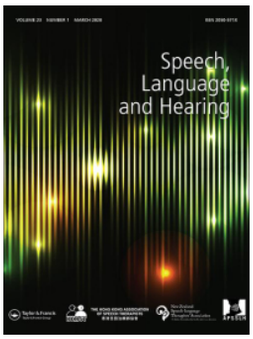

Speech, Language and Hearing

ISSN: 2050-571X (Print) 2050-5728 (Online) Journal homepage: www.tandfonline.com/journals/yslh20

Identifying areas for improvement in laryngectomy care: insights from concept mapping with patients

Laurie Wennerholm, Elizabeth C. Ward, Clare L. Burns, Jasmine Foley, Gina Palma, JK Rasamny & Craig Berzofsky

To cite this article: Laurie Wennerholm, Elizabeth C. Ward, Clare L. Burns, Jasmine Foley, Gina Palma, JK Rasamny & Craig Berzofsky (2026) Identifying areas for improvement in laryngectomy care: insights from concept mapping with patients, Speech, Language and Hearing, 29:1, 2654524, DOI: 10.1080/2050571X.2026.2654524

To link to this article: https://doi.org/10.1080/2050571X.2026.2654524

Published online: 04 Apr 2026.

SPEECH, LANGUAGE AND HEARING
2026, VOL. 29, NO. 1, 2654524
https://doi.org/10.1080/2050571X.2026.2654524

Taylor & Francis
by informa

RESEARCH ARTICLE

OPEN ACCESS Check for updates

Identifying areas for improvement in laryngectomy care: insights from concept mapping with patients

Laurie Wennerholm[a,b], Elizabeth C. Ward[a,c], Clare L. Burns[a,d], Jasmine Foley[a], Gina Palma[e,f], JK Rasamny[e] and Craig Berzofsky[e]

[a]School of Health and Rehabilitation Sciences, The University of Queensland, Brisbane, QLD, Australia; [b]Department of Speech-Language Pathology - Rusk Rehabilitation and Perlmutter Cancer Center, NYU Langone Health, New York, NY, USA; [c]Centre of Functioning and Health Research, Metro South Health, Queensland Health, Brisbane, QLD, Australia; [d]Speech Pathology Department, The Royal Brisbane and Women's Hospital, Metro North Health, Queensland Health, Brisbane, QLD, Australia; [e]Department of Otolaryngology, Head and Neck Surgery, White Plains Hospital, White Plains, NY, USA; [f]Department of Otorhinolaryngology, Montefiore Medical Center, Bronx, NY, USA

ABSTRACT

Care for individuals with laryngectomy (IWL) is complex, requiring access to specialized multidisciplinary services along the full care continuum. However, evidence supports that challenges are experienced by some IWL accessing supportive care, with current care systems not addressing patients' postoperative and long-term needs, contributing to poor outcomes and increased patient and caregiver burden. This study explored perceptions of IWL about overall health services and speech-language pathology (SLP) care to identify and prioritize opportunities for supportive care optimization. Concept mapping methodology was used to identify what IWL perceived were important to support their care. Through the multistep concept mapping process, qualitative and quantitative data were used to identify, then prioritize, critical elements of care that IWL feel should be optimized in the care pathway. Fourteen IWL from two health services generated 32 unique statements. Hierarchical cluster analysis revealed that statements fell within seven clusters: (1) comprehensive healthcare professional access and support; (2) psychological care and trust in healthcare; (3) supporting adjustment to life after surgery; (4) managing the treatment and recovery pathway; (5) communication restoration and peer-support; (6) inpatient care; and (7) no underlying theme. The Go-Zone map revealed 15 statements that were rated highest for importance, with the majority of these focusing on improving psychological care and adjustment postsurgery. IWL identified and prioritized actions to enhance services relating to preoperative education, psychological care, access to healthcare professionals, peer support, and financial supports. These findings can be used to inform an enhanced care pathway for IWL.

ARTICLE HISTORY
Received 26 December 2025
Accepted 29 March 2026

KEYWORDS
Laryngectomy; concept mapping; service access and delivery; patient experience; person-centered care; care pathways; care optimization; speech-language pathology

Introduction

Patient-centered care (PCC) has been a 'call to attention' for health and medical service providers since the 1980's (Barry & Edgman-Levitan, 2012). As its name implies, PCC has the patient and family at the center of decision-making, instead of peripherally receiving care directed by the healthcare team. In an increasingly complex and potentially fragmented healthcare system, PCC emphasizes the need for healthcare professionals to shift focus from treating the disease, and instead, place greater emphasis on treating the person and their family. In this model, the healthcare experience is seen through the lens of the patient and includes respect for the patient's values, coordinated and integrated care, clear and high-quality information and education (including materials), physical comfort including pain management and emotional support, involvement of family and friends as appropriate, continuity of care transitions, and easy access to care (Gerteis, 1993).

CONTACT Laurie Wennerholm l.wennerholm@student.uq.edu.au School of Health and Rehabilitation Sciences, NYU Langone Health, The University of Queensland, 240 East 38th Street, New York, NY, 10016, USA

For complex clinical populations, like individuals with head and neck cancer (HNC), PCC is of particular importance to ensure patients' needs are met and that care is coordinated and integrated (Bickford et al., 2019; Ellis et al., 2019; Rosengren & Koinberg, 2021; van Overveld et al., 2017; van Sluis et al., 2020). A recent randomized control trial revealed that participants who received PCC during their HNC treatment consistently reported better scores on quality-of-life measures including swallowing, social eating, and overall wellness than their counterparts who received traditional care (Hansson et al., 2017). While most HNC surgeries are considered intricate with risks to the airway, deglutition, and communication, a laryngectomy is one of the most radical surgeries of the head and neck region requiring complete removal of the larynx and its adjacent structures (Bickford et al., 2019). For individuals with a laryngectomy (IWL), there is a delicate balance between survival and morbidity, including permanent physical, functional, and quality-of-life consequences (Hoesseini et al., 2020). Due to their complex care needs, IWL require long-term care by a specialized health care team (Bickford et al., 2019; van Overveld et al., 2017) that is expected to be both coordinated and patient-centered (Brody-Camp et al., 2021; Chen et al., 2000; Hanna et al., 1999; Levin et al., 2000; Sherman et al., 2001). Though an organized care trajectory is considered optimal, it is often not the case for IWL (Frowen & Perry, 2001; Bickford et al., 2019). This can have devastating impacts on patients' functional outcomes and overall survival (Brody-Camp et al., 2021).

Although PCC is reportedly the aim of the modern healthcare system for all populations and is a critical component of quality cancer services (Zucca et al., 2014), there is an overwhelming challenge of turning 'rhetoric into reality' (p. 781) (Barry & Edgman-Levitan, 2012). Despite a systematic review highlighting the importance of including patients' preferences in decision-making and determining which outcomes are most critical to them, implementing PCC remains a challenge in HNC care provision (Blanchard et al., 2016). Hence, to improve this situation, there is a call for clinicians to relinquish their roles as leaders and ask their patients what is needed, what is critical, what is missing, and what requires prioritization (Barry & Edgman-Levitan, 2012).

The goal of creating a complete, patient-centered pathway for individuals with complex cancers requires a systematic process (Petit-Steeghs et al., 2020). The initial step in developing a pathway that is person-centered is first to identify areas of strength and opportunity in current laryngectomy services. Then, patients themselves need to define what is imperative in their care (Petit-Steeghs et al., 2020). Concept mapping is a methodology used widely in healthcare to enable a group of individuals to express and graphically depict a concept of interest or importance (Bogdanovic et al., 2019; Hargett et al., 2017; van Bon-Martens et al., 2017), and has been used in prior research with HNC clinicians to inform service improvement (Alolayan et al., 2023; Foley et al., 2021). With focus turning toward PCC, a recent concept mapping study engaged both HNC patients (two with laryngeal cancer) and health care professionals to prioritize critical aspects of care (Alolayan et al., 2023). Authors reported that both groups prioritized similar things, including timely care, education, and person-centered care. In a similar study by Foley et al., which identified actionable goals for service change, their findings were utilized to inform the development of a new speech-language pathology (SLP) service model for people with HNC (Foley et al., 2021). To elucidate this same type of information for IWL, the aim of the current exploratory study was to use concept mapping with a cohort of IWL to gather their perspectives and identify and prioritize important issues to change in laryngectomy management. The objective of the research is to then use this information, in combination with other existing evidence, to guide laryngectomy service enhancement and improve the quality of care provided to IWL.

Materials and methods

The current study used a concept mapping methodology to examine the perceptions of IWL regarding all care accessed before, during and after their laryngectomy surgery, and develop a set of statements that reflect issues that patients believe are important and changeable. Concept mapping is a structured methodology that identifies and prioritizes actionable items for change from the perspective of critical stakeholders and displays information in several easy-to-understand maps (Trochim & McLinden, 2017). Ethical approval was obtained from White Plains Hospital, Montefiore Medical Center, and The University of Queensland (Ref # 061125, IRB# #2020-11238, # 2020001304/#20-030). All participants provided written consent prior to participation.

Setting and participants

Participating sites included two hospital facilities from a large health network in New York State, USA. Both provided HNC services but with varying degrees of program longevity and service integration. Site 1 was a 290-bed community-based acute care hospital with a separate, but co-located, cancer center. This site was in the process of developing a comprehensive HNC service, with some but not all professionals located onsite, and had been providing care for complex surgical cases for only five years. Site 2 was a 750-bed, urban, tertiary, academic medical center with on-campus outpatient cancer services. This facility had been providing HNC services for over 15 years with all MDT professionals located centrally. Each site performed approximately 5–8 laryngectomy surgeries per year. Both facilities had a multidisciplinary HNC team comprised of head and neck surgeons (HN surgeons), plastic surgeon/reconstructive specialists (PS), SLPs, medical oncologists, radiation oncologists, registered dietitians (RDs), physical therapists (PTs), and social workers (SWs). At the time of the study, neither site had a clinical navigator dedicated to HNC patients, a formal set of patient education materials, or any form of a stepwise clinical pathway for patients undergoing laryngectomy.

