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### Patient Education and Support Pre and Post Total Laryngectomy

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Patient Education and Support Pre and Post Total Laryngectomy

Heidi Schaab

Illinois State University

PATIENT EDUCATION AND SUPPORT PRE AND POST TOTAL LARYNGECTOMY

Heidi M. Schaab

An Independent Study Submitted in Partial Fulfillment of the Requirements  
for the Degree of

MASTER OF SCIENCE

Department of Communication Sciences and Disorders

ILLINOIS STATE UNIVERSITY

Spring 2017

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Student's Signature

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### **Abstract**

Approximately 12,740 new cases of laryngeal cancer (LC) are diagnosed each year, often resulting in compromises to vital life functions. In particular, LC may be treated via surgical removal of part or all of the larynx (laryngectomy) resulting in major nutrition, respiration, and communication challenges; each which can substantially impact a patient's quality of life (QOL). At this time, there is little research available regarding patients' perceived QOL and preparedness for life after total laryngectomy. To fill this gap, a survey study, asking participants to rate their perceived level of agreement or disagreement with a number of statements regarding QOL and adjustment and preparation for life pre and post-laryngectomy, was initiated. Overall, the findings in this study indicated that respondents were generally satisfied with the education and support they received from health care providers pre and post-laryngectomy. Still, survey responses did indicate that specific aspects of care might benefit from additional improvement including pre and post-procedure counseling and education regarding recovery and stoma and tracheoesophageal puncture care, a team approach to patient care, provision of support to patients when navigating physiological changes post-surgery, and the provision of support for caregivers.

## Introduction

Sapienza and Ruddy (2013) reported that head and neck cancers (HNCs) make up 3% of all cancers diagnosed each year in the United States, amounting to 12,740 new cases of laryngeal cancer (LC). LC impacts patients and their families in a variety of ways by compromising eating, breathing, and communicating. When these vital functions are compromised, subsequent large effects on the patient's lifestyle and quality of life (QOL) are expected. Damage to the larynx may result from tumor growth or treatment for LC, which often involves removal of cancerous laryngeal sites. The most common surgery for LC is called a laryngectomy. Patients who undergo this procedure have part or all of their larynx removed. Those who have their entire larynx removed will breathe by way of surgical hole in the neck (called a stoma), since removal of their larynx will disconnect the pharynx from the oral cavity such that inspiration can take place through the mouth or nose. Removal of laryngeal structures will lead to considerations for speaking, swallowing, and breathing and may have tremendous psychological effects on patients. Total laryngectomy involves removing the vocal folds and all of their muscular attachments that allow them to come together to create sound, which accounts for a person's voice. Removal of the larynx could affect the surrounding structures that are involved in swallowing, such as the pharynx and the esophagus. Additionally, total laryngectomy can affect respiration, as patients become "neck breathers," breathing through the stoma, or hole, created in the neck as a result of removal of the larynx (Hirani, Siddiqui, and Khyani, 2015).

The purpose of this literature review is to explore patients' perceptions regarding their and their caregivers' preparation for laryngectomy as well as education regarding life pre and post-laryngectomy in the United States.

### **Training for Hospital Staff**

A major downfall for recovery of laryngectomy patients is a lack of hospital medical staff who are fully trained on laryngectomy post-procedures. A recent study completed in the United Kingdom indicated potentially serious shortfalls in the experience and training of medical intensive care unit (ICU) personnel in laryngectomy care, particularly stoma care. In particular, only 68% of the ninety-nine health care respondents surveyed felt confident in caring for neck breathers (Paton, Monro-Somerville, Gibson, Gemmell, 2015). Data indicated that the majority of the trainees gained confidence over time through real life situations in the hospital rather than receiving formal training.

