

RUNNING TITLE: Carers' experiences of dysphagia in head and neck cancer

TITLE: Carers' experiences of dysphagia in people treated for head and neck cancer: A qualitative study

Dysphagia

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Abstract

The implication of dysphagia for people treated non-surgically for head and neck cancer (HNC) and its detrimental effects on functioning and quality of life has been well documented. To date however, there has been a paucity of research investigating the effects of dysphagia following HNC on carers, independent of the consequences of a gastrostomy. The objective of this qualitative study was to report on the experiences of carers of people with dysphagia (non-gastrostomy dependent) following non-surgical treatment for HNC and to identify the support needs of this group. A purposive, maximum variation sampling technique was adopted to recruit 12 carers of people treated curatively for HNC since 2007. Each participated in an in-depth interview, detailing their experience of caring for someone with dysphagia, and the associated impact on their life. Thematic analysis was adopted to search the transcripts for key phases and themes that emerged from the discussions. Analysis of the transcripts revealed four themes: (1) dysphagia disrupts daily life; (2) carers make adjustments to adapt to their partner's dysphagia; (3) the disconnect between carers' expectations and the reality of dysphagia; and (4) experiences of dysphagia-related services and informal supports. Carers generally felt ill-prepared for their role in dysphagia management. The qualitative methodology successfully described the impact of dysphagia on the everyday lives of carers particularly in regard to meal preparation, social events, and family lifestyle. Clinicians should provide adequate and timely training and support to carers and view carers as co-partners in dysphagia management.

Keywords: deglutition, deglutition disorders, head and neck cancer, carers, qualitative research

Introduction

Research has demonstrated that ongoing chronic dysphagia following head and neck cancer (HNC) treatment is associated with numerous changes to patient functioning, reduced social and emotional well being, and changes in perceptions of food and mealtimes [1-9]. However, few studies have explored the effects of dysphagia following HNC on the carer. Given that eating and mealtimes are profoundly social events that sustain not only our physiologic needs but also our social and emotional life, the potential for dysphagia to impact on the life of the carer is great. Whilst current clinical models of rehabilitation and support post HNC focus primarily on the needs of the person with dysphagia, emerging evidence would suggest that comprehensive dysphagia management also needs to address the currently under-recognized needs of the carer [10-12].

In the specific case of carers who support relatives with severe dysphagia who require nutrition via gastrostomy, some issues have been identified [10-11]. Mayre-Chilton and colleagues [10] noted that both patients and carers experienced a negative impact on social aspects of their lives, with carers showing a greater negative impact on their daily lives because of their role in gastrostomy management. Few carers felt they received support or preparation for their role, and many discussed self-discovered strategies employed to assist their adjustment to the caring role. Penner and colleagues [11] found similar issues in their cohort of six carers, and observed that few had received any formal support. Rather carers discussed using common processes including “negotiating a new normal” and “negotiating changing roles” to help adapt to the role of caring for a person requiring alternative nutrition following HNC [11].

Likewise, a recent mixed methods study, exploring the quality of life and perceptions of carers of people with dysphagia following HNC, found similar results [12]. This study focussed on carers of people who required gastrostomy feeding (n=17 at 3 months and n=11 at 12 months post) and those who didn't (n=31 at 3 months and n=49 at 12 months post). Results indicated suboptimal carer quality of life scores at pre-treatment and three months post-treatment. A significant improvement in carer quality of life was observed between 3 and 12 months post-treatment, which was attributed to improvements in patient functioning. However subsequent interviews echoed earlier findings [10] [11], noting difficulties with monitoring symptoms, motivating the patient to eat, providing appropriate meals for the patient, and changes to the carers' lifestyles.

These studies indicate that caring for a person with dysphagia who is gastrostomy dependent has a significant impact on the life of the carer, and that substantial support services are needed for people providing such care. However, the extent to which these data are reflective of the needs of those caring for people with dysphagia who are not gastrostomy dependent is unclear. Given that they are not faced with the “medical” and tangible duties associated with managing tube feeding, it is possible that they may receive even less support, preparation, or assistance. Further, since those who do not require gastrostomy feeding are by far the larger cohort living with dysphagia in the post-treatment phase [13-18], the significance of these concerns is evident. To date, only the study by Patterson and colleagues [12] included some carers of non-gastrostomy dependent patients, however their qualitative data was not analysed separately. Hence the aim of the current study is to elucidate carers’ experiences of dysphagia following HNC in the absence of a gastrostomy. The objective is to increase our understanding of caring for a person with dysphagia following HNC, to identify support needs of this group, and determine if additional services are required.