Potential participants were recruited from all IWL receiving SLP services at either site for voice and/or swallowing restoration. Individuals were invited to participate via study flyer provided to them at a routine speech follow-up visit by the administration officer. Patients who expressed interest met immediately with the SLP who explained the study, answered any questions and provided information and consent forms. Patients were considered eligible if they had undergone a laryngectomy (+/− partial or circumferential removal of the pharynx) as primary or salvage treatment for cancer, were at least 12 months postsurgery (to allow participants to have accessed the range of services required during recovery and rehabilitation), with no evidence of active disease. Other eligibility criteria included the ability to consent independently, communicate either verbally or in text (writing or text to speech), and no history of a cognitive impairment that may impact on their ability to participate in an interview, or the sorting and ranking tasks involved in concept mapping.

Concept mapping methodology

Concept mapping is a mixed-methods research approach with several integral processes incorporating: (1) preparation, (2) statement generation using brainstorming, (3) structuring, (4) representation, (5) interpretation, and (6) utilization (Bar & Mentch, 2017; Green et al., 2012; Trochim & McLinden, 2017; Trochim & Linton, 1986). Only stages 1–5 are presented in this paper. This study is part of a larger body of work exploring what is required to develop an optimal care framework for SLP laryngectomy management, and as such, the data from this study, and the other studies within that larger body of research, will be used in the future to inform Stage 6 'utilization' (i.e. the actioning or implementation of the recommended changes). Within the methods section of this paper, authors have provided the main details of concept mapping, while a more detailed description of the analytic process and reliability of concept mapping is available in Trochim (1993, 1989).

Stages 1 and Stage 2 – preparation phase and statement generation phase

In Stage 1 – preparation phase, participants received information about the concept mapping approach and participated in a semi-structured interview. All interviews were completed by one of two study investigators (LW or GP), audio-recorded and transcribed verbatim. The interview encouraged participants to reflect on their experience of the general health service provided by all members of the MDT, as well as services provided specifically by speech-language pathology. They were also encouraged to consider the current strengths and opportunities for improvement in service provision overall. At the end of the interview, participants were then asked to brainstorm '*general health or speech-language pathology services that all patients with laryngectomy (or their caregivers) should have access to either before or after surgery*', and in this stage discrete action statements were generated. There was no limit to the number of action statements participants could generate, but these statements could not be in question form and had to include things that could enhance care or facilitate improvements in care. Participants

were interviewed individually, either in person or via telephone based upon location, personal preference, or other reasons e.g. communication challenges using the phone.

After this session, each participant's statements were emailed to them or verbally reviewed with them, to verify accuracy and to permit edits or additional statements after reflection. According to prior literature, 100 statements or less sufficiently represents the variety of issues raised by a group while maintaining a manageable number of statements for analysis (Kane & Trochim, 2007). The research team collated all statements, removed duplicates, and then compiled statements into a final list. Of note, it is not uncommon that groups may generate highly similar statements with overlapping concepts (Trochim, 1989). As such, it is essential that duplicates be removed, leaving a singular statement to represent a concept in the analysis. Importantly, in the statement generation phase, the quality of the data is dependent on data saturation and not the size of the participant sample (Kane & Trochim, 2007).

Stage 3 – structuring phase

The Stage 3 – structuring phase, involves both sorting and ranking tasks (Trochim & McLinden, 2017). In the current study, participants completed the sorting task first. They were provided with the final list of unique statements printed on individual index cards and asked to '*sort these statements into groups in a way that makes sense to you*' while complying with three rules: (1) each statement could only be included in one group, (2) groups could consist of a single statement, and (3) they had to create more than one group using the statements. The number of groups and the statements included in each group were recorded by the researcher. The cards were shuffled between participants to remove a priming effect.

After the sorting task, participants were provided a printed document of all statements, and they were asked to consider each statement, and rank each on 5 point (0–4) scale according to (a) its importance (0 = not at all important, 1 = a little important, 2 = neutral; 3 = very important, 4 = extremely important) and, (b) its changeability, (0 = not at all changeable 1 = a little changeable, 2 = neutral; 3 = very changeable, 4 = extremely changeable).

Stages 4 and 5 – representation phase and interpretation phase

The data generated in Stage 3 then underwent a series of analysis steps using free open-source software (R-CMap) (Bar & Mentch, 2017). The first step was multidimensional scaling which generates a two-dimensional point map. This map displays the relationship of statements by their proximity to one another on the map (i.e. those that were more closely related/often sorted together appear closer on the point map). The statistical strength or 'goodness of fit' of the plot is represented by a stress value ranging from 0 to 1 (a lower stress value implies a better fit), with the upper acceptable stress values being around 0.39 (Green et al., 2012).

The next stage involved hierarchical cluster analysis, a process that is based upon the statements and their interrelationship (not the number of participants). This process analyzes how the statements were grouped by participants, as determined by the statement sorting task to be represented by a dendrogram. The information generated by cluster analysis was then systematically reviewed using an iterative process in which researchers reviewed the statements within each cluster, reached consensus on the final cluster configuration, and then assigned cluster titles.

The generation of the cluster rating map was the next analysis step. This is a critical component in concept mapping used to visually display (1) the relationship between the statements within each cluster (the closer the statements are to each other, the greater their conceptual similarity), as well as (2) discrete topics and issues (smaller clusters indicate better agreement, while closer clusters display more conceptual similarity) (Trochim & McLinden, 2017). Important in a cluster map is the absence of an overlap of edges indicating that each group represents a meaningful domain and distinct theme (Trochim & McLinden, 2017).

Using data from the importance and changeability ratings, the pattern matching graph was generated. This graph depicts relationships, highlighting the degree of relative importance and changeability that participants rated items in each cluster (Trochim & McLinden, 2017). For example, an individual cluster could be rated with high importance, but low changeability. Of note, importance and changeability ratings can differ between clusters by only small values (e.g. a mean score difference of 0.3 points); however, this is still considered an important difference if it changes prioritization (Kane & Trochim, 2007). According to

Kane and Trochim (2007), pattern matching and Go-Zone maps (discussed below) are made to enhance visual interpretation of the data and are not meant to be regarded by strict statistical significance.

Finally, a critical endpoint in concept mapping analysis is the generation of the 'Go Zone' map, which depicts the relationship between the two variables of interest for each discrete statement, i.e. importance and changeability (Trochim & McLinden, 2017). In the Go-Zone map, the upper right quadrant is considered the 'go-zone' and contains the statements that have scored highest in both importance and changeability, as determined by the group (Trochim & McLinden, 2017). While the Go-Zone results are typically the singular results discussed in concept mapping, in this current analysis consideration was given to all statements that were considered by IWL as important – even if they felt that the ability to change them may be more difficult. For this reason, analysis first prioritized the Go-Zone statements, but then also considered statements which fell in lower right quadrant. This way, statements that were of high importance to patients, but were not rated as highly changeable, were also considered priority areas for change.

Results

All parties who received the flyer consented to participate in the study. There were 14 participants recruited, 7 from each site. This represented 30%–40% of the IWL currently being managed at each institution by SLP services. The included participants represented a range of demographic characteristics across gender, age, race/ethnicity, primary or salvage surgery, primary and secondary tracheoesophageal voice restoration, level of education, public and private insurance, social support, comorbidities, time postsurgery and distance from primary care site. Full demographics are provided in Table 1. While all fourteen IWL participated in the statement generation task, 4 participants from Site 1 were unable to complete the sorting and ranking tasks. Three were for health reasons (2 males, 1 female), and 1 had deceased (1 male). Attrition often occurs across concept mapping due to the multiple-stage process, and it is not critical for all participants to take part in every step of the concept mapping process (Trochim, 1989). Early concept mapping studies typically included between 10 and 20 participants (Trochim, 1989); hence, the sample size remained adequate, and sample diversity was maintained (Table 1).

Stages 1, 2, and 3

The 14 participants initially generated 73 statements. Following collection of all statements from the group, two members of the research team (LW, EW) met and consolidated the statements into a preliminary list. These researchers read through and discussed each statement to ensure that it represented a discrete idea. Duplicate statements (i.e. those with identical ideas) were reviewed and consensus was reached on a single statement to represent that idea in the final data set. Statements were not merged or reworded to maintain their original integrity. A final set of 32 unique statements was included in analysis. About three months after the initial interview and statement generation phase, participants were brought back to the respective centers to complete ranking and sorting of the unique statements.

Stages 4 and 5

Multidimensional scaling was used to generate the two-dimensional point map and stress value was the first analysis step. Although only 10 participants completed the ranking and sorting, the stress value of the multidimensional scaling plot was 0.325 which falls within the acceptable range, indicating that the results were sufficient to proceed with further analysis. This value is consistent with other healthcare-focused concept mapping studies such as Alolayan et al. (2023) and Foley et al. (2021), who reported stress values of 0.2213 and 0.308, respectively.

Hierarchical cluster analysis revealed the statement groupings as sorted by participants represented by a dendrogram. This information was systematically reviewed using an iterative process during which four members of the research team (LW, EW, CB, JF) reviewed the statements within each cluster, then reached consensus via discussion on the final cluster configuration representing groupings of similar statements in conceptually unique clusters. Cluster titles were determined once consensus was reached on a descriptor that characterized the group of statements within each cluster. This process identified a seven-cluster

Table 1. Participant demographics ($n = 14$).

