Clinical Nutrition 38 (2019) 1382–1389

Contents lists available at ScienceDirect

Clinical Nutrition

journal homepage: http://www.elsevier.com/locate/clnu

Original article

Patients' experience of enteral feeding following (chemo) radiotherapy for head and neck cancer: A qualitative study

Gillian F. Williams [a], [*], Helen White [b], Mehmet Sen [c], Robin J.D. Prestwich [c]

[a] Department of Nutrition and Dietetics, Leeds Cancer Centre, St James's Institute of Oncology, Leeds, UK
[b] School of Clinical & Applied Sciences, Leeds Beckett University, Leeds, UK
[c] Department of Clinical Oncology, Leeds Cancer Centre, St James's Institute of Oncology, Leeds, UK

ARTICLE INFO

Article history:
Received 6 December 2017
Accepted 8 June 2018

Keywords:
Head and neck cancer
Enteral feeding
(Chemo) radiotherapy
Gastrostomy tube
Nasogastric tube
Qualitative research

SUMMARY

Background & aims: Enteral feeding is commonly required during radiotherapy treatment for head and neck cancer. Only limited qualitative research into head and neck cancer patients' experiences of enteral tube feeding has been undertaken. The aim of this qualitative study was to evaluate patients' experiences of EF and the surrounding decision making process.
Methods: Semi-structured, face-to face interviews were conducted with ten patients who had completed (chemo)radiotherapy/radiotherapy for head and neck cancer at a cancer centre in the North of England. Interviews were recorded, transcribed verbatim and analysed qualitatively using Thematic Analysis.
Results: Participants described the restrictions on daily living caused by enteral feeding tubes and enteral feeding. Despite these restrictions, participants recognised the value of the enteral feeding tube including its role in their survival and the importance of their involvement in decision making. Participants described coping mechanisms used to deal with the difficulties associated with enteral feeding.
Conclusions: The results of this study provide a unique qualitative insight into the lived experiences of H&N cancer patients managed with enteral feeding and the impact of the decision making process. The results have relevance for professionals supporting this patient group with enteral feeding.

1. Introduction

Two main approaches can be used to provide enteral feeding (EF) for head and neck (H&N) cancer patients during definitive or adjuvant (chemo)radiotherapy: a reactive tube insertion (often with a nasogastric tube (NGT)) placed if and when required; or a prophylactic tube (often a gastrostomy tube (G-tube)) placed prior to treatment. There is on-going debate over the selection of EF routes and a recent Cochrane Review concluded that the optimal method of EF has yet to be established [1–3].

Quantitative studies have indicated that the use of prophylactic G-tubes is associated with reduced weight loss, fewer hospital admissions and fewer radiotherapy delays [4–7]. Prospective and retrospective studies indicate that G-tubes may have potential advantages over NGTs through enhanced patient mobility and improved quality of life (QOL) [8,9]. NGTs are associated with increased discomfort, increased risk of tube displacement and blockage when compared with Percutaneous Endoscopic Gastrostomy (PEG) in patients with H&N Cancer [9]. However, disadvantages of prophylactic G-tube placement prior to treatment include the possibility that EF will not be required and a small risk of tube insertion-related morbidity. In additions several studies have reported a significantly increased duration of EF with prophylactic G-tubes compared with a reactive approach [7,10,11] with uncertainty regarding a negative influence of G-tubes upon long term EF dependency rates [1,7,12]. Some studies have suggested a potential detrimental impact of prophylactic G-tubes upon long term swallow function [13–15].

Prior randomised trials comparing routes of EF have failed to complete recruitment [1,16]. With on-going controversy, the choice of route for EF is regarded as an area of clinical equipoise [1] and there is no consensus guidance [1–3].

To date, research investigating quality of life (QOL) in H&N patients with EF tubes have mainly used quantitative measures to describe QOL outcomes [17]. Qualitative studies can provide an

---

[*] Corresponding author. Department of Dietetics – Head & Neck Oncology Office, Rehabilitation Unit, Level 1, Leeds Cancer Centre, St James's Institute of Oncology, Beckett St., Leeds LS9 7TF, UK.

E-mail addresses: Gillian.Williams16@nhs.net (G.F. Williams), H.White@leedsbeckett.ac.uk (H. White), Mehmet.sen@nhs.net (M. Sen), Robin.Prestwich@nhs.net (R.J.D. Prestwich).

https://doi.org/10.1016/j.clnu.2018.06.958
0261-5614/

invaluable insight into patients' experiences. A number of qualitative studies have explored only the use of PEG but none have also considered the experiences of those patients who are managed with NGTs, and the decision-making processes involved in the selection of route [18,19].

The aim of this qualitative study was to evaluate patients' experiences of EF and the surrounding decision making process.

2. Materials and methods

2.1. Ethical approval

This prospective study was approved by West of Scotland NHS Research Ethics Committee (Reference 14/WS/1072).

2.2. Participants and setting

Participants were recruited September 2014–February 2015, during radiotherapy outpatient appointments at a tertiary cancer centre. Purposive sampling was used to identify participants with NGTs and G-tubes in-situ, with the intention to recruit until data saturation was achieved.