Similarly, after conducting an audit across three hospitals in northwest England, Darr, Siddiq, Jolly and Spinou (2016) found that nursing and care staff working with patients with stomas were also under-trained. Additionally, access to the necessary equipment (suction for cleaning the stoma, replacement stoma, etc.) was often limited. Further, proper identification of type of surgery, stoma care, and type of tubing/routing was not displayed at the patient's bedside (Darr et al., 2016). In fact, while all ICU patients in this hospital had bedside care kits, only 80% of patients in the rehabilitation unit had bedside stoma care kits available. This is problematic because a lack of supplies is a safety issue, and can hinder care when medical personnel are under-trained. Without proper training and proper supplies, medical personnel are unable to give patients proper laryngectomy care. While there are a limited number of studies that discuss training for healthcare workers, medical personnel's confidence in caring for patients after laryngectomy appears to be lacking based on the few studies that were identified and reviewed.

## **Patient Confidence and Fear**

Quality of life (QOL) is often diminished in total laryngectomy patients due to the major emotional and physical repercussions for a patient including voice loss and changes to one's self-perception and identity (Evitts, Kasapoglu, Demirci, & Sterne-Miller, 2011). Other causes of stress, fear, and diminished QOL following a total laryngectomy include financial fears, stress over caretaking, recovery fears, and social changes.

Hirani, Siddiqui, and Khyani (2015) surveyed 125 total laryngectomy patients in Pakistan about their fears following their surgery. Seventy-four percent of patients noted that financial uncertainty was a significant concern with 44% of those indicating this uncertainty was related to job loss (Hirani, et al., 2015). Patient's voice loss was also a significant concern as noted by 67% of patients (Hirani, et al., 2015). In particular, patients were apprehensive about social activity (e.g., relationships with their spouse) and physical appearance (e.g., cosmetic disfigurement due to removal of the larynx).

Hirani et al. (2015) also surveyed total laryngectomy patients about the quality of post-laryngectomy education and counseling they received from healthcare providers. Survey respondents indicated that this education was focused on alternative forms of communication following voice loss and that healthcare providers "hardly bother about the psycho-social and financial aspects of life" (Hirani et al., 2015, p. 1214). The researchers here noted, based on patient responses, that prolonged treatment and many hospital visits interfered with work, social life, and activities of daily living. (Hirani et al., 2015).

Like Hirani et al. (2015), Bickford and colleagues (2013) also explored patients' experiences regarding their adjustment to life five years post-laryngectomy, but did so by way of patient interviews rather than by using a survey instrument. The majority of the patients

interviewed stated they had difficulty adjusting to their new life because of their altered physical appearance after surgery. In particular, participants “felt self-conscious of their neck and tracheostoma and deliberately covered it” (Bickford et al., 2013, p. 330). Other patients stated that “despite advances in rehabilitation, adjustment appeared to take time, and for some was a painful experience” (Bickford et al., 2013, p. 331). Further, several interviewees indicated inadequate support from healthcare professionals due to a focus on physiological and anatomical mechanisms of their cancer and surgery rather than its psychosocial outcomes (Bickford et al., 2013).

Based on the literature reviewed, patients who have undergone total laryngectomy procedures often experience reduced QOL due to financial fears, dissatisfaction with physical appearance, and lack of psychosocial support from healthcare providers. Current studies indicate that greater patient supports are needed, but recommendations are broad. Evitts, et al. (2011) noted that healthcare providers need a better understanding of communication changes and challenges following a laryngectomy procedure. Cnossen, et al. (2016) also noted that healthcare providers require a better education regarding care for laryngectomy patients so that they can provide those patients with education on self-care post-procedure. The current study was initiated to determine specific areas that are lacking in regards to health care providers’ support and education to laryngectomy patients. In particular, it will examine participants’ impressions of their experience directly following laryngeal cancer diagnosis, pre and post laryngectomy procedure, following their return home post-laryngectomy, and in relationship to their personal lives. By targeting these specific areas, potential strengths and deficits in patient education, training, and psychosocial needs may be identified.

## **Methods**

### **Participants**

Participants were recruited via email announcement and social media to the WebWhispers listserv and Facebook page, respectively. WebWhispers is an online support group for individuals who have undergone a laryngectomy. Participants qualified for inclusion in this study if they were between the ages of 35 and 80 years, received their laryngectomy within the last 10 years, and resided within the United States. Participation in the survey was voluntary and could be ended at any time by participants discontinuing their survey. Before beginning the survey, participants were required to check a box indicating that they met the inclusion criteria listed above on the electronic consent form, understood the information in the form, and freely consented to study participation.

