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The patient experience of having a feeding tube during treatment for head and neck cancer: A systematic literature review

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SUMMARY

Background and aims: Patients undergoing treatment for head and neck cancer (HNC) can experience severe weight loss, malnutrition and dehydration which can cause treatment delays. Enteral feeding can reduce the risk of these. However, the use of feeding tubes (FT), including FT type and placement timing is debated. This paper aimed to describe the patient experience of having a FT during treatment for HNC.
Methods: A systematic literature review of qualitative studies was undertaken in the databases Web of Science, CINAHL, Scopus and Science Direct using Prospero and Joanna Brigg's Institute guidelines.
Results: Nine studies were included providing the perspectives of 159 patients who had a FT during treatment for HNC. 150 findings and 183 illustrations which were primarily patient quotes were extracted. Analysis resulted in 42 categories from which nine synthesized findings were produced. These are summarized as: initial reluctance and fear; different understandings and expectations; individual preferences around choice; physical discomfort; restrictions to social life and daily living; new challenges and responsibilities; gradual acceptance; a challenging but rewarding transition process; and overall a worthwhile decision.
Conclusion: These findings highlight the nutrition-related burden patients with HNC experience and support the need for interdisciplinary healthcare teams that integrate dietetics and speech pathology. This review supports individualized approaches to FT placement decisions. Further well-designed studies are needed to better understand patient and cancer-service structural factors that may influence the experience of having a FT, to ensure that decisions are evidence-based and patient-centered for best outcomes.

1. Introduction

Head and neck cancer (HNC) is one of the ten most common cancers in the world [1]. Treatment is intense and typically involves several weeks of daily high dose radiotherapy, often in addition to surgery and chemotherapy [2]. Severe disease and treatment side effects are common and can include oral mucositis, dysphagia, nausea and odynophagia [3–5]. Consequently, many patients with HNC experience reduced oral intake, significant weight loss, malnutrition and dehydration [6–13]. For example, rates of significant weight loss (i.e. >5% in one month or ≥10% at 6 months from the start of treatment) can be up to 67–80% [14] and malnutrition can be up to 88% among patients with HNC during treatment [15]. Unfortunately, these nutritional issues can cause treatment interruptions for re-planning or hospitalization and are associated with poorer disease control and reduced quality of life [11,15–18].

To promote better nutritional status and minimize treatment interruptions and unplanned contacts, governing oncology organisations and international evidence-based guidelines recommend that early enteral feeding be considered for nutritionally vulnerable HNC patients, including those with T4 or hypo-pharyngeal tumours, who are to receive multi-modality treatment, who have pre-existing, malnutrition or dysphagia or who have limited social support [19–23].

Two common forms of enteral feeding tubes (FTs) for patients with HNC are a percutaneous endoscopic gastrostomy (PEG) tube

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that is placed prophylactically (prior to, or early in treatment in anticipation of inadequate oral intake), or a reactive nasogastric tube (NGT) (placed at the time when oral intake is unable to provide adequate nutrition). From studies that have compared the PEG to the NGT approach for patients with HNC, some evidence suggests that those with a PEG have significantly less weight loss and have lower rates of unplanned contacts with health services, compared to those who receive an NGT [17,24–28]. Moreover, those with an NGT have been found to have more tube dislodgements and report greater altered body image and interference with social activities [25,29]. However, the cost of NGT placement is lower and patients with an NGT have less infections and less dysphagia six months post treatment compared to those with a PEG [29–32]. In contrast, evidence from one randomised trial and several other observational studies have found no difference in dysphagia or weight loss six months post treatment between groups [25,33]. Therefore, due to study limitations including small sample size, unreported or inadequate blinding, non-randomised sampling in observational studies and conflicting results, no conclusion can be made about whether a PEG or reactive NGT is best [25,26,34–36]. Subsequently, different perspectives among physicians about the overall value of a FT for patients exists, as do varied opinions about what type of FT is preferential when patients require enteral nutrition support [35].

Due to the limitations of the current quantitative evidence base on this topic, several authors have recognised the value in qualitative research to better understand the patient experience of having a FT [37]. This evidence suggests that: fear, choice, physical impact, support, social impact, adaptation, reassurance and survival are key ideas that patients associate with having an FT throughout treatment for HNC [38–42]. While two systematic literature reviews have summarised qualitative research relating to patient experiences of eating post treatment [43] and experiences managing nutrition impact symptoms during treatment [44] among HNC patients respectively, neither have summarised the research on patient experiences of having a FT while undergoing treatment for HNC. Addressing this gap in the literature is important to explore and help explain the usability and efficacy of FTs to facilitate a more patient-centred approach in FT placement decision-making [45]. Therefore, the aim of this review was to provide a summary of key findings related to the patient experience of having a FT during treatment for HNC.

2. Methods

2.1. Design

This review was carried out in three stages following the Preferred Reporting Items for Systematic Review and Meta-Analyses (PRISMA) format: (a) development of criteria for inclusion and literature search; (b) extraction and coding of study characteristics and findings; and (c) data analysis and aggregation of findings. Because this review aimed to summarise patient perspectives from qualitative studies, The Joanna Briggs Institute [45] Reviewer's Manual was utilised to guide the handling of qualitative data. A protocol for the review has been made available through PROSPERO (registration number: CRD42017069016).

2.2. Inclusion criteria

As recommended by The Joanna Briggs Institute [45], the eligibility criteria was developed using the 'PiCO' format (Phenomena of interest; Context and Outcome) (Table 1). However, they suggest that in qualitative reviews the phenomena of interest is the outcome, therefore there is no requirement for an outcome statement [45] (p 27).

2.3. Types of studies

This review included original research papers that focused on, or included qualitative data captured via individual interviews, focus groups or open-ended survey questions, to provide patient perspectives that are less prone to bias from closed-question survey methods [46]. Study designs included, but were not limited to, descriptive, grounded theory, phenomenology and ethnography studies.

2.4. Participants

Eligible studies included the perspectives of non-palliative adult patients that had been treated for HNC and had a FT during that time. In this review, HNC is the broad term used to include squamous cell cancers of the oral cavity, nasopharynx, oropharynx, hypopharynx and larynx. The term 'feeding tube' includes gastrostomy, jejunostomy and nasogastric tubes. Total parenteral nutrition was excluded as its management is significantly different, particularly in the outpatient setting and typically patients with HNC can tolerate enteral nutrition, as the digestive tract (beyond the oral cavity) remains unaffected by treatment. Method of the FT insertion was not restricted, allowing endoscopically, radiologically and surgically inserted FTs that were placed in either the inpatient or outpatient setting to be included. Time of FT placement was restricted to FTs placed pre-radiotherapy in anticipation of treatment side effects that might limit oral intake (prophylactically), during treatment and up until three months post treatment. It was decided that it was less likely that FTs placed outside of this time frame were because of the effects from HNC and its treatment. The length of time the FT was utilized for nutrition was not restricted, nor was the proportion of total nutrition that was delivered via the FT, allowing perspectives of patients who received both total enteral nutrition and supplementary enteral nutrition to be included.

2.5. Phenomena of interest

This review considered studies that investigated the experience of having a FT throughout treatment for HNC. Studies that included the perspectives of patients with other diagnoses and studies that included non-patients such as caregivers and healthcare professionals were only included if HNC patients comprised greater than fifty percent of the total sample and if specific findings could be directly attributed to a patient with HNC via direct quotes or descriptions of observations.

2.6. Literature search

A three-step search strategy was implemented as advised by the Joanna Briggs Institute [45] and was carried out between October and December 2018. First, to identify all relevant key terms for inclusion in the search strategy, an initial pilot search was undertaken in the databases Web of Science using broad terms related to patient perspectives, feeding tube and head and neck cancer. The search strategy was then developed (Table 2) and applied to the databases: Web of Science, CINAHL, Scopus and Science Direct. Finally, the reference lists of studies identified for appraisal were searched to capture additional relevant studies. The searches were restricted to journal articles published in English. A time frame in relation to their publication date was not applied to increase the opportunity for all relevant literature to be captured.

Table 1
Eligibility criteria.

Category	Inclusion	Exclusion
Phenomena of interest	Experiences of adults who had a feeding tube during treatment for head and neck cancer	Experiences of patients who were <18 years old, did not have a feeding tube or did not receive treatment for head and neck cancer Perspectives of others (i.e. carers or healthcare professionals)
Context	Feeding tubes placed pre-treatment in anticipation of radiotherapy or during treatment for head and neck cancer.	Pre-existing long term feeding tubes prior to head and neck cancer diagnosis Feeding tubes placed three months or later post treatment
Design considerations	Qualitative studies Mixed method studies Participant experiences collected via interview, focus group or open-ended survey question Full-text studies English language	Quantitative studies Data collection via closed question surveys Non-original research papers Non-English language

Table 2
Search strategy.

Patient OR adult OR person
Perspective OR experience OR view OR attitude
Enteral OR feeding tube OR gastrostomy OR nasogastric OR jejunostomy
Cancer OR oncology OR neoplasm OR malignancy OR tumour

2.7. Study selection

A three-step screening and eligibility inclusion process was undertaken by authors EH and SG using the PRISMA flow diagram (Fig. 1). Articles were first scanned for duplicates and these were removed. Titles and abstracts of all remaining articles were independently screened for eligibility using the eligibility criteria (Table 1). Finally, all remaining articles were then read in full for inclusion in the review.

2.8. Quality appraisal

The qualitative studies identified for inclusion were assessed by EH and SG for methodological validity prior to inclusion in the review using the standardized critical appraisal instruments from the Joanna Briggs Institute Qualitative Assessment and Review Instrument (JBI-QARI) [45] (Supplementary File 1). Any disagreements that arose between reviewers were resolved through discussion.

2.9. Data extraction

The data extraction and synthesis of the qualitative studies was guided by The Joanna Briggs Institute [45] Reviewer's Manual. Information extracted from the eligible studies included primary author, publication year, geographical location, methodology, phenomena of interest, data collection and analysis methods, relevant study population information, and the papers summarised results and conclusions (Table 3). The author's findings (i.e. verbatim extracts of the authors analytic interpretations, related to an 'illustration' (i.e. a participant quote) with regards to patient experiences of FTs were also extracted, along with supporting illustrations (supplementary file 2). The extraction of the author's findings was also the first step of data synthesis [45].

2.10. Data synthesis

Data was synthesised using The Joanna Briggs Institute [45] model of meta-synthesis which uses a met-aggregative approach. This methodology is sensitive to the primary author's findings and does not seek to re-interpret those findings. This methodology seeks to allow the development of statements which can be used as practice recommendations.

Data synthesis was carried out by EH and SG. First, through repeated reading of the included papers, 'author's findings' (i.e. relevant categorised main findings, sub findings and verbatim descriptions of findings), were identified and extracted, along with the related illustrations. Each finding was assessed for credibility using the The Joanna Briggs Institute [45] credibility scale (p 41) (i.e. U = Unequivocal: findings accompanied by an illustration that is beyond reasonable doubt and therefore not open to challenge; C = Credible: findings accompanied by an illustration lacking clear association with it and therefore open to challenge and N = Unsupported: findings not supported by data) (Supplementary File 2).

'Findings' were then grouped together based on similar concepts into 'Categories'. 'Synthesised findings' were then developed to describe the overarching conceptual basis of a group of categorised findings. Consensus for the 'synthesised findings' was reached by EH and SG through discussion. These were then reviewed by KW and AM and finalised. The final synthesised findings were expressed as 'indicatory' statements that can be developed into recommendations for practice.

3. Results

3.1. Searching

The initial search yielded 1134 papers after duplicates were removed. Following eligibility screening of titles and abstracts 1110 papers were removed. The remaining 24 studies were read in full to assess their eligibility. Fifteen studies were excluded due to: the use of closed-question survey data only (n = 6), author findings could not be directly attributed to patients with HNC (n = 4), patients with HNC represented less than half of all participants and their perspectives could not be differentiated from other participants (n = 2), less than two author findings related to a FT (n = 2) and participants were palliative (n = 1). The nine remaining articles were then appraised for quality and were eligible for inclusion in the review (Fig. 1).

3.2. Description of included studies

All nine studies included in the final review were high quality according to the QARI critical appraisal tool scoring 8/10 or above [45] (supplementary file 1). Five of the included studies were conducted in the United Kingdom [40,42,47–49], three from

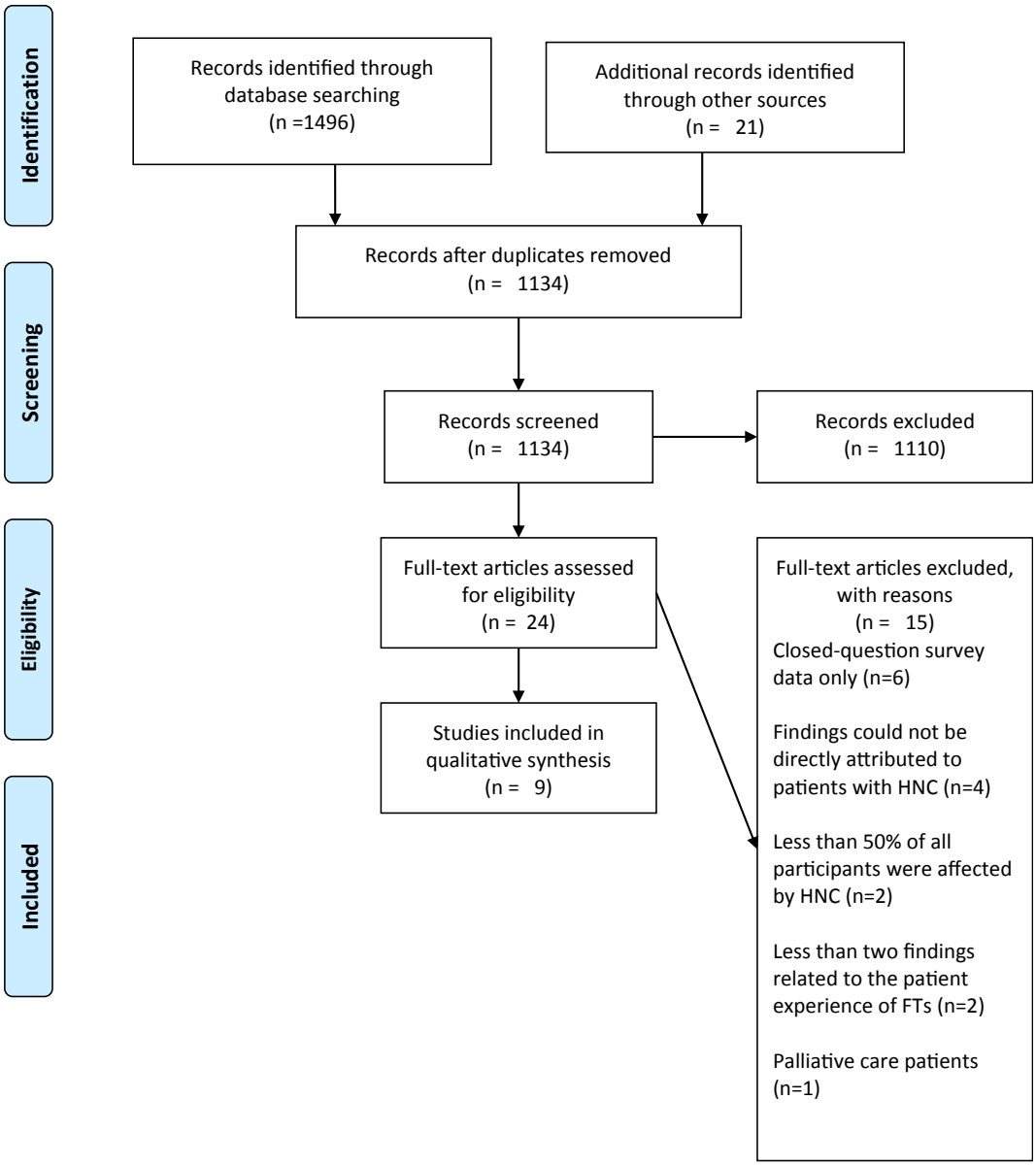

Fig. 1. PRISMA 2009 flow diagram.

Canada [39,41,50] and one from Sweden [51]. No studies were published prior to 2011. Seven studies used a descriptive qualitative study design. Six of these utilised patient interviews [41,42,47,48,50,51] and one used focus groups with the patient and their carer [49]. One study used a Q-methodology design which included patient interviews with a subsample of five patients with HNC [40] and one used a mixed-method study design which included four open-ended survey questions with patients [39]. Seven of the studies solely included patients with HNC [39–42,47,50,51], one also included carers [49] and one also included patients with other disease and clinical conditions who had FTs [48]. Five studies solely included patients who had a PEG [39–41,47,49]. Two studies included patients who had either an NGT or PEG [50,51] and one study included patients with either a PEG, NGT or RIG [42] and one study more broadly included patients with gastrostomy tubes [48] (Table 3).

3.3. Synthesis

Collectively the nine included studies provided the perspectives of 159 patients who had a FT while undergoing treatment for HNC. From the studies 150 verbatim author findings that related to the patients experience of having a FT were extracted, along with 183 illustrations, the majority of which were direct patient quotes. These were analysed and then grouped into 42 categories; from which nine synthesised findings were produced (Table 4). See Table 5 for the synthesised findings with their categories and author findings.

4. Discussion

This review aimed to synthesise the current qualitative evidence on the patient experiences of having a FT while undergoing

Table 3
Summary of included studies.

Author, year, geographical location	Study Design/ methodology	Phenomena of interest	Data collection method	Data analysis	Participants		Author's summary of results	Author's conclusion
Alberda, 2017, Canada	Qualitative descriptive study	The patients' experiences with nutrition care in the context of their treatment and recovery	Semi-structured interviews	Content analysis	Number of HNC participants Mean age, y Tumour locations Tumour staging Treatment FT Type Duration FT in situ: Mean (range), mo	Total: n = 10 Female: n = 2 Male: n = 10 62.6 (45–79) n/d **n/d** RT: n = 1 RT + CT + surgery: n = 3 RT + surgery: n = 9 Surgery + RT: n = 6 NGT: n = 10 (perioperatively, but removed pre RT) PEG: n = 2 **n/d**	Three main themes 1 Coping with the physical and psychosocial aspects of illness and nutrition 2 Understanding the nature of the illness, treatment and nutrition pathways 3 Being supported during the trajectory of care	Patients with HNC need individualized complex support that include ongoing medical information and guidance, along with nutrition and emotional support for the patients and their families. The resources should be available inside and outside the walls of the hospital or cancer care center. The results point to the need for patient-focused evidence-based guidelines as 1 of the primary enablers of nutrition care so that all patients receive the benefit of nutrition care, and health services are modelled to provide consistent care from all healthcare providers. The conflicting messages provided by different professionals were a constant source of anxiety and uncertainty and may have been Interpreted as lack of support.
Ehrsson, 2015, Sweden	Qualitative descriptive study	quality of life with head and neck cancer patients, with focus on which areas in life re important to quality of life, and which are influenced by the disease and by having oral or enteral nutrition; and which areas in life are influenced by having a NGT or a PEG	Semi-structured interviews	Content analysis	Number of HNC participants Mean age, y Tumour locations Tumour staging Treatment FT Type Duration FT in situ: Mean (range), mo	Total: n = 41 Total with FT: n = 23 62.3 Oropharynx: n = 15 Oral cavity: n = 8 Larynx: n = 5 Unknown primary: n = 4 Nasopharynx: n = 3 Salivary glands: n = 3 Hypopharynx: n = 2 Oral cavity and oropharynx: n = 1 T1: n = 6 T2: n = 5 T3: n = 4 T4: n = 22 No stage: n = 4 RT: n = 16 RT + CT ± surgery: n = 13 RT + surgery: n = 9 Surgery + RT: n = 3 Total: n = 23 PEG: n = 14 NGT: n = 9 n/d	Four main categories, thirteen sub-categories: 1 Nutrition - Nutritional comfort - Maintaining and gaining weight - Long feeding time - Missing oral eating - Losing weight 2 Function - Functioning well - Difficult to handle - Gastrointestinal problems - Nose and throat problems - Pain 3 Limitations - Feel unhygienic - Confined to a tube - Social limitations 4 Miscellaneous	Eating aspects are fundamental in life for patients with head and neck cancer, but the perception of general or disease-related quality of life did not differ between patients receiving enteral nutrition and patients who did not. Patients receiving enteral nutrition regarded that type of treatment as something positive and necessary. However, both NGT and PEG were associated with restrictions with different spectra. From the patients' perspective neither of the two feeding tubes was clearly in favour.

Govender, 2017, United Kingdom	Qualitative descriptive study drawn upon the theoretical domains framework (TDF) and the COM-B (Capability, opportunity, motivation behaviour) model	The barriers and facilitators to swallowing exercise adherence from a patient perspective	Semi-structured interviews	Content analysis	Number of HNC participants Age Tumour locations Tumour staging Treatment FT Type Duration FT in situ: Mean (range), mo	Total: n = 13 Total with FT: n = 11 Females: n = 4 Male: n = 9 60 years and over: n = 4 Less than 60: n = 9 n/d Advanced RT: n = 3 RT + CT: n = 5 RT + CT + surgery: n = 4 CT + surgery: n = 1 PEG: n = 11 n/d	Barriers and facilitators to exercise adherence Barrier: - Inadequate knowledge of how treatment will affect own swallowing. Facilitator: - To prevent negative consequences such as long-term tube feeding (reflective motivation)	Patient adherence is one aspect of the complex intervention involved in swallowing rehabilitation after HNC. This study described the use of a theory-based qualitative approach in examining what drives adherent/non-adherent exercise behaviours in patients with HNC.
Kwong, 2017, Canada	Qualitative descriptive study	The decision making process for PEGs tube from the patient's perspective	Semi-structured interview	Qualitative thematic analysis	Number of HNC participants Mean age (range), y Tumour locations Tumour staging Treatment FT Type Duration FT in situ: Mean (range), mo	Total: n = 15 Female: n = 3 Male: n = 12 60.2 (44–77) Throat, tongue, nasopharynx, tonsil, oropharynx, lymph node “Advanced” RT: n = 1 RT + CT: n = 13 RT + CT + surgery: n = 1 PEG: n = 15 7 (3–10)	Thirteen major codes: 1 Choices wround PEG tube insertion* 2 Weight 3 Eating/oral intake 4 Experiences of daily living with the PEG tube* 5 PEG feeding 6 Spillage 7 The cap as a problem 8 Support 9 Socialization 10 PEG tube challenges 11 Transitioning from the PEG tube back to an oral diet* 12 Thoughts and feelings associated with the PEG tube 13 Recognition of the value of the PEG tube* (*Four codes that summarised the overarching ideas and progressive experience or patient journey with the PEG)	The experience of patients with HNC living with a PEG tube can be described overall as a dichotomy. While there were issues with the PEG tube, all participants found the tube to be beneficial.
Mayre-Chilton, 2011 England	Qualitative descriptive study	The daily impact of gastrostomy feeding on head and neck patients and their care givers	Focus group interviews	Qualitative thematic analysis	Number of HNC participants Mean age (range), y Tumour locations Tumour staging	Total: n = 6 Female: n = 2 Male: n = 4 64 Oropharynx: n = 2 Larynx: n = 2 Sarcoma mandible: n = 1 Unknown primary: n = 1 T1: n = 2 T2: n = 1 T3: n = 1 T4: N = 1 Pre-tumorous stage: n = 1	Eight key themes: Three themes were experienced differently between patients and caregivers: 1 Knowledge and understanding why the tube was necessary 2 Personal perceptions 3 Objectives of nutritional support Five themes were experienced similarly between patients and caregivers:	The findings identify factors that contribute to the challenges of weaning from enteral to oral nutrition. The present study shows that a support process involving multidisciplinary specialists is required to guide head and neck cancer patients and their care-givers through the treatment process together: from diagnosis and the pre-assessment clinic, before and during treatment, and finally to the rehabilitation and re-

(*continued on next page*)

Table 3 (*continued*)

Author, year, geographical location	Study Design/ methodology	Phenomena of interest	Data collection method	Data analysis	Participants		Author's summary of results	Author's conclusion
					Treatment	n/d	4 Developing positive coping strategies	establishment of daily living for long-term survivorship.
					FT Type	PEG: n = 6	5 Preventing nutritional decline	
					Duration FT in situ: Mean (range), mo	n/d	6 Gastrostomy tube dependency	
							7 Recognition of survival	
							8 Support network	
Merrick, 2012, United Kingdom	Qualitative Q-methodology	The experience of PEG tube feeding in HNC patients undergoing cancer treatment	Semi structured interviews thematically analysed	Thematic analysis and PQ Method software package	Number of HNC participants	Total: n = 5 Female: n = 1 Male: n = 4 (M = 4, F = 1) 48–79 years	Four global themes: 1 Psycho-Social Impact: Physical (Complications, Practicalities, Discomfort, Care),Psychosocial impact on me (Emotional, Social, Confidence, Intrusion, Sleep), Psychosocial Impact on Others (Emotional, Social, Burden), In Context of Diagnosis (Treatment, Temporary) 2 Physical Impact: Effects of the Feed (Abdominal Effects, Sensation of Feed, Volume), Treatment Effects (Practical, Psychological), Process (Practicalities, confidence, Time) 3 Affective Impact: Placement (Support, Being Told Information), Tube (Ability to Self-Care, Capability), Feeding Method (Sensation, Ease, Pump) 4 Clinical/Medical Impact: Provision of Nutrition and Fluids (Life Saving, Quality of Life); vs Cons (Social, vs a Nasogastric tube) Q methodology analysis: 1 'Constructive cognitive appraisal' – positive adaptation and acceptance of PEG 2 'Cognitive-affective dissonance' ambivalence between acceptance and rejection of PEG	The findings broadly confirm Levanthal et al.'s Self-Regulatory Model of coping (driven by the need to re-establish a state of normality, the patient interprets the problem posed by the illness within a cognitive and emotional framework, develops a coping strategy based on this and then appraises the success of the coping strategy). The findings highlight the need for an impartial and genuinely patient-centred approach to nutritional care, reflecting the heterogeneity in patient attitude to, and experience of, gastrostomy feeding by head and neck cancer patients undergoing curative treatment.
					Age range, y	48–79		
					Tumour locations	n/d		
					Tumour staging	n/d		
					Treatment	Curative treatment		
					FT Type	Prophylactic PEG: n = 5		
					Duration FT in situ	n/d		

							3 'Emotion-focused appraisal' – tube focused anxiety and fear	
Osborne, 2012, Canada	Cross-sectional, retrospective descriptive study	The experience of patients living with a PEG tube	A mixed-method, PEG-specific questionnaire (Four open-ended questions)	Grounded theory analysis	Number of HNC participants Age, y Tumour locations Tumour staging Treatment FT Type Duration FT in situ	Total: n = 51 Female: n = 14 Male: n = 37 18-40: n = 11 41-50: n = 8 51-60: n = 18 61-75: n = 14 Oropharynx: n = 21 Oral cavity: n = 8 Nasopharynx: n = 13 Hypopharynx: n = 4 Glottic: n = 4 Other: n = 1 Stage 3–4 RT: n = 1 RT + CT ± surgery: 50 PEG: n = 51 PEG placed pre RT: 4 PEG placed between days 1–21 or RT: 29 PEG placed from day 22 of RT: 18 n/d	Main responses to the four open ended questions: 1 Main advantage of having the PEG tube: - Provided nutrition when I couldn't eat orally - Kept me alive/survival - Kept my weight up - provided relief from metal burden 2 Main disadvantage: - No disadvantage - Leaking/cap coming off - Discomfort - Caring for the tub - Awkward when showering 3 How could the experience with he PEG be improved: - No improvement - Improve the cap to avoid leakage 4 One thing about your experience with a PEG that you would tell another patient - Get it - It doesn't hurt - It can be essential to save your life - The benefits outweigh the negatives - It's not that big of a deal - Trust the advice of the professionals.	Most patients with advanced HNC who went through the outpatient PEG tube program at the OCC had a positive or neutral experience and would recommend the PEG tube to patients in similar situations.
White, 2018, United Kingdom	Qualitative descriptive study	Patient views on the role of considering their values in the decision to have a gastrostomy	Semi-structured interviews	Grounded theory approach	Number of participants Mean age (range) y Tumour locations Tumour staging Treatment FT Type Duration FT in situ, mean (range) mo	Total: n = Total with HNC: n = 7 Females: n = 3 Males: n = 4 63 (53–76) n/d n/d n/d GT: n = 7 9.4 (3–12)	Three main themes and seven sub-themes: 1 Weighing up the benefits and concerns - Benefits of starting home enteral feeding - Concerns about home enteral feeding 2 Perceptions of choice - Felt had a choice - Felt no choice given - Felt ha no choice due to no viable alternative	Patients may have a varied need for their values to be clarified during decision making to have an enteral feeding tube placed. Therefore, the decision-making approach may need to be modified based on patient preferences for involvement and the context in which the decision is being made.

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Table 3 (*continued*)

Author, year, geographical location	Study Design/ methodology	Phenomena of interest	Data collection method	Data analysis	Participants		Author's summary of results	Author's conclusion
							3 Expectations and decision regret - Expectations - Decision regret	
Williams, 2018, North England	Qualitative descriptive study	Patients' experiences of enteral feeding and the surrounding decision making process.	Semi structured interviews	Thematic analysis	Number of HNC participants	Total: n = 10 Female: n = 2 Male: n = 8	Seven key themes and 12 sub-themes: 1 The battle to eat 2 Fear - Insertion/procedure - Tube displacement 3 Restricted life - Going out/body image - Missing eating - Enteral feeding regimen restrictions - Activities of daily living - Relationships 4 Coping mechanism - Reducing burden - Living a normal life - Downward social comparison - Hope/loss of hope - Resilience - Control 5 “It's our body”- having choice 6 Support Value of tube	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 [enteral feeding] 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 [enteral feeding]; future developments could increasingly look to integrate peer-support into [enteral feeding] 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.
					Median age (range), y	54 (43–65)		
					Tumour locations	Tonsil: n = 6 Base of tongue: n = 2 Lateral tongue: n = 1 Glottis: n = 1		
					Tumour staging	T2: n = 1 T3: n = 1 T4: n = 8		
					Treatment	RT: 1 RT + CT: n = 9		
					FT Type	RIG: n = 6 PEG: n = 1 NG: n = 3		
					Duration FT in situ: Mean (range), mo	n/a		

Table 4
Synthesised findings.

1	Patients may initially experience feelings of reluctance, fear and anxiety toward FTs, including FT insertion and removal, nutritional decline through treatment, FT permanence, social stigma and the risks of FTs.
2	Understandings and expectations of FTs can vary among patients with HNC. Some patients may understand the FT as a necessary part of cancer treatment, while others may have uncertain expectations about the FT. Being informed may positively influence patient understanding of FTs; whereas conflicting view from healthcare professionals may negatively impact patient understanding.
3	The experience of choice with regards to FTs can vary among patients with HNC. Some patients may feel that the choice was presented as theirs to make, while other may feel that a FT is a necessary part of cancer treatment. Some may value having choice, while other patients may feel overwhelmed with that responsibility.
4	Physical discomfort due to the FT may be experienced by patients with HNC, such as discomfort with the presence and insertion of the FT, NGT related nose and throat irritation, or G-tube insertion-site pain.
5	For patients with HNC, a FT may place restrictions on their social life and activities of daily living, which may include missing eating orally, personal relationships and self-consciousness.
6	Having a FT may present new challenges and responsibilities for patients with HNC, including in relation to finances, feeding regimen burden and tube use and maintenance.
7	Patients with HNC may become more accepting of the FT over time by adapting their routine, through developing coping strategies, if the FT is less burdensome than expected, by receiving social support and when eating orally becomes a significant struggle.
8	For patients with HNC, transitioning from a FT to an oral diet can be a challenging, learning and rewarding process, as experiences may include gradual progression, oral intake discomfort, removal impatience and FT dependence.
9	Patients with HNC may recommend a FT to other patients as an overall worthwhile decision, as having a FT may help patients manage their disease and treatment side effects, prevent nutritional decline

treatment for HNC. From the results of this review, the experience of having a FT while undergoing treatment for HNC can be summarised as: initial reluctance and fear; different understandings and expectations; individual perceptions and preferences around choice; physical discomfort; restrictions to social life and activities of daily living; new challenges and responsibilities; gradual acceptance; a challenging, learning and rewarding transition process; and overall, a worthwhile decision. Previously, most of the research on the use of FTs with HNC patients has focused on quantitative data [26,29,52]. Other authors have previously summarised experiences of patients with HNC relating to eating post treatment [43] and managing nutrition impact symptoms during treatment [44]. Therefore, this review adds important insight on the debated topic of FTs for HNC patients, to help explain the usability and efficacy of this intervention and to facilitate a more patient-centred approach to FT decisions.

Comparing the findings from this review, to those of Ganzer, Touger-Decker [43] and Bressan, Bagnasco [44] it is evident that undergoing treatment for HNC can present similar challenging experiences for patients with or without a FT. For example, a common theme is the sense of restriction to one's social life and their activities of daily living, as eating can feel like a laborious chore rather than a pleasant experience to share with others [41–44,48,49,51]. Likewise, adaptation is a phenomenon that may be experienced by HNC patients with or without a FT, as individuals may have to alter their daily routines and usual diet to manage side effects including dysphagia, xerostomia and pain [40–42,47–49]. Overwhelmingly, the evidence from this review, in addition to those by Ganzer, Touger-Decker [43] and Bressan, Bagnasco [44] bring attention to nutrition, as one of the most challenging aspects of undergoing treatment for HNC for those patients. This reflects the high rates of nutritionally restrictive side-effects experienced within this population and the subsequent high incidence of malnutrition and dehydration [3–5,11,53]. Therefore, this demonstrates the need for collaborative interdisciplinary healthcare teams, which include dietitians, to provide patient-centred support [19–23].

Positively, by focusing on the experience of FTs, the present review demonstrates that patients undergoing treatment for HNC can come to value the FT as a source of reassurance and as a medical intervention that can lessen the burden of treatment [40–42,48,51]. One concern that has been discussed in the literature is the risk of unnecessary FT placement with the PGT approach [54]. However, an interesting finding by Osborne, Collin [39] suggested that even if patients did not use the FT, they still felt reassured by its presence. Related to this, in three of the studies patients were asked whether they would advise future patients with HNC to have a FT placed. The authors concluded that most of their participants would, if it was recommended by that patient's healthcare professionals [39,41,42]. Therefore, the evidence from this review suggests that for nutritionally vulnerable patients, a FT could be a positive intervention to help them cope during a very challenging time. This provides patient-centred support for quantitative evidence that demonstrates that nutritionally vulnerable patients undergoing treatment for HNC can benefit from having a FT from a morbidity perspective, by reducing significant weight loss, malnutrition, nutrition-related hospitalisations and treatment delays [17,55,56].

Reluctance, anxiety and fear can be experienced by patients when faced with the prospect of having a FT during treatment for HNC. These feelings may relate to the insertion and removal procedure, the risk of permanence and pain and the social stigma associated with having a FT [40–42,47,48,50]. Moreover, some patients may feel that using a FT is a sign of personal failure [42,50]. Being adequately informed via regular access to healthcare professionals and peer-support can help patients to have clearer understandings and expectations of the FT [42,48,49]. Having choice in relation to FT type, the timing of placement and in feeding mode (i.e. bolus or continuous) can also promote a more positive FT experience [41,42,48]. These findings are supported by a systematic review by Jaafar, Mahadeva [37] who summarised the attitudes towards PEG feeding among patients, healthcare professionals and carers and found that a major barrier to PEG acceptance was a lack of choice and knowledge [37]. To help address this concern, they recommend that attention be paid to staff competency and skill to help patients feel more confident in FT decisions [37,57]. Overall, the qualitative evidence on patient experiences with FTs indicates that individuals can have different feelings of reluctance and acceptance and different preferences about their involvement in choices surrounding FTs. This may be in part explained by Martin et al. who found that the differing perspectives on FTs among patients with HNC can be influenced by factors including age, gender and education level [58]. Therefore, the present review supports the need to adopt an individual patient-centred approach to FT placement decision-making, which includes hearing the experiences of other patients.

Three of the studies included patients with both PEG's and NGTs [42,50,51] and the remaining six included patients who had

Table 5

Synthesised finding	Categories	Findings
1 Patients may initially experience feelings of reluctance, fear and anxiety toward FTs, including FT insertion and removal, nutritional decline, FT permanence, social stigma and the risks of FTs.	Being tube fed	Constant fear of being fed via feeding tube, if not compliant, added to patient stress and frustration (Alberda p. 669) Most individuals talked about wanting to avoid a feeding tube, hoping to maintain the ability to eat and drink by mouth throughout the treatment (Govender p. 563) Participants described hope that [enteral feeding] would be short-term and that they would resume normal eating (Williams p. 4) Participants who declined a G-tube before treatment reported … the hope that they would not require enteral feeding as rationale for their decision. (Williams p. 3) Participants with both prophylactic G-tube and reactive NGTs described starting treatment with hope that they would not require enteral feeding (Williams p. 2) Pre-treatment they hoped that they would be able to continue to maintain oral intake during treatment and would not require [enteral feeding]. When this hope was lost and they realised that they did require [enteral feeding] they did not cope well. (Williams p. 4) Prior to PEG tube insertion, participants … felt a reluctance about the idea of having one inserted (Kwong p. 528) When a PEG tube was offered as a supportive measure for nutrition during treatment, participants often struggled with the decision to accept it's placement (Kwong (p. 528)
	Insertion and removal	Distinguishing statements included … marked anxiety around the procedure to insert the tube (Merrick p. 500) Their concerns were focused on initial tube insertion, removal of G-tube (Williams p. 2) Participants had initial fears, including the tube falling or being pulled out (Kwong p. 529) Participants who declined a G-tube before treatment reported the risks and apprehension associated with a surgical procedure (Williams p. 3) Their concerns were focused on accidental tube displacement (Williams p. 2) Their primary response of this group was fear and anxiety, which appeared to be focused on the PEG tube but specifically the procedure to insert the tube (Merrick p. 500)
	Nutritional decline	Their concerns were focused on … nutritional decline during treatment (Williams p. 2) Their inability to eat meant they could not achieve their recommended calorie and protein goals, which they were told was needed for physical healing and recovery (Alberda p. 668)
	Permanence	Importantly participants discussed their motivation to set goals and to progress with eating, with a view to avoiding dependence on their tube (Williams p. 2) Some healthcare providers informed patients of a risk of relying on the feeding tube too much and, as a result, a risk of permanently losing swallowing capacity. Therefore, most patients in the HN cancer group were reluctant, fearing that the feeding tube would be a permanent solution (Alberda p. 668) The expected time that the tube would remain in-situ was a major source of anxiety for many participants (White p. 1048) Their concerns were focused on … the risk of enteral feeding tube dependence (Williams p. 2)
	Social stigma	Participants with NGTs experienced anxiety over public reaction which influenced their confidence in socialising (Williams p. 3) Some participant responses indicated that they viewed starting enteral feeding as an admission of defeat, describing feelings of disappointment and failure (Williams p. 2) The patients with HN cancer viewed tube insertion as a personal failure and therefore chose not to have a feeding tube placed (Alberda p. 668)
	Tube feeding risks	Another participant reported being distressed when he was only told about the risks associated with having the gastrostomy placed on arrival in the endoscopy suite. He suggests that improved knowledge prior to tube placement could have prevented the significant anxiety he experienced, allowing time for any questions to be answered (White p. 1050) Knowing the risks may have made him more anxious during the time leading up to the gastrostomy placement (White p. 1048) Participants had initial fears, including anticipation of pain (Kwong p. 529) Some felt that being asked to fully consider the impact of [home enteral feeding] may have caused additional anxiety and were content with dealing with any adverse consequences as they occurred (White p. 1049)

2	Understandings and expectations of FTs can vary among patients with HNC. Some patients understand the FT as a necessary part of cancer treatment, while others experience uncertainty toward the FT. Being informed can positively influence understanding of FTs; whereas conflicting view from healthcare professionals can negatively impact patient understanding.	Being informed	As the expected time that the tube would remain in-situ was a major source of anxiety for many participants, this was felt an important issue to be addressed, in terms of managing their expectations (White p. 1048) 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. (Williams p. 3) Patients were more able to cope [compared to caregivers] because they were the main focus of the treatment and time had been dedicated to help them make an informed decision (Mayre-Chilton p. 452) Another participant reported being distressed when he was only told about the risks associated with having the gastrostomy placed on arrival in the endoscopy suite. He suggests that improved knowledge prior to tube placement could have prevented the significant anxiety he experienced, allowing time for any questions to be answered. (White p. 1048) Those participants who were informed about the possibility of pain post-gastrostomy placement, felt that this knowledge prepared them better for it (White p. 1048) Communication with the healthcare team aided participants' decision making (Kwong p 529)
		Conflicting views from healthcare professionals	There was an element of conflicting advice and the omission of information, which resulted in a negative impact on the patients (Mayre-Chilton p. 452) They received mixed messages from different professionals involved in their care (Alberda p. 668)
		Necessary part of cancer treatment	A positive health outcome was the driving force in most participants' decision to have a gastrostomy (White p. 1047) As most patients had the gastrostomy placed in preparation for radiotherapy to the head and neck, the tube placement was perceived to be part of a treatment package that included radiotherapy and the removal of teeth rather than a decision in its own righ (White p. 1049) Most participants had undergone radiotherapy for ENT (Ear Nose and Throat) cancer, and decided to have the gastrostomy placed thinking that it would maximise their chances of a successful outcome (White p. 1047) Others found it easier to accept enteral feeding and viewed the tube as a necessity (Williams p. 2) There was discussion about participants feeling there was no choice in the matter; the tube was viewed as a necessity (Kwong p. 529) They perceived that gastrostomy placement was not the priority for the treating health professionals; it was just something that had to be done as part of the treatment However, one participant was dissatisfied with gastrostomy placement being considered part of a treatment package (White p. 1048)
		Uncertain expectations	Most participants 'didn't know what to expect' (P4) about what it would be like to live on [home enteral feeding] (White p. 1049) Patients with [head and neck] cancer felt uncertain about the role of the feeding tube (Alberda p.668) Prior to PEG tube insertion, participants were unfamiliar with the tube (Kwong p. 528) Some participants felt that they would not have been able to imagine what it would be like to be on HEF; and if asked to consider the potential impact, they may have reacted by thinking that this wouldn't be the case for them (White p. 1049)
3	The experience of choice with regards to FTs can vary among patients with HNC. Some patients may feel that the choice was presented as theirs to make, while other may feel that a FT is a necessary part of cancer treatment. Some may value having choice, while other patients may feel overwhelmed with that responsibility.	Given a choice	A minority of patients felt they had a choice about gastrostomy placement. These patients described being presented with some information on gastrostomy placement and the reasons why the medical team felt it was necessary, but were also made aware that it was their decision to make (White p. 1049) Choices around the PEG tube focused on decision −making processes around the tube insertion and the timing of the procedure. Tubes were inserted prior to treatment when serious eating problems were present or anticipated. Other PEG tubes were inserted at various stages of treatment after challenges with oral intake emerged (Kwong p. 528) 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 (Williams p. 3) The option of having a feeding tube during radiation and chemotherapy, when the ability to eat and swallow was affected most, was presented to patients as their own choice (Alberda p. 668)
		No choice- tube is a necessity	As most patients had the gastrostomy placed in preparation for radiotherapy to the head and neck, the tube placement was perceived to be part of a treatment package that included radiotherapy and the removal of teeth rather than a decision in its own right (White p. 1049) Others found it easier to accept enteral feeding and viewed the tube as a necessity (Williams p. 2) There was discussion about participants feeling there was no choice in the matter; the tube was viewed as a necessity (Kwong p. 529)

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Table 5 (*continued*)

Synthesised finding	Categories	Findings
	Overwhelmed by choice	From diagnosis with cancer, decisions regarding the treatment plan were being made very quickly and there was little time to think too far into the future (White p. 1049) Participants informed that they have ENT cancer described having to cope with the shock of the diagnosis; the treatment plan; the removal of teeth; in addition to the need for a gastrostomy (White p. 1048) Participants were faced with many difficult decision regarding treatment options. When a PEG tube was offered as a supportive measure for nutrition during treatment, participants often struggled with the decision to accept it's placement (Kwong (p. 528) Several participants thought that being asked to consider the potential consequences of being on [home enteral feeding] may have been too much information and even discourage patients from having the tube placed (White p. 1048) Some felt that being asked to fully consider the impact of [home enteral feeding] may have caused additional anxiety and were content with dealing with any adverse consequences as they occurred (White p. 1048)
	Value having a choice	All of the participants described strong rationale for their selection of enteral feeding 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. (Williams p. 3) 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 (Williams p. 3) Most participants had undergone radiotherapy for ENT (Ear Nose and Throat) cancer, and decided to have the gastrostomy placed thinking that it would maximise their chances of a successful outcome (White p. 1047) Participants coped well if they had control over the choice of enteral tube; the timing of the commencement of enteral feeding; and their enteral feeding regimen and tube care. Most did describe control over these aspects during their treatment and, as a result, appeared to cope well (Williams p. 3)
4 Physical discomfort related to FTs may be experienced by patients with HNC, such as discomfort with the presence and insertion of FTs, NGT related nose and throat irritation, or G-tube insertion site pain.	Gastrostomy site	Despite the fact that the negatively loaded statements suggest that the respondents had no real feeding problems with the PEG tube, they nonetheless reported a number of negative concerns, such as … having problems with the site. (Merrick p. 500) Other negative problems described by the patients were … that the stomach area around the PEG tube hurt (Ehrsson p. 287) Patients with PEG more frequently reported problems with … pain around the stoma compared to patients with NGT (Ehrsson p. 287)
	Nose, throat and gastrointestinal	Other negative problems described by the patients were about having the tube), how it was irritating to have the NGT in the nose and throat (Ehrsson p. 287) Patients with NGT talked more about irritation in the nose and throat, drooling, viscous phlegm, and feelings of nausea when eating than did patients with PEG (Ehrsson p. 287)
	Tube presence and insertion	A typical experience for patients having PEG was that the tube was disturbing and uncomfortable (Ehrsson p. 287) In comparison with patients with NGT, patients with PEG more often stated that the manner of insertion of the PEG tube was a negative experience (Ehrsson p. 287) Participants described the presence and insertion of a NGT as uncomfortable (Williams p. 2) Participants described varying experienced of G-tube insertion ranging from those who found the procedure easy, to those who described significant pain and discomfort. (Williams p. 2) Two participants suggested that they regretted having the tube placed (P1 and P3). They believed that the placement of a gastrostomy had not met their expectations. Notably, they were also the only participants who experienced significant distress relating to tube placement and the impact of [home enteral feeding] (White p. 1050)
5 For patients with HNC, FTs may place restrictions on their social life and activities of daily living, negative social and daily life experiences may include missing eating, relationships and self-consciousness.	Activities of daily living	Other participants recognized the PEG tube as not fitting into a normal lifestyle (kwong p. 530) [home enteral feeding] tubes placed restrictions on hobbies, holiday plans, physical activity and return to work (Williams p. 4) They felt unhygienic, for example, as the tube was disturbing when they tried to sleep (Ehrsson p. 287)
	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 (Williams p. 4) Some patients also described that they missed eating and drinking orally (Ehrsson p. 287)
	Relationships	Although only one of the participants identified that [enteral feeding] 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 (Williams p. 4) One issue brought up was intimacy (Mayre-Chilton p. 453)

	Self-consciousness	For others, there was stigma associated with the tube (Kwong p. 530) In comparison with patients with NGT, patients with PEG stated less often that it was embarrassing. (Ehrsson p. 287) 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 (Williams p. 4) Participants with NGTs experienced anxiety over public reaction which influenced their confidence in socialising (Williams p. 3) Patients with PEG more frequently reported problems with the unhygienic feeling of the PEG tube with regard to leakage and a bad odour (Ehrsson p. 287) 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 (Williams p. 3) They felt unhygienic, for example, as the tube was disturbing when they tried to sleep, and they felt embarrassed being around other people (Ehrsson p. 287) Typical for patients with NGT was that they felt embarrassed because part of the tube is visible, which in turn hindered social activities (Ehrsson p. 287)
	Social life impact	There was a negative impact of perception and feelings of both groups, specifically for the social aspects of their lives (Mayre-Chilton p. 453) There were discussions around socialization and daily living. Some participants reported no problems (Kwong p. 529) When making the decision P11 admitted being a 'stick your head in the sand type of person' but was surprised by the impact that [home enteral feeding] had on her home life, describing the effect on her social life as 'massive' (White p. 1050)
6 Having a FT may result in new challenges and responsibilities for patients with HNC, including finances, feeding regimen burden and tube use and maintenance.	Finances	Issues about waiting for funding for a low profile gastrostomy tube by the Primary Care Trust were expressed as a negative impact (Mayre-Chilton p. 455)
	Feeding regimen burden	For some participants, the [enteral feeding] regimen was particularly restrictive and time consuming. (Williams p. 4) The negative aspects described in the interviews by the patients concerned problems with the feeding procedure as it was time-consuming and for some patients it was difficult to manage to take all the planned nutritional bags per day (Ehrsson p. 287)
	Tube use and maintenance	Insertion, care, and use of a PEG tube added additional elements to manage, which greatly affected the participants' daily lives. Activities described included tube and equipment care, feeding, ensuring adequate nutrition and hydration, and administration of medication. There was much discussion around the work associated with the maintenance of the tube (Kwong p. 529) Some participants commented on spillage (Kwong p. 529) They also described practical difficulties with handling the tube and in connection to the feeding procedure (Ehrsson p. 287) Unlike the many disadvantages that participants considered to be associated with NGTs, those participants with G-tubes considered the restrictions of the [enteral feeding] regimen the main disadvantage associated with the tube (Williams p. 4)
7 Patients with HNC may become more accepting of the FT over time by adapting their routine, through developing coping strategies, if the FT is less burdensome than expected, by receiving social support and when eating orally becomes a significant struggle.	Adapting to daily life	Caring for the tube became easier with time suggesting that these participants adapted effectively to their situation (Merrick p. 498) Despite changes to the way of life they were accustomed to, most participants described how they adapted to being on [home enteral feeding] by adopting a new routine. (White p. 1050) Participants were able to learn, manage and incorporate many tube-related activities into their livese. To some, there was a sense of normalization; the tube became part of their routine (Kwong p. 529) The ability to adapt was reflected in the way participants described getting used to the presence of the tube; the change to their daily routine (White p. 1050)
	Developing coping strategies	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 [enteral feeding] and the care of their [enteral feeding] tube (Williams p. 4) Both patients and caregivers demonstrated the development of strategies to help them cope with changes in their daily lives as a result of the gastrostomy tube. In the case of patients most positive outlooks and strategies were observed in accepting decisions, as well as in the areas of daily, lifestyle and social activities (Mayre-Chilton p. 452)

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Synthesised finding	Categories	Findings
		For patients who recognized that swallowing function might be impaired, a desire to prevent negative consequences such as reliance on a gastrostomy tube was identified as an important facilitator for initiating swallowing exercises (Govender p. 566)
		Participant attempts to reduce financial burden to the NHS by minimising the waste of feed and equipment (Williams p. 4
		Participants gave consideration to bolus and overnight pump regimens to reduce the burden of the [enteral feeding] regimen. (Williams p. 4)
		Participants learned how to adapt to the tube and discovered strategies that worked well for them (Kwong p. 530)
		Participants liked the option of either bolus feeding via syringe or gravity drip depending on their lifestyle and preference (Kwong p. 530)
		Participants mentioned various strategies for oral intake that included soaking foods, adding gravies and sauces, eating slowly, carrying water, and trialling different foods (Kwong p. 531)
		Personal control appeared to have been significant in how participants coped with having an [enteral feeding] tube and with [enteral feeding]. Participants coped well if they had control over the choice of enteral tube; the timing of the commencement of enteral feeding; and their enteral feeding regimen and tube care. Most did describe control over these aspects during their treatment and, as a result, appeared to cope well (Williams p. 3)
		Some participants appeared to use downward comparison as a coping strategy e comparing themselves to others whose problems were worse than their own, enabling them to view their own situation in a more positive light. (Williams p. 4)
		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 (Williams p. 3)
	Less burdensome than expected	Being able to go out because no one could see the tube was also a distinguishing statement. (Merrick p. 498)
		On reflection, most participants generally felt that being on [home enteral feeding] was less of a burden than they thought it would be. (White p. 1050)
		The tube was easier to look after than expected as was the process of feeding. There was no mess associated with feeding; organising it around hospital visits was not considered problematic and it did not preclude holidays (Merrick p. 500)
	Social acceptance and support	Participants thought being honest, comfortable, and inclusive of others made interactions easier (Kwong p. 530)
		Some patients expressed a lack of active care after their treatment and discharge into the community, which had a negative impact on them (Mayre-Chilton p. 455)
		Some required support for feeding while others did not (Kwong p. 530)
		The patients and care-givers expressed a positive impact on approaching the hospital multidisciplinary team, especially those patients receiving radiotherapy who attended the weekly treatment multidisciplinary clinic, where they had access to the registrar, dietitian, nurse and other professionals in one clinic (Mayre-Chilton p. 455)
		There was divided opinion on the role of the family in support with [enteral feeding] tubes and with [enteral feeding]. Only one participant described a reliance on her husband to support her with [enteral feeding]. Other participants involved family members as a way of supporting that family member. (Williams p. 3)
		Timely dietetic management helped them wean off tube reliance with more confidence (Mayre-Chilton p. 454)
	The struggle to eat	Initially, participants did not realize how difficult oral intake would become as treatment progressed (Kwong p. 529)
		Participants experienced many nutrition-related concerns during treatment that influenced their decision to accept a medical/dietetic recommendation for enteral feeding. 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 enteral feeding during treatment (Williams p. 2)
		Participants experienced various nutrition-related concerns that affected the decision to have a PEG tube placed, including pain, swallowing issues, and significant weight loss. These difficulties were related to side effects of treatment or symptoms of the cancer, including xerostomia, taste alterations, and trismus (Kwong p. 529)
		Participants' described a steady decline in their oral intake as treatment progressed. (Kwong p. 529)
		The ability to adapt was reflected in the way participants described … their inability to take oral diet (White p. 1050)

8 For patients with HNC, transitioning from a FT to an oral diet can be a challenging, learning and rewarding process, as experiences may include oral intake discomfort, removal impatience and tube dependence.	Gradual progression	Individuals described feeling rewarded by small improvements in their swallowing which motivated them to do their exercises in the hope that they could achieve more. This included receiving positive feedback about the outcome of doing their exercises (for example increased mouth opening, seeing with biofeedback that they could reduce aspiration) or experiencing an improvement in function such as the ability to drink something after a long period of being unable to (Govender p. 566) Participants mentioned various strategies for oral intake that included soaking foods, adding gravies and sauces, eating slowly, carrying water, and trialling different foods (Kwong p. 531) They felt their lives could go back to some sort of normalcy (kwong p. 531) Transitioning was described as a gradual progression and a learning experience (Kwong p. 530) While challenging, participants saw a gradual improvement in their eating/oral intake (Kwong p. 530)
	Oral intake discomfort	Both groups expressed the difficulties in weaning off the tube onto oral foods. Overall, the data highlight the many influential factors, such as taste, smell, lack of saliva, pain, length of time taken to eat (Mayre-Chilton p. 454) When asked to describe the first experience of returning to an oral diet, participants used words like "weird", "strange", and "unexplainable"(Kwong p. 531)
	Removal impatience	Despite the fact that the negatively loaded statements suggest that the respondents had no real feeding problems with the PEG tube, they nonetheless reported a number of negative concerns, such as the desire to have the PEG removed. (Merrick p. 500) Distinguishing statements included looking forward to having the tube removed (Merrick p. 500) Most participants reported frustration at the time it had taken for their dysphagia to resolve, and the subsequent effect it had on the length of time the gastrostomy had remained in-situ (White p. 1050) Most participants were either awaiting gastrostomy removal or heralded some hope of future tube removal. (White p. 1048)
	Tube dependence	There was an awareness of eating and understanding foods needed to have value (Kwong p. 530) Both groups expressed many possible reasons that prevented them from weaning off the gastrostomy tube onto normal foods. Overall, the data highlight the many influential factors, such as … psychological concerns, that the tube feeding helps them to cope with (Mayre-Chilton p. 454) For some, there was a dependence on the tube (kwong p. 531) Participants celebrated tube removal but, at the same time, were fearful of no longer being able to rely on the tube (Kwong p. 531) Timely dietetic management helped them wean off tube reliance with more confidence (Mayre-Chilton p. 454)
9 Patients with HNC may recommend a FT to other patients as an overall worthwhile experience, as a FT may help with managing disease and treatment side effects, prevent nutritional decline, relieve the fear of choking, be a source of reassurance through treatment and be associated with survival.	Benefits outweigh the negatives	Having a tube attached is an inconvenience but lifesaving (Osborne p. 664) Most patients felt they did not regret having the tube placed and would make the same decision again. This is despite experiencing some of the negative impacts of being on [home enteral feeding] (White p. 1050) The benefits outweigh the negatives (Osborne p. 664) While viewed as a slight inconvenience, all participants recognized the value that the PEG tube held (kwong p. 531) With the benefit of hindsight some patients accepted that they needed to have the tube placed (White p. 1049)
	Managing cancer and treatment side effects	Participants referred to the PEG tube as something they had to have in order to endure their cancer and treatment experience (Kwong p. 531) Participants valued their tubes … in supporting recovery. (Williams p. 3) The tube was viewed as a functional benefit—equipment that helped participants manage side effects of cancer treatment (Kwong p. 531)
	Prevented nutritional decline	Both groups found the main benefit and positive impact of the tube placement to be weight management (Mayre-Chilton p. 453) Initially, participants did not realize how difficult oral intake would become as treatment progressed (Kwong p. 529) Participants also acknowledged that the PEG tube either stopped or reduced their weight loss as it provided them with an alternate means of obtaining nutrition (Kwong p. 531) Maintaining nutritional intake, weight control … were amongst the positive outcomes mentioned. (White p. 1047) Participants, who described their expectations being met, generally referred to how being on [home enteral feeding] had facilitated the achievement of a positive outcome, including … maintaining nutritional intake (White p. 1050 Participants recognized the problem-solving value of the PEG tube (Kwong p. 531)

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Table 5 (*continued*)

Synthesised finding	Categories	Findings
		Participants valued their tubes in practical terms (nutrition, fluid and medication provision) (Williams p. 3)
		Realised they would have lost weight without it (Ehrsson p. 287)
		The PEG tube was also identified as some patients' sole source of nutrition (Kwong p. 531)
	Relieved fear of choking	Participants made comments about the emotional/psychological benefits that having a PEG tube provided as it helped relieve the fear of choking and the pain with swallowing (Kwong p. 531)
		Participants, who described their expectations being met, generally referred to how being on [home enteral feeding] had facilitated the achievement of a positive outcome, including preventing choking (White p. 1050
		Preventing aspiration … amongst the positive outcomes mentioned. (White p. 1047)
	Source of reassurance	Issues around reassurance when unable to eat also featured strongly (Merrick p. 498)
		The PEG tube gave a sense of hope to participants (kwong p. 531)
		They also acknowledged the emotional/psychological benefits of an [enteral feeding] tube including making life easier; providing a relief from worry and the pain of eating; and providing reassurance (Williams p. 3)
		They did not have to battle with each meal and to worry about not getting beverage and food, they received calories (Ehrsson p. 287)
		They had underestimated how difficult maintaining oral intake would be during treatment (Williams p. 2)
		Tolerating treatment … amongst the positive outcomes mentioned. (White p. 1047)
	Survival	Overall, both groups expressed a positive impact for having the gastrostomy tube placed before any further cancer treatment because they recognised that they would not have survived without it (Mayre-Chilton p. 455)
		Participants often described the tube as having saved their lives (Kwong p. 531)
		Participants perceived had they not had the gastrostomy placed, they would not have been able to take adequate oral diet, which may have had serious consequences in terms of their prognosis (White p. 1049)
		Participants, who described their expectations being met, generally referred to how being on [home enteral feeding] had facilitated the achievement of a positive outcome … and in many cases survival (White p. 1050
		Survival were amongst the positive outcomes mentioned. (White p. 1047)
	Would recommend to others	All participants would recommend to future patients that they have a tube placed if recommended by their healthcare professional (Kwong p. 531)
		Because the value of the [enteral feeding] tube was recognised, all participants recommended that future patients have [enteral feeding] tubes placed if advised, with only one participant recommending the alternative tube (G tube) to the one he had decided on (NGT) (Williams p. 3)
		Two individuals who did not find the PEG tube worthwhile themselves would still recommend it to someone else (Osborne p. 667)
		When asked what they would tell another patient about their experience with having a PEG tube, 51% independently responded with the same spontaneous message of “get it.” (Osborne p. 664)

a gastrostomy tube (primarily a PEG) [39–41,47–49]. Hence several findings relate to the experience of having that specific type of FT. For example, nose and throat irritation was a physical symptom that was only voiced by patients with an NGT [42,51], whereas gastrostomy insertion site pain was only voiced by patients with a gastrostomy tube [40,42,51]. Interestingly, it is apparent that patients may be reluctant to have a PEG placed pre-treatment due to concerns of the surgical procedure [40–42]. However, those that initially decline a PEG tube and then need a reactive NGT placed later in treatment may experience a sense of regret due to the social stigma attached to the visibility of a NGT [42,51]. Comparatively, one of the factors that helped patients who had a PEG tube accept their FT, was the discretion that it offered [40]. These experiences of patients are supported by a randomised trial that found that patients with an NGT experienced greater altered body image and greater FT related interference with social activities, compared to patients with a PEG [25]. This is an important finding that should be considered and discussed with patients with HNC who could benefit from a FT, to help them make an informed decision about FT type.

FT dependence is a central argument in the debate around whether a reactive NGT approach is better than placing a PEG tube prophylactically, to minimise the risk of permanent swallow function impairment [30,59,60]. This review confirms that patients can feel emotionally dependent on the tube, which can present a challenge to transitioning off the FT [41,49]. The evidence also suggests that patients can appreciate the risk of swallow function decline from lack of use [42,48,50]. This can be a reason why some patients are reluctant to have a PEG tube, but for others it can be a source of motivation to adhere to swallow exercises throughout treatment [42,47,50]. The evidence summarised from this review indicates that access to dietetic support can help patients overcome feelings of dependence and help them to wean off the tube with more confidence [47,49]. Therefore, this supports other research which shows that if patients have regular access to a speech pathologist for swallow therapy and to a dietitian to facilitate a patient's transition from the FT, tube dependence is a manageable concern [61–63]. This is a particularly important consideration if a PEG is more appropriate due to the patient's individual preferences [42,51].

4.1. Limitations

The potential for bias in each of the nine studies included in this review is recognised. However, the nine studies reported strategies to minimise bias, such as adequately representing participant voices through the inclusion of direct quotes, disclosing potential author biases and including their theoretical and cultural backgrounds. Furthermore, this review helps to validate the individual findings from each study, as all the synthesised findings were saturated with examples from most of the included studies. Despite implementing a systematic search strategy guided by The Joanna Briggs Institute [45] it is possible that some qualitative studies may have been missed. Qualitative studies can be more difficult to find, as it is accepted that the level of indexing and archiving is poorer than for quantitative studies [64]. Studies conducted following this literature search were not included. Additionally, only articles available in English were included with the majority carried out in the United Kingdom. As HNC incidence rates are high among many other countries around the world including India and Central Europe [65] and as experiences can be culturally and socially influenced [58] this could restrict the transferability of results to other populations. This review may need to be updated in the future as new studies emerge and to include those written in other languages.

5. Conclusion

From this review, having a FT while undergoing treatment for HNC can be an evolving experience for patients. Initially patients may feel a sense of reluctance, fear and uncertainty and experience physical and social life challenges related to the new experience of having a FT. However, a sense of acceptance through adaptation often occurs, along with a challenging but rewarding transition process back to oral intake. Overall, having a FT placed when it is recommended is typically perceived by patients as a worthwhile decision while undergoing treatment for HNC. These synthesised findings highlight the nutrition-related challenges faced by patients undergoing treatment for HNC and support the need for interdisciplinary healthcare teams, which include regular access to dietitians and speech pathologists. Furthermore, the synthesised findings support the need to adopt an individual patient-centred approach to FT placement decision-making for patients, which includes hearing the experiences of other patients, as summarised in this review. Further qualitative and well-designed quantitative studies are needed to provide deeper insight into patient and cancer-service structural factors that may influence patient experiences with a FT to ensure that future decisions are evidence-based and patient-centred for best outcomes.

Statement of authorship

EH and SG were involved in conceptualisation, data curation, formal analysis, investigation, methodology development and implementation. EH completed the first draft of this paper. KW, AM, MM and LT provided research questions and design support, supervised the project and critically reviewed the results and edited the draft paper. All authors critically reviewed and agreed upon the final version of this paper for submission.

Conflicts of interest

None declared.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.clnesp.2019.07.005.

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