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Identifying Areas for Improvement in Laryngectomy Care: Insights From Concept Mapping With Healthcare Professionals

Laurie Wennerholm, MA, CCC-SLP, BCS-S, CLT (PhD candidate)[1,2], Elizabeth C. Ward, BSpThy(Hons), PhD, FSPAA[1,3], Clare L. Burns, BSpPath, PhD[1,4], Jasmine Foley, MSpPath, PhD[1], Gina L. Palma, MS, CCC-SLP, BCS-S[5], JK Rasamny, MD[6], and Craig Berzofsky, MD[6]

Abstract

Objectives: Evidence suggests individuals with a laryngectomy (IWL) face multiple challenges accessing the necessary multidisciplinary healthcare professionals (HCPs) needed to provide optimal care. This study examined the perceptions of HCPs regarding current laryngectomy care models to identify and prioritize opportunities for service improvement. **Methods:** A concept mapping methodology was utilized, which combines both qualitative and quantitative data, enabling HCPs to identify and then prioritize critical elements of care that require refinement to improve the current care pathway. Twenty HCPs were recruited from 2 services within the United States (10 per site) including participants from medical, nursing and allied health disciplines. Considering differences in services, separate analysis was conducted by site. **Results:** Participants generated 31 and 36 unique statements from each site respectively. Both sites identified highly similar issues. Go-Zone analysis revealed 49% of Site 1 statements and 33% of Site 2 rated highest for both importance and changeability. Prioritized issues related to the importance of education, access to skilled HCPs, coordinated services, the need for a post-acute care pathway and improving financial supports. **Conclusions:** HCPs identified multiple actionable changes to help optimize the care pathway for IWLs which can be used by services to direct improvements in care.

Plain Language Summary

In this study, researchers asked healthcare professionals (e.g., doctors, nurses, speech-language pathologists, dietitians) from 2 different hospital centers to identify areas for improvement in the care of patients who have lost their voice box (larynx) due to cancer. Once areas for improvement were identified (statements), their importance was prioritized (ranking of statements). Healthcare professionals identified and prioritized - patient education, access to competent professionals, coordinated care and financial support. This information will help optimize care for this complex patient population.

[1]School of Health and Rehabilitation Sciences, The University of Queensland, Brisbane, QLD, Australia
[2]Department of Speech-Language Pathology - Rusk Rehabilitation, Perlmutter Cancer Center, NYU Langone Health, New York, NY, USA
[3]Centre of Functioning and Health Research, Metro South Health, Queensland Health, Brisbane, QLD, Australia
[4]Speech Pathology Department, The Royal Brisbane and Women's Hospital, Metro North Health, Queensland Health, Brisbane, QLD, Australia
[5]Department of Otorhinolaryngology, Montefiore Medical Center, Bronx, NY, USA
[6]Department of Otolaryngology, Head and Neck Surgery, White Plains Hospital, White Plains, NY, USA

Corresponding author:
Laurie Wennerholm, School of Health and Rehabilitation Sciences, The University of Queensland, Brisbane, QLD, Australia; NYU Langone Health, Perlmutter Cancer Center, 160 East 34th Street, New York, NY 10016, USA.
Email: wennel01@nyu.edu

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Introduction

Laryngectomy is a highly complex surgery, leading to significant breathing, swallowing and communication challenges that require ongoing management throughout survivorship.[1] For individuals with a laryngectomy (IWL) and their caregivers, navigating the multitude of morbidities of their "new normal" can be overwhelming.[2-4] In fact, patients with head and neck cancers, including IWL, have the highest levels of distress, depression and suicide compared to other cancer types.[5,6] This is often exacerbated in the context of poor service access and patient education.[4,5] Therefore, optimization of care for IWL is critical to enhance functional outcomes and quality of life.

Due to its complexity, laryngectomy requires both acute and long-term services from a range of skilled healthcare professionals (HCPs) within a multidisciplinary team (MDT).[7,8] The MDT is typically comprised of multiple HCPs, including head and neck surgeons, medical and radiation oncologists, dentists, dietitians, speech-language pathologists, advanced practice professionals (i.e., physician assistants, nurse practitioners), social workers, physical and occupational therapists, and pain/palliative care specialists amongst others.[9-12] The role of the MDT is not only to diagnose and lead cancer treatment but also to address the significant physical, functional and quality of life changes that result from surgery, and any accompanying adjuvant treatment(s) and toxicities.[7,10]

Best practice recommendations specify that laryngectomy care needs to be specialized and integrated[13-17] and should be conducted in a center with a trained MDT with relevant expertise.[16,18] Multiple studies confirm the benefits of care provided by a dedicated cancer care MDT, including optimal staging, faster initiation of service delivery, availability of clinical trials, improved functional outcomes, and most critically higher survival rates.[9,19-23] However, although specialist MDT care is recommended, the provision of coordinated, expert care is not consistently actualized in practice.[3,7] In fact, many head and neck cancer (HNC) programs are insufficiently resourced with poor accessibility for patients due to geographical or cost constraints, and there are acknowledged issues with care fragmentation and enhanced patient burden accessing care.[24-26] Additionally, despite recognition of the importance of "patient-centered care," it has been noted that the care provided to IWL often lacks this critical element.[27] Hence it is recognized that improvements are needed.[28,29]

The process of improving care for IWL requires a methodological approach that involves identifying what the current path looks like, its strengths and areas of opportunity, and the perceptions of stakeholders within the community of care.[30] Recognizing this, there has been an emergence of approaches that engage critical stakeholders in clinical research to improve quality of care.[31] Alolayan et al.[32] recently used concept mapping methodology to examine and compare the priorities of both HNC patients (2 with laryngeal cancer) and HCPs. Although that study was not specific to laryngectomy care, it identified a number of issues to address, including financial support for care, long term/continued care, psychosocial concerns, nutrition, education, person-centered care, managing treatment side effects and persistent/lifelong challenges.[33] Although both HCPs and patients identified similar issues, there were noted differences in prioritization. Patients prioritized access to care, education, and continued care. In comparison, addressing the psychosocial impacts of cancer treatment (i.e., the influence cancer treatment has on social and life participation) were rated higher by HCPs. The study authors hypothesized that this difference could be related to research available to HCP about suicide rates in HNC patients,[33] as well as the growing evidence of the important role clinicians' empathy plays in patient recovery.[34]

Other recent work by Wennerholm et al.[35] similarly utilized concept mapping with 14 IWL from 2 health services in the United States (US) to specifically explore their perceptions about current laryngectomy care. Through the mapping process, a total of 32 unique statements were identified as areas for supportive care optimization, which grouped across key areas including inpatient care issues, supporting adjustment to life after surgery, psychological care and trust in healthcare, comprehensive healthcare professional access and support, communication and peer support, and managing the treatment and recovery pathway. Statements that were rated by participants as highest in importance and changeability focused primarily on improving psychological care and post-surgical adjustment. While that study yielded valuable information for process improvement from the voice of patients who have undergone a laryngectomy, it did not explore the perceptions of another critical group of stakeholders – MDT clinicians.

While the results of Alolayan et al.[32] suggest there may be similarities in what HCPs and patients think about improving HNC care in general, a systematic study of the perceptions of HCPs and what they see as important to optimize care for IWL has yet to be explored. Engagement of the healthcare team can improve the value of research endpoints by reflecting on their clinical experience, alongside the lived experience of IWL, as they navigate the complex care pathway, balancing mortality,

morbidity and quality of life.[32] Therefore, the aim of the current study was to use concept mapping to capture HCPs perspectives as unique stakeholders, and to explore what HCPs identify and prioritize as issues important to deliver quality care during laryngectomy management. The ultimate objective of this work is to use these data, alongside other published evidence from patient perceptions,[35] to provide direction for change in laryngectomy care.