### **Survey Instrument**

The survey was administered through the online survey system, Google Forms (Google, Mountain View, CA). Survey design and data were only accessible through the password-protected account of the investigators.

### **Survey Sections.**

After providing biological and demographic information, participants were asked to identify both the medical procedure they underwent, as well as their primary mode of communication. The survey instrument was divided into four main sections, each representing an important timeframe in understanding the QOL issues faced by patients as a result of laryngectomy: post-diagnosis of laryngeal cancer, pre and post-surgery, home life post-surgery, and personal care post-surgery. Statements in each section were rated by participants on a 1 to 5

Likert-type scale with one representing strongly agree, two representing agree, three representing neutral, four representing disagree, and five representing strongly disagree. Following completion of the survey, participants were asked to provide one "tip" for other patients who will undergo laryngectomy, with the intention that this information could be used by future care teams to help prepare laryngectomy patients for life post-surgery. Excluding biographical information and medical history, each survey section is briefly described below. A copy of the survey instrument can be found in Appendix A.

***Post-diagnosis of laryngeal cancer.*** The first section included questions that targeted the time period immediately following the diagnosis of LC. The purpose of this section was to gain an understanding of the information respondents were given about their condition and its potential treatment. Specifically, question items addressed patient's knowledge of their diagnosis, and perceptions as to whether healthcare providers offered sufficient education regarding it.

***Pre- and post-surgery.*** The second section of this survey focused on the time periods directly before and after each participant's surgery. Items focused on the education and/or information the respondents were given regarding their procedure and any complications or emotional needs addressed.

***Home life post-surgery.*** The third section of the survey was designed to gain an understanding of participants' recovery at home following their laryngectomy. Specifically, items addressed how confident and prepared each respondent felt when handling subsequent treatments, needs, stoma care processes, or problems during their recovery at home. This section of the survey instrument also asked patients to indicate the accessibility of additional resources.

***Personal care post-surgery.*** The fourth section of the survey sought information related to personal concerns the respondent had regarding their life following laryngectomy social-emotional areas (i.e. struggles with identity, self-care, support) that might have been eliminated or alleviated had they been better targeted by the recovery team as part of the pre- or post-surgical recovery process.

## **Analysis of Data**

**Demographic results.** Demographic information was catalogued by gender, age, years post-laryngectomy, and state procedure was done in. Number of participants and percentages were calculated for each area. With such a wide variety of states, responses were then calculated based on the five “areas” of the United States: Northeast, Southeast, Southwest, Midwest, and West.

**Quantitative survey results.** Survey result on the Likert scale (1=strongly agree, 2=agree, 3=neutral, 4=disagree, 5=strongly disagree) were averaged across all participant’s response for each item within the survey. Next, the mean values for each of the questions in each survey section (i.e. post-diagnosis, pre and post-surgery, home, and personal) were averaged to generate an overall section average.

**Qualitative survey results.** Following the survey questions, respondents were asked to leave any tips they may have had for future patients of total laryngectomy. In order to get quantitative results from written responses, a set of codes were created. First, the responses were read to identify any trends. During a second read-through, a list of common theme codes was generated.

## Results

### Demographics

Fifty-two males and twenty-two females between the ages of 49 and 80, who reported previously undergoing total laryngectomy, were included in this study. Participants who indicated having partial laryngectomy were excluded from the analysis. The median age range for the total laryngectomy respondents was 65 to 69 years old, while the majority of respondents were seventy-five to seventy-nine years old (24.7%). The majority (46.6%) of respondents reported being two to six years' post-laryngectomy procedure. The United States regions with the highest number of procedures based on respondents were the Midwest (25.7%) and the northeast (25.7%); although, respondents also represented the west (15.7%), southeast (15.7%) and southwest (11.4%). Responses that were not applicable (11.4%), or were not given (n = 4) were eliminated from this data. A table of response data and percentages for each demographic category can be found in Tables 1-3 below.