Eligibility criteria includes males or females aged ≥18 years, pathologically proven H&N cancer, completed definitive or adjuvant (chemo)radiotherapy with curative intent, received EF. Exclusion criteria included patients receiving in-patient only administration of EF, patients receiving unilateral radiotherapy, T1/T2 Glottic tumours, patients requiring other methods of artificial nutrition (total parenteral nutrition, nasojejunal or jejunostomy feeding) and patients unable to vocalise or unable to give written consent.

2.3. Institutional approach to enteral feeding

Routine institutional practice for pre-treatment care for patients included consultation with an oncologist with consideration of the likelihood of need for EF during and after treatment. If indicated, options for prophylactic gastrostomy placement or reactive NG tube insertion were discussed with the patient with subsequent Dietetic assessments considering the practical aspects of EF and patient preference for EF route.

2.4. Data collection

Semi-structured face-to-face interviews were selected to address the research aims and objectives. An Interview Guide was devised and utilised. The guide was produced to consider themes which had been generated through the review of literature and through the researcher's clinical experience within the field. There was scope within the interview for participants to raise unanticipated issues and flexibility to follow such leads. Interviews were conducted by the principal investigator and were audio-recorded.

2.5. Data analysis

Data analysis was sequential. The principal investigator transcribed the participant audio-interviews, verbatim, into transcript which was analysed using Thematic Analysis (TA). In the second stage initial codes were generated. The third stage entailed refocussing of these codes which were combined to take account of repetition, enhanced emotions and impact on life to form Organising Themes and Overarching Global Themes. The interview transcripts and themes generated were reviewed by the co-author (H. White) to ensure that they were grounded in the original data set. Finally, respondent validation was invited to provide participant feedback on the researchers' interpretations of their responses. The final set of themes then emerged.

TA was selected as the intention of the analysis was to focus on patterned meaning across the data set (i.e. patterns of experiences with NGT and gastrostomy tubes (G-tube)).

3. Results

Data saturation was reached within the ten interviews. The eligibility and enrolment of participants is shown in Fig. 1.

Characteristics of the sample are shown in Table 1. A choice of enteral feeding tube was offered to 9 (90%) participants, which was standard institutional practice during the period of the study in the absence of medical factors which would suggest preference for one route. Interviews were conducted a median of 26 days after final radiation treatment (range 3–231 days).

Thematic analysis identified seven key themes (with associated sub-themes) related to experiences of enteral feeding (EF) tubes and EF itself:

1. The Battle to Eat;
2. Fear;
3. Restricted Life;
4. Coping Mechanisms;
5. "It's our Body" (Choice);
6. Support; and
7. Value of the Tube.

Each theme is described and a range of participant quotations are included in Table 2.

1. The Battle to Eat

Participants with both prophylactic G-tube and reactive NGTs described starting treatment with hope that they would not require enteral feeding and that they had underestimated how difficult maintaining oral intake would be during treatment.

Participants experienced many nutrition-related concerns during treatment that influenced their decision to accept a medical/dietetic recommendation for EF. They described a battle and worry over physical symptoms (weight loss, dysphagia, pain and taste disturbances) as the key reason for accepting the recommendation to commence EF during treatment.

Some participant responses indicated that they viewed starting EF as an admission of defeat, describing feelings of disappointment and failure. In contrast, others found it easier to accept EF and viewed the tube as a necessity. Importantly participants discussed their motivation to set goals and to progress with eating, with a view to avoiding dependence on their tube.

2. Fear

Fear and worry were common among participants. Their concerns were focused on initial tube insertion, removal of G-tube, accidental tube displacement, nutritional decline during treatment and the risk of EF tube dependence. Additionally participants with NGTs experienced anxiety over public reaction which influenced their confidence in socialising.

Participants described the presence and insertion of a NGT as uncomfortable, whilst in comparison; participants described varying experienced of G-tube insertion ranging from those who found the procedure easy, to those who described significant pain and discomfort.