Methods

This study employed concept mapping, a mixed methodology that combines qualitative and quantitative data, capitalizing on the strengths of both types of information, including statistical findings and the "why" behind the statistics.[36] It is a detailed process used with groups of people with lived experience of the issue under investigation[37,38] and can be used with both small (10-15) numbers of participants[37-40] and large (>15) participant groups.[41-44] It involves an integrated approach with six critical stages[45]: 1) preparation, 2) statement generation, 3) structuring, 4) representation, 5) interpretation and then 6) utilization.[37,46] Only stages 1-5 are represented in this current research, since this paper is one of a series of studies being conducted to ultimately inform the development of a framework of care for SLP management of IWL. Hence, it is the intent that the results of this study will later be combined with other published work[35] to inform the 6th and final stage - the utilization stage. Reporting of concept mapping methodology was guided by the ConMapT checklist specifically designed for concept mapping studies.[47]

Participants

As per the previously published patient concept mapping study involving patients by Wennerholm et al.,[35] the HCPs were recruited from two health services within a larger healthcare system in the US. HCPs were approached by one of the two primary investigators (PIs)(LW, GP) during clinic hours or at tumor board and provided with a study flyer inviting them to participate. Inclusion criteria for HCPs included employment at one of the sites, care provision for IWL for at least 2 years, and working as an HNC MDT professional (i.e., HN surgeon, SLP, nurse, medical or radiation oncologist, registered dietitian, occupational therapist, etc.). Site 1 was a small, 290-bed, acute, community hospital with a co-located cancer center, managing complex head and neck patients for about 5 years. Site 2 was a large,750-bed, academic, urban center with integrated cancer care, managing IWL for greater than 15 years. In the design of this study, due to the differences in the functions of the MDT between the two sites, and the inherently different service models at each site, an a priori decision was made to treat the participants and data sets from each site separately.

Stages 1 and 2 – Preparation and Statement Generation

During the preparation stage, HCPs first engaged in a semi-structured interview designed to have participants reflect on their services and consider what is important for, and what could be improved about current services for IWL. Question prompts for these interviews were created by the lead authors (EW, CB and LW, all speech-language pathologists (SLPs) with over 20 years' experience in research/laryngectomy care) to facilitate reflection on the current care provided to IWL (See Supplemental Table 1 (S1) – Interview Guide). Interviews were conducted either face-to-face or via telephone by one of two PIs (LW or GP, both SLPs, each with over 18 years of experience in HN clinical care). The aim of the interviews in concept mapping is simply to prime the participants to the topic and provide context to assist them in the statement generation stage. Directly after the interview, each HCP was asked to generate action statements for ensuring high quality care/or facilitating improved care for IWL. There was no limit on the number of statements that could be generated; however, each statement had to be an actionable item that would help optimize care. After this session, each participant was sent an email listing their action statements and asking them to: (1) ensure accuracy of their action statements and/or (2) provide any additional action statements generated after further reflection. In this statement generation process it is not uncommon that multiple, highly similar statements are generated by participants. Therefore, all statements generated by each site were reviewed by the research team, duplicates removed, and a final list of discrete items per site was compiled leaving only one relevant statement per concept in the analysis for each site.

Stage 3 – Structuring

The structuring stage marks the beginning of data collection in concept mapping,[48] during which participants both ranked and then sorted statements generated by the group. This stage was completed within 3 months from the initial interview. First, statements written individually on index cards were sorted by participants into thematic groupings. The rules for sorting included (1) each statement can only be included in one group, (2) a single statement can comprise one group, and (3) more than one group must be created. The researchers then documented the groupings and the statement(s) within each group. The index cards were shuffled between participants to prohibit any priming effect.

Second, participants were given a document containing all statements and a scoring paradigm to rank each statement on a 5-point (0-4) scale based upon its degree of importance and changeability (feasibility for change) in the current state of care. For importance, statements could be ranked as: 0 = not important at all, 1 = a little important, 2 = neutral, 3 = very important, 4 = extremely important. Changeability was rated using a similar scale: 0 = not changeable at all, 1= a little changeable, 2 = neutral, 3 = very changeable, 4 = extremely changeable.

Stages 4 and 5 – Representation and Interpretation

In this stage, data from each site were analyzed separately and represented in the form of a series of graphs and maps using free open-source software (R-CMap).[49] The initial step involves multidimensional scaling of the similarity matrix created,[49] which generates a two-dimensional point map, illustrating the strength of the relationships amongst the statements by their "closeness" to one another. For example, the closer the statements are represented on the point map, the greater the frequency that they were sorted together.[50] "Goodness of fit" or the statistical strength of the plot is noted by a stress value ranging from 0-1, with a lower stress value indicating a "better fit." The upper acceptable stress value, indicting the model is viable to progress, is defined as 0.39.[51]

Hierarchical cluster analysis[52] is then used to group the statements from each site into clusters representing similar concepts, determined by the sorting task.[37] This stage of the analysis is based on the statements and their interrelationship. Researchers reviewed the dendrogram generated by the software, and the final number of clusters was created using an iterative process. Once it was agreed upon that the clusters represented distinct themes in the data, unique cluster titles were assigned by the research team.

A critical step in concept mapping, constituting the conceptual framework,[37] is the cluster rating map. This map illustrates the relationship amongst the statements within each cluster, the discrete themes that the statements have been organized into, and the size and location of the clusters on the map. Specifically, the closer statements appear within an individual cluster, the more similar they are thematically, and the smaller the cluster, the better agreement within that cluster. Finally, the proximity of clusters to one another on the map represents greater thematic likeness.[48]

The next analysis step is generation of the pattern matching graph. This graph uses data from the importance and changeability ratings to depict the relationship between importance and changeability for each cluster visually.[48] This enables the interpretation of these two variables for each cluster, for example a cluster with high importance may have low ratings for changeability or vice versa. In this representation, the importance and changeability ratings between clusters may differ by only small differences in mean score; however, this is still considered an important difference if it changes their prioritization.[46]

The ultimate map in concept mapping displaying critical information to guide change is the "Go-Zone".[48] This depicts the relationship between the importance of a statement and its changeability. Statements in the Go-Zone that appear in the upper right quadrant are rated with both the highest importance and highest changeability by participants, and therefore, represent priority targets for immediate action. Conversely, statements in the lower left quadrant are rated of low importance and changeability, identifying them as low priority by stakeholders.[48] As per the typical analysis of the Go-Zone,[38,46,48] the key focus of the analysis of the Go-Zone maps was on those statements which fall in the upper right quadrant.

Results

Participants

Table 1 displays the demographic data of the 20 recruited participants from the 2 sites. Participants from Site 1 (n = 10) comprised 5 medical, 2 nursing and 3 allied health providers. Site 2 (n = 10) comprised 6 medical, 1 nursing and 3 allied health providers. Of note, there were 3 HN surgeons in the cohort (n = 1 from Site 1 and n= 2 from Site 2) with n = 2 performing both tumor resections and microvascular reconstruction - both from Site 2. While all 20 HCPs participated in the statement generation task, 3 participants from Site 2 (2 medical oncologists and 1 oncology nurse) were unavailable to complete the sorting and ranking tasks. In concept mapping methodology there is often attrition across the stages of the process, and it is not critical that all participants complete all steps.[37] However, it is recognized that due to this attrition, there was no representation from nursing involved in the sorting and ranking stages of the analysis for Site 2.

Concept Mapping

Results of the concept mapping analysis are discussed by site, with key data relating to similarities and differences between sites noted.

Table 1. Demographics of HCPs From Site 1 (n =10) and Site 2 (n = 10)

Site	Participant	Profession	Gender	Laryngectomy experience (in years)
1	1	RD	Female	5
1	2	Radiation oncologist	Male	8
1	3	Medical oncologist	Male	2
1	4	Laryngologist	Male	10
1	5	Medical oncologist	Female	8
1	6	SLP	Female	4
1	7	SLP	Female	4
1	8	HN surgeon	Male	10
1	9	Oncology nurse	Female	5
1	10	Pain and palliative care NP	Female	5
2	1	RD	Female	5
2	2	RD	Female	5
2[#]	3	HN surgeon	Male	16
2[#]	4	HN surgeon	Male	17
2	5	SLP	Female	8
2	6	Medical oncologist	Male	3
2	7	Radiation oncologist	Male	4
2*	8	Medical oncologist	Male	12
2*	9	Medical oncologist	Female	7
2*	10	Oncology nurse	Female	10

Note. HCPs = healthcare professionals, HN = Head and neck, SLP = speech-language pathologist, RD = registered dietitian, NP = nurse practitioner.
*unable to complete ranking and sorting stage of data analysis.
[#]HN surgeons performing microvascular reconstructive techniques in addition to tumor resection.

