and you do talk about it to each other”</i>
Others with lived experience		9	16	<i>“I would have liked to have talked to someone who has been through the same thing, you can’t replace that”</i>
Alternative therapies		5	12	<i>“We had access to ... some of the natural therapies like acupuncture to see whether that would help stimulate my salivary glands”</i>

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

ref = number of times category/subcategory was mentioned

Table 6. Theme 5: Perceptions of dysphagia-related services

Categories	n	ref	Example participant quotes
Practicality of sessions	20	44	<i>“They’d write everything down. They’d advise you to do this and set goals for recovery”</i>
Focus on weight and oral intake	13	19	<i>“They kept checking the weight and asking what are you eating and how are you feeding”</i>
Personalisation of information	12	27	<i>“I remember asking ... what can we eat and I was given this list and there were things on it that no way you eat”</i>
Understanding speech and language therapists role	8	11	<i>“I saw the speech and language therapist ... every week [during treatment] and I don’t know why ... I didn’t have a lot of issues with being able to speak”</i>

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

ref = number of times category/subcategory was mentioned