Participant	Site	Age	Gender	Race	TNM stage	Surgery	Timing of TEP	Education level	Social support	Insurance type	Comorbid conditions	Time from surgery to discussion (months)	Return distance traveled from home to primary site (miles)
1#	1	67	Male	White	T3N0 SCC TG	Salvage	Secondary	High school	No caregiver	Private	Cardiac	24	18
2#	1	56	Male	Hispanic	T4aN0 SCC TG	Primary	Secondary	High School	No caregiver	Private	Renal	38	10
3#	1	77	Male	White	T3N0 SCC TG	Salvage	Secondary	College	Caregiver	Public + Private	COPD	32	30
4*	1	72	Male	White	T1 SCC GL	Salvage	Secondary	High School	No caregiver	Public + Private	HTN, DM	25	31
5*	1	43	Male	White	T4aN0 SCC TG	Primary	Secondary	High School	Caregiver	Public	GI	18	46
6*	1	54	Male	White	T3N3b SCC TG	Primary	Secondary	College	No Caregiver	Public + Private	GU	12	16
7*	1	65	Female	White	T4aN0 SCC SGL	Salvage	Secondary	High School	Caregiver	Public	COPD	27	52
8#	2	75	Female	White	T3N1 SCC SGL	Salvage	Primary	High school	No caregiver	Public	Cardiac	12	7
9#	2	56	Male	Black	T4aN0 SCC GL	Primary	Primary	High school	Caregiver	Private	GI + DM	38	4
10#	2	63	Female	White	T4aN0 SCC SGL	Salvage	Primary	High School	Caregiver	Private	COPD	18	10
11#	2	64	Male	White	T1N0 SCC GL	Primary	Primary	College	No caregiver	Public	HTN + DM	21	5
12#	2	67	Female	Hispanic	T3N1 SCC SGL	Salvage	Primary	High school	No caregiver	Public	Vascular	27	8
13	2	78	Male	Black	T4aN1 SCC GL	Primary	Primary	High School	Caregiver	Public + private	COPD	29	5
14	2	57	Female	White	T4aN0 SCC SGL	Salvage	Primary	High school	No caregiver	Public	DM + renal	41	4

Note: # = Participated in Stages 1–5 of concept mapping; * = Participated in Stage 1 Statement Generation task only; TMN = T = tumor, N = node, M = metastasis; SCC = squamous cell carcinoma; SGL = supraglottic larynx; TG = transglottis; GL = glottic larynx; GI = gastrointestinal; HTM = hypertension; DM = diabetes mellitus; COPD = chronic obstructive pulmonary disease; GU = genitourinary; TEP = tracheooesophageal puncture/prosthesis.

arrangement. The dendrogram generated is provided in Figure 1. The unique clusters were: 1) *Comprehensive Healthcare Professional Access and Support, (2) Managing the Treatment and Recovery Pathway, (3) Psychological Care and Trust in Healthcare, (4) Unclassified, (5) Supporting Adjustment to Life After Surgery, (6) Inpatient Care*, and finally, (7) *Communication and Peer Support*. Of note, the 'Unclassified' cluster contained 3 statements that could not be thematically labeled, and there is precedence for a 'no unifying theme' cluster in prior concept mapping investigations (Hargett et al., 2017). These small clusters can occur when participants have sorted the statements inconsistently and therefore, they conceptually span a number of themes and cannot allocate to one single theme. This variation in sorting can be due to differences in interpretation due to differing participant perspectives or lived experience (Kane & Trochim, 2007). Thus, retaining this unclassified cluster allows these statements to remain conceptually intact without attributing them to a theme that does not accurately reflect participants' intent (Bar & Mentch, 2017). Data representing cluster names and descriptions, example statements, and overall mean importance and changeability ratings for each cluster are presented in Table 2. Details of all statements included in each cluster, including each statement's importance and changeability ratings are provided in Table 3.

Tables 2 and 3 can be read in conjunction with the cluster rating map (Figure 2) in which original statements are enclosed by a polygon-shaped outline that connects the points of each statement, creating a cluster. The statements relating to *Supporting Adjustment to Life After Surgery* were more loosely related and represented by a larger polygon cluster shape, compared to statements related to *Inpatient Care* which had more participant agreement, and were represented by the smallest polygon cluster shape in Figure 2. There were no overlapping edges of the shapes, indicating that each cluster accurately represented a discrete theme. Hence, the tables provide detailed information of the context of each cluster, while the map visually represents the way clusters compare to one another in overall importance. Together, these tools provide a high-level and detailed representation of the themes and their relative significance.

The pattern matching graph is provided in Figure 3. This revealed that all clusters were rated highly (>3.1) for both importance and changeability. Specifically, participants ranked the cluster *supporting adjustment to life after surgery* as one of the highest in importance (average rating 3.7), and higher than or equal to other clusters in changeability (average rating 3.5), while *Psychological Care and Trust in*

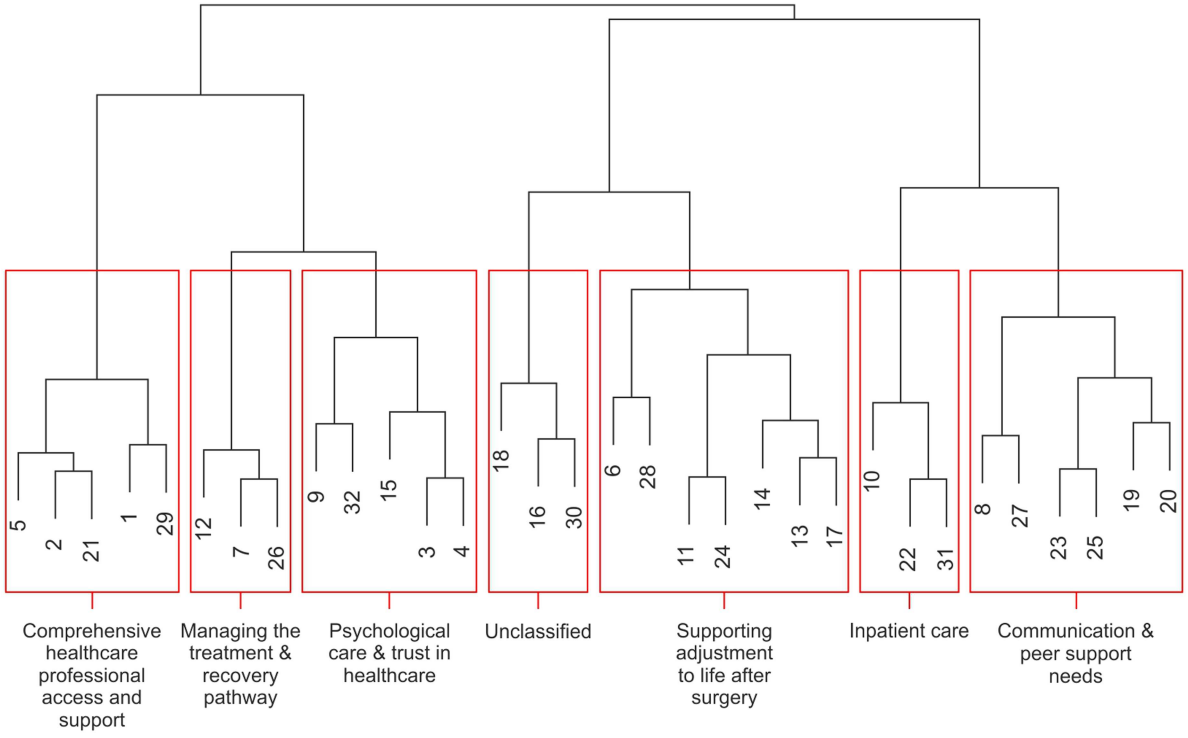

Figure 1. Dendrogram of seven clusters, representing meaningful cluster themes for partici

Table 2. Characteristics of cluster themes.

Cluster ID	Cluster theme	Theme description	Example statement	# of statements	Mean importance rating	Mean changeability rating
1	Comprehensive healthcare professional access and support	Describes access to healthcare professionals for education and ongoing support	All patients should be able to access everything by email –this should be a law.	5	3.48	3.42
2	Managing the treatment and recovery pathway	Describes information desired and importance of standard path	All patients should go through the same steps (first you do this, then this).	3	3.43	3.33
3	Psychological care and trust in healthcare	Describes the importance of psychological care and transparency	All patients should have access to psychological care for adjustment issues.	5	3.7	3.32
4	Unclassified/No unifying theme	Unrelated statements	There should be a public service announcement to prepare strangers for listening to laryngectomy speech.	3	3.5	3.5
5	Supporting adjustment to life after surgery	Describes the counseling required for success in postsurgical period	All patients should have pre-op counseling that really helps to understand what a life changer this surgery is.	7	3.7	3.46
6	Inpatient care	Describes care needed in hospital or long-term care setting	When the patient is in the hospital, the caretaker should have some training on daily care like bathing	3	3.13	3.1
7	Communication and peer support needs	Describes communication restoration and importance of peer support	All patients should have access to and a trial with hands free training—early on in their use of TEP.	6	3.43	3.36

Note: TEP = tracheoesophageal puncture/prosthesis.

Healthcare was ranked highly important (3.7), but less changeable (3.3*). Inpatient Care* was ranked the lowest in both importance and changeability.

The Go-Zone map is displayed in Figure 4. In total, 15 statements (47% of all statements) were ranked high in importance. Eleven of the 15 statements appeared in the Go-Zone which indicated items both high in importance and in changeability (Table 4). The cluster *supporting adjustment to life after surgery* had the greatest number of Go-Zone statements represented ($n = 4$), and included statement 6 'All patients should have good presurgery counseling from the team, social worker and the therapist', which received the highest rating of all statements for importance and changeability. An additional four statements did not fall within the Go-Zone; however, were considered by IWL as high in importance even if they felt that the ability to change may be more difficult (i.e. falling in lower right-hand quadrant of Figure 4). Three of these four additional statements were from the cluster *Psychological Care and Trust in Healthcare*.