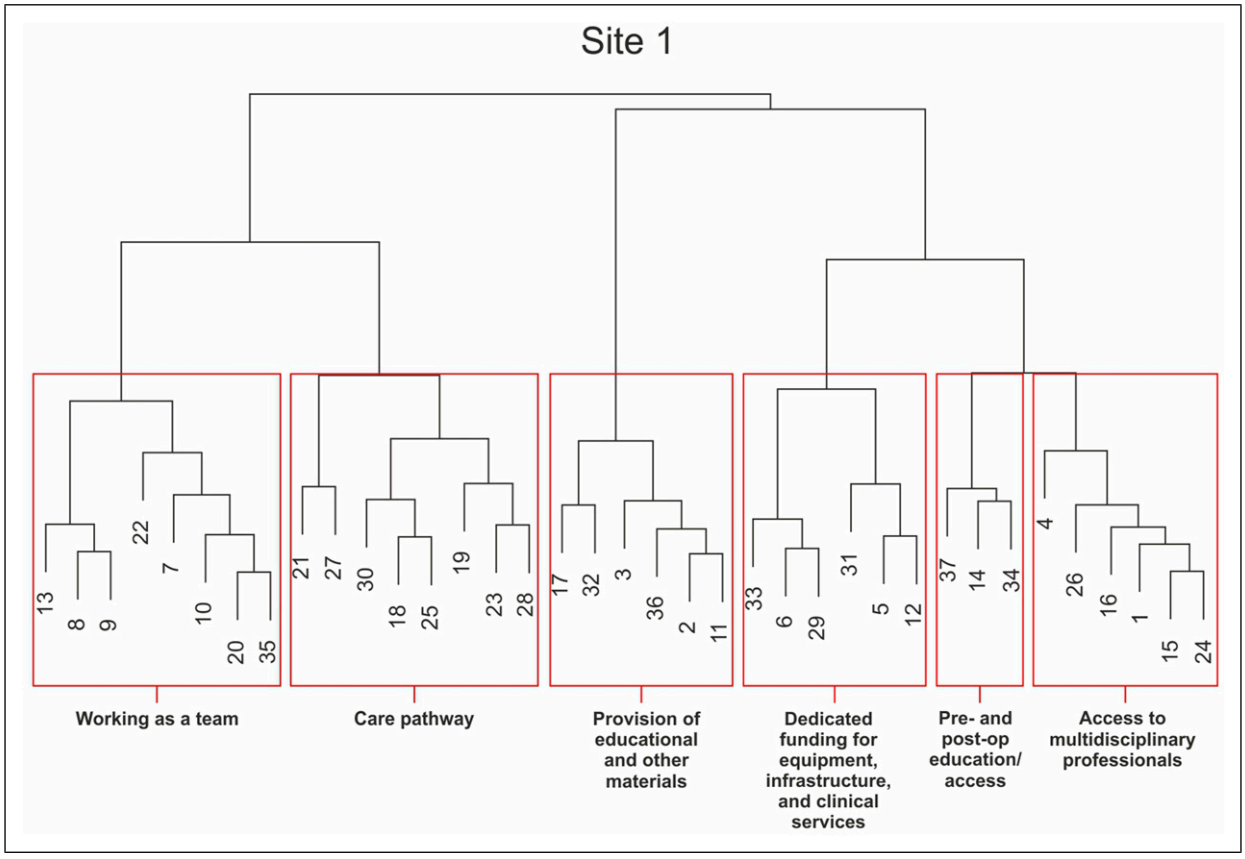

Figure 1. Dendrograms of the 6 clusters for site 1 and 8 clusters for site 2, representing meaningful cluster themes for participants

Stages 1, 2 and 3

Site 1 participants initially generated 55 statements and Site 2, 43 statements. After reviewing and eliminating duplicates, there were 37 unique statements from Site 1 and 36 from Site 2 included in analysis. The list of unique statements by site with average ratings of importance and changeability is provided as supplementary material (Table S2 and Table S3).

Stages 4 and 5

Two-dimensional point maps were generated using multidimensional scaling. Analysis revealed the models had a stress value of 0.265 for Site 1 and 0.277 for Site 2. Although the numbers in the cohorts were small, both stress values fell within the acceptable range, and hence subsequent analysis was able to proceed.[51]

The cluster analysis process yielded a 6-cluster dendrogram for Site 1 and an 8-cluster dendrogram for Site 2 (Figure 1). Team members (EW, CB, LW and JF) collectively reviewed the statements in each cluster using an iterative process and assigned a name for each, reflecting discrete and meaningful themes. Table 2 is provided to illustrate the data for both sites including all cluster names, description of clusters, cluster statement examples, and mean importance and changeability ratings. For Site 1, the 6 clusters included: (1) *Working as a team*, (2) *Care pathway*, (3) *Provision of education and other materials*, (4) *Dedicated funding for equipment, infrastructure and clinical services*, (5) *Pre-and post-op education/access,* and (6) *Access to multidisciplinary professionals*. Clusters for Site 2 included: (1) *Interprofessional relationships and integrated MDT*, (2) *Dedicated navigator*, (3) *Patient education and access to support*, (4) *Communication between team members to support the care pathway*, (5) *Peer support*, (6) *Dedicated funding for equipment and infrastructure*, (7) *Access to multidisciplinary professionals*, and (8) *Supporting access to care*.

The Cluster Rating Maps (Figure 2) provide a visual display of how the statements were grouped by the cluster analysis.[37] A critical component of the cluster rating map is absence of abutting edges, indicating each cluster represents a discrete theme. Notably, in the current study, both cluster rating maps have no overlap of edges indicating that each represents a unique concept/theme.

Review of the clusters generated by the two groups revealed they related to highly similar issues, despite some slight differences in groupings and/or cluster names. Core issues included the importance of access to the MDT, teamwork and communication amongst MDT members, the importance of education to ensure patients are prepared and have access to

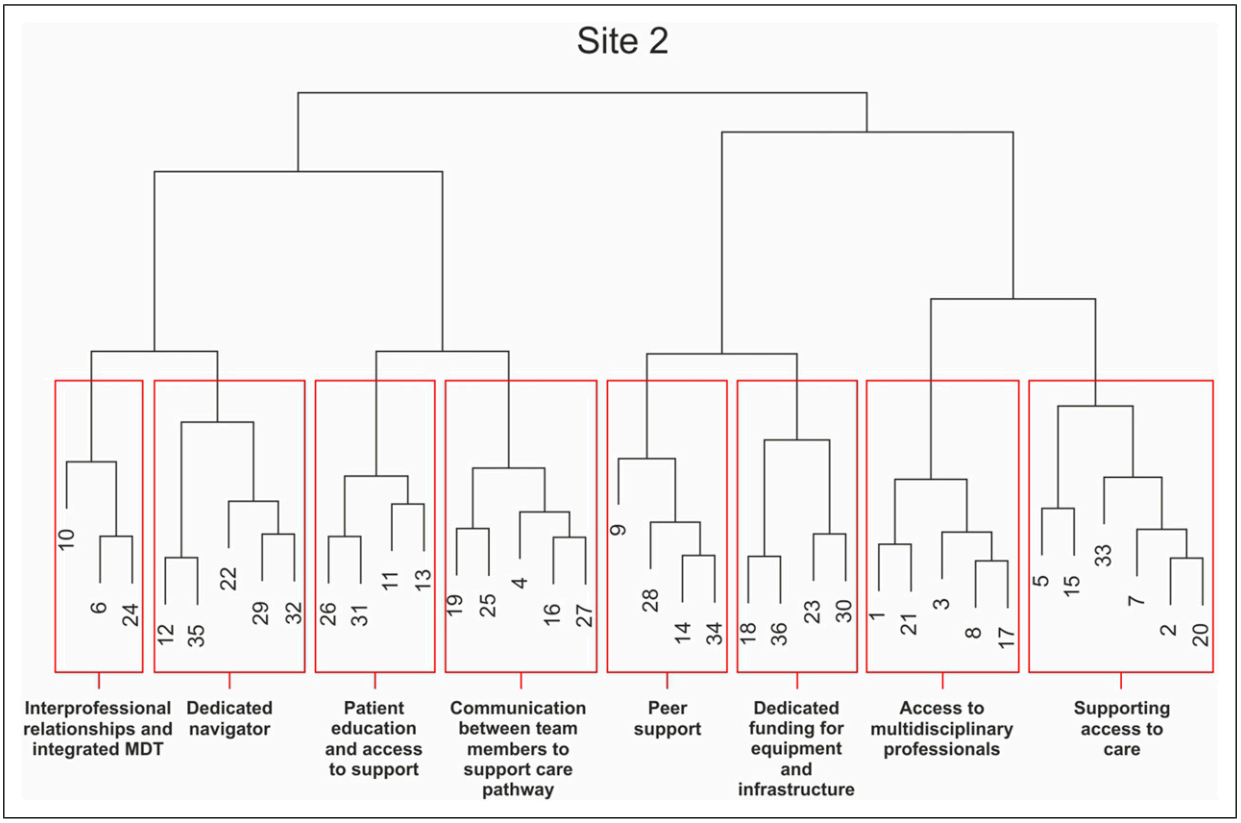

Figure 1. Continued.

Table 2. Characteristics of Cluster Themes – Site 1 and 2

Cluster ID	Cluster theme	Theme description	Example statement	Number of statements	Mean importance rating	Mean changeability rating
Site 1						
1	Working as a team	Describes interprofessional training to ensure competency, communication, and collaboration within the multidisciplinary team	The core team should conduct staff education, at least annually since staff rotate and there is turn-over, to ensure that everyone is comfortable and competent to work with patients with laryngectomy	8	3.34	2.79
2	Care pathway	Describes the importance of standard pathway to avoid variance	There should be a protocol set up with an inter-disciplinary pathway for patients to follow that involves RD, SLP, psychosocial and involves pre op, acute needs and post op needs	8	3.28	3.16
3	Provision of education and other materials	Describes the importance education and materials to support successful transition	All patients should have education materials at the bedside re: stoma care…and explanation of equipment	6	3.72	3.43
4	Dedicated funding for equipment, infrastructure, and clinical services	Describes financial supports as well as coordination of services for convenience of patient/caregiver	All patients should have access to financial assistance for their surgical costs, supplies, equipment needs, etc.	6	3.20	2.33
5	Pre- and Post-op education/access	Describes access to critical MDT members for preoperative education and importance of ongoing patient/caregiver viewed as part of team	All patients (and caregivers) should be able to participate in discussions with the MDT pre-surgically, post-surgically and prior to DC from the hospital.	3	3.67	3.30
6	Access to multidisciplinary professionals	Describes ongoing support from MDT including psych, SLP, RD as well as peer support	All patients should have access to psych and receive assessments before their surgery if needed as well as access to social work “early and often.	6	3.40	2.88
Site 2						
1	Interprofessional relationships and integrated MDT	Describes knowledge of roles within the MDT, dedicated space and easy access amongst professionals	There should be a head and neck clinic that includes all disciplines.	3	3.33	2.67
2	Dedicated navigator	Describes importance of a clinical navigator who follows a standard pathway of care	All patients should ideally have access to a nurse navigator who will help them get to all of their appointments based upon a care pathway.	5	3.23	2.83

(continued)

Table 2. (continued)

Cluster ID	Cluster theme	Theme description	Example statement	Number of statements	Mean importance rating	Mean changeability rating
3	Patient education and access to support	Describes modalities of education and knowledge of roles of team members, access to these individuals	All patients should have a cheat sheet of all providers and their roles and responsibilities to help improve the continuity of care.	4	2.93	2.89
4	Communication between team members to support care pathway	Describes necessity for easy and ongoing communication amongst team members	The team should have MDT meetings to discuss inpatients and outpatients, ensure we are meeting their needs. If not, figure out how we can do better.	5	3.27	3.00
5	Peer support	Describes the critical importance of laryngectomy peers to support adjustment	All patients with laryngectomy should have access to a support group with others with their diagnosis.	4	2.77	2.27
6	Dedicated funding for equipment and infrastructure	Describes supporting financial needs such as equipment, advocacy by team members and close proximity of providers	There should be philanthropy or other care programs that take the economic burden away from the laryngectomy patient-everyone should have their equipment paid for.	4	3.13	1.46
7	Access to multidisciplinary professionals	Describes access to MDT members imperative for care	All patients should be seen in a timely manner by nutrition and SLP.	5	3.57	3.17
8	Supporting access to care	Describes access to education, supplies, referrals to MDT that is ongoing	All laryngectomy patients should have access to the right supplies (larytubes, HMEs, suction machines) and get these supplies in an easier way via mail.	6	2.77	2.31

Note. SLP= speech-language pathologist, RD= registered dietitian HME= heat and moisture exchange, MDT = multidisciplinary team.

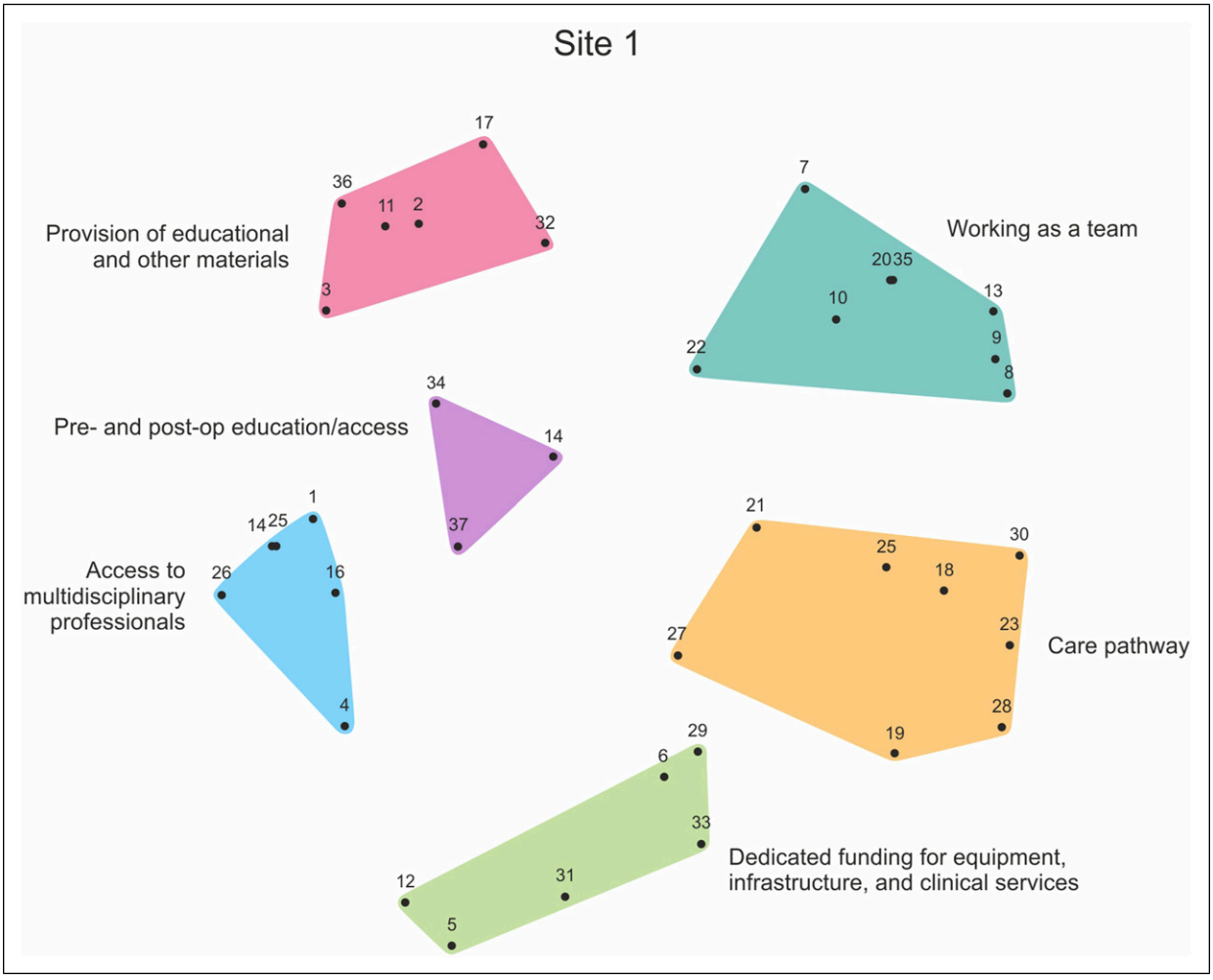

Figure 2. Cluster rating maps of each cluster theme by importance for site 1 & 2

educational materials that are both standardized and patient friendly, and dedicated funding to support care. Although Site 2 had 2 additional designated clusters relating to a *Dedicated Navigator* and *Peer Support,* it was noted that dedicated support for clinical navigation was still mentioned by Site 1 participants but was included in the cluster *Dedicated funding for equipment, infrastructure and clinical services*.

Although both sites generated highly comparable statements, which were grouped into similar clusters, the Pattern Matching graphs (Figure 3) revealed some slight differences in the ranking of the order of importance and potential for change. For Site 1, all 6 clusters were rated high (mean 3.2 and above) for importance, with the clusters *Provision of education and other materials* and *Pre-and post-op education/access* rated the top 2 most important and most changeable. The relationship between importance and changeability was indicated with a negative gradient for all clusters, signifying lower ratings for changeability. Despite the three clusters *Access to multidisciplinary professionals, Working as a team* and *Dedicated funding for equipment, infrastructure and clinical services* being rated high in importance, they rated lowest for changeability.

For Site 2, again most (5 of the 8 clusters) were rated as above 3.2 for importance, though at this site *Access to multidisciplinary professionals* and *Supporting access to care* were the top 2 clusters rated highest for importance, with *Access to multidisciplinary professionals* also being rated highest for changeability (Figure 3). Of these, only *Access to multidisciplinary professionals* also rated high in changeability. Across the clusters there was again a negative gradient noted between importance and changeability ratings, indicating that the potential to change most issues was considered more difficult. The only exception was *Patient education and Access to Support* which was rated equally important and changeable. The clusters identified as being the lowest in changeability scores were highly similar to those identified by Site 1, with the cluster *Dedicated funding for resources and Infrastructure* also rated by this site as falling far below all other clusters regarding potential changeability.

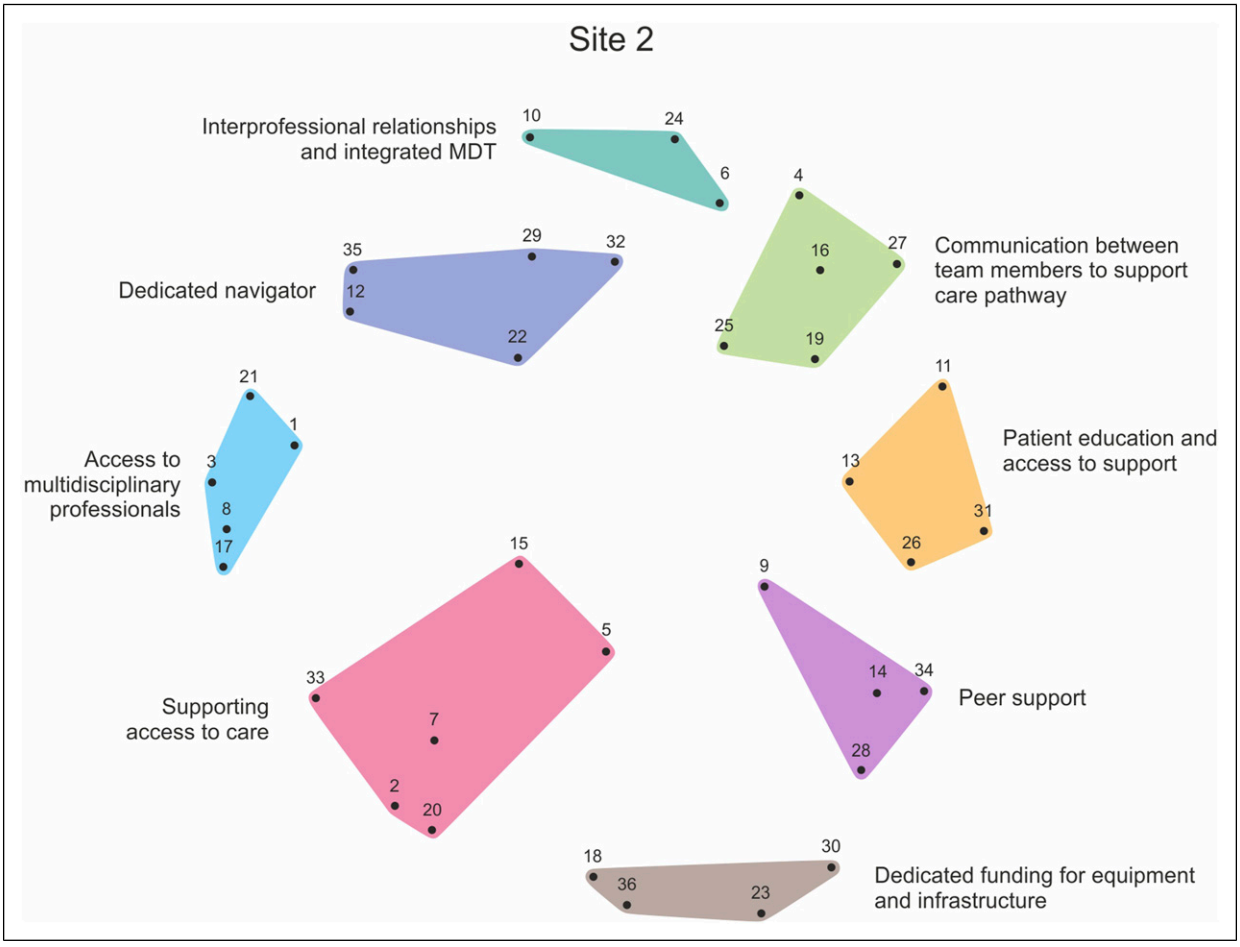

Figure 2. Continued.

The Go-Zone plots are represented in Figure 4. For Site 1, there were 18 statements represented in the Go-Zone, indicating that 49% of statements were considered high for both importance and changeability (Table 2). Statements came from all 6 clusters, though the majority came from the clusters *Provision of education and other materials* (n = 4) and *Care Pathway* (n = 4). Statement 2 "*All patients should have education materials at the bedside re: stoma care and explanation of equipment*" received the highest rating for importance and changeability. For Site 2, there were 12 statements in the Go-Zone, comprising 33% of the statements generated by the group (Table 2). Clusters *Access to multidisciplinary professionals, Interprofessional relationships and integrated MDT* and *Communication between team members to support the care pathway* had the highest number of Go-Zone items (n = 3, n = 2, n = 3, respectively). Statement 8 *"All patients should have access to nutrition/registered dietitian"* was the highest rated statement for importance and changeability for Site 2.

Exploring the individual statements within the Go-Zone for the 2 sites revealed many similarities (Table 3). Both sites prioritized comprehensive, standardized and culturally appropriate education (e.g. *Site 1: All patients should have good quality handouts and education….; Site 2: All patients should have a dedicated, comprehensive pre-operative counseling…*), the importance of having access to well-trained HNC team members with specialist skills and clear role delineation (e.g. *Site 1: All inpatient and outpatient staff should have access to multidisciplinary education with regards to the needs of the TL patient; Site 2: All patients should have a dedicated team with members that specialize in the HN cancer population*), having a standard and specific care pathway with formal follow-up (e.g. *Site 1: There should be a clear TL pathway for staff that defines the surgery, and complications…; Site 2: There should be a care pathway for all laryngectomy patients to ensure they have the proper experience*), and the important role of allied health, including the SLP, social worker (SW) and registered dietitian (RD) to support recovery (e.g. *Site 1: After diagnosis, all patients should be required to meet with the SLP and RD…All patients should have access to social work…; Site 2: All patients should have access to SLP., All patients should have access to RD… All patients should have access to SW*). Site 1 also had some additional unique statements within the Go-Zone relating to the importance of care coordination and receiving care at a single facility, the importance of patients and family

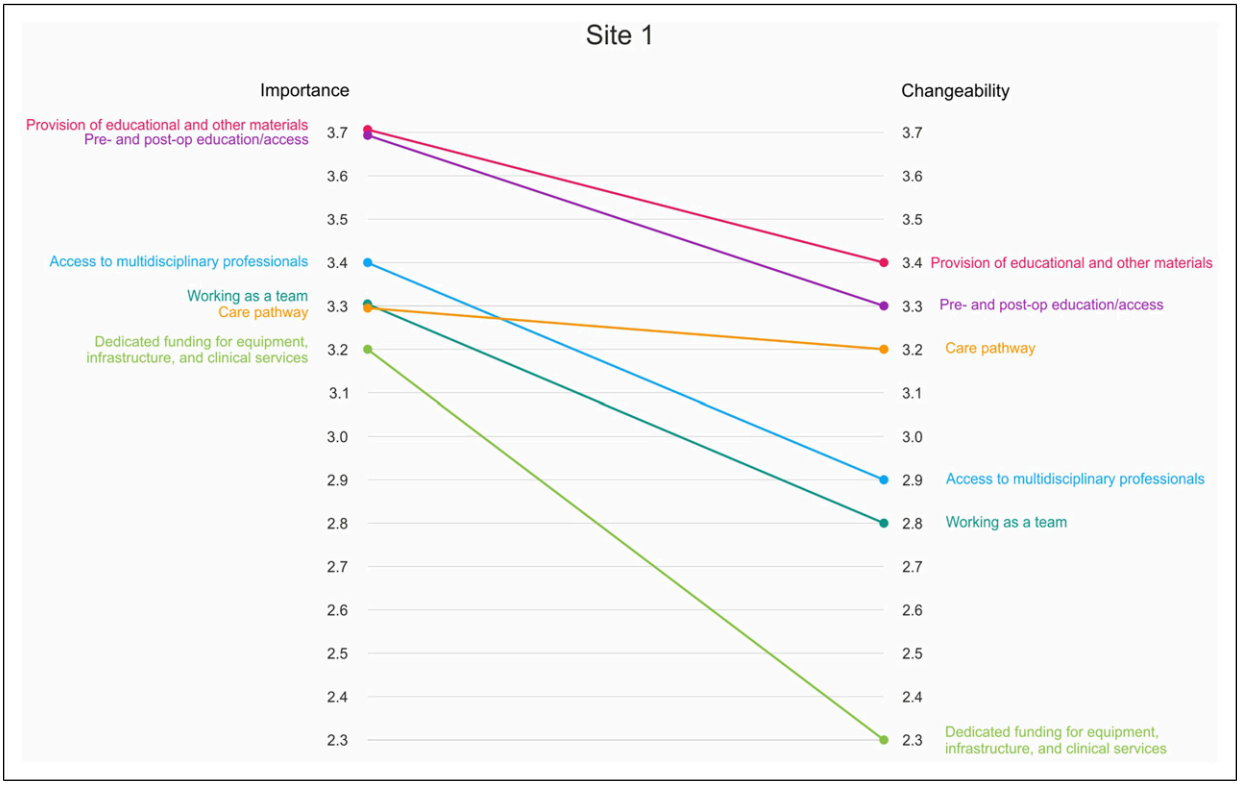

Figure 3. Pattern matching graphs comparing importance and changeability for site 1 & 2

participation in team discussions, providing realistic expectations of surgery and overall cancer recovery and supporting patients with their equipment needs on discharge.

Discussion

This exploratory study engaged two different groups of HNC MDT professionals to identify and prioritize items for enhanced laryngectomy care. Findings confirmed that despite working in two different types of cancer services (i.e., urban versus suburban, academic versus community; different maturity of services), both groups identified and prioritized highly similar issues. Critically, a third or more of all statements generated by each site fell within the Go-Zone, indicating many of the issues raised were considered both highly important and highly changeable. This work builds on prior concept mapping work with patients[35] and provides insight into what HCPs perceive are important issues and provides a list of important and actionable statements that can be considered by services to guide improved care for IWL.

Both sites considered patient education as a key supportive care issue, with Site 1 ranking the provision of educational materials and access to pre- and post-op education as the 2 most important clusters. Go-Zone statements from both sites highlighted education as a priority area for service enhancement. Participants emphasized the importance of providing IWL with realistic expectations about treatment and recovery, while also acknowledging the importance of involving family members in education and care discussions. This finding is consistent with recent concept mapping work which explored what HCPs and patients with HNC prioritized as critical for care.[32] In that work, *Education* received the highest priority ratings for both groups, highlighting the crucial nature of information giving for patients and caregivers before, during and after treatment. From Site 1, HCPs advocated comprehensive, transparent and standardized pre-op education in multiple formats (e.g., handouts, videos) to better prepare patients for their post-operative phase. This is consistent with multiple studies emphasizing the importance of pre-operative, as well as ongoing education and counseling, considering the long-term, life-altering sequalae of laryngectomy.[53-58]

Despite studies supporting the importance of education for IWLs,[54,57,58] there remains high variability in both delivery and quality.[59] A systematic review of educational materials for HNC patients revealed that none met the sixth grade reading level recommended to ensure patient understanding.[60] Distress and anxiety can also limit the processing of information from healthcare providers[61,62] as depicted in prior research where a patient noted "pre-operative information giving - it was just

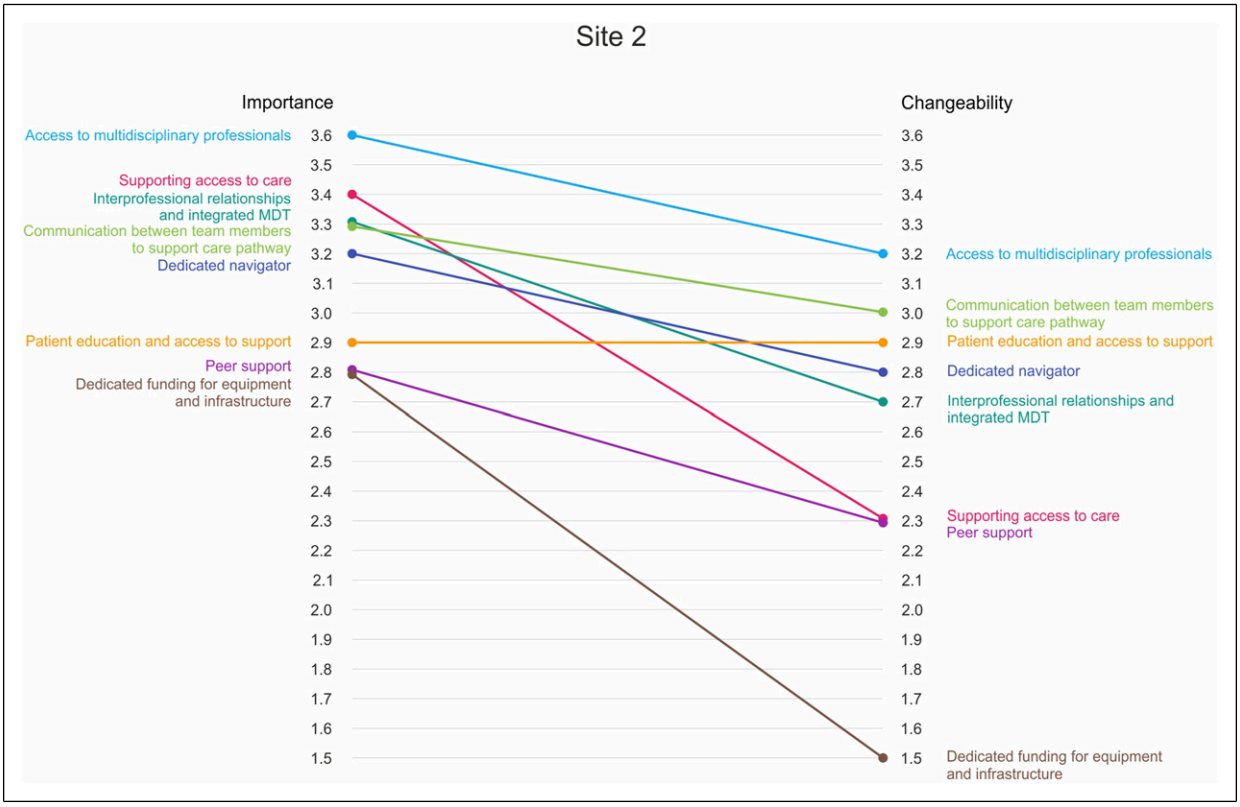

Figure 3. Continued.

words".[4] In a recent qualitative study, Basta et al.[53] found that patients with HNC and their caregivers identified gaps in current pre-operative education and provided recommendations for oncology teams. These included improving education on treatment sequelae; use of multiple modalities to enhance understanding of education provided; facilitating connections with peers who have undergone surgery to provide support; improving communication between patients and providers in the context of hearing, speech, or vision impairments; and providing patients with greater transparency regarding possible surgical outcomes (i.e., best- and worst-case scenarios).[53] Evidence also supports that pre-operative nursing and SLP education can also help reduce length of stay for complex surgical populations, including IWL.[63,64] Therefore, providing high quality patient education not only has benefits for the IWL, but also the health service.[65]

Both sites prioritized the importance of teamwork in laryngectomy care, which is consistent with prior literature,[7,8,66] and is aligned with recommended models of care.[16,18,66] It is recommended that care delivered by the MDT be both coordinated and patient-centered.[13-15,17,27] However, with the complexity of laryngectomy rehabilitation, the number of professionals involved, and the potential for services to be provided across different settings, it is recognized that receiving a coordinated team approach can be challenging, and, if ineffective, can lead to care fragmentation.[25] Hence, it was not surprising that HCPs from both sites prioritized the need for a nurse/care coordinator. This role involves case management, care navigation, surveillance, management of symptom burden during active treatment (i.e., pain, mucositis, radiation dermatitis, etc.), health education, emotional support, and, importantly, referral to other professionals.[67]

Supporting access to care and enabling access to necessary multidisciplinary specialists were also strong messages in the data from both sites, with Site 2 rating these as their top 2 issues of highest importance. Recognizing the complexity of laryngectomy surgery and its post-surgical rehabilitation, both groups highlighted the importance of having specialist trained HNC MDT members with core competencies in laryngectomy care, clearly defined roles, and effective communication processes within the team. Both groups prioritized multiple statements within the Go-Zone regarding the need for early and ongoing access to specific professionals, including oncology nurses, RDs, psychology, SWs, and SLPs. While HNC teams are traditionally led by physicians, impaired daily function, psychosocial issues and quality of life related changes underscore the essential role of related health professionals to optimize care, which is well-supported in the literature.[18,67,68] A key point raised was the importance of access to psychological support. Psychosocial distress is common in IWL[69] and it is purported that the severity of treatment morbidities for IWL contributes to the highest level of emotional distress compared to any other

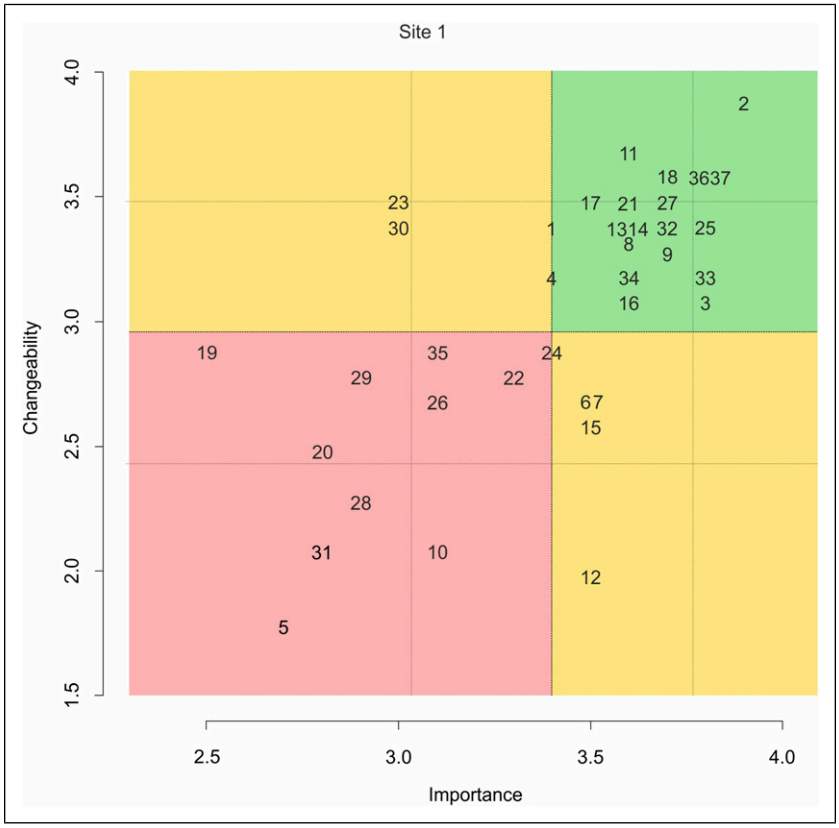

Figure 4. Go-zone maps with quadrants of interest site 1 & 2

surgical procedures.[70] Despite this, it is recognized that there is a paucity of psychosocial support personnel embedded in HNC teams.[71] Similarly, Alolayan et al.[32] identified the need for psychosocial support for HNC patients as a high priority amongst their HCPs, underscoring the importance of access to healthcare specialists that manage the multitude of psychosocial needs for IWL.[33]

Similar to needing a care coordinator, participants recognized the importance of having clear care pathways for IWL in the Go-Zone statements. Care pathways are "road maps" to navigate the healthcare process and standardize care to help avoid variance.[72] Evidence reporting the utility of laryngectomy care pathways suggests that early, post-surgical care within a coordinated, acute care pathway benefits patients and the health care team by improving overall efficiency, reducing length of stay, surgical complications, and cost of care.[13-15,17] These pathways have critically evolved to optimize oncologic outcomes. While care pathways with specific MDT responsibilities have been created for IWL in an attempt to coordinate roles and encourage teamwork,[13-15,17,27] they remain limited in breadth and scope, and focus primarily on the acute surgical management phase. There is currently a dearth of laryngectomy care pathways that support long-term management or care co-ordination beyond the acute hospital stay. Findings of this study identify an additional need for structured, longitudinal care that addresses the multitude of physical, psychosocial, functional and survivorship needs of IWL and caregivers. This does not diminish acute care, oncologic-centered pathways, rather augments them and extends focused laryngectomy care beyond the bedside. Participant statements in the current study highlighted the need for care pathways that represent all phases of laryngectomy care, from pre-operative to long term survivorship, with formal steps and regularity of follow-up.

Although participants identified the need to ensure patients have access to appropriate financial support and equipment, they also recognized that this had least potential to change. HNC is one of the most expensive cancers to treat with substantial out-of-pocket expenses[72] and remains financially toxic throughout survivorship due to the ongoing need for healthcare appointments and their associated costs (i.e., travel, co-pays), time-off work, and equipment needs.[73,74,75] This is particularly true for IWL.[76] Financial hardship is a substantial concern for HNC patients as up to one third cannot return to work after treatment due to functional disability.[77] Dedicated funding to support IWL including philanthropy, improved insurance coverage, as well as governmental and institutional assistance were all action statements raised by HCPs at both

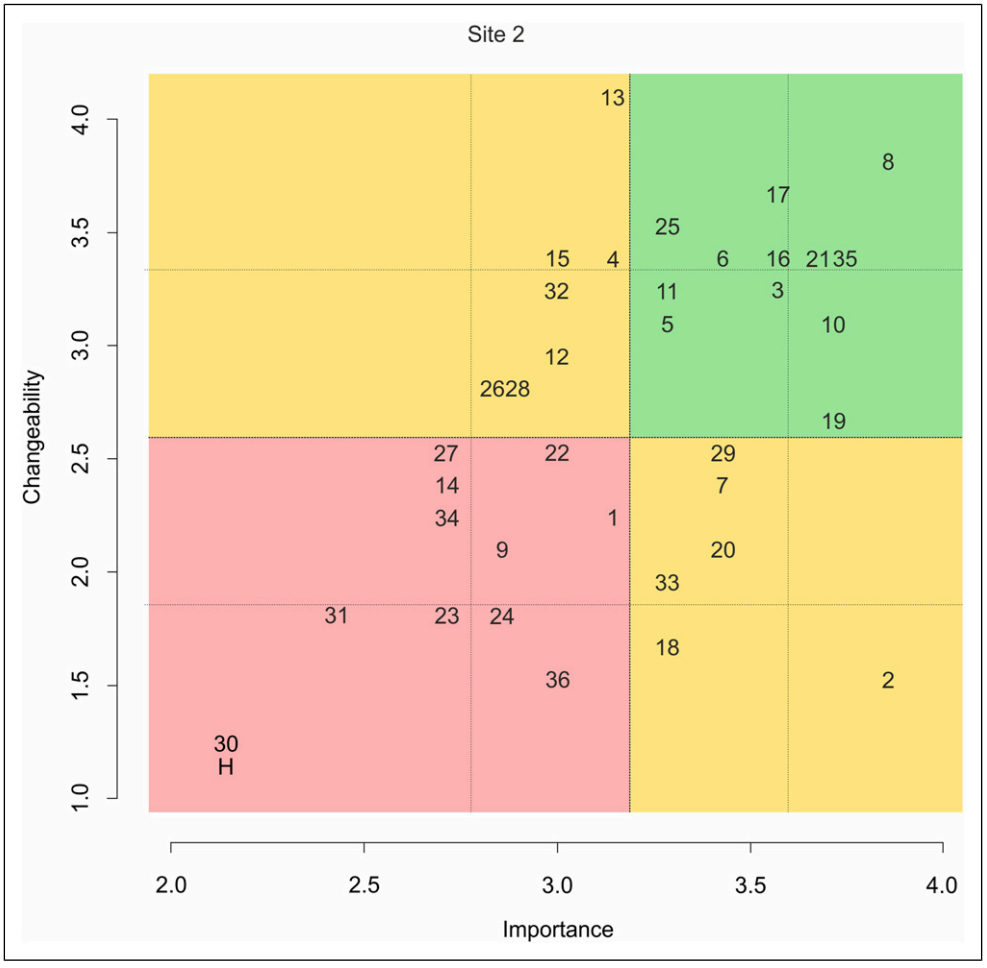

Figure 4. Continued.

sites. Alolayan et al.[32] also found that both HNC patients and HCPs prioritized monetary support to offset the burden of treatment. The low changeability ratings observed would appear to reflect HCPs inherent understanding of limitations in funding sources (i.e., insurance and institutionally based financial assistance), as well as guarded expectations for improvement within the privatized health system of the US. Regardless of the challenges, the findings highlight the need for HCPs to consider all actions that could channel greater financial support into laryngectomy care, to minimize the economic burden for patients and avoid the multitude of negative consequences associated with financial toxicity.

Limitations

This study has captured the perceptions of a self-selected group of HCPs within a health system in the northeast US and so may not reflect the concerns of clinicians nationally or internationally regarding laryngectomy care. For example, issues such as financial concerns may be less critical for countries with established public health services. The current analysis also focused primarily on those statements given the highest prioritization within the Go-Zone. However, participants saw importance in all statements, and as such, all collected statements should be reviewed and considered by services wishing to enhance practice. It is recognized that some statements may be considered overly broad, obvious or 'standard of care' for established multidisciplinary teams. It should be noted that the prompts for statement generation were to list action items specifying "what all IWL should have access to", and not necessarily what was missing. As such, statements could include items that were already standard practice, or those that are not - but in future state could enhance service optimization. Although HCPs are a key stakeholder group in service design, it is also important that the concerns they have raised are considered alongside those of IWL elucidated from prior work[35] to provide greater depth of understanding of current service issues. Additionally,

Table 3. Individual Statements Identified Within the Go-Zone

Quadrant	Cluster ID	Cluster theme	Statement ID	Statement
Site 1 – Go-Zone (n = 18)				
Go-zone	1	Working as a team	8	The core team should conduct staff education, at least annually since staff rotate and there is turnover, to ensure that everyone is comfortable and competent to treat patients with laryngectomy.
Go-zone	1	Working as a team	9	All team members SLP, RN, RespT, RD should be trained via education, in-services and observations, indirect and direct training to treat these patients.
Go-zone	1	Working as a team	13	All inpatient and outpatient staff should have access to multidisciplinary education with regards to the needs of the TL patient.
Go-zone	2	Care pathway	18	The cancer center should work on a standard care pathway for patients with laryngectomy.
Go-zone	2	Care pathway	21	There should be a protocol set up with an interdisciplinary pathway for patients to follow-up that involves RD, SLP, psychosocial and involves pre-op, acute needs and post op needs.
Go-zone	2	Care pathway	25	There should be a clear TL pathway for staff that defines surgery, any complications.
Go-zone	2	Care pathway	27	All patients should have a standard follow-up with the team and not just when they are running into problems.
Go-zone	3	Provision of education and other materials	2	All patients should have education materials at the bedside re: stoma care…and explanation of equipment.
Go-zone	3	Provision of education and other materials	3	All patients should have access to early intervention and education in the form of a team meeting to orient them to the team, the setting and enable them to feel like they are part of their care.
Go-zone	3	Provision of education and other materials	11	All patients should have access to good quality handouts and education about what to expect when one has a TL, lists any potential complications and prepare them for surgery and life after laryngectomy.
Go-zone	3	Provision of education and other materials	17	All patients should have a patient manual/ orientation book with relevant staff names (discipline and their roles) and an example of a patient pathway.
Go-zone	3	Provision of education and other materials	32	There should be a take-home package with additional equipment (HMEs, larytubes, saline bullets etc.) to aid in the transition between hospital to home.
Go-zone	3	Provision of education and other materials	36	All patients should have a true understanding of surgery with regards to their larger cancer care; whether they need RT, chemo RT, etc. so it is not a surprise, and they have realistic expectations.
Go-zone	4	Dedicated funding for equipment, infrastructure, and clinical services	33	Care “under one roof” should be encouraged for total laryngectomy patients: team approach.
Go-zone	5	Pre- and Post-op education/ access	14	All patients should have plans “laid out” for their post-op and long-term needs.
Go-zone	5	Pre-and Post-op education/access	34	All patients and caregivers should be able to participate in discussions with the MDT pre-surgically, post-surgically and prior to DC from the hospital.

(continued)

Table 3. (continued)

Quadrant	Cluster ID	Cluster theme	Statement ID	Statement
Go-zone	5	Pre- and Post-op education/ access	37	After diagnosis all patients should be required to meet with SLP and RD for education and assessment.
Go-zone	6	Access to multidisciplinary professionals	16	All patients should have access to social work and accurate and appropriate DC planning for equipment and staff services.
Site 2 – Go-Zone (n =12)				
Go-zone	1	Interprofessional relationships and integrated MDT	6	All members of the interdisciplinary team should know the roles of all other members of the team.
Go-zone	1	Interprofessional relationships and integrated MDT	10	All patients should have a dedicated team with members that specialize in the HN cancer population.
Go-zone	2	Dedicated navigator	35	There should be a pre-op SLP eval for all planned TLs.
Go-zone	3	Patient education and access to support	11	All patients should have a dedicated, comprehensive pre-op counseling, e.g. video or something standard.
Go-zone	4	Communication between team members to support care	16	All patients should have continuing communication amongst their interdisciplinary members.
Go-zone	4	Communication between team members to support care	19	All patients should have comprehensive navigation through the whole process.
Go-zone	4	Communication between team members to support care	25	There should be a care pathway for all laryngectomy patients to ensure they have the proper experience.
Go-zone	7	Access to multidisciplinary professionals	3	All patients should have easy access to SLP.
Go-zone	7	Access to multidisciplinary professionals	8	All patients should have access to RD/nutrition.
Go-zone	7	Access to multidisciplinary professionals	17	All patients should have access to social work.
Go-zone	7	Access to multidisciplinary professionals	21	All patients should be seen in a timely manner by nutrition and SLP.
Go-zone	8	Supporting access to care	5	All patients should have access to education in their native language.

Note. SLP= speech-language pathologist, RN = registered nurse, RespT= respiratory therapist, RD= registered dietitian,, DC= discharge, RT= radiotherapy, TL= total laryngectomy, HME= heat and moisture exchange, MDT = multidisciplinary team.
Note. HN = head and neck, MDT = multidisciplinary team, SLP = speech-language pathologist, RD= registered dietitian, TL= total laryngectomy.

gathering the perceptions of HCPs in other regions of the US and from multiple types of health systems would improve the overall validity and generalizability of these findings.

Conclusions

HCPs from two care sites identified and prioritized lists of important and changeable items to improve laryngectomy care. Both groups identified many action statements which were clustered into similar themes. Specifically focusing on those statements rated most important and changeable (i.e., the Go-Zone) revealed key issues for immediate action related to improved education, coordinated access to skilled professionals, and a more comprehensive care pathway. While this paper's findings represent the perceptions of HCPs, informing care improvements must also consider the perceptions of patients themselves. Therefore, information from the current study will be combined with results of other research conducted by the current team exploring patient perceptions[35] to help inform service change and optimize care for IWL. The ultimate goal of this cumulative research is to create a consensus-driven framework of care for IWL that is patient-centered, holistic, addressing all phases of laryngectomy care with particular emphasis on the role of the SLP. Additionally, a longer-term goal is to conduct an implementation evaluation to ascertain the utility of such a framework in diverse clinical settings, gathering quantitative and qualitative data from patients and HCPs, to refine and enhance the framework for real world clinical practice.

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ORCID iD

Laurie Wennerholm https://orcid.org/0000-0002-5639-7284

Ethical Considerations

Ethical approval was sought and granted by White Plains Hospital (WPH), Montefiore Medical Center/Albert Einstein College of Medicine (MMC) and The University of Queensland (UQ) (WPH & MMC Ref # 061125, IRB# #2020-11238, UQ # 2020001304/"#20-030).

Consent to Participate

Individual written consent was provided by all participants.

Consent for Publication

The participant information and consent forms clearly stated that de-identified results would be published.

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.

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Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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 to the authors and relevant human research and ethics committee.

Supplemental Material

Supplemental material for this article is available online.

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