Methods

A qualitative-descriptive approach based on phenomenology [19-20] was adopted to allow a comprehensive exploration of the experiences of carers of people with dysphagia (non-gastrostomy dependent) following HNC. Qualitative descriptive methods are best suited when descriptions of a particular experience are required, as they allow for a comprehensive portrayal of the facts of an event in everyday language [19]. A phenomenological stance was adopted for the current study as it was concerned with describing the *lived experience* of carers of people with dysphagia following HNC. This allows the researcher to explore deeper understandings of the meaning of everyday experiences [21].

Sampling

Demographically diverse participants were recruited using purposive, maximum variation sampling [20]. Maximum variation sampling is especially useful when the researcher wishes to capture and describe central themes which are consistent across a great deal of variation within the sample. Any common patterns that emerge are of particular interest and value in describing the core experience of a phenomenon [20]. Sampling was sought across five characteristics: gender (male/female); age (<65 years/ ≥65 years); months since partner’s treatment (<3months/ ≥3months); years of relationship (<10years/>10 years); and employment status (paid employment/not in paid

employment). Recruitment continued until the studies criteria for maximum variation sampling was met (i.e. at least one participant in each of the maximum variation categories). Participant details with maximum variation sampling parameters and other demographic details are reported in Table 1.

[Insert Table 1 near here]

Participants

Carers were recruited through the Radiation Oncology Department at a tertiary hospital in Brisbane, Australia, where their partners had received curative, non-surgical treatment for a primary HNC. In addition to meeting the requirements for purposive sampling, to be eligible for inclusion participants were required to engage in regular meals with the person with dysphagia (i.e., average of one meal/day). Carers were excluded if they were undergoing or had undergone treatment for HNC, had any pre-existing conditions associated with dysphagia, or had limited proficiency in English. In addition, participants were also excluded if the person with dysphagia following HNC had received primary surgery, had a co-morbid condition associated with dysphagia, were receiving enteral nutrition via gastrostomy, or were considered palliative. Twelve carers, ten females and two males, of people who had completed curative non-surgical treatment for a mucosal HNC participated in this study. Carer participants ranged in age from 45 to 67 years, with a mean of 53.9 (SD = 6.2). All participants were in a defacto relationship or were married with a range in relationship length from 5 to 37 years (mean = 23.4; SD = 9.9). The partners with dysphagia ranged in age from 43 to 71 years of age and had self-reported swallowing difficulties during and/or following their treatment.

Procedure

Permission was obtained from the relevant ethics committees and participants provided written informed consent. Each carer participated in an in-depth, semi-structured, individual interview with the principal investigator. An interview guide was developed to ensure relevant topics were addressed during the discussion; however participants were encouraged to speak openly about their experiences of caring for someone with dysphagia following treatment for HNC. Open-ended questions were adapted, omitted or elaborated depending on the individual to encourage a conversation style interview [20]. To assist in preparation for the interview, each participant was sent a list of stimulus questions to encourage personal reflection [20]. Interviews ranged in duration from 20 minutes to 1.5 hours and were audio-recorded and transcribed verbatim.

Data analysis

The interview transcripts were analysed using thematic analysis following the phases outlined by Braun and Clarke [22]. An inductive approach was used to identify and analyse patterns within the data, with themes and descriptions sourced directly from the interviews [20]. Initially the principal investigator read each transcript several times to familiarise herself with the data and to gain a general sense of the participants' experiences [22]. An opening coding approach [23] was adopted to systematically examine the data set and generate initial codes. Coding of the transcripts was conducted with the assistance of the NVivo9 software program and a record was kept regarding the number of participants who commented on each category (n) and the number of times each category was referred (ref) to. Related codes were then collated into categories and potential themes [22]. Consensus coding was conducted by an independent researcher on two of the transcripts using the list of themes and categories. Themes and categories were then refined and all transcripts were subsequently recoded using the revised list of themes and categories [20, 22]. Each theme and category was reviewed against the entire data set to ensure they reflected an accurate interpretation of the carers' experiences [22]. To ensure rigor and agreement in the data, the co-investigators reviewed and refined the codes, categories, and themes at regular research meetings [20, 22]. Each participant was sent a written summary of the main findings of the analysis and asked to confirm the interpretation. Three out of twelve responded to the request and all confirmed the authors' interpretation of their experiences.