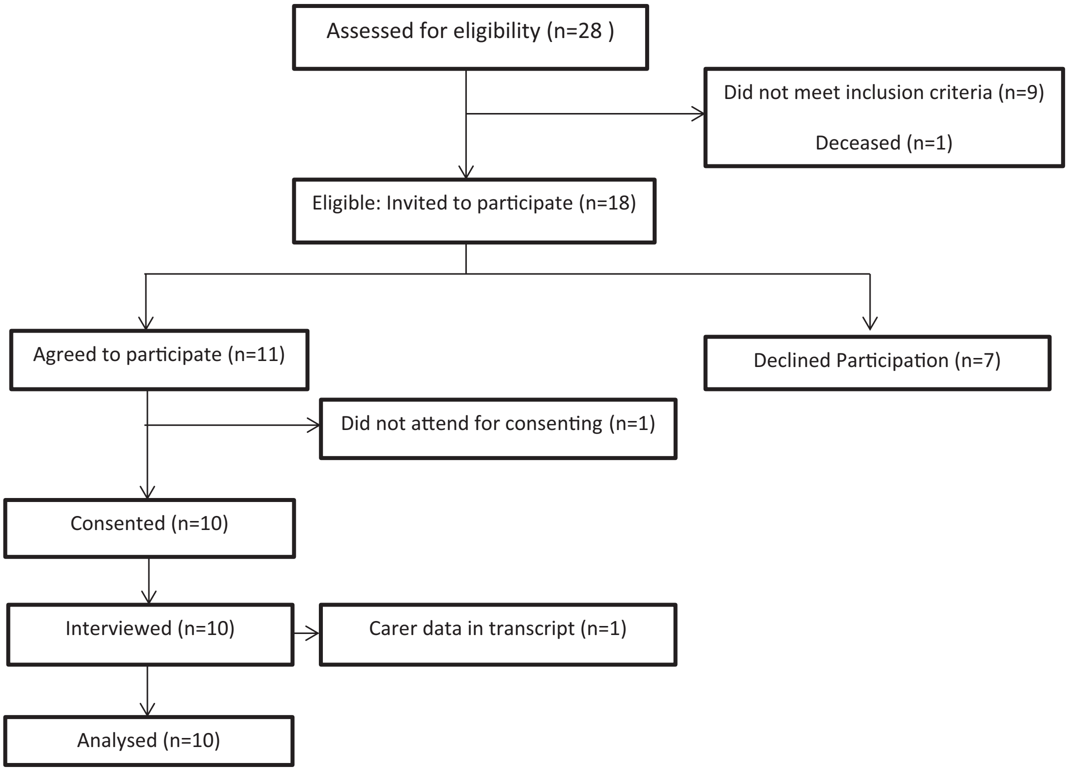

Fig. 1. Enrolment and eligibility of study participants.

3. Restricted Life

Participants with both NGT and G-tubes recalled how their everyday lives were affected by the tube and the restrictions it placed on them.

Going out:

Those participants who described restrictions around going out spoke of the reaction of members of the public to the EF tube and about the practicalities of using the EF tube when away from home.

Participants with NGTs described the reaction they received from members of the public, commonly describing people (often children) staring. The experiences of those participants with G-tube were in stark contrast to the experiences of participants with NGTs, reporting that discreet nature of the G-tube actually *enabled them* to continue to go out.

Missing eating:

Missing eating and craving for food was a particular challenge for many participants. This was reinforced at family meal-times, when preparing food for other members of the family and when exposed to food on television and in magazines.

Enteral Feeding Regimen Restrictions:

There was much discussion about the restrictions caused by the EF regimen itself. For some participants, the EF regimen was particularly restrictive and time consuming. Participants gave consideration to bolus and overnight pump regimens to reduce the burden of the EF regimen.

Unlike the many disadvantages that participants considered to be associated with NGTs, those participants with G-tubes considered the restrictions of the EF regimen the main disadvantage associated with the tube.

Activities of Daily Living:

EF tubes placed restrictions on hobbies, holiday plans, physical activity and return to work.

Relationships:

Although only one of the participants identified that EF tubes had affected relationships within her family, the significance of this data warrants its inclusion. This participant talked about how her NGT had affected her relationship with her grand-child and how, later in her treatment, her G-tube affected intimacy in her relationship with her husband.

4. Coping Mechanisms

In order to manage the difficulties associated with EF tubes and EF, participants adopted specific coping mechanisms. Participants who coped better with their EF tube had many of these mechanisms in place. Those participants struggled to cope with their tubes it appeared to lack/have lost of one of these mechanisms.

Reducing Burden:

Attempts to reduce burden both on family members and on healthcare professionals were used as a coping mechanism by some participants. Participants described a personal responsibility for managing EF and the care of their EF tube. This also extended to participant attempts to reduce financial burden to the NHS by minimising the waste of feed and equipment.

Table 1
Demographics of participants in the study (N = 10).

Characteristic	Value (percentage %)
Age (years)	
<40	0 (0)
40–49	3 (30)
50–59	5 (50)
60–69	2 (20)
Median age, years (range)	54 (43–65)
Sex	
Male	8 (80)
Female	2 (20)
Marital status	
Married/Cohabiting	6 (60)
Single, divorced, widowed	4 (40)
Cancer diagnosis	
Tonsil	6 (60)
Base of Tongue	2 (20)
Lateral Tongue	1 (10)
Glottis	1 (10)
Tumour stage	
T2	1 (10)
T3	1 (10)
T4	8 (80)
Nodal stage	
N0	3 (30)
N1	2 (20)
N2b	2 (20)
N2c	3 (30)
Treatment modality	
Definitive concurrent chemoradiotherapy	9 (90)
Adjuvant radiotherapy	1 (10)
Elapsed time since final radiation treatment (weeks)	
0–12	9 (90)
13–24	0 (0)
25–36	1 (10)
Enteral feeding tube type	
Gastrostomy	7 (70)
Radiologically Inserted Gastrostomy	6 (60)
Percutaneous Endoscopic Gastrostomy	1 (10)
Nasogastric	3 (30)
Offered choice of tube	
Yes	9 (90)
No	1 (10)
Enteral feeding tube in situ at time of interview	
Gastrostomy	5 (50)
Nasogastric	3 (30)
Nil	2 (20)

Living a normal life:

Participants coped better if they were able to continue living a *normal life*. Those with G-tubes reported this was possible due to the privacy and discreetness offered by the G-tube.

Downward social comparison:

Some participants appeared to use downward comparison as a coping strategy – comparing themselves to others whose problems were worse than their own, enabling them to view their own situation in a more positive light.

Maintaining hope:

Participants relied on hope as a coping mechanism at different points in treatment. Pre-treatment they hoped that they would be able to continue to maintain oral intake during treatment and would not require EF. When this hope was lost and they realised that they did require EF they did not cope well. Participants described hope that EF would be short-term and that they would resume normal eating.

Developing resilience:

The level of resilience varied between participants. Those participants who had NGTs showed significant resilience although it is not clear whether their resilient characteristics were the reason they felt able to cope with an NGT or if they developed resilience after having the NGT.

When considering attitudes of others, male participants with NGTs appeared to show more resilience than female participants.

Having control:

Personal control appeared to have been significant in how participants coped with having an EF tube and with EF. Participants coped well if they had control over the choice of EF tube; the timing of the commencement of EF; and their EF regimen and tube care. Most did describe control over these aspects during their treatment and, as a result, appeared to cope well.

5. “It's our Body” – Having a choice

Discussion around choice focused on the selection of feeding tube, the timing of NGT insertion and the timing of the commencement of EF via the G-tube.

Participants commonly reported that they felt they had been included in the decision-making process at pre-treatment and that *they* had made the final decision regarding the choice of tube. Most acknowledged that this was important and the involvement in this decision may contribute to the positivity participants reported regarding the value of their tube (see theme ‘Value’).

All of the participants described strong rationale for their selection of EF tube. Participants who chose prophylactic G-tubes believed they would not tolerate the physical presence of the NGT nor would they be able to cope with the social stigma associated with it.

Participants who declined a G-tube before treatment reported the risks and apprehension associated with a surgical procedure and the hope that they would not require EF as rationale for their decision.

6. Receiving support

All participants felt well supported on both a practical and emotional level. Participants valued information as a form of support and received it from sources within the healthcare setting, via internet research and through information sharing with fellow patients.

There was divided opinion on the role of the family in support with EF tubes and with EF. Only one participant described a reliance on her husband to support her with EF. Other participants involved family members as a way of supporting that *family member*.

7. Perceived value of the tube

Although most participants discussed restrictions in lifestyle caused by their EF tube, all recognised the value the EF tube offered. Participants valued their tubes in practical terms (nutrition, fluid and medication provision) and in supporting recovery. They also acknowledged the emotional/psychological benefits of an EF tube including making life easier; providing a *relief* from worry and the pain of eating; and providing *reassurance*.

Because the value of the EF tube was recognised, all participants recommended that future patients have EF tubes placed if advised, with only one participant recommending the alternative tube (G-tube) to the one he had decided on (NGT).

Table 2
Examples of participant quotations illustrating each theme.

Theme	Sub Theme	Examples of participant quotes
The Battle to Eat		**M4**: *"My tongue was so sensitive it was like eating raw chillies…my gums were all white, my tongue was white, anything that touched it, it was just stinging…I thought "no I'm not gonna do this anymore, I'm gonna do what xxxx said and use the tube".* **M7**: *"I battled and tried [with eating], but I was just failing miserably…yeah if you've set your mind to "well I'm not having that [nasogastric tube]" and you do, well then you've failed haven't you then…I didn't want it doing but I had to accept that…my weight's going to drop to a dangerous level, so I had to do it".*
Fear	Insertion/Procedure	**M3**: *"I were expecting it, you still get apprehensive…obviously first time it's awkward…it's uncomfortable* [*NGT*]*…… once it's in it's a relief… it's the worry like if you're choking".* **F2**: "*I didn't like it* [*NGT*]*…I could feel it in my, in my throat all the time and it were making me gip*" **M2**: *"I actually had the tube* [*NGT*] *put in only two and a half hours before* [*RIG*] *but I found the two and a half hours horrendous, absolutely horrendous".* **F2**: *"I was very nervous about having it* [*RIG*] *done, it didn't hurt me…I could feel it but it didn't hurt…I know this might sound silly but I found it* [*RIG*]*…a lot better than when they were putting that one down me nose, I didn't like that at all…I did find that better when they put it in my stomach".*
	Tube displacement	**M8**: "*I find that I always put tape on to hold it* [*G-tube*] *in place because I'm always wary that it's gonna pull out…you know you might catch it on your clothes or you might catch it turning over in bed…So I tend to tape… a bit of peace of mind".* **M6**: *"I'm always aware that the [NG] tube is there, you know and what could happen…while I'm asleep I could actually pull the tube straight out…one of the reasons that I would think about, and suggest to other people that they take the stomach one".*
Restricted Life	Going out/ Body Image	**F1**: *"I didn't want to go out at all* [*NGT*] *…I wouldn't go to the pub, I wouldn't go to the cafe, I wouldn't go shopping…I like me bingo on a Thursday and I stopped going there".* **M2**: "*When I went into the treatment…I decided I wanted to lead as normal a life as possible, for as long as I could until I couldn't…so we do a lot of socialising…and I thought "if I have the RIG fitted…it's not visible by anybody, nobody will know it's there, if I have a tube sticking out of me nose, everybody's gonna know it's there"* **F1**: "*I went shopping once, and a little one, he were about three [years old], "Oh look mummy, that lady's got a worm out of her mouth, out of her nose and she's got a hole in her neck"…It were upsetting, I couldn't wait to get home"* **F1**: "*Everybody used to stare at me which made me feel uncomfortable more, so that's why I wanted it in me belly".* **M2**: *"If somebody asked me about it* [*RIG*]*…, I would just tell them my personal experience…I continued working in my garage, going shopping, going out to the pub, going out for a meal even though you know I didn't eat much, we were still going out, I didn't want a tube sticking out me nose"*
	Missing Eating	**M7**: *"I keep watching programmes during the day on cooking, every time I see one I want to eat something"* **F2**: *"I just can't imagine never eating again, that bit's hard…I make my husband teas now…like yesterday…I made him a leek and potato pie and I thought "oh I could just right eat that"*
	Enteral feeding regimen restrictions	**M1**: *"The only drawback from using* [*G-tube*]*,that I feel is the amount of time it takes to absorb the right amount… So to sit on there for ten hours is very onerous…I found the ten hours quite tedious"* **M2**: *"The only downside, I would say is, is the volume of stuff you've got to get in…Lansoprazole tablets, anti-sickness tablets, another chemo anti-sickness tablet, three types of pain killers…then you've got to get some milkshakes down, so you've got that lot three times a day which is…twenty one syringes, plus you've got another twelve syringes of food, that's twenty three syringes, you should really have some water in between each…plus then you've got some normal hydration you want…it is very time consuming"*
	Activities of Daily Living	**M8**: "*Even though it's probably ok…I wouldn't go to a gym, I wouldn't play football, I wouldn't have a knock about with my friends, you know because I'd be scared"* **F2**: *"We were actually thinking about going abroad but…we didn't go…we cancelled…the tube were part of it…it's a lot of hassle… …you've got to fill the form in, send it off…you've got to give them either six or eight weeks' notice… I…had to ring the hotel and see if they would accept [the feed and equipment]…at the time it was too much hassle…we are going to try it but, when, I don't know…I'd love to really go abroad again".* **F2**: *"Going back to work…it involves heavy lifting…and I don't know whether with that [G-tube]… I think this [G-tube]…is going to be a draw-back having my job"*
	Relationships	**Husband of F1**: *"He's not two yet [Grandchild] and so you can imagine he's hands all over the place, so it were like, basically keep away from her face".* **F1**: *"He couldn't cuddle me [Husband]".*
Coping Mechanisms	Reducing Burden	**M1**: *"I wouldn't be reliant on anybody…everybody's busy, my family's busy and I didn't want them messing about…luckily I was able to do it all myself".* **M7**: *"I've got all this food left and my old machine…obviously she wants you on their feed straight-away so I said "well I'm not doing that because that's cost money"… it's the NHS int (sic) it…you can't be wasting stuff".*
	Living a Normal Life	**F1**: *"I wanted it done [G-tube]…and then I could start living again…I go to the café now, to t'pub, play bingo".* **M1**: *"You've got a little bit of hardware on the outside with the tube and I found…then it doesn't impinge on anything, it doesn't protrude as such, you can't see it really from the outside, it's not as though it's obvious…so that's the dignity part I suppose".*
	Downward Social Comparison	**M1**: *"Elderly people may need help and support to even start the feeding process, where…I'm a bit younger, fairly mobile, reasonably fit, got a family around me…very lucky because I've seen some people here that come on their own, possibly feed themselves and if they are having to do that all on their own…isn't going to be very pleasant".* **M2**: *"Without being disrespectful I don't know how an older person might've coped with it [EF pump]…I could just go You Tube, I could have a look at it, I could go on the website, I knew there was a phone number there…but how somebody older would have coped with it I don't know".*
	Hope/Loss of Hope	**M1**: *"Dr X advised that at least 80% of patients do have to use it [gastrostomy], I thought I may be in the lucky 20% but I wasn't".* **M7**: *"I just decided it wasn't going to happen [NGT insertion], and that's why, as you know I was very upset when I couldn't do that".* **F2**: *"Last week…he told me that it [G-tube] was going to be permanent…that's a bit hard…I just can't imagine never eating again, that bit's hard".*

	Resilience	**M6**: *"I've always been a person that "you take me as I am" and…it's never stopped me going out…doing whatever I want to do, or talk to people. People looking at me, never bothered me…'cause I know why it's there…so if other people want to know they can ask me can't they?"*
	Control	**M2**: *"Just my own decision, I spoke to me family and they said "yeah we agree … but it's still my choice, you know if they'd disagreed I wouldn't have changed my mind"* ***M5***: *"I could have had [Support with enteral feed administration], but I didn't, you know, I just did it on my own, I just wanted some time on me own to work it out"*
"It's our Body" — Choice		**F1**:*"It's what's best for the patient, it's what the patient wants, not what the doctors want…at the end of the day it's our body, it's not their body"*. **M2**: *"You're going out…on a Saturday night, there's one hundred and fifty people in a pub and you've got a tube sticking out of your nose, it just wasn't for me"*.
Support		**M6**: *"When I went in to have me teeth extracting I bumped into another guy that had just had the same sort of cancer and…he had the stomach one done [G-tube] and it were a God's Gift, you know a blessing for him at that particular time so that's… when… I had discussion with wife I thought…that might be a better option for me before the treatment starts"*. **M2**:*"So I've got the pamphlets, I've got the phone numbers I know it's there if I need it but I've not needed it…and everybody, the nurses, the nutritionists, everybody, the external people…I think the tie between everybody is really good and when somebody's said they're going to ring me they've rung me, when somebody's said that if there's a problem you ring this number there will be somebody there it's always been there, I don't think it could be improved"*. **M6**: *"[my] wife likes to have a go now and again she says she feel lonely, feels left out"* **F1**; *"We got the kids involved… For them so they can understand and all. XXX he's ten…like the machine on a night-time he'd set it all up for me…everything"*.
Value of the tube		**M2**: *"Just relief really that I'm getting something into me, you know nutrition, because if I didn't have this, I don't know, what would you do?"* **M8**: *"Medication and food can go down, which was a big relief because I were losing weight…because I couldn't eat…and me weight's coming back up"*. **M5**: *"Getting me nourishment, well that's the main thing because they didn't want me to lose weight …keep me nourishment in to me to help me get better"*. **M4**: *"It's like everything else it's* [G-tube] *just a backup, it's like what they say on the TV "if you're going out in the snow and the weather always carry a spade in the back of the car, a blanket" because you don't know if you're ever going to need it…I don't regret having it* [G-tube] *put into my stomach because it could have been a life saver"*. **M8**: *"I'd have either one* [G-tube or NGT] *if anybody was starting from the beginning, don't say "no" to either because you will need one or the other…don't refuse, because you'll be stuck"*.

Italics represent direct quotations, ellipses (…) depict omitted words/phrases, and brackets [ ] denote words included for clarification.

4. Discussion

This is the first qualitative study in patients with Head and neck cancer that explores the experience and decision making process associated with the choice of NGT or G-tube placement. Participants placed high importance on their ability to be given a personal choice and their own involvement in the selection of EF route. The sense of control gained through ownership of decision making enabled them to cope with difficulties and restrictions encountered not only with the EF tube but also with EF itself. Participants had strong views on the suitability of the EF tube types for their own situation and these were key factors in their decision e.g. social stigma associated with a NGT and the perceived greater significance of G-tube insertion.

The sense of '*inclusion*' in the decision making for EF tubes reported by participants is in contrast to the '*exclusion*' reported by Brotherton & Abbott [20]. These differences may be as a result of recommendations within H&N cancer that have sought a more standardised approach to care. UK guidance documentation 'Improving outcomes in Head and Neck Cancer' advocates a coherent approach to patient-centred care achieved through the presence of a named principal clinician and structured multidisciplinary management [21].

All participants hoped they would not require EF during treatment (even those who had opted for G-tube insertion before commencement of treatment). Contrasting views, encompassing a sense of failure and also relief, were evident when participants described the point when enteral feeding was commenced.

Fear was a predominant emotion associated with both NGT and G-tube insertion and with the risk of accidental NGT and G-tube displacement. Participants provided detailed descriptions of the restrictions they encountered as part of daily living with an EF tube, although participants with a G-tube reported that this route reduced restrictions and enabled them to continue leading a more normal life. All participants struggled both with food cravings and also with missing eating and described their aim to discontinue EF and return to normal eating. This supports previous findings in those undergoing enteral tube feeding at home [22].

Participants had, or had developed a number of coping mechanisms which enabled them to deal with the EF tube. These included resilience to social stigma, hope for a short-term requirement for EF and a control over the care of the EF tube and the administration of enteral feed.

Resilience and its role in coping with cancer is an emerging area of research although largely studied in colorectal and breast cancer. Research suggests that there is lower emotional distress and increased resilience with increasing age [23] and in male cancer patients [24]. The findings of this study showed that male participants had a higher resilience related to their coping with an EF tube compared to female participants, although these conclusions are limited by sample size.

One of the most significant findings was that, despite the challenges associated with their tubes, participants valued them highly both in terms of providing relief from worry about declining nutritional status and from the pain of eating. In line with previous research findings [19] they also strongly believed in the benefits of EF in terms of survival and in supporting recovery.

In the current study participants readily offered suggestions to support other patients in the decision-making process for EF tubes, indicating the value that patients placed on their interaction with and provision of support for other patients. This is corroborated by a previous qualitative study in head and neck cancer [25]. It follows that healthcare professionals should recognise the importance of peer support in H&N cancer and should develop structured peer support as a method of assisting with decisions on EF.

The positive value associated with EF tubes found in this study – and that of Kwong et al. [19] – contradicts the largely negative impact of PEG tubes described by participants in previous studies by Brotherton et al. [26] and Roberge et al. [27]. These differences may in part be explained by the level of support provided by the healthcare organisations involved which, in this study, was highly valued by participants. Methodological differences may have also contributed; the semi-structured interviews employed in the current study enabled participants to express positive or neutral experiences not captured by the structured, closed questioning used by others [27].

The majority of participants reported a high level of independence and a reluctance to ask family and friends for support with EF. This contrasts with a previous study by Mayre-Chilton et al. [28] and appears to be related to the ability to maintain personal control over this element of their lives as a coping strategy and an attempt to reduce the burden on family members. Interestingly, this research uncovered a new concept, that some participants only considered family members'/caregivers' involvement with their EF as a mechanism of support for *family members* and not for themself.

Participants placed great importance on the provision of nutritional support throughout treatment and their subsequent recovery, commonly reporting concerns regarding weight loss prior to commencement of EF and the positive association between weight maintenance (or weight gain) and recovery after it was established. This may be due to the intensive nutrition counselling participants received during their radiotherapy treatment (patients standardly received dietetic review once or twice per week during radiotherapy and regular dietetic review post-treatment). The findings support the specialist role of the Dietitian during radiotherapy and supports the results of Isenring et al. [29] who reported that oncology outpatients receiving nutrition intervention (rather than standard care) during radiotherapy treatment perceived nutrition being of higher importance to their health.

It is recognised that this study does not fully address the experiences of EF tubes in either the younger or more elderly population, in addition to limited representation of female gender. Gender-specific experiences were identified within the study which may suggest that some experiences of EF tubes and EF may be gender specific. While this was not reported by Kwong et al. [19] further exploration is needed.

5. Conclusions

These findings provide a unique qualitative insight into the lived experiences of H&N cancer patients managed with EF. Patients highly valued inclusion and personal choice in the pre-treatment decision making process. As part of this process it is important patients are prepared for the likelihood of EF so that it is not subsequently perceived as a failure on their part. Patients frequently offered suggestions based around peer-support for decision making and coping mechanisms during EF; future developments could increasingly look to integrate peer-support into EF practices.

A patient centred approach including informed decision making, underpinned by an understanding of health literacy, peer support and strategies to improve resilience, should be considered for all those who require enteral tube feeding.

Funding sources

This research did not receive any specific grant from funding agencies in the public, commercial or non-profit sector.

Statement of authorship

G. Williams is the principal investigator and independently designed, conducted and wrote up the study with the support of H. White as academic supervisor. H. White, R. Prestwich and M. Sen critically reviewed the article.

Conflicts of interest

All authors confirm there were no conflicts of interest.

References

[1] Paleri V, Patterson J. Use of gastrostomy in head and neck cancer: a systematic review to identify areas for future research. Clin Otolaryngol 2010;35(3):177–89.

[2] Moor JW, Patterson J, Kelly C, Paleri V. Prophylactic gastrostomy before chemoradiation in advanced head and neck cancer: a multiprofessional web-based survey to identify current practice and to analyse decision making. Clin Oncol (R Coll Radiol) 2010;22(3):192–8.

[3] Nugent B, Lewis S, O'Sullivan JM. Enteral feeding methods for nutritional management in patients with head and neck cancers being treated with radiotherapy and/or chemotherapy. Cochrane Database Syst Rev 2010;2013(1). https://doi.org/10.1002/14651858.CD007904.pub3. Art. No.: CD007904.

[4] Nguyen NP, North D, Smith HJ, Dutta S, Alfieri A, Karlsson U, et al. Safety and effectiveness of prophylactic gastrostomy tubes in patients undergoing chemoradiation. Surg Oncol 2006;15(4):199–203.

[5] Lee JH, Machtay M, Unger LD, Weinstein GS, Weber RS, Chalian AA. Prophylactic gastrostomy tubes in patients undergoing intensive irradiation for cancer of the head and neck. Arch Otolaryngol 1998;124(8):871–5.

[6] Wiggenraad RCJ, Flierman L, Goosens A, Brand R, Verschuur HP, Croll GA. Prophylactic gastrostomy placement and early tube feeding may limit loss of weight during chemoradiotherapy for advanced head and neck cancer, a preliminary study. Clin Otolaryngol 2007;32:384–90.

[7] Williams GF, Teo MT, Sen M, Dyker KE, Coyle C, Prestwich RJ. Enteral feeding outcomes after chemoradiotherapy for oropharynx cancer: a role for a prophylactic gastrostomy? Oral Oncol 2012;48(5):434–40.

[8] Gibson S, Wenig BL. Percutaneous endoscopic gastrostomy in the management of head and neck carcinoma. Laryngoscope 1992;102(9):977–80.

[9] Lees J. Nasogastric and percutaneous endoscopic gastrostomy feeding in head and neck cancer patients receiving radiotherapy treatment at a regional oncology unit: a two year study. Eur J Cancer Care 1997;6:45–9.

[10] Chen AM, Li BQ, Lau DH, Farwell DG, Luu Q, Stuart K, et al. Evaluating the role of prophylactic gastrostomy tube placement prior to definitive chemoradiotherapy for head and neck cancer. Int J Radiat Oncol Biol Phys 2010;78(4):1026–32.

[11] Mekhail TM, Adelstein DJ, Rybicki LA, Larto MA, Saxton JP, Lavertu P. Enteral nutrition during the treatment of head and neck carcinoma: is a percutaneous endoscopic tube preferable to a nasogastric tube? Cancer 2001;91(9):1785–90.

[12] Koyfman Shlomo A, Adelstein David J. Enteral feeding tubes in patients undergoing definitive chemoradiation therapy for head-and-neck cancer: a critical review. Int J Radiat Oncol Biol Phys 2012;84(3):581–9.

[13] Sethugavalar B, Teo MT, Buchan C, Ermis E, Williams GF, Sen M, et al. Impact of prophylactic gastrostomy or reactive NG tube upon patient-reported long term swallow function following chemoradiotherapy for oropharyngeal carcinoma: a matched pair analysis. Oral Oncol 2016;59:80–5.

[14] Goff D, Coward S, Fitzgerald A, Paleri V, Moor JW, Patterson JM. Swallowing outcomes for patients with oropharyngeal squamous cell carcinoma treated with primary (chemo) radiation therapy receiving either prophylactic gastrostomy or reactive nasogastric tube: a prospective cohort study. Clin Otolaryngol 2017;42(6):1135–40.

[15] Oozeer NB, Corsar K, Glore RJ, Penney S, Patterson J, Paleri V. The impact of enteral feeding route on patient-reported long term swallowing outcome after chemoradiation for head and neck cancer. Oral Oncol 2011;47:980–3.

[16] Corry J, Poon W, McPhee N, Milner AD, Cruickshank D, Poceddu SV. Prospective study of percutaneous endoscopic gastrostomy versus nasogastric tubes for enteral feeding in patients with head and neck cancer undergoing (chemo) radiation. Head Neck 2009;31(7):867–76.

[17] Bjordal K, Hammerlid E, Ahlner-Elmqvist M, de Graeff A, Boysen M, Evensen JF, et al. Quality of life in head and neck cancer patients: validation of the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-H&N35. J Clin Oncol 1999;17:1008–19.

[18] Osborne JB, Collin LA, Posluns EC, Stokes EJ, Vandenbussche KA. The experience of head and neck cancer patients with a percutaneous endoscopic gastrostomy tube at a Canadian Cancer Center. Nutr Clin Pract 2012;27:661–8.

[19] Kwong JPY, Stokes EJ, Posluns EC, Fitch MI, McAndrew A, Vandenbussche KA. The experiences of patients with advanced head and neck cancer with a percutaneous endoscopic gastrostomy tube: a qualitative descriptive study. Nutr Clin Pract 2014;29:526–33.

[20] Brotherton AM, Abbott J. Clinical decision making and the provision of information in PEG feeding: an exploration of patients and their carers' perceptions. J Hum Nutr Diet 2009;22:302–9.
[21] National Institute for Health and Clinical Excellence. Guidance on cancer services: improving outcomes in head and neck cancers. London: NICE; 2004.
[22] Bjuresater K, Larsson M, Athlin E. Patients' experience of home enteral tube feeding (HETF) – a qualitative study. J Res Nurs 2015;20(7):552–65.
[23] Cohen M, Basiliansky S, Beny A. The association of resilience and age in individuals with colorectal cancer: an exploratory cross-sectional study. J Geriatr Oncol 2014;5(1):33–9.
[24] Schmidt CE, Bestmann B, Kuchler T, Longo WE, Krmer B. Impact of age on quality of life in patients with rectal cancer. World J Surg 2005;29:190–7.
[25] Egestad H. The significance of fellow patients for head and neck cancer patients in the radiation treatment period. Eur J Oncol Nurs 2013;17(5):618–24.
[26] Brotherton A, Abbott J, Aggett P. The impact of percutaneous endoscopic gastrostomy feeding upon daily life in adults. J Hum Nutr Diet 2006;19:355–67.
[27] Roberge C, Tran M, Massoud C, Poiree B, Duval N, Damecour E, et al. Quality of life and home enteral tube feeding; a French prospective study in patients with head and neck or oesophageal cancer. Br J Cancer 2000;82:263–9.
[28] Mayre-Chilton KM, Talwar BP, Goff LM. 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 2011;24:449–59.
[29] Isenring E, Capra S, Bauer J. Patient satisfaction is rated higher by radiation oncology outpatients receiving nutrition intervention compared with usual care. J Hum Nutr Diet 2004;17:145–52.