Discussion

Engagement with patient consumers to define what is critical and what requires prioritization is a crucial step toward improved PCC (Barry & Edgman-Levitan, 2012). Participants prioritized 32 statements across numerous aspects of care. These insights, from patients who have 'walked the path of care', provide direction to improve PCC and current care pathways for patients undergoing a laryngectomy. Importantly, the statements generated are not to be misinterpreted as a list of things that are not being provided, rather they are what patients deemed to be most important, and so should be part of an optimal care pathway. Statements appearing in the upper right quadrant of the Go-Zone map, represented issues that the patients identified clinical teams can immediately act upon including: access to skilled MDT professionals across levels of care; compassionate understanding, truthfulness and transparency of the healthcare team; comprehensive preoperative education and counseling; peer support to facilitate adjustment to the 'new normal'; and financial assistance for essential supplies. Statements in the lower quadrant of the map

Table 3. Clusters with corresponding statements – importance and changeability ratings.

1. Comprehensive healthcare professional access and support		
Statement	Mean importance	Mean changeability
5. All patients should be able to contact the office via email because some of us have difficulty speaking.	3.4	3.4
2. All patients should have information about cleaning their stoma and what is normal and not normal.	3.8	3.8
21. The doctors should do more education with the family.	3.5	3.5
1. All patients should be able to access everything via email this should be a law.	3.1	2.7
29. All patients should be able to see the doctor either on the computer or in the office.	3.6	3.6
2. Managing the treatment and recovery pathway		
Statement	Mean importance	Mean changeability
12. All patients should have more transparency with regard to the side effects of treatment and the prognosis.	3.5	3.2
7. All patients should be given information about proper wound healing with pictures....	3.5	3.4
26. All patients should go through the same steps... and this should be a formal pattern.	3.3	3.4
3. Psychological care and trust in healthcare		
Statement	Mean importance	Mean changeability
9. Every patient should do what their doctors say... go to your appointments...	3.6	3.1
32. When people are at the hospital, they should get answers and their families should get answers.	3.8	3.5
15. All patients should have faith in their doctors.	3.8	3.2
3. All patients should have access to psychological care for adjustment issues.	3.6	3.3
4. All patients should have access to truthful and transparent handouts with FAQs.	3.7	3.5
4. Unclassified		
Statement	Mean importance	Mean changeability
18. All patients should have TEP supplies covered by insurance.	3.9	3.5
16. All patients should have the opportunity to 'meet and greet' other TL patients before the operation as a rule.	3.6	3.6
30. There should be a public service announcement to prepare strangers for listening to laryngectomy speech.	3.0	3.3
5. Supporting adjustment to life after surgery		
Statement	Mean importance	Mean changeability
6. All patients should have good presurgery counseling from the team, SW and the therapist.	3.9	3.6
28. All patients should have some literature about what to expect with the voice prosthesis...	3.4	3.6
11. All patients should have access to speech services for voice restoration.	3.9	3.2
24. All patients should get the education that things will be different.	3.7	3.6
14. All patients should be educated on anatomical changes from SLP prior to swallowing therapy.	3.9	3.5
13. Health care people should have the understanding that this is very frustrating and listen better.	3.2	3.4
17. All patients should have pre-op counseling that really helps to understand what a game changer this surgery is.	3.9	3.5
6. Inpatient care		
Statement	Mean importance	Mean changeability
10. All patients should have access to grooming in the hospital (like shaving)... electric razor.	2.3	2.1
22. When the patient is in the hospital, the caretaker should have some training on daily care, like bathing.	3.3	3.6
31. There should be better care of patients with laryngectomy in the nursing home...help with the electric voice box.	3.8	3.6
7. Communication and peer support needs		
Statement	Mean importance	Mean changeability
8. All patients should have access to credible web-based information.	3.2	2.7
27. All patients should be taught how to communicate with other people who don't understand them... role playing.	3.4	3.5
23. All patients should have access to a trial with hands free early on in their use of TEP.	3.5	3.4
25. People should have the speech valve earlier and be able to talk... electric voice box did not work...	3.5	3.4
19. The home care therapists should be educated on what the TL patient needs. They didn't know.	3.5	3.7
20. All patients should have peer support, either individually or in a group.	3.5	3.5

Note: FAQs = frequently asked questions; TL = total laryngectomy; TEP = tracheoesophageal puncture/prosthesis; SW = social work; SLP = speech-language pathologist; Ellipses (...) are used in quotes to reduce word length, remove nonessential wording and highlight meaningful context within the text without changing the intended meaning.

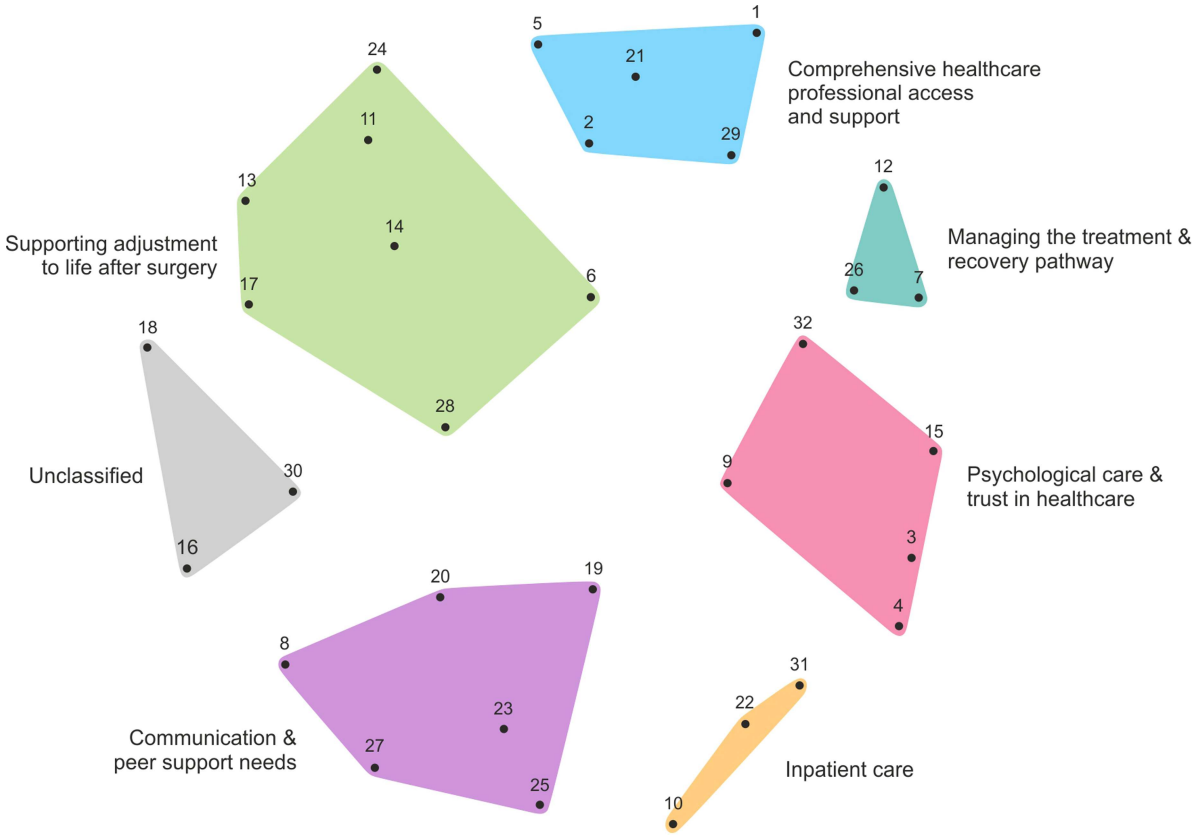

Figure 2. Cluster rating map of each cluster theme by importance.

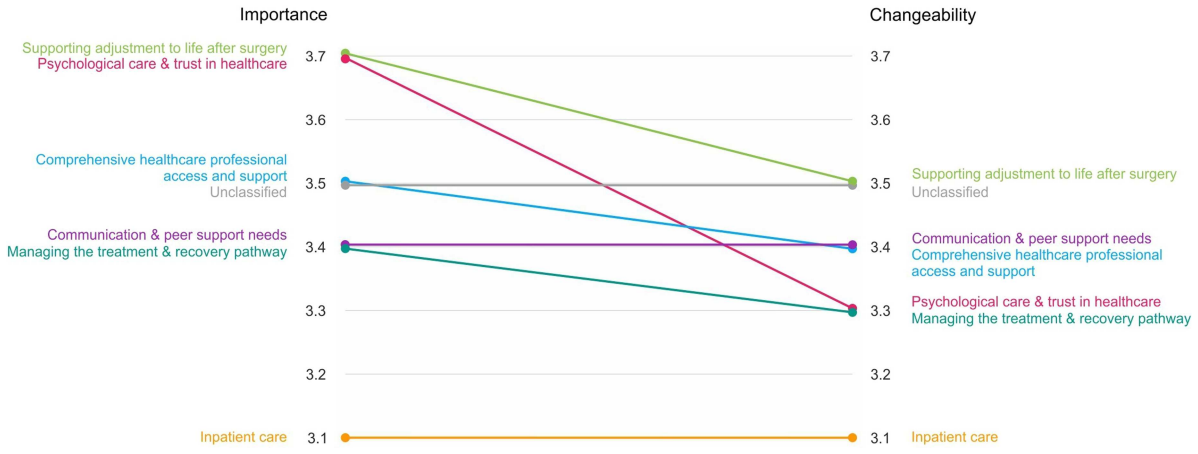

Figure 3. Pattern matching graph comparing importance and changeability.

(important but not as changeable) highlighted areas that patients identified as critical but may require longer-term strategies to support implementation.