Age Range	Number of Responses	Percentages
45-49	1	1.4%
50-54	3	1.4%
55-59	14	19.2%
60-64	13	17.8%
65-69	16	21.9%
70-74	18	24.7%
75-79	6	8.2%
80+	2	2.7%

Table 1: Category of age ranges and number of responses per range.

Years Post-Laryngectomy	Number of Responses	Percentages
Less than 1-year post	8	11%
Less than 2-years post	11	15.1%
2 to 4 years' post	20	27.4%

4 to 6 years' post	14	19.2%
6 to 8 years' post	8	11%
8 to 10 years' post	8	11%
10+ years post	4	5.5%

Table 2: Years post-laryngectomy and number of responses per category.

<b>Geographical Location</b>	<b>Number of Responses</b>	<b>Percentages</b>
Northeast	18	25.7%
Southeast	11	15.7%
Southwest	4	11.4%
Midwest	18	25.7%
West	11	15.7%

Table 3: Geographical locations and number of responses per location.

## **Survey Results**

### **Post-Diagnosis**

The survey questionnaire results for the post-diagnosis section indicated that participants primarily agreed (a rating of 2 indicated agreement with the question or statement provided) with favorable statements regarding the education and counseling they received post-diagnosis (2.08). When breaking down the average self-report rating of each of the four questions in this section, three out of the four showed average agreement of respondents with the statements/questions provided. On average, respondents indicated that they generally had sufficient understanding of their diagnosis (2.01), that their healthcare providers discussed all treatment options (2.06), and that they were equipped to make an informed decision about treatment (2.09). On the other hand, respondents indicated overall disagreement with the statement “your healthcare providers worked in a team to communicate with you and one another regarding your diagnosis and

treatment options” (4.24). A table of response data for each item in this section and the overall average rating for all post-diagnosis items can be found in Table 4 below.

### Post-Diagnosis

Survey Question	Average Self-Report Rating	Number of Responses
You had sufficient understanding of your laryngeal cancer diagnosis	2.01	73
Your healthcare providers discussed all the treatment options available for your cancer	2.05	74
You felt like you were well-equipped to make decisions about your own treatment	2.1	72
Your healthcare providers worked in a team to communicate with you and one another regarding your diagnosis and treatment options	4.24	73
<b>Overall Section Average</b>	2.08	

Table 4: Survey items addressing patient perceptions of their experience post-diagnosis. Average rating for all items and number of responses are provided (Survey scale: 1=strongly agree, 2=agree, 3=neutral, 4=disagree, 5=strongly disagree).

### Pre and Post-Surgery

The survey questionnaire results for the pre and post-surgery section indicated that participants were, on average, neutral regarding favorable statements about the education, support and counseling they received pre and post-surgery from their healthcare providers (2.95). When breaking down the seven questions of this section, there were four items with which, on average, respondents indicated being between agreement and neutral (neither agreeing or disagreeing with the statement provided) towards. In particular, respondents were, on average, neutral (2.72), towards the statement “your healthcare providers counseled you regarding any concerns you may have had about the recovery process.” They were also neutral towards statements about receiving sufficient information about their recovery process (3.05) and pre-operative counseling (3.05) from their healthcare team, between neutral and disagreement in regards to receiving proper education regarding stoma care prior to the surgery (3.58), and

receiving proper education regarding tracheoesophageal punctures and voice prosthesis prior to the surgery (3.37). Respondents were in overall agreement with statements indicating that were given proper education on caring for their TEP/stoma post-surgery and received sufficient counseling on the recovery process. A table of response data for each item in this section and the overall average rating for all pre and post-surgery items can be found in Table 5 below.

### Pre- and Post-Surgery

Survey Question	Average Self-Report Rating	Number of Responses
You were given sufficient information about what recovery would be like prior to your total laryngectomy	3.05	73
You had sufficient pre-operative counseling with your surgeon, speech-language pathologist, and other healthcare providers to discuss changes to your communication, swallowing, and respiration	3.05	74
Your healthcare providers counseled you regarