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# “Change the sales pitch”: A qualitative study of patient perspectives on discussing enteral nutrition in head and neck cancer

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# Abstract

**Background:** People with head and neck cancer (HNC) are at high risk of malnutrition and may require enteral nutrition (EN). How EN is initially communicated may influence patients' understanding, expectations, and preparedness for this aspect of treatment. However, little is known about what information people with lived experience of HNC and EN consider most important when EN is first introduced as a potential intervention. Therefore, in collaboration with patient partners, the aim of this study was to engage people with lived experience of HNC and enteral feeding to co-design a conversation guide for oncologists introducing the possibility of EN to patients.

**Methods:** In January and March 2026, two focus groups were conducted with nine HNC survivors who had received EN. Focus groups were co-facilitated with a patient partner, recorded, transcribed verbatim, and analyzed using thematic analysis.

**Results:** Four themes emerged: (1) reframing tube feeding from threat to support; (2) the value of the interdisciplinary team in tube feeding management; (3) the need for self-advocacy; and (4) from fear and challenge to gratitude. Recommendations for healthcare providers were also developed from pragmatic suggestions raised during the focus groups.

**Conclusion:** These findings highlight the importance of introducing EN as a supportive intervention, while providing clear, practical information and engaging the broader interdisciplinary team in ongoing education and support. The study demonstrates how people with lived experience can contribute directly to shaping both research and the way healthcare information and supportive care are delivered.



# Plain English Summary

People with head and neck cancer are at high risk of malnutrition and may need a feeding tube during treatment. How feeding tubes are first discussed may affect how prepared and supported patients feel. In collaboration with two patient partners, this study explored what information is most important when feeding tubes are first introduced. Two focus groups were held with nine head and neck cancer survivors who had used a feeding tube. Participants described four main experiences: seeing the feeding tube as a support rather than a threat, valuing help from the wider healthcare team, needing to speak up for themselves, and moving from fear and difficulty toward acceptance and gratitude. Participants also suggested practical ways healthcare providers could improve these conversations. The findings highlight the importance of clear, supportive communication, practical information, and ongoing education from the broader healthcare team.


# 1. Background

Head and neck cancer (HNC) is the sixth most common cancer worldwide, accounting for approximately 5% of all cancer diagnoses. In 2022, nearly 950,000 people were diagnosed with HNC globally[1], with an

estimated 8,200 new cases expected in Canada in 2026 [2]. HNC encompasses malignancies of the lip and oral cavity, larynx, nasopharynx, oropharynx, hypopharynx, and salivary glands.

People with HNC are at high risk of malnutrition, with many already experiencing malnutrition at the time of diagnosis [3–5]. The causes are multifactorial and often compounded throughout the disease trajectory. Tumours located near structures involved in chewing and swallowing can impair oral intake, resulting in inadequate energy and nutrient intake and poor diet quality. Tumour-associated inflammation can also alter metabolism, suppress appetite, and contribute to loss of lean body mass and the development of pre-cachexia, cachexia, or refractory cachexia [5, 6]. Smoking and excessive alcohol consumption, established risk factors for HNC [7], may further compromise nutritional status through poor diet quality, micronutrient deficiencies, protein-energy malnutrition, altered nutrient requirements, and impaired digestion and absorption [8–10]. Malnutrition among people with HNC is associated with poorer treatment tolerance, impaired wound healing, reduced quality of life, and poorer survival [11]. Consequently, prevention and management of malnutrition are important components of multidisciplinary HNC care.

When oral intake is insufficient or unsafe, enteral nutrition (EN) can be used to provide nutrition, hydration, and medications directly into the gastrointestinal tract. EN can help maintain nutritional status during treatment and, in some circumstances, may be a life-saving intervention [12]. However, feeding tube insertion and enteral feeding are associated with potential complications, including infection, bleeding, perforation, tube blockage or leakage, aspiration, and errors related to administration or tube connections [13, 14]. Initiating nutrition support in people who are severely malnourished may also increase the risk of refeeding syndrome [15]. Thus, decisions regarding EN require consideration of its potential benefits, risks, and impact on the patient experience. Given the potential significance of EN during HNC treatment, clear and timely communication is important to ensure patients understand and are prepared to make an informed decision about enteral feeding.

BC Cancer (BCC) is a provincial network of six tertiary outpatient cancer centres serving residents of British Columbia, Canada. For people with HNC, the possibility of requiring EN is often introduced during the initial consultation with a radiation oncologist. This consultation also involves discussion of the patient's diagnosis, prognosis, and treatment options, resulting in a substantial amount of complex information being communicated at a distressing time [16, 17]. How information about the potential need for EN is initially communicated may therefore influence patients' understanding, expectations, and preparedness for this aspect of treatment. Little is known about what information people with lived experience of HNC and EN consider most important when EN is first introduced as a potential component of their treatment.

Understanding these perspectives may help clinicians provide information about EN in a way that better prepares patients for treatment and supports informed, patient-centred discussions. Therefore, the aim of this study was to collaborate with patient partners to engage people with lived experience of HNC and enteral feeding to co-design a conversation guide for oncologists when introducing the possibility of EN

to patients. The research question was: What discussion points do people with lived experience of HNC and enteral feeding consider important for oncologists to include when introducing EN as a potential component of treatment?

## 2. Methods

# 2.1 Ethics

The study was conducted in accordance with the Declaration of Helsinki and approved by the Institutional Review Board of BC Cancer- University of British Columbia (UBC) (H25-00057 on May 16, 2025). Informed consent was obtained from all subjects involved in the study. Consent was maintained by reviewing key consent principles at the beginning of each focus group.

# 2.2 Participants and recruitment

Potential participants were recruited using convenience sampling, with a target of 4–10 participants per focus group. Recruitment materials were distributed through the BCC Head and Neck Support Group, members of the interdisciplinary HNC care team, social media, and REACH BC (a patient oriented, online, health research study platform) [18]. Interested individuals were screened according to the eligibility criteria outlined in Table 1. Those who met the eligibility criteria were contacted by telephone and invited to participate. Informed consent was obtained prior to participation. Depending on participant preference, consent was completed by mail, email, or electronically using REDCap software [19]. Participants received a copy of their completed consent form by mail or email, according to their preference.

Table 1
Inclusion and exclusion criteria.

| Inclusion | Exclusion |
|---|---|
| Carcinoma of (any stage):<br><br>Lip, oral cavity, larynx, nasopharynx, oropharynx, hypopharynx, salivary glands, parotid | Cancers other than head and neck |
| Location: Treated at a BCC centre (6 centres) | Location: Not treated at a BCC centre |
| Feeding tube type: any (e.g., nasogastric, gastrostomy, etc.) | Did not receive feeding tube |
| Treatment: Radiation therapy, +/- chemotherapy, +/- surgery, best symptom management (Pain and Symptom Management Clinic, for example) | Treatment: No treatment |
| Timeframe:<br><br>Received/completed treatment within the previous 2 years | Timeframe:<br><br>Received/completed treatment over 2 years ago |
| Age: adults (age 19 + years) | Age: <19 years |
| Language: English (verbal skills for focus group) | Language: Unable to speak proficiently in English |

## 2.3 Focus Groups

Two virtual focus groups were planned, with a target of 4–10 participants per group. This group size was selected to capture a diversity of experiences while remaining small enough to facilitate meaningful discussion and sharing among participants [20]. Focus groups were conducted using a secure, UBC-hosted version of Zoom and were approximately 75 minutes in duration. Sessions were audio- and video-recorded.

A semi-structured focus group guide (Supplementary Material A) was co-developed by the research team and two patient partners with lived experience with HNC and EN. The guide included a combination of primary and follow-up questions while allowing sufficient flexibility for the natural progression of discussion [20]. The approach was informed by phenomenological and trauma-informed principles, with questions and discussions centred on participants' experiences of HNC and EN. The focus group format also provided an opportunity for participants to reflect on and respond to the experiences shared by others, facilitating exploration of both common and differing perspectives.

Each focus group was facilitated by two clinician investigators, both experienced in working with people with HNC, and one patient partner. Facilitators followed the semi-structured guide while allowing participants to introduce and expand upon topics they considered important.

Regarding researcher positionality, the primary researcher (ES) is a female dietitian and researcher with prior training and experience in qualitative and patient-oriented research. The other two clinician

investigators (AN, LVM) are also both female dietitian with expertise in head and neck cancer. Two patient partners with lived experience with HNC and EN informed the research methods, with one patient partner (BS) co-facilitating the focus groups. No researcher was involved in the clinical care of any focus group participants.

## 2.4 Data Collection and Analysis

The focus groups were audio- and video-recorded and transcribed verbatim using Zoom's embedded transcription software. Transcripts were manually reviewed against the recordings and corrected for accuracy prior to analysis. Transcripts were thematically analyzed using NVivo [21] 14.23.2 qualitative data analysis software, following an inductive-deductive approach informed by Braun and Clarke [22, 23]. Codes were developed iteratively and refined throughout the coding process. Two researchers (AN, ES) independently coded the transcripts and subsequently compared and discussed their coding to reach consensus. A third researcher (LVM) was available to review and discuss discrepancies when consensus could not be reached.

Following initial coding, the researchers reviewed and refined the codes, including merging overlapping or related codes. Codes were then organized into broader conceptual categories, which informed the development of themes and subthemes. The themes and subthemes were reviewed and refined through discussion with the broader research team, including a patient partner (BS).

As a method of participant validation, preliminary themes and subthemes were shared with focus group participants, who were invited to provide feedback, including confirmation, corrections, or additions. Participant feedback was incorporated into the final interpretation of the findings. Study methods and findings are reported in accordance with the Consolidated Criteria for Reporting Qualitative Research criteria [24].

# 3. Results

## 3.1 Participant Demographics

A total of nine HNC survivors participated in two focus groups conducted in January and March 2026, with four participants in the first group and five in the second. Comments from our patient partner (BS) was also included in the analysis as survivor of head and neck cancer with experience with EN. The majority (78%) of participants were males with a median age of 66 years. All participants had a squamous cell carcinoma with six distinct tumor locations represented, with base of tongue beginning the most common (45%) with all stages represented. See Table 2 for participant demographics.

Table 2
Participant characteristics at the time of focus group participation, n = 9.

| Characteristic | Count (percentage) |
|---|---|
| Age | Median, 66 (52–73) |
| Sex | |
| Male | 7 (78) |
| Female | 2 (22) |
| Non-binary | 0 (0) |
| Tumor location | |
| Hypopharyngeal | 1 (11) |
| Base of tongue | 4 (45) |
| Oral tongue | 1 (11) |
| Glottic larynx | 1 (11) |
| Epiglottis | 1 (11) |
| Tonsil | 1 (11) |
| Staging at time of diagnosis | |
| I | 2 (22) |
| II | 3 (33) |
| III | 3 (33) |
| IV | 1 (11) |

## 3.2 Coding and themes

A total of 52 unique codes were applied across both focus groups, with 388 references. The frequency and patterns cross the codes informed four themes, each containing several subthemes (Table 3). While the interview guide followed the structure of the research questions, additional themes emerged that were relevant to tube feeding in head and neck cancer but extended beyond the research questions. The four themes were: reframing tube feeding from threat to support; the value of the interdisciplinary team in tube feeding management; the need for self-advocacy; and from fear and challenge to gratitude. The themes were validated by study participants and the patient partner. Lastly, a list of recommendations for healthcare providers was developed based on pragmatic suggestions raised during the focus groups.

Table 3
Themes and subthemes from focus groups.

| Theme | Subtheme |
|---|---|
| 1. Reframing tube feeding from threat to support | A. Reframe the conversation: Present TF as a potential part of treatment rather than as a consequent of not eating enough or as a sign of failure.<br><br>B. Tube feeding is a lifeline: Earlier placement may provide support and ease challenges as treatment progresses<br><br>C. From initial burden to a valued support: TF may initially feel psychologically, emotionally, and physically challenging but can become a valued support over time. |
| 2. Value of the interdisciplinary team in tube feeding management | A. Empower the broader health care team to support TF discussions: Recognize time constraints within oncology care and enable other healthcare providers to participate in TF education and decision-making.<br><br>B. Supportive relationships with allied health providers (dietitian, SLP): Positive relationships with dietitians and speech-language pathologists were valued throughout the TF experience |
| 3. Need for self-advocacy | A. Advocating for a feeding tube: Need for persistence when a FT felt necessary.<br><br>B. Navigating communication gaps across care settings: Challenges were particularly evident when care involved multiple institutions.<br><br>C. Limited supports for managing TF: Gaps in practical and ongoing support for FT<br><br>D. Desire for standardization in TF care: Variation in tube types, sizes, and supplies placed additional responsibility on patients to obtain supplies |
| 4. From fear and challenge to gratitude | A. Fears, stress, worry around FT: Emotional distress around the possibility of needing a FT<br><br>B. Challenges across the treatment trajectory: Challenges through treatment and recovery<br><br>C. Gratitude for TF: Despite initial challenges, patient expressed gratitude for the support of TF.<br><br>D. Desire to improve care for future patients: Reflections on lived experienced highlighted opportunities to improve tube feeding care for others. |

## 3.2.1 Reframing tube feeding from threat to support

The first theme, reframing the tube feeding from threat to support, was by far the largest and most consistent theme across participants in both focus groups. The code “threat” was one of the most frequently applied codes, with 17 references. Participants described a need to change the conversation

around tube feeding so that it was not presented as a consequence of inadequate effort or eating, but rather as a supportive tool through treatment. "*I feel it was almost presented like a punishment. If you don't eat well, you don't keep up with your eating, then we're going to put you on a feeding tube.* (P1)"

Nearly all participants described feeling threatened by the possibility of needing a feeding tube. "'*But if you're not being careful and making sure you're getting all the calories you need, we may end up needing to do a feeding tube, and you really don't want that.' That is not the right conversations to have around it. That shouldn't be the first thing you hear about a feeding tube.* (P3)"

This negative framing influenced participants initial perception of tube feeding and contributed to additional stress. Participants described receiving the impression that "*getting a [feeding tube] is an absolute last resort. And I kind of ran with it from there.* (P4)" "*I don't think I understood the implications. When it was being discussed with me, I feel there should have been like a handout or something provided… because I kind of walked out of my initial meeting with my oncologist going, 'well that sounds terrible and I definitely don't want to do that.*' (P4)" For some, this framing was internalized: "*There's a lot of fear. I think because of the unknown, and there's a lot of unknowns, maybe I framed [tube feeds] myself in my mind it was a failure, but that's how I thought.* (P1)" One participant described this messaging as "*unintended shaming* (P2)," while another recalled "*that wag of the finger, you know, 'you don't eat properly we're going to give you the tube.*'"

Once participants received a feeding tube; however, many described it as a lifeline and expressed gratitude for having it. "*Once I got the feeding tube in, it really helped in terms of my anxiety around getting food in and taking my meds.* (P2)" Another participant reflected, "*I was also fearful of getting the feeding tube and, in hindsight, once again, it basically saved my life. Once it was in, it wasn't a big deal at all. In fact, it made life so much easier, and I finally have the energy to do things again.* (P8)" One participant wished the tube had been "*put in right from the very beginning.* (P6)" Participants suggested that their initial perceptions of tube feeding may have contributed to delaying placement. "*Because I didn't know, it's kind of like the fear of the unknown, and if I would have known it was that easy I probably would have had it put in earlier because once it was int, you know, my well-being went way up. I had more energy. I felt better.* (P5)" Another participant described tube placement as "*kind of a relief, actually, to get it done. Because at that point, it was such a struggle to drink, to keep hydrated, to try to deal with any kind of food, the Boost. It wouldn't go down, I was choking... If I didn't have [the tube] I don't think I'd be here.* (P1)"

This theme also highlighted how patients sometimes felt blamed or shamed for not eating enough, despite treatment side effects making oral intake extremely difficult. Participants described profound changes in taste and swallowing: "*Everything tasted either really really salty or very metallic. And everything tasted the same. Like I could eat a rubber boot and it would taste like eating a spoon.* (P6)" "*One of the first things to happen to me was my inability to swallow.* (P2)" As another participant summarized, "*There comes a time where you just can't eat anymore.* (P3)" Participants emphasized that rather than framing tube feeding as a consequence of inadequate intake, it should be introduced early as a potential

supportive care strategy during treatment. Ultimately, as one participant said, "*the sales pitch could be better, for sure.* (P4)"

## 3.2.2 Value of the interdisciplinary team in tube feeding management

The second theme reflected the value of the interdisciplinary team in the planning and management of tube feeding. Although less prominent than the first theme, it was woven throughout both focus groups. This was reflected in the coding, with "interdisciplinary team" referenced 27 times and "dietitian" 10 times. While the aim of the study was to develop speaking point recommendations for oncologist, who are often among the first team members to introduce feeding tubes to patients, participants noted that other members of the interdisciplinary team may be well-positioned to support these conversations. "*I only saw my oncologist, who was fantastic, once a week. But I saw the nursing staff 5 days a week and then, so you've got more of a relationship. They see what's going on day-to-day. They're the ones who are weighing you… And so by the time I saw my doctor, the oncologist, it was already recommended that I go on a feeding tube. So I agree that it's not solely the responsibility of the oncologist, I think it's the whole team as a whole.* (P1)"

Many participants described trusting relationships with members of the interdisciplinary team, including registered nurses, nurse practitioners, dietitians, counsellors, and speech-language pathologists. "*[My Registered Nurse] is fantastic! I had a very good relationship with her. She was a very, very kind person…and because I trusted her so much, I wasn't scared [about the tube feed].* (P1)" Similarly, another participant explained that their "*nutritionist was really good. She's the one that...said, you know, I think you better look at a feeding tube because I was loosing so much weight. So anything to do with the feeding tube I got from [my dietitian], not from the oncologist.* (P5)"

Based on these positive experiences, participants suggested that, given oncologists' competing demands and primary role in cancer treatment, other members of the healthcare team should also be empowered to lead or contribute to tube feeding discussions. "*I'm not sure the oncologists are really the best people to talk [about tube feeding] because, beyond the first meeting, I don't ever remember having a conversation with my oncologist about feeding tubes. It was always the nurse practitioner, the nurses at the clinic, the nutritionist, and the speech language staff. They're the ones who do the day-to-day work out of the clinics. (*P2)"

Allied health is part of the supportive care team. Mentions of allied health were consistently positive, with the codes "interdisciplinary team," "dietitian," and "good support" frequently co-coded. "*My team at BC Cancer Vancouver were absolutely incredible when it came to support around [my tube feed].* (P3)" "*I didn't really deal with my oncologists. I dealt with the BC Cancer clinic nurses and they were phenomenal. Like the communication and caring was second to none. At the end of the day, it was the nurses, the nutritionists, and the speech-language pathologist who really provided me the most ongoing kind of outreach throughout the whole treatment.* (P2)"

These experiences highlighted the role of allied health and nursing in providing ongoing, wraparound support. "*I feel like I had balanced information because of the fact that I had an outside source. It might be worth dietitians and your nursing support systems framing it differently than your oncologist does. You know, those people who are closer to you and more informal.* (P3)" Building on this idea, one participant suggested that "*it might have been handy to able to speak to either a current or former patient. (P4)*"

## 3.2.3 Need for self-advocacy

An unexpected theme was the degree of self-advocacy participants described in navigating and managing their feeding tubes. Several participants felt they had to advocate to receive a feeding tube in the first place. "*My problems with feeding really started after they took the biopsy…and the whole mouth became infected and I had difficulties when I started my treatments. I spoke to the oncologist 'Why don't you just put the feeding tube in and be done with it?' and they said no, they're going to wait and while they're waiting, it cost me quite a bit. I lost a lot of weight because I was unable to eat, and then had 15 days without eating drinks, I had to go to the hospital for an IV… So…waiting for the feeding tube didn't work for me. I should have been put in right from the very beginning.* (P6)" Similarly, another participant recalled, "*Because they were doing to [discharge me home] and then come back [for the feeding tube] and I'm like 'No way! I'm staying in this hospital bed or be there until I get the tube.' So anyways, got the tube.* (P7)"

As participants described their experiences, a subtheme of navigating communication gaps across care setting and institutions emerged. "*Communication with me was wonderful. The communication between the hospital and BC Cancer was lacking. And that's, I think, what ended up being a bigger issue for me.* (P3)" Several participants described similar situations in which urgent tube feeding support was required on weekends when BC Cancer clinics were closed. When Emergency Department staff did not know which tube device or supplies were needed to resolve the problem, one participant described being "*kind of placed in a positions where I'll go the medical supply place and see what they've got and then you walk in there and they go 'Well, I need a produce number or a barcode or something to be able to know exactly what you're looking for.' So you kind of fumbled through a lot of this stuff.* (P2)"

Another subtheme was limited support for ongoing management of tube feeding, particularly its practical aspects. Several participants spoke positively about the education they received when the tube was first inserted: "*The orientation was just phenomenal. They really took their time and showed me how to use it, how to clean it, how it keep it clean and all that stuff. I consider myself really lucky.* (P8)" More than one participant expressed gratitude for the quality of this initial teaching but described limited ongoing support for troubleshooting problems, particularly when issues arose outside regular cancer clinic hours. Participants sometimes needed to seek care through Emergency Departments, placing additional responsibility on them to navigate between institutions and coordinate aspects of their own care.

Participants' extensive experiences of self-directed care also highlighted a perceived lack of standardization in tube feeding management. One participant summarized the group's concerns: "*Hopefully coming out of this kind of focus group will be some kind of standardization, as I said, about the products, the feeding through the products themselves, as well as maybe a bit of a connection from a*

*supply chain standpoint, in terms of having the products available, the tubes but also the best nutritional supplements.(P2)*" Participants described these challenges as broader system and process issues rather than solely staffing concerns. As one participant explained, "*This isn't a staffing issue, I found. It was more of kind a systemic thing where, you know, we need to hopefully take this feedback and fill in some gaps in terms of the system and the processes.* (P2)"

### 3.2.4 From fear and challenge to gratitude

The fourth theme captured the emotional journey participants described, from initial fear and challenges to eventual gratitude. Difficulties maintaining adequate nutrition and hydration were often deeply distressing. Six emotion-related codes were applied across 43 passages, with "fear" and "gratitude" among the most frequently applied. The prominence and equal use of these codes reflected the emotional trajectory described by many participants: initial fear about needing and adjusting to a feeding tube, followed by gratitude for the tube and for the support received in learning to manage it. "*I was told, like, 'We're going to put a hold through your abdomen and that's what you'll deal with through your treatment' and so, that terrified me right from the get-go.* (P4)" "*Because I never had one before, it's a little bit scary….But once I got the feeding tube in, certainly nothing to be scared of.* (P6)" Similarly, another participant reflected, "*I was also fearful of getting the feeding tube, and in hindsight, one again, it you know it basically saved my life and it wasn't a big deal at all. (*P8)"

Participants described a range of emotions related to tube feeding, including shock, stress, fear, and worry. Challenges occurred throughout the treatment journey, from before and during treatment to the post-treatment period. Despite these challenges, participants also expressed considerable gratitude for the care and support they received. "*I was really lucky because I had super invested caretakers.* (P3)" "*My treatment was incredible. The level of care that I received was out of this world. I talk about it with people all the time about how unbelievable the care was. (P3)*" "*The cancer clinic was wonderful.* (P8)" Reflecting on their experiences, there was consensus on the desire to improve tube feed care and support for future patients.

## 3.3. Recommendations for providers

Participants validated the need for more comprehensive information, explained in an empathetic manner, when tube feeding first introduced. *"Patients need practical information, but they also need someone to acknowledge what that information may mean for their identity, independence, relationships and social life. (P9)"* The primary recommendation was to reframe tube feeding as a supportive intervention during treatment rather than as a sign of failure, consistent with the first theme. Participants also suggested providing information in multiple formats, including videos, written handouts, and practical tutorials. Specific recommendations regarding the information oncologists should provide when first discussing tube feeding with patients are summarized in Table 4.

Table 4
Information oncologists and care providers should cover when discussions TF for the first time with patients.

| Recommendation | Explanation | Quote |
|---|---|---|
| Multi-modality information | Provide information in multiple formats (e.g., video, in print, etc) | "If you got an information package specifically around the feeding tube, right on the front end with everything else you get. That would have been more helpful. (P2)"<br><br>"A YouTube video about how to put your food in, how to put your medication it and all that stuff, and really specific to our brand. (P3)" |
| Offer a more balanced perspective | Present tube feeding as a supportive tool when eating becomes difficult. | "You'll get into the rhythm of using it… everything will be fine, you've got lots of support. (P3)" |
| Timing: earlier can be better | Avoiding delays in feeding tube placement may help patients maintain adequate nutrition through treatment. | "Get an effing feeding tube. It's not the end of the world. It'll give you 6 weeks of peace. (P3)" |
| Explain the basics | Explain what tube feeding involves and what patients can expect in daily life with a feeding tube. | "I don't feel like there was any sort, like, a pamphlet or brochure or anything that was given to me at the start to sort out, here are the A, B's, and C's, and this is what you can expect. (P4)"<br><br>"Issues like maintenance… keeping it clean, keeping it free of infection, how often do I have to go in to get it looked at? What is the process around all of that? Am I going to be in pain all the time? Will I be able to sleep? (P4)"<br><br>"Can I go off with someone for dinner?...When you go to the gym, how do you feel? That you've got to hide it? When you go swimming, now you've got to figure out what embarrassment I'm going to have, should I go swimming?...This is still a psychological situation… How do I handle this correctly? Where is the support for me in the system? (P9)" |
| Discuss managing complications | Potential complications should be discussed, including clear guidance on where and how to seek help, particularly outside regular cancer clinic hours. | "I wish somebody had told me the right hospital to go to when I threw [my NG tube] up. Because the hospital didn't know what they were doing, and I would prefer that the hospital have more training around our specific feeding tubes. (P3)"<br><br>"I would have preferred that both of those hospital had the materials they needed and the training to put them in properly. (P3)" |

| Recommendation | Explanation | Quote |
|---|---|---|
| Cover FT options (NG vs G) | Mention feeding tube options, including NG and G-tubes, and how long each may be needed. | “I want there to be a discussion about how there are options, because I didn’t know there were. (P4)”<br><br>“A lot of pain in the nose for that, so I would have rather had the g-tube in my stomach so that my coughing and all the phlegm from my lunch didn’t have to compete with the actual tube down my nose and down my throat. (P9)” |
| Offer upfront communication about treatment risk | Link treatment side effects to the potential need for tube feeding and provide local data to improve transparency around treatment risks. Include mention of swallowing difficulties. | “You’d have a pretty good percentage of people with squamous cell carcinoma that went through this, that you would be saying, ‘Well, 30% of you will probably have to go on a feeding tube’ or what that percentage is. (P10)”<br><br>“I don’t remember there being anything in my package about the feeding tube and that was pretty major. (P3)”<br><br>“It’s less a matter of what they could have said or not said. I think it’s a matter if they could just kind of present the information. (P3)” |
| Utilize the whole team is a resource | Introduce the roles of other healthcare providers involved in tube feeding education and support. | “The [ENT] who did the biopsy perhaps could have started the conversation already on the feeding tube log before the oncologist got involved. (P6)”<br><br>“I wonder if it’s maybe putting too much on the oncologist, and rather it on the nurse practitioner or the [General Practitioner in Oncology] or whoever’s there. (P6)”<br><br>“Could the nurse practitioner be discussing this with you, or…does it have to strictly be your oncologist? (P4)”<br><br>“The oncologist is super super busy. (P10)” |

# 4. Discussion

The findings from this study highlight the emotional burden associated with managing treatment-related side effects and enteral nutrition in HNC. The first theme, which emphasized reframing tube feeding as a source of support rather than something punitive or threatening, illustrates the emotional complexity surrounding both the diagnosis and its treatment. Notably, of all the questions posed during the focus groups, participants provided the least detail in response to questions about what their oncologist had told them about tube feeding. Most recalled that tube feeding had been mentioned but had difficulty remembering the specific information provided. In contrast, they clearly described the emotions

surrounding these conversations- the fear, uncertainty, and sense of being overwhelmed- as well as the lingering impact of these feelings as they processed the information over the days that followed.

Research suggests that the way medical information is framed can influence how it is perceived, a phenomenon known as the framing effect. Positively framed messages have been associated with more favourable perceptions of effectiveness than negatively framed messages, although differences in persuasiveness or subsequent behaviours have not been consistently observed [25]. Similarly, among individuals with advanced cancer, positive reframing has been associated with better quality of life and fewer depressive symptoms [26]. Although medical communication and decision-making are complex and influenced by multiple psychological processes [27, 28] our findings draw attention to the potential importance of how tube feeding is framed during initial conversations. This may be particularly relevant in HNC, where patients are often required to process difficult information while simultaneously managing the emotional burden of diagnosis and treatment. Research examining patient information needs further underscores the importance of clear and transparent communication to support confidence in medical decision-making, with strategies for eating during and after treatment identified as an area of high informational need [29].

At our cancer centres, feeding tubes are usually first introduced by the radiation oncologist, which informed the study objective of developing recommendations to support these initial conversations. However, participants also recognized the limitations of relying on oncologists alone and, based on their experiences, emphasized the importance of involving the broader interdisciplinary team in discussions about tube feeding. Participants spoke at length about the close relationships they developed with nursing and supportive care providers and the trust that emerged from these relationships, which made conversations about tube feeding feel more approachable and acceptable. Similar research examining patient perspectives on dietetic care in oncology has described dietitians as “indispensable,” providing practical and individualized advice [30]. This and other studies [31–33] highlight the role dietitians can play not only in providing nutrition care, but also in facilitating communication and coordinating care across the treatment trajectory. In a Canadian study, patients with HNC similarly described gaps in care coordination that contributed to uncertainty, confusion, and feelings of isolation [34]. Taken together, our findings build on this literature by highlighting the potential role of dietitians and nurses not only in managing nutrition-related concerns, but also in helping lead conversations and coordinate care related to tube feeding.

Our finding that tube feeding is a highly emotional experience is well supported by the broader literature on HNC. In a scoping review examining the palliative care needs and experiences of people with advanced HNC, 16 studies addressed psychological and spiritual well-being [35], with two reporting psychological symptoms, including worry, fear, sadness, and depressed mood, in more than half of participants [36, 37]. The importance of psychological well-being has also been demonstrated among patients receiving enteral nutrition. In a study of 52 patients with HNC (67%) or upper gastrointestinal cancer (33%) receiving home enteral nutrition, the authors recommended integrating early psychological

support and strategies to promote activity into nutrition care to help mitigate depression and declines in quality of life [38].

Our findings found that feelings of fear eventually turned to gratitude. This adaptions and changes in feelings towards their feeding tube is also found in the literature. A systematic review of nine studies capturing the experiences of 159 patients who received a feeding tube during HNC treatment closely mirrored our findings. Patients commonly described initial reluctance and fear, followed by gradual adaptation and acceptance, with many ultimately viewing the feeding tube as a worthwhile component of their care [39]. Together, these findings reinforce the importance of recognizing and addressing the emotional dimensions of tube feeding alongside its nutritional and clinical role.

Lastly, the pragmatic recommendations identified by participants highlight opportunities to review and strengthen care pathways, including greater standardization of feeding tube order sets, insertion timelines and procedures, and supports for the prevention and management of complications. These considerations are particularly important within geographically dispersed cancer systems, where differences in local resources and service availability can influence how care is delivered [39–41]. Ensuring equitable access to consistent, high-quality tube feeding care across cancer centres should therefore remain a priority.

A strength of this study was the inclusion of patient partners who advised on the study design based on their lived experience. For example, at the recommendation of our patient partners, more time was dedicated to group introductions and an icebreaker activity at the beginning of the focus groups. This helped establish a foundation for trusting relationships, mutual learning, and a comfortable environment that encouraged deeper sharing. Additionally, including a patient partner in the focus groups bridged the gap between the clinical research team and patient participants. The patient partner's involvement also supported deeper probing of participants' experiences by building on their own lived experience.

Limitations of this study include a potential selection bias, such as volunteer bias, based on convenience sampling methods. Sampling from individuals who all were treated at the same cancer institutions, potentially limits the relevance of findings to other institutions. While we held two focus groups to gather a broader range of perspectives and reduce the influence of group dynamics, a third focus group would help better establish thematic saturation.

# 5. Conclusion

Drawing on the lived experiences of nine HNC survivors who received enteral nutrition, these findings highlight the importance of framing tube feeding as a source of support rather than a threat when it is first introduced. Recognizing the time constraints within oncology care, the broader interdisciplinary team can play an important role in tube feeding education, shared decision-making, and ongoing support. Participants' experiences of resilience and self-advocacy also drew attention to persistent gaps in support and variation in tube feeding practices across care settings. Ultimately, tube feeding is not only a clinical and nutritional intervention, but also a deeply emotional experience. Thoughtful, patient-

centred communication and coordinated care are therefore essential when introducing and discussing tube feeding to support the best possible patient experience.

## Abbreviations

HNC
head and neck cancer
EN
enteral nutrition
BCC
BC Cancer
UBC
University of British Columbia

## Declarations

# Ethics approval and consent to participate:

Institutional review board ethics approval was granted on May 16, 2025 by the BC Cancer- University of British Columbia (UBC) ethic board (H25-00057) and informed consent was obtained from all subjects involved in the study.

# Consent for publication:

Informed consent for publication was obtained from all subjects involved in the study.

# Competing interest:

Nothing to decare

# Funding:

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# Author Contribution

Conceptualization, KT, ES, and LVM; Methodology, ES and BS; Software, ES and AN; Validation, BS and LVM; Formal Analysis, AN and ES; Investigation, AN, KT, BS, LVM; Resources, ES; Data Curation, AN; Writing – Original Draft Preparation, ES; Writing – Review & Editing, AN, BS, KT, LVM; Project Administration, ES; Funding Acquisition, ES, KT, LVM.

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# Data Availability

The datasets used and analysed during the current study are available from the corresponding author on reasonable request.

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