Results

Four themes emerged from the transcripts which captured the experience of caring for a person with dysphagia following HNC treatment including: (1) dysphagia disrupts daily life; (2) carers make adjustments to adapt to their partner's dysphagia; (3) the disconnect between carers' expectations and the reality of dysphagia; and (4) experiences of dysphagia-related services and informal supports.

Theme 1: Dysphagia disrupts daily life

Analysis of the interviews revealed that the carers had experienced a broad range of consequences as a result of caring for someone with dysphagia following HNC. This theme incorporated a number of categories including the effects of dysphagia on meal preparation, effects of dysphagia on the family, effects of dysphagia on social life and

eating out, and emotional responses to dysphagia. Each category is discussed below and further summarised with examples of participant quotes in Table 2.

Effects of dysphagia on meal preparation

Over half the participants commented on changes to meal preparation as a result of dysphagia. A range of modifications to food were described by participants including adding a “*huge amount of sauce*”, ensuring food was soft and moist, ensuring there was plenty of drinks available at meals, chopping food into small pieces, avoiding spices and other irritants, having smaller more frequent meals, and adding flavour enhancers to meals. As a result “*finding the right things for him to eat was hard*” and preparing a meal was no longer easy. Meal preparation required conscious and intentional thought and planning “*The major thing is now you have to orchestrate your meals ... you gotta plan and organise your meals.*” Carers would often have to prepare two separate meals. Consequently meal preparation was a longer and more intense process than it had been previously “*meal preparation ... takes more time and effort.*”

Effects of dysphagia on the family

The majority of carers spoke about how they and the rest of their family had learnt to accommodate the needs of the person with dysphagia. For many, what they now ate was largely dictated by the needs of the person with dysphagia “*I now eat finely chopped vegies ...*” and many carers would not eat particular foods they knew their family member with dysphagia could not eat “*I don't eat stuff at home he can't eat*”. Two of the participants commented how dysphagia “*changes life for the rest of the family.*” Over half the participants had experienced changes to their family mealtime and no longer ate dinner together. Those who continued to eat meals together discussed changes to what mealtimes now meant. They had experienced a loss of the social bonds of food and mealtimes “*We [don't] sit at the table...there is less talk... less other things happening...because we don't want to go anywhere because he can't eat.*” One carer noted the financial impact of dysphagia, particularly in relation to having to throw food away that their partner could not eat. A number of participants also reported on the effects of dysphagia on their relationship. One carer spoke about a disruption to a twenty-year routine in her relationship with her partner with dysphagia where they no longer shared in their “*together time*” over coffee in the morning because “*he couldn't drink coffee.*” The majority of carers, however, did not feel that dysphagia had had a detrimental effect on their relationship “*in lots of ways I think we're much closer ... it's bound us together more.*”

Effects of dysphagia on social life and eating out

The majority of carers reported the effects of their partners' dysphagia on their social life. Restrictions on the choice and texture of food for their partner meant that eating outside the home was more challenging. Due to the lack of understanding of dysphagia at cafes and restaurants, meals out had to be planned events and required purposeful preparation "*we do research so we know where to go.*" As a result, going out for a meal was viewed as too difficult for some carers. One carer spoke about how eating out with friends prior to treatment, was an important social event for her and her partner. Two-years following treatment "*we still haven't got to be going out with friends to dinner.*" Some carers were selective about which friends they would share a meal with. Another carer wondered "*why are we at a restaurant when it is so hard? Why couldn't we have done something else, go to a movie or a play or somewhere else?*"

Emotional responses to dysphagia

Carers reported experiencing a range of emotions as a result of their partners' dysphagia. In particular, carers noted emotions in response to the challenges of meal preparation. Frustration was the most common emotion expressed "*it was frustrating trying to find things that she could have [to eat].*" In addition, participants described feelings of worry and concern watching their partner cough and choke on food and drinks "*how do I cope with this, what do I do ... to make it so he doesn't choke on his food?*" Participants also worried about the amount of weight their partner lost during and following treatment "*constant worry ... with him losing weight.*" Some participants expressed feelings of sympathy for people with dysphagia "*I can eat normal and you just feel for people [with dysphagia].*"

[Insert Table 2 near here]

Theme 2: Carers make adjustments to adapt to their partner's dysphagia

Carers in this study spoke about the adjustments required in order to adapt to the dysphagia. This theme is summarised in Table 3. Central to adapting to the effects of dysphagia was the acceptance of a 'new normal' "*You have to live with the new life ... and the new life is that meal preparation is different from anybody else's or different from what it used to be.*" Six of the twelve carers spoke about the importance of having a positive attitude in order to adapt to the new normal. Living with someone with dysphagia also meant changes to the carers' roles "*that's how I adjusted...I just took on all those other roles*" and responsibilities "*I tried to ... do all the jobs ... all the cooking... all the shopping ... look after the kids... I did everything.*" Over half the participants felt unprepared for this

necessary adjustment *“It’s tough stuff after the treatment finishes...after that it’s up to the home carer and they haven’t been there before, they’ve got no expertise and to a great extent no technical information either”*. The additional roles taken on by the carers in this study included problem solver, household manager or “parent”, nutritionist, chef, and life coach.

Carers also spoke about a number of practical strategies that had helped them adapt to their partners’ dysphagia. Many carers did not want to eat food their partner could not eat in front of them and therefore looked for opportunities to eat these foods when their partner was not present *“I go out for lunch when he [patient] is playing golf and eat what I want to eat”*. When it came to food and mealtimes during the treatment period, a quarter of the carer participants noted that it was important to give their partner space to make their own decisions *“I’d encourage him to make milkshakes ... but he was pretty negative ... I decided I’d look after the three of us [carer and children] in terms of food.”* Following treatment, trial and error was commonly used by carers, both in order to learn what their partner could and could not eat as well as learn the easiest way to prepare appropriate meals *“I’ve got a whole array of discarded graters and choppers.”*

[Insert Table 3 near here]

Theme 3: The disconnect between carers’ expectations and the reality of dysphagia

The third theme to emerge from analysis of the interviews was the disconnect between carers’ expectations and the reality of dysphagia post-treatment. The majority of the carers in the current study had not anticipated the severity and duration of the side effects of treatment on their partner’s swallowing (n=10, ref = 29) *“I didn’t realise how bad the eating was going to get.”* Once treatment was complete, many carers believed that the side-effects would quickly resolve and life would go back to normal, however this was not the case (n=8, ref =26) *“previously you get a cold you get over it you get back to normal really quickly, this wasn’t going to happen ... this was never going to go back to normal.”* Four of the twelve carers commented that the weeks following post-treatment were actually more difficult than the treatment period itself (n=4, ref = 11) *“Nothing prepared us for after day 45 and the 3rd chemo. That for both of us in hindsight ... was the hardest part.”*

Theme 4: Experiences of dysphagia-related services and informal supports

The fourth theme to emerge from the interviews was the experiences of dysphagia-related services. The categories pertaining to this theme have been summarised in Table 4 with supporting quotes from participants. Carers in this study noted that whilst frequent monitoring and support of eating and weight maintenance was provided during treatment, many carers noted that *“Once treatment is over you are cast off to sail alone, it is a very lonely, fearful and frustrating time ... much worse than during treatment when there is wonderful support.”* One carer summed up the experience stating *“I don’t really think there is a lot of support there for carers.”* The majority of carers believed that information provided needed to be practical, personalised, and delivered in lay terms rather than in medical terms *“[health professionals] think their knowledge is everybody’s knowledge and it’s not ... they [have] got to use ... patient language.”* Though some carers found the dysphagia-related services of the speech pathologist and dietician helpful for half of the participants the role of the speech pathologist in the management of swallowing difficulties was not clear *“her speech wasn’t really affected ... there wasn’t really any call for a speech therapist.”*

The carers in this study also shared their views on support from family, friends, and other carers of people with dysphagia following HNC. In particular, the majority of carers commented on the value of support from other carers *“there was a fellow that was a month ahead of us ... we used to keep judging ourselves by him, he and his wife and I still keep in contact so that we can get a feel of how they’re going and compare that and sometimes bounce ideas”* and the desire for opportunity to talk to someone who had been there *“just having someone to say ‘try this’ if you are frustrated ... somebody who knows what you are going through.”* However not all participants were positive about the idea of a carers support group *“if there was a carer support group ... I don’t think I would’ve gone.”* A small number of participants made comments regarding the support they’d received from family in regards to food and meals *“we were very lucky that we had support within the family as well, that understood.”* One carer noted however that a lack of understanding on the behalf of their friends meant they no longer went to friends places for dinner *“that is something we probably don’t do [eat at friend’s houses] ... they don’t understand the problem of him swallowing.”*