As highlighted in the results, three statements were grouped into an 'unclassified cluster'. This is common in concept mapping and reflects when variability in the grouping of statements by participants means that they conceptually span a number of domains and therefore cannot be allocated to one single theme. Despite this variability, these statements were not dismissed by the participants. Importantly the 'unclassified' cluster ranked third in relation to importance, highest in in relation to changeability, and two out of the three statements in this cluster (Cluster ID #4 - Statement ID #16 and Statement ID #18) were

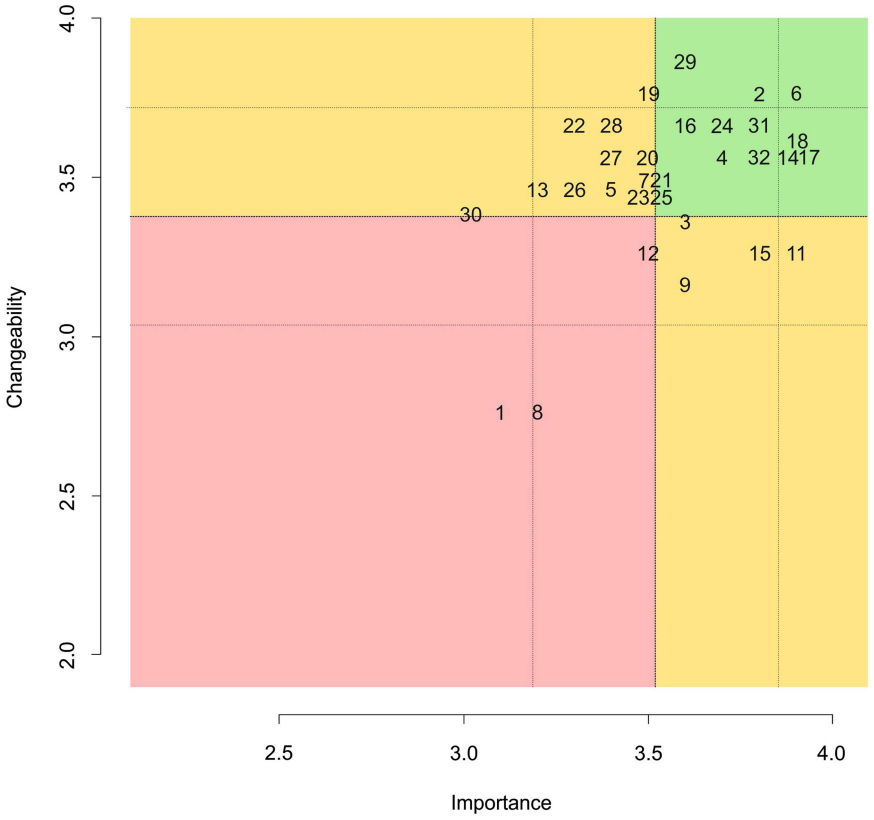

Figure 4. Go-Zone map with quadrants of interests. Note: upper right quadrant indicating high importance and changeability (the go-zone), lower right quadrant being highly important but not easily changed, upper left quadrant representing items of lower importance but highly changeable, and lower left quadrant indicating both low importance and changeability.

prioritized by the participant group in the Go Zone. Accordingly, the importance of these items suggests that conceptual ambiguity does not diminish their relevance but rather highlights the complexity of the patient experience and that these patient-identified needs warrant equal attention in developing an optimal care pathway.

Of the Go-Zone statements rated highest for both importance and in changeability, a number came from the cluster *Supporting Adjustment to Life After Surgery*. This included statements about the critical nature of counseling to facilitate understanding of anatomical and life-long changes to support adjustment postsurgery having the highest importance and changeability (e.g. Cluster ID #5: Statement ID #6). It has long been recognized that patients who undergo surgical oncologic procedures desire detailed information regarding potential anatomical and functional changes, and potential complications prior to consenting to surgery (Evrard et al., 2005). In their concept mapping study of HNC patients and health care professionals, participants prioritized education as the most important aspect of care (Alolayan et al., 2023). Despite long standing and widespread agreement on the importance of preoperative counseling for IWL (Berkowitz & Lucente, 1985; Salva & Kallail, 1989; Zeine & Larson, 1999), delivery of information remains highly variable (Fitzgerald & Perry, 2016). Even when provided, preoperative education and counseling can be overwhelming for patients, as exemplified by this quote in prior qualitative research - 'preoperative information giving...it was just words' (Watson et al., 2022, p. 737). It has also been reported that patients failed to recall any information provided regarding longer-term issues or lifestyle changes that impact their survivorship (Watson et al., 2022). The provision of easily accessible and reliable online information for IWL has been shown to have a positive impact on patient's level of comfort, highlighting the value of offering evidence-based internet-based resources (van Uden-Kraan et al., 2019) in-conjunction with direct face-to-face education. Hence the type of information provided, as well as its mode and delivery, needs ongoing consideration to meet patient support and educational needs.

Table 4. Individual statements identified as either within the Go-Zone ($n = 11$) or the lower right quadrant (important but ranked lower for changeability) zone ($n = 4$).

Quadrant	Cluster ID	Cluster theme	Statement ID	Statement
Go-zone	**1**	Comprehensive healthcare professional access and support	**2**	All patients should have information about cleaning their stoma and what is normal and not normal.
Go-zone	**1**	Comprehensive healthcare professional access and support	**29**	All patients should be able to see the doctor ...either on the computer or in the office.
Go-zone	**3**	Psychological care and trust in healthcare	**4**	All patients should have truthful and transparent handouts with frequently asked questions.
Go-zone	**3**	Psychological care and trust in healthcare	**32**	When people are at the hospital, they should get answers and their family should get answers.
Go Zone	**5**	Supporting adjustment to life after surgery	**6**	All patients should have good pre surgery counseling from the team, social worker and the therapist
Go-Zone	**5**	Supporting adjustment to life after surgery	**14**	All patients should be educated on anatomical changes from SLP prior to swallowing therapy.
Go-Zone	**5**	Supporting adjustment to life after surgery	**17**	All patients should have pre-op counseling that really helps to understand what a life changer this surgery is.
Go-Zone	**5**	Supporting adjustment to life after surgery	**24**	All patients should get the education that things will be different.
Go-Zone	**6**	Inpatient care	**31**	There should be better care of patients with laryngectomy in the nursing home... help using the electric voice box..
Go-Zone	**4**	Unclassified/No unifying theme	**16**	All patients should have an opportunity to 'meet and greet' other IWL before the operation as a rule.
Go-Zone	**4**	Unclassified/No unifying theme	**18**	All patients should have their TEP supplies covered by insurance.
Lower right	3	Psychological care and trust in healthcare	3	All patients should have access to psychological care for adjustment issues.
Lower right	3	Psychological care and trust in healthcare	9	All patients should do what their doctors/SLPs say to do. Go to your appointments and don't miss anything.
Lower right	3	Psychological care and trust in healthcare	15	All patients should have faith in their doctor.
Lower right	5	Supporting adjustment to life after surgery	11	All patients should have access to speech services for voice restoration.

Note: TEP = tracheoesophageal puncture/prosthesis; Items in bold print – critical items for immediate action; Items not bolded – critical items for longer-term consideration/integration

The importance of having access as needed to healthcare professionals was also prioritized in the Go-Zone (e.g. Cluster ID #1: Statement ID #29). It is important to recognize that most participants in this study received care during the COVID-19 pandemic, and as such were acutely aware of options for online services, as well as in person care models. Although the impacts of the pandemic have passed, access issues associated with travel and distance may remain for some IWL. One option to help reduce patient burden and improve patient access to services is telehealth. Although telehealth services were rapidly adopted in many locations globally, these services were not widely used within the USA at the time of this study (Longobardi et al., 2023). Telehealth can be used to enhance access to care for patients with HNC (Mayadevi et al., 2018; Metcalfe et al., 2022), as well as SLP services for HNC patients including IWL (Burns et al., 2012; 2017; Ward et al., 2007; 2009). Clinical teams also need to recognize the difficulty that IWL may experience, seeing multiple different medical and health professionals at different facilities, across all stages of care, and implement strategies to help mitigate these challenges. These include adopting electronic medical record platforms (EMRs) to allow for shared patient data between practitioners and seamless transition of care across organizations (Das et al., 2011; Stan et al., 2022), as well as patient health records (PHRs) which permits them access to all health records, allowing the patient to directly participate in their care, fostering a patient-centered model (Burns et al., 2024).

Of note, all statements within the cluster *Psychological Care and Trust in Health Care* were identified as being of the highest importance within the Go-Zone analysis. Although psychological support, and the issue of trust in health care may be seen by health professionals as distinct topics, these concepts were often grouped together by participants. However, it is acknowledged that each statement provides a unique and clear direction for service improvement. A clear need was identified by the participants for improving psychological support services for patients (e.g. Cluster ID #3 Statement ID #3). For patients and their caregivers, navigating the multitude of morbidities of their 'new normal' can be overwhelming (Frowen & Perry, 2001; Watson et al., 2022) and patients with HNC, including IWL, have the highest levels of distress, depression and suicide compared to other cancer types (Mehnert et al., 2014; Osazuwa-Peters

et al., 2018). Hence, the integration of psychological support services within laryngectomy pathways is critical and providing optimal access to care through offering both in-person (Murariu et al., 2025) and telehealth models is one potential way of achieving this.

The other statements in this cluster highlighted the need to improve perceived trust and the patient-practitioner relationship (e.g. Cluster ID #3, Statement ID #4; Cluster ID #3; Statement ID #15). Trust in health care includes expectations that the patient has for the physician and the health system in general, to help them move toward healing their illness (Gopichandran & Chetlapalli, 2013). Trust in US health care has declined substantially since the 1960's (Khullar, 2019). Patients may feel unheard when describing their symptoms, leading to feelings that their perception of their illness is unimportant. Watson et al. (2022) explored the perceptions of IWL of the postoperative phase of care, and found participants extensively discussed the importance of positive therapeutic relationships with clinical staff and their impact on making them feel 'like a person' (Watson et al., 2022, p. 744). Actionable ways to develop a positive patient-practitioner relationship include the provision of reassurance to reduce stress and fear, encouraging patients to ask questions, reviewing test results together to promote shared decision-making, and avoiding judgment (Dang et al., 2017). HNC teams can use these strategies, as well as a consistent, honest and transparent approach during all interactions with IWL, to foster patients' trust in their healthcare providers (Hall et al., 2001).

While current evidence supports that IWL should have access to clinical specialists with skill sets consistent to meet their care needs (Hinni & Crujido, 2013; Ward et al., 2007; Cancer Council Victoria & Department of Health Victoria, 2021), the competency of clinicians working outside specialist cancer centers varies, leading to a potential disparity in the skills of the health professionals that IWL can access (Foley et al., 2022). This challenge for patients was highlighted in another highly important statement expressing the need for improved care of IWL in nursing homes/rehabilitation centers (e.g. Cluster ID #6, Statement ID #31). Patients have real concerns when they are managed in facilities by healthcare professionals who have not had clinical exposure to laryngectomy management and may not be equipped to handle their complex needs. Recognizing this challenge, recent research has described the use of a shared care model to support HNC SLP care in rural areas (Foley et al., 2023), whereby less experienced clinicians have ongoing mentoring and support from experienced clinicians. This may be one solution to enable patients to receive quality care in services that do not routinely provide HNC care, such as general rehabilitation centers and nursing homes.

Recognition of the significant financial impacts associated with both laryngectomy surgery and functional rehabilitation was captured in the Go-Zone statement about coverage for supplies for voice restoration (e.g. Cluster ID #4; Statement ID #18). In the United States, HNC is one of the most expensive cancers to treat with substantial out-of-pocket expenses for patients and their caregivers (Jacobson et al., 2012). Many costs are ongoing, considering the multitude of long-term health needs (Cohen et al., 2016; Massa et al., 2022). In particular, for IWL who use tracheoesophageal speech, access to specialized and often costly equipment, such as regular replacement tracheoesophageal voice prostheses and other related communication and pulmonary rehabilitation consumables require long term financial commitment (Leemans et al., 2020; van den Boer et al., 2015). Consequences of financial toxicity include complete bankruptcy, adaptive coping behaviors including rationing of medications and skipping appointments due to inability to afford copayments, high levels of distress and possibly poor oncologic outcomes (Beeler et al., 2020). Mott et al. (2022) found that financial hardship is a substantial concern for patients with HNC considering that up to one-third of patients cannot return to work after treatment. To reduce financial burden, dedicated financial counseling has been found to be a beneficial inclusion within HNC teams with multiple positive outcomes reported including early detection of distress related to costs and a reduction in financial hardship for patients and their families (Farrugia et al., 2021). Therefore, financial impacts to patients should be considered and systematically addressed to improve care.

In this study, concept mapping served as a useful tool to inform service changes that are both necessary and feasible from the perspective of the patient. Many of the findings prioritized by the participants in this study (e.g. presurgical education, access to specialized staff and psychological care) have been reported in the literature as insufficient to support patient needs (Fitzgerald & Perry, 2016; Keszte et al., 2013; Rameau et al., 2023), highlighting the necessity for continued development and refinement of laryngectomy management practices. Addressing these issues has the potential to pragmatically and efficiently improve

clinical pathways for IWL and guide HNC teams to provide truly patient-centered care. It is the intention of this research team to use this information to inform the development of an optimal care framework for SLP laryngectomy management.

Limitations

Although many of the statements align with prior literature defining best practice (Cancer Council Victoria & Department of Health Victoria, 2021; Hinni & Crujido, 2013; Ward et al., 2007; 2009; Watson et al., 2022), it is recognized that this work was conducted with a small sample of participants within a specific region in the northeastern USA, who had ongoing specialist follow-up, involving only two hospital centers, and hence may not represent the perceptions of IWL in other health systems or in other locations within the USA. Future studies engaging a larger cohort of IWL to review the prioritized statements and validate their relevance would provide greater insight into the wider generalizability of the findings. Of note, this study was conducted during the COVID-19 pandemic. Therefore, some of the statements reflective of this time (e.g. telehealth as critical for access to healthcare), may not be considered necessary or generalizable to the postpandemic care context. Additionally, this work focused on medical and SLP care, and it is unclear if this lens of reflection influenced the range of issues raised. For example, if participants had been asked to reflect on other rehabilitation services, perhaps the prioritized items might differ. Further work with health care professionals who deliver laryngectomy services to determine what they see as improvements that are needed in laryngectomy care pathways would also help expand our understanding of wider stakeholder perceptions.

Conclusions

Concept mapping enabled the identification and prioritization of key issues that IWL feel were most important to improve laryngectomy care. Participants prioritized key issues including preoperative education, psychological care, access to healthcare professionals, peer support, and financial access to supplies as important and changeable in the current model of care. Considering most statements were rated by participants as highly important, the issues raised by these IWL can be used by services to reflect on current practice and identify and address areas for service improvement to help optimize laryngectomy care.

Acknowledgements

The authors wish to acknowledge the study participants for their time and generously sharing their healthcare experiences. The authors would also like to thank Rachel Carlson and Ryan Marynowski for their assistance with the transcription of participant interviews. Finally, the authors would like to thank Zoltan Sarkany for producing the maps and graphs in this work.

Disclosure statement

No potential conflict of interest was reported by the author(s).

Funding

No funding was allocated to this project.

Notes on contributors

Laurie Wennerholm is a board-certified specialist in swallowing and swallowing disorders with over 26 years devoted to medical speech pathology. Laurie has a specialization in head and neck cancer and is considered a leader and sought-after speaker in topics including optimal care for individuals with laryngectomy (IWL) in the United States. She is nearing completion of a PhD where her research aims to create a framework of care for IWL. Her focus has always been the provision of evidence-based care for the patient to maximize quality of life.

Professor Elizabeth Ward is a speech pathologist and the Director of the Center for Functioning and Health Research, Queensland Health, and Professor at The University of Queensland. With over 450 publications she is an international leader in the field of speech language pathology and has led multiple changes to improve care for people with head and neck cancer. Full profile at https://about.uq.edu.au/experts/304.

Dr. Clare Burns is an Advanced Speech Pathologist & Research Coordinator at the Royal Brisbane & Women's Hospital, Queensland Health and Senior Research Fellow at The University of Queensland, Brisbane. She has over 20 years of clinical experience specializing in head and neck cancer and dysphagia services. Her research focuses on clinical research and technology enhanced healthcare models to improve patient access and outcomes relevant to speech pathology and broader allied health services. See profile – Dr Clare Burns – RECOVER Injury Research Center – The University of Queensland.

Dr. Jasmine Foley is an Affiliate of The University of Queensland Center for Hearing Research (CHEAR) Center for Hearing Research, and a Research Fellow in the School of Health and Rehabilitation Sciences, Faculty of Health, Medicine and Behavioral Sciences, The University of Queensland. She is an early career researcher and her PhD studies focused on improving access to speech pathology services for patients with head and neck cancer who live is rural/remote areas in Australia. See more information regarding publications and current projects at https://about.uq.edu.au/experts/39368.

Dr. JK Rasamny is the Chief of the Otolaryngology Department at White Plains Hospital. He has specific expertize in the application of transoral robotic surgery (TORS) for the minimally invasive treatment of head and neck cancers. Dr. Rasamny is highly skilled to perform open and endoscopic approaches for treatment of tumors of the skull base and paranasal sinuses as well as complex reconstructions of head and neck deficits including laryngectomy. JK Rasamny, MD | White Plains Hospital Physician Associates.

Dr. Craig Berzofsky is the section chief of Laryngology in the Otolaryngology Department at White Plains Hospital. He conducted research in laryngeal nerve injury and reinnervation at the New York Eye and Ear Infirmary where he completed his residency. He currently treats adults and pediatrics with complex voice and swallowing issues of multiple etiologies. He is considered a leader in voice and swallowing care in Westchester, New York. Craig Berzofsky, MD, MHS | White Plains Hospital Physician Associates.

Gina Palma is a board-certified specialist in swallowing and swallowing disorders. She works at Montefiore Medical Center in the Department of Otorhinolaryngology/Head and Neck Surgery. She works with all adult populations with a specialization in assessment and management of speech, voice and swallowing disorders in individuals with head and neck cancers, including those who have undergone laryngectomy. Gina is a sought-after speaker at national conferences on the topic of head and neck cancer, specifically in maintaining oral intake and preserving quality of life.

Author contributions

All authors contributed to the study conception and design. Data analysis was completed by Laurie Wennerholm, Elizabeth Ward, Clare Burns and Jasmine Foley. The first draft of the manuscript was written by Laurie Wennerholm and all authors provided revisions to subsequent versions of the manuscript. All authors read and approved of the final manuscript.

Data availability statement

The dataset generated during this study is not publicly available to maintain the confidentiality of the participants and the relevant health services. Access to this data may be available at the request of the authors and relevant human research and ethics committee.

References

Alolayan, W. R., Rieger, J. M., & Yoon, M. N. (2023). Head and neck cancer treatment outcome priorities: A multi-perspective concept mapping study. *PloS one*, *18*(11), e0294712. https://doi.org/10.1371/journal.pone.0294712

Bar, H., & Mentch, L. (2017). R-CMap-An open-source software for concept mapping. *Evaluation and program planning*, *60*, 284–292. https://doi.org/10.1016/j.evalprogplan.2016.08.018

Barry, M. J., & Edgman-Levitan, S. (2012). Shared decision making — the pinnacle patient- centered care. *The New England Journal of Medicine*, *366*(9), 780–781. https://doi.org/10.1056/NEJMp1109283

Beeler, W. H., Bellile, E. L., Casper, K. A., Jaworski, E., Burger, N. J., Malloy, K. M., Spector, M. E., Shuman, A. G., Rosko, A., Stucken, C. L., Chinn, S. B., Dragovic, A. F., Chapman, C. H., Owen, D., Jolly, S., Bradford, C. R., Prince, M. E. P., Worden, F. P., Jagsi, R., …Swiecicki, P. L. (2020). Patient-reported financial toxicity and adverse medical consequences in head and neck cancer. *Oral oncology*, *101*. 104521. https://doi.org/10.1016/j.oraloncology.2019.104521

Berkowitz, J. F., & Lucente, F. E. (1985). Counseling before laryngectomy. *The Laryngoscope*, *95*(11), 1332–1336. https://doi.org/10.1288/00005537-198511000-00007

Bickford, J., Coveney, J., Baker, J., & Hersh, D. (2019). Validating the changes to self-identity after total laryngectomy. *Cancer Nursing*, *42*(4), 314–322. https://doi.org/10.1097/NCC.0000000000000610

Blanchard, P., Volk, R. J., Ringash, J., Peterson, S. K., Hutcheson, K. A., & Frank, S. J. (2016). Assessing head and neck cancer patient preferences and expectations: A systematic review. *Oral oncology*, *62*, 44–53. https://doi.org/10.1016/j.oraloncology.2016.09.008

van den Boer, C., Muller, S. H., van der Noort, V., Olmos, R. A., Minni, A., Parrilla, C., Hilgers, F. J., van den Brekel, M. W., & van der Baan, S. (2015). Effects of heat and moisture exchangers on tracheal mucociliary clearance in laryngectomized patients: A multi-center case-control study. *European archives of oto-rhino-laryngology: official journal of the European Federation of Oto-Rhino-Laryngological Societies (EUFOS): affiliated with the German Society for Oto-Rhino-Laryngology - Head and Neck Surgery*, *272*(11), 3439–3450. https://doi.org/10.1007/s00405-014-3336-4

Bogdanovic, J., Petralito, S., Passerini, S., Sax, H., Manser,, T., & Clack, L. (2019). Exploring healthcare providers' mental models of the infection prevention "patient zone"-a concept mapping study. Antimicrobial Resistance & Infection Contro, l(8), 1–10.

Brody-Camp, S. A., Parsel, S. M., Freeman, Z. A., McCoul, E. D., Hasney, C., & Moore, B. A. (2021). Decreased complications after total laryngectomy using a clinical care pathway. *Ochsner Journal*, *21*(3), 272–280. https://doi.org/10.31486/toj.20.0070

Burns, E., Hutcheson, K. A., Cunnigham, C., & Ward, E. C. (2024). Supporting head and neck cancer management: Use of technology. In I. E. C. Ward, & C. J. van As-Brooks (Eds.), *Head and neck cancer: Treatment, rehabilitation*and outcomes (pp. 579–616 2nd ed.). Plural Publishing.

Burns, C. L., Kularatna, S., Ward, E. C., Hill, A. J., Byrnes, J., & Kenny, L. M. (2017). Cost analysis of a speech pathology synchronous telepractice service for patients with head and neck cancer. *Head & Neck*, *39*(12), 2470–2480. https://doi.org/10.1002/hed.24916

Burns, C. L., Ward, E. C., Hill, A. J., Malcolme, K., Bassett, L., Kenny, L. M., & Greenup, P. (2012). A pilot trial of a speech pathology telehealth service for head and neck cancer patients. *Journal of Telemedicine and Telecare*, *18*(8), 443–446. https://doi.org/10.1258/jtt.2012.gth104

Cancer Council Victoria and Department of Health Victoria.(2021). *Optimal care pathway for people with head and neck cancer* (2nd ed.). Melbourne: Cancer Council Victoria.

Chen, A. Y., Callender, D., Mansyur, C., Reyna, K. M., Limitone, E., & Goepfert, H. (2000). The impact of clinical pathways on the practice of head and neck oncologic surgery: The university of texas MD anderson cancer center experience. *Archives of Otolaryngology–Head & Neck Surgery*, *126*(3), 322–326. https://doi.org/10.1001/archotol.126.3.322

Cohen, E.E.W., LaMonte, S.J., Erb, N.L., Beckman, K.L., Sadeghi, N., Hutcheson, K.A., Stubblefield, M.D., Abbott, D.M., Fisher, P.S., Stein, K.D., Lyman, G.H., & Pratt-Chapman, M.L. (2016). American cancer society head and neck cancer survivorship care guideline. CA: A Cancer Journal for Clinicians, 66, 203–239. https://doi.org/10.3322/caac.21343

Dang, B. N., Westbrook, R. A., Black, W. C., Rodriguez-Barradas, M. C., & Giordano, T. P. (2017). Building trust and rapport early in the new doctor–patient relationship: A longitudinal qualitative study. *BMC Medical Education*, *17*, 32. https://doi.org/10.1186/s12909-017-0868-5. Article.

Das, A. K., Eichner, J., & Reid, M. (2011). Realizing the benefits of electronic health records: A guide for clinicians and administrators. *Healthcare Informatics Research*, 17(2), 72–79. https://doi.org/10.4258/hir.2011.17.2.72

Ellis, M. A., Sterba, K. R., Day, T. A., Marsh, C. H., Maurer, S., Hill, E. G., & Graboyes, E. M. (2019). Body image disturbance in surgically treated head and neck cancer patients: A patient-centered approach. *Otolaryngology–Head and Neck Surgery*, *161*(2), 278–287. https://doi.org/10.1177/0194599819837621

Evrard, S., Mathoulin-Pelissier, S., Larrue, C., Lapouge, P., Bussieres, E., & Tunon De Lara, C. (2005). Evaluation of a preoperative multimedia information program in surgical oncology. *European Journal of Surgical Oncology*, *31*(1), 106–110. https://doi.org/10.1016/j.ejso.2004.09.019

Farrugia, M., Yu, H., Ma, S. J., Olsen, J. R., Koyfman, S. A., Lamarre, E. D., & Joshi, N. P. (2021). Financial counseling is associated with reduced financial difficulty scores in head and neck cancer patients treated with radiation therapy. *Cancers*, *13*(11), 2516. https://doi.org/10.3390/cancers13112516

Fitzgerald, E., & Perry, A. (2016). Pre-operative counselling for laryngectomy patients: A systematic review. *The Journal of Laryngology & Otology*, *130*(1), 15–20. https://doi.org/10.1017/S0022215115002984

Foley, J., Ward, E. C., Burns, C. L., Nund, R. L., Wishart, L., Graham, N., Comben, W., Patterson, C., Ashley, A., Fink, J., & Tiavaasue, E. (2021). Speech pathology service enhancement for people with head and neck cancer living in rural areas: Using a concept mapping approach to inform service change. *Head & Neck*, *43*(11), 3504–3521. https://doi.org/10.1002/hed.26850

Foley, J., Nund, R. L., Ward, E. C., Burns, C. L., Wishart, L. R., Graham, N., Patterson, C., Ashley, A., Fink, J., Tiavaasue, E., & Comben, W. (2022). Clinician and consumer perceptions of head and neck cancer services in rural areas: Implications for speech pathology service delivery. *The Australian Journal of Rural Health*, *30*(2), 175–187. https://doi.org/10.1111/ajr.12829

Foley, J., Ward, E. C., Burns, C. L., Nund, R. L., Wishart, L. R., Graham, N., Patterson, C., Ashley, A., Fink, J., Tiavaasue, E., & Comben, W. (2023). Enhancing speech-language pathology head and neck cancer service provision in rural Australia:

Using a plan, do, study, act approach. *International Journal of Speech Language Pathology*, *25*(2), 292–305. https://doi.org/10.1080/17549507.2022.2050300

Frowen, J., & Perry, A. (2001). Reasons for success or failure in surgical voice restoration after total laryngectomy: An Australian study. *The Journal of laryngology and otology*, *115*(5), 393–399. https://doi.org/10.1258/0022215011907956

Gerteis, M., Picker/Commonwealth Program for Patient-Centered Care.(1993). In Gerteis M. (Ed.), Through the patient's eyes: understanding and promoting patient-centered care. San Francisco: Jossey-Bass.

Gopichandran, V., & Chetlapalli, S. K. (2013). Dimensions and determinants of trust in health care in resource poor settings - A qualitative exploration. *PloS One*, *8*(7), e69170–e69170. https://doi.org/10.1371/journal.pone.0069170

Green, A. E., Fettes, D. L., & Aarons, G. A. (2012). A concept mapping approach to guide and understand dissemination and implementation. *Journal of Behavioral Health Service Res*, *39*(4), 362–373. https://doi.org/10.1007/s11414-012-9291-1

Hall, M. A., Dugan, E., Zheng, B., & Mishra, A. K. (2001). Trust in physicians and medical institutions: What is it, can it be measured, and does it matter?. *The Milbank Quarterly*, *79*(4), 613–639. https://doi.org/10.1111/1468-0009.00223

Hanna, E., Schultz, S., Doctor, D., Vural, E., Stern, S., & Suen, J. (1999). Development and implementation of a clinical pathway for patients undergoing total laryngectomy: Impact on cost and quality of care. *Archives of Otolaryngology–Head & Neck Surgery*, *125*(11), 1247–1251. https://doi.org/10.1001/archotol.125.11.1247

Hansson, E., Carlström, E., Olsson, L. E., Nyman, J., & Koinberg, I. (2017). Can a person-centred-care intervention improve health-related quality of life in patients with head and neck cancer? A randomized, controlled study. BMC nursing, 16, 1–12.

Hargett, C. W., Doty, J. P., Hauck, J. N., Webb, A. M., Cook, S. H., Tsipis, N. E., & Taylor, D. C. (2017). Developing a model for effective leadership in healthcare: A concept mapping approach. Journal of healthcare leadership, 9, 69–78.