[Insert Table 4 near here]

Discussion

The current study has provided an in-depth description of the impact of dysphagia following HNC on the carer. This unique perspective provided information regarding the effects of dysphagia on the everyday lives of carers, particularly in terms of meal preparation, social events and eating out, and family lifestyle. Many carers in this study were not prepared for, and had not anticipated, the severity and duration of the side effects their partner would experience and the associated impact on their own life. In response to these impacts, carers described the need to adapt to their partner's dysphagia and to negotiate a new normal. Overall the current data confirms that, as for carers of gastrostomy dependent patients, carers of other HNC patients are in need of support services to assist coping and adjustment.

Consistent with previous research, carers in this study expressed challenges with everyday activities such as meal preparation and consumption [10, 12, 24]. Patterson and colleagues [12] discussed the increased responsibility and time required to prepare a special diet which amplified the level of disruption to the carers' lives. Feelings of fear, frustration, and guilt over not being able to provide an appropriate meal were expressed by carers [12]. Similarly, carers in the current study reported feelings of frustration, anger, stress, helplessness, and guilt over the enforced changes to meal preparation. Preparing and eating meals is not only a physical activity but a profoundly social activity that solidifies social relationships [25]. It is therefore likely that a disruption to the normal mealtime activities can lead to a loss of social bonds during shared meals, impacts on relationships, and diminished social lives as noted in the current study. This was also consistent with previous studies exploring the experiences of individuals caring for a person with dysphagia with HNC who was reliant on a gastrostomy [10, 12]. This indicates that the effects of dysphagia on the carer go beyond the physical management of a gastrostomy, and result in numerous compounding negative psychosocial consequences and restrictions to their social participation, regardless of dysphagia severity.

Carers provide important social support to people with dysphagia following HNC. In order to cope with their partner's dysphagia, carers in the current study described a number of adjustments and strategies they had adopted. In particular, carers spoke about the importance of accepting a new normal and needing to adopt a number of additional roles within their family. These themes also emerged from the work by Penner and colleagues [11] who found that negotiating a new normal and negotiating changing roles were central to the experiences of carers of people with dysphagia following HNC who were dependent on a gastrostomy. In addition, carers in the present

study underestimated the severity and duration of the side effects of treatment and their partner's swallowing ability, with most commenting that adjustment to their partner's dysphagia was a long process that continued for months and years post-treatment. Generally the healthcare system assumes that carers are automatically capable of performing the carer role and therefore limited support and guidance is provided [26]. Indeed, the need for interventions to develop carers' skills in managing a gastrostomy has been recognized in the literature [10-11]. However carers in the current study felt similarly unprepared for their role in managing dysphagia even in the absence of a gastrostomy. The current data supports the need for carer specific interventions to build capacity in the multiple roles they must perform in assisting their partner with dysphagia regardless of the severity of the swallowing impairment.

These data have important implications for speech pathologists and other health professionals working to support people with dysphagia following HNC, as well as their carers. It would appear that it is important for health professionals to discuss psychological, social and practical impacts of dysphagia with patients and their carers, prior to and in early stages of treatment. Further, ongoing interaction with the carer during and after treatment will help to address their needs regarding their role in mealtime management, as a part of more holistic long-term supportive care intervention. Locher and colleagues [24] recommended the comprehensive assessment of meal preparation and consumption activities to identify potential sources of distress for carers. Carers of people with dysphagia following HNC may also benefit from global support programs that incorporate a specific focus on the challenges of meal preparation and meal consumption, as well as skill-building programs which include routine activities such as meal planning and food shopping [24].

Counselling to reduce anxiety, psychosocial interventions that teach carers how to communicate their distress associated with food and mealtimes, and problem solving or skill-building programs to improve coping skills have also been suggested to promote carers' physical and emotional well-being [7, 24, 26]. Carers in the current study also emphasised the benefit of speaking with other carers, suggesting that for some, informal support through carer support groups may be beneficial. At minimum, a process for ongoing monitoring of a carer's mental health and psychosocial adjustment, which incorporates aspects in relation to dysphagia management, is warranted. Although tools to conduct such monitoring do not yet exist, there are general measures of carer distress [27], quality of life,

and unmet needs [28], which could be utilised. Through such tools, fast efficient screening of carer needs could be implemented easily within the clinic, and allow for timely referrals to appropriate sources of information and/or support. The development of a quality of life tool which is sensitive to the issues associated with caring for relatives with dysphagia is needed. However, it is acknowledged that screening for distress related to dysphagia should be conducted in the context of a carer's global mental health status. Future research is needed to provide evidence for the strengthening of clinical referral pathways to relevant mental health professionals to address such issues.

This study has further expanded on the understanding of the effect of dysphagia following treatment for HNC on the carer. Due to the cross-sectional design of the study, the participant sample was diverse and reflected the insights of people at different points post-treatment. As such, determining when issues were of greater importance, or when adjustments occur across various time points in the post-treatment period was not possible. In order to best inform services for carers, further research which explores the experience of dysphagia impact and adjustment over time is warranted.

Conclusion

It is evident that the presence of dysphagia following treatment for HNC has the potential to impact negatively on the life of the carer. Health professionals should be able to assess the psychosocial and practical effects of dysphagia on the carer and understand their associated support needs. Timely intervention, which may include educational, psychosocial and skill building activities appears indicated to more adequately prepare and support carers of people with dysphagia following HNC. There also needs to be greater recognition of the significant role carers play in supporting people with dysphagia. They need to be trained and prepared for the important role they play and supported in that role by members of the healthcare team.

Conflict of Interest

The authors declare that they have no conflict of interest.

References

1. Cartmill B, Cornwell P, Ward E, Davidson W, Porceddu S (2012) Long-term functional outcomes and patient perspective following altered fractionation radiotherapy with concomitant boost for oropharyngeal cancer. *Dysphagia* 27:481-490. doi:10.1007/s00455-012-9394-0
2. Larsson M, Hedelin B, Athlin E (2003) Lived experiences of eating problems for patients with head and neck cancer during radiotherapy. *J Clin Nurs* 12:562–570. doi: 10.1046/j.1365-2702.2003.00751.x
3. Larsson M, Hedelin B, Athlin E (2007) Needing a hand to hold: Lived experiences during the trajectory of care for patients with head and neck cancer treated with radiotherapy. *Cancer Nurs* 30:324–334. doi:10.1097/01.NCC.0000281722.56996.07
4. McQuestion M, Fitch M, Howell D (2011) The changed meaning of food: Physical, social and emotional loss for patients having received radiation treatment for head and neck cancer. *Eur J Oncol Nurs* 15:145–151. doi:10.1016/j.ejon.2010.07.006
5. Molassiotis A, Rogers M (2013) Symptom experience and regaining normality in the first year following a diagnosis of head and neck cancer: A qualitative longitudinal study. *Palliat Supportive Care* 10 : 197–204. doi:10.1017/S147895151200020X
6. Ottosson S, Laurell G, Olsson C (2013) The experience of food, eating and meals following radiotherapy for head and neck cancer: A qualitative study. *J Clin Nurs* 22:1034–1043. doi: 10.1111/jocn.12151
7. Semple CJ, Dunwoody L, Kernohan WG, McCaughan E, Sullivan K (2008) Changes and challenges to patients' lifestyle patterns following treatment for head and neck cancer. *J Adv Nurs* 63:85–93. doi:10.1111/j.1365-2648.2008.04698.x
8. Wells M (1998) The hidden experience of radiotherapy to the head and neck: A qualitative study of patients after completion of treatment. *J Adv Nurs* 28:840–848
9. Wilson PR., Herman JA, Chubon SJ (1991) Eating strategies used by persons with head and neck cancer during and after radiotherapy. *Cancer Nurs* 14:98-104.
10. Mayre-Chilton KM, Talwar BP, Goff LM (2011) Different experiences and perspectives between head and neck cancer patients and their caregivers on their daily impact of a gastrostomy tube. *J Hum Nutr Diet* 24:449–459. doi:10.1111/j.1365-277X.2011.01165.x
11. Penner JL, McClement S, Lobchuk M, Daeninck P (2012) Family members' experiences caring for patients

- with advanced head and neck cancer receiving tube feeding: A descriptive phenomenological study. *J Pain Symptom Manag* 44:563–571. doi:10.1016/j.jpainsymman.2011.10.016
12. Patterson JM, Rapley T, Carding PN, Wilson JA, McColl E (2012) Head and neck cancer and dysphagia: Caring for carers. *Psycho-Oncol*. doi:10.1002/pon.3226
 13. Agarwal J, Dutta D, Palwe V et al (2010) Prospective subjective evaluation of swallowing function and dietary pattern in head and neck cancers treated with concomitant chemo-radiation. *J Cancer Res Ther* 6:15–21. doi:10.4103/0973-1482.63563
 14. Cartmill B, Cornwell P, Ward E, Davidson W, Porceddu S (2011) Swallowing, nutrition and patient-rated functional outcomes at 6 months following two non-surgical treatments for T1–T3 oropharyngeal cancer. *Supportive Care Cancer* 20:2073–2081. doi:10.1007/s00520-011-1316-4
 15. Feng FY, Kim HM, Lyden TH et al (2010) Intensity-modulated chemoradiotherapy aiming to reduce dysphagia in patients with oropharyngeal cancer: Clinical and functional results. *J Clin Oncol* 28:2732–2738. doi:10.1200/JCO.2009.24.6199
 16. Garcia-Peris P, Paron L, Velasco C et al (2007) Long-term prevalence of oropharyngeal dysphagia in head and neck cancer patients: Impact on quality of life. *Clini Nutri* 26:710-717. doi:10.1016/j.clnu.2007.08.006
 17. Hutcheson KA, Lewin JS (2012) Functional outcomes after chemoradiotherapy of laryngeal and pharyngeal cancers. *Curr Oncol Rep* 14:158–165. doi:10.1007/s11912-012-0216-1
 18. Nguyen NP, Frank C, Moltz CC et al (2005) Impact of dysphagia on quality of life after treatment of head-and-neck cancer. *Int J Radiat Oncol Biol Phys* 61:772–778. doi:10.1016/j.ijrobp.2004.06.017
 19. Sandelowski M (2000) Whatever happened to qualitative description? *Res in Nurs Health* 23:334-340.
 20. Patton MQ (2002) *Qualitative research and evaluation methods*. Sage Publications, California
 21. Van Manen M (1997) *Researching the lived experience: Human science for an action sensitive pedagogy*. The Althouse Press, Ontario
 22. Braun V, Clarke V (2006) Using thematic analysis in psychology. *Qual Res Psychol* 3:77–101.
 23. Strauss AL, Corbin JM (1998) *Basics of qualitative research: Techniques and procedures for developing grounded theory*. Sage Publications, California
 24. Locher JL, Robinson CO, Bailey FA, et al (2009) Disruptions in the organization of meal preparation and

consumption among older cancer patients and their family caregivers. *Psycho-Oncol* 19:967–974.

doi:10.1002/pon.1656

25. DeRenzo E (1997) Ethical considerations in the dysphagia treatment and research: secular and sacred. In: Sonies B (ed) *Dysphagia: A Continuum of Care*, Aspen Publishers, Gaithersburg, pp 91– 106
26. Glajchen M (2004) The emerging role and needs of family caregivers in cancer care. *J Supportive Oncol* 2:145–155
27. Robinson BC (1983) Validation of a caregiver strain index. *J Gerontology* 38:344-348
28. Hodgkinson K, Butow P, Hobbs KM, Hunt GE, Lo SK, Wain G (2007) Assessing unmet supportive care needs in partners of cancer survivors: The development and evaluation of the Cancer Survivors' Partners Unmet Needs measure (CaSPUN). *Psycho-Oncol* 16:805-813

Table 1 Participant characteristics (n=12)

Demographic	Parameters	Number of Participants
Age	≤65 years	11
	> 65 years	1
Gender	Male	2
	Female	10
Months since treatment	<3 months	1
	>3 months	11
Years of relationship	≤10 years	1
	> 10 years	11
Employment status	Paid employment	9
	Not in paid employment	3
Partner's Age	≤65 years	10
	> 65 years	2
Relationship	Defacto	2
	Married	10

Table 2 Theme 1: Dysphagia disrupts daily life (n=12)

Categories	Sub-Categories	n	ref	Example participant quotes
Meal preparation	Food modifications	10	55	<i>“he needs much more sauce ... and the food smaller, and he needs to drink milk with his food”</i>
	Need to think ahead with meals	7	26	<i>“mealtimes ... a lot more thought went into it”</i>
	“I’m cooking ... two meals”	6	12	<i>“I have to make an ... impaired throat meal and as much as possible a standard meal for me”</i>
	Finding the right food is difficult	5	11	<i>“The different meals, trying to find the right foods ... is complex”</i>
	It’s more intense	4	14	<i>“preparing food is more intense because you are always thinking more carefully about it”</i>
Family Life	Meal is dictated by needs of the patient	11	44	<i>“we don’t have rice anymore ... which is another favourite of the kids”</i>
	Effects on the family mealtime	7	22	<i>“He didn’t eat with us or I wasn’t going to eat at the table with him ... he’s concentrating so hard on trying to eat ... he gets really stressed out”</i>
	Relationships	5	14	<i>“it has just been quite stressful. It has probably put a lot of strain on our relationship”</i>
	Family members	3	5	<i>“[Our] granddaughter gets embarrassed, upset, and scared because of things at mealtimes”</i>
	Financial effects	1	2	<i>“the cost ...we’ve paid \$15 for two mouthfuls”</i>
Social life and eating out		10	41	<i>“going out to dinner ... it’s better not to do it now because it’s just too hard to find something that suits [partner]”</i>
Emotions	Meal preparation	9	47	<i>“I think I’m the hard done by guy, ‘cause I’m the one that has to make all the special stuff”</i>
	Aspiration and choking	3	5	<i>“That was scary [when the patient aspirated] ... because I didn’t really know what to do”</i>
	Weight Loss	3	4	<i>“constant worry ... with him losing weight”</i>

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

ref = number of times category/subcategory was mentioned

Table 3 Theme 2: Carers' make adjustments to adapt to their partner's (n=12)

Categories	Sub-Categories	n	ref	Example participant quotes
Emotional adjustment	Acceptance of a new normal	10	47	<i>"That's just what you do...that's what life is now"</i>
	Attitude	6	8	<i>"You have to be positive and find foods that they can cope with and just go with that"</i>
	Remain hopeful	3	3	<i>"that's the dream world ... that it won't be long and she'll be eating everything again"</i>
Carer takes on more roles	Feels unprepared for role	7	26	<i>"You were just sort of dropped off and all of a sudden [following treatment], right we've gotta work this lot out ourselves"</i>
	Problem solver	8	46	<i>"you gotta be able to find solutions to problems, if you're not a problem solver it would be very difficult"</i>
	Household manager "parent"	7	23	<i>"when you ... [look] after somebody over a length of time you do become the carer and you do become the parent"</i>
	Nutritionist	4	17	<i>"I wanted to make sure he was getting the right foods and that balance was right"</i>
	Chef	3	4	<i>"I do all of the cooking ... I'm normally the only one in the kitchen"</i>
	Life coach	1	5	<i>"I started to get him slowly to take control of stuff ... he'd work out his breakfast"</i>
	Practical strategies	"I go out to eat with friends"	6	11
	I gave him space	4	7	<i>"If he think he'd prefer to have a can of soup then I just leave that with him..."</i>
	Trial and error	4	7	<i>"It was just trial and error of what things didn't work"</i>
	Slowing introducing food	1	2	<i>"I just slowly brought things back in"</i>

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

ref = number of times category/subcategory was mentioned

Table 4 Theme 4: Experiences of dysphagia-related services and informal support (n=12)

Categories	n	ref	Example participant quotes
Information needs to be practical	10	28	<i>“if they could make up sheets ... from people who’d been there to say this is what didn’t work or that worked”</i>
Other carers (includes waiting room)	10	26	<i>“if you had people you could contact by email ... like a chat room sort of thing that you could post up something and someone chucks their two bobs worth to it ...”</i>
Support given throughout trajectory of care	7	23	<i>“That would have been much more helpful ... even if they [health professionals] rang me and said ‘how are you getting on’ and gave me some ideas”</i>
Information needs to be given in “patient language”	7	10	<i>“The explanations before treatment ... sore throat, you may not be able to produce saliva ... was put in a medical way but the reality is the human element ... no one tells you about that”</i>
Information should be personalised	6	13	<i>“they gave us plenty of handout sheets but they were terribly general and not specific”</i>
Roles were not clear – “their big thing was weight”	5	13	<i>“we saw the dieticians a lot ... the speech therapist... but we were never sure why because there wasn’t much to do with his speech”</i>
Support for carers	4	5	<i>“we didn’t get a lot of support through the hospital so far as food”</i>
Family	3	5	<i>“my daughter-in-law she is a great cook and she baked lots of things ... he wasn’t always able to eat them”</i>
Friends	3	4	<i>“if they’re real friends ... they will accommodate you”</i>

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

ref = number of times category/subcategory was mentioned