Hinni, M. L., & Crujido, L. R. (2013). Laryngectomy rehabilitation: A perspective from the United States of america. *Current Opinion in Otolaryngology & Head and Neck Surgery*, *21*(3), 218–223. https://doi.org/10.1097/MOO.0b013e3283604001

Hoesseini, A., Dronkers, E. A., Sewnaik, A., Hardillo, J. A., Baatenburg de Jong, R. J., & Offerman, M. P. (2020). Head and neck cancer patients' preferences for individualized prognostic information: A focus group study. *BMC cancer*, *20*, 1–14. https://doi.org/10.1186/s12885-020-6554-8

Jacobson, J. J., Epstein, J. B., Eichmiller, F. C., Gibson, T. B., Carls, G. S., Vogtmann, E., Wang, S., & Murphy, B. (2012). The cost burden of oral, oral pharyngeal, and salivary gland cancers in three groups: Commercial insurance, Medicare, and medicaid. *Head & neck oncology*, *4*, 15. https://doi.org/10.1186/1758-3284-4-15

Kane, M., & Trochim, W. M. K. (2007). In M. Kane, & W. M. K. Trochim (Eds.), *Concept mapping for planning and evaluation* (Vol. *50*, 1st ed.). Sage Publications, Inc. https://doi.org/10.4135/9781412983730

Keszte, J., Danker, H., Dietz, A., Meister, E., Pabst, F., Vogel, H.-J., Meyer, A., & Singer, S. (2013). Mental disorders and psychosocial support during the first year after total laryngectomy: A prospective cohort study. *Clinical Otolaryngology*, *38*(6), 494–501. https://doi.org/10.1111/coa.12194

Khullar, D. (2019). Building trust in health Care—Why, where, and how. *JAMA: The Journal of the American Medical Association*, *322*(6), 507–509. https://doi.org/10.1001/jama.2019.4892

Leemans, M., Sluis, K. E., Son, R. J. J. H., & Brekel, M. W. M. (2020). Interaction of functional and participation issues on quality of life after total laryngectomy. *Laryngoscope Investigative Otolaryngology*, *5*(3), 453–460. https://doi.org/10.1002/lio2.381

Levin, R. J., Ferraro, R. E., Kodosky, S. R., & Fedok, F. G. (2000). The effectiveness of a "critical pathway" in the management of laryngectomy patients. *Head & Neck: Journal for the Sciences and Specialties of the Head and Neck*, *22*(7), 694–699. https://doi.org/10.1002/1097-0347(200010)22:7<694::AID-HED9>3.0.CO;2-0

Longobardi, Y., Savoia, V., Libero, R., Marenda, M. E., Proietti, I., Picciotti, P. M., Mari, G., Parrilla, C., & D'alatri, L. (2023). Rehabilitation after total laryngectomy: An integrated protocol remotely delivered during COVID-19. *International Journal of Telerehabilitation*, *15*(1), 1–8. https://doi.org/10.5195/ijt.2023.6548

Massa, S. T., Chidambaram, S., Luong, P., Graboyes, E. M., & Mazul, A. L. (2022). Quantifying total and out-of-pocket costs associated with head and neck cancer survivorship. *JAMA Otolaryngology-- Head & Neck Surgery*, *148*(12), 1111–1119. https://doi.org/10.1001/jamaoto.2022.3269

Mayadevi, M., Thankappan, K., Limbachiya, S. V., Vidhyadharan, S., Villegas, B., Ouyoung, M., Iyer, S., Balasubramanian, D., Menon, J. R., & Sinha, U. (2018). Interdisciplinary telemedicine in the management of dysphagia in head and neck. *Dysphagia*, *33*, 474–480. https://doi.org/10.1007/s00455-018-9876-9

Mehnert, A., Bra¨hler, E., Faller, H., Brähler, E., Härter, M., Keller, M., Schulz, H., Wegscheider, K., Weis, J., Boehncke, A., Hund, B., Reuter, K., Richard, M., Sehner, S., Sommerfeldt, S., Szalai, C., Wittchen, H., & Koch, U. (2014). Four-week prevalence of mental disorders in patients with cancer across major tumor entities. *J Clin Oncol*, *32*, 3540–3546. https://doi org/10.1200/JCO.2014.56.0086

Metcalfe, C., Dogan, M., Glazzard, N., Ross, E., & George, A. (2022). Introduction of a novel telescopic pathway to streamline 2-week-wait suspected head and neck cancer referrals and improve efficiency: A prospective service evaluation. *Laryngoscope Investigative Otolaryngology*, *7*(1), 117–124. https://doi.org/10.1002/lio2.721

Mott, N. M., Mierzwa, M. L., Casper, K. A., Shah, J. L., Mallen-St Clair, J., Ho, A. S., Zumsteg, Z. S., Prince, M. E. P., Dossett, L. A., & Chen, M. M. (2022). Financial hardship in patients with head and neck cancer. *JCO oncology practice*, *18*(6), e925–e937. https://doi.org/10.1200/OP.21.00683

Murariu, M. O., Boia, E. R., Sitaru, A. M., Mot, C. I., Negru, M. C., Brici, A. C., Zahoi, D. E., & Balica, N. C. (2025). Psychological distress and quality of life in patients with laryngeal cancer: A review. *Healthcare (Basel, Switzerland)*, *13*(13), 1552. https://doi.org/10.3390/healthcare13131552

Osazuwa-Peters, N., Simpson, M. C., Zhao, L., Boakye, E. A., Olomukoro, S. I., Deshields, T., Loux, T. M., Varvares, M. A., & Schootman, M. (2018). Suicide risk among cancer survivors: Head and neck versus other cancers. *Cancer*, *124*(20), 4072–4079. https://doi.org/10.1002/cncr.31675

Petit-Steeghs, V., Schuitmaker-Warnaar, T. J., Pruijssers, C. A., van Oortmerssen, G., & Broerse, J. E. (2020). A qualitative research on co-creating care pathways for sarcoma and GIST by stimulating reflection. *International Journal of Care Coordination*, *23*(1), 24–32. https://doi.org/10.1177/2053434520907743

Rameau, A., Cox, S. R., Sussman, S. H., & Odigie, E. (2023). Addressing disparities in speech-language pathology and laryngology services with telehealth. *Journal of Communication Disorders*, *105*. 106349. https://doi.org/10.1016/j.jcomdis.2023.106349

Rosengren, K., & Koinberg, I. (2021). A transition out of the darkness: Patients' experience of the recovery phase after treatment for head and neck cancer. *European Journal of Oncology Nursing*, *51*. 101902. https://doi.org/10.1016/j.ejon.2021.101902

Salva, C., & Kallail, K. (1989). An investigation of the counseling needs of Male and female laryngectomies. *Journal of Communication Disorders*, *22*(4), 291–304. https://doi.org/10.1016/0021-9924(89)90023-3

Sherman, D., Matthews, T. W., Lampe, H., & LeBlanc, S. (2001). Laryngectomy clinical pathway: Development and review. *Journal of Otolaryngology-Head & Neck Surgery*, *30*(2), 115

Stan, A., Penciu, D., & Păunescu, C. (2022). Interoperability of electronic medical records and the impact on continuity of care: A systematic review. *International Journal of Environmental Research and Public Health*, 19(9), 5123. https://doi.org/10.3390/ijerph19095123

Trochim, W. M. (1989). An introduction to concept mapping for planning and evaluation. *Evaluation and Program Planning*, *12*, 1–16. https://doi.org/10.1016/0149-7189(89)90016-5

Trochim, W. M. (1993). The reliability of concept mapping [Conference presentation], Annual Conference of the American Evaluation Association, Dallas, TX, United States.

Trochim, W. M., & Linton, R. (1986). Conceptualization for planning and evaluation. *Evaluation and program planning*, *9*(4), 289–308. https://doi.org/10.1016/0149-7189(86)90044-3

Trochim, W. M., & McLinden, D. (2017). Introduction to a special issue on concept mapping. *Evaluation and program planning*, *60*, 166–175. https://doi.org/10.1016/j.evalprogplan.2016.10.006

van Bon-Martens, M. J., van de Goor, I. A., & van Oers, H. A. (2017). Concept mapping as a method to enhance evidence-based public health. *Evaluation and Program Planning*, *60*, 213–228. https://doi.org/10.1016/j.evalprogplan.2016.08.014

van Overveld, L. F., Braspenning, J. C., & Hermens, R. P. (2017). Quality indicators of integrated care for patients with head and neck cancer. *Clinical Otolaryngology*, *42*(2), 322–329. https://doi.org/10.1111/coa.12724

van Sluis, K. E., Kornman, A. F., van der Molen, L., van den Brekel, M. W., & Yaron, G. (2020). Women's perspective on life after total laryngectomy: A qualitative study. *International Journal of Language & Communication Disorders*, *55*(2), 188–199. https://doi.org/10.1111/1460-6984.12511

van Uden-Kraan, C. F., Drossaert, C. H. C., Taal, E., Seydel, E. R., & van de Poll-Franse, L. V. (2019). Health-related and cancer-related Internet use by patients treated with a total laryngectomy. *Supportive Care in Cancer*, *27*(3), 707–715. https://doi.org/10.1007/s00520-018-4451-7

Ward, E., Crombie, J., Trickey, M., Hill, A., Theodoros, D., & Russell, T. (2009). Assessment of communication and swallowing post-laryngectomy: A telerehabilitation trial. *Journal of Telemedicine and Telecare*, *15*(5), 232–237. https://doi.org/10.1258/jtt.2009.081204

Ward, E., White, J., Russell, T., Theodoros, D., Kuhl, M., Nelson, K., & Peters, I. (2007). Assessment of communication and swallowing function post laryngectomy: A telerehabilitation trial. *Journal of Telemedicine and Telecare*, *13*(3_suppl), 88–91. https://doi.org/10.1258/135763307783247293

Watson, L., Hamilton, D., & Patterson, J. M. (2022). Patient experience of the acute post-surgical period following total laryngectomy during the COVID-19 era. *International Journal of Language & Communication Disorders*, *57*(4), 737–748. https://doi.org/10.1111/1460-6984.12709

Zeine, L., & Larson, M. (1999). Pre- and post-operative counseling for laryngectomees and their spouses: An update. *Journal of Communication Disorders*, *32*(1), 51–71. https://doi.org/10.1016/S0021-9924(98)00029-X

Zucca, A., Sanson-Fisher, R., Waller, A., & Carey, M. (2014). Patient-centred care: Making cancer treatment centres accountable. *Supportive Care in Cancer*, *22*, 1989–1997. https://doi.org/10.1007/s00520-014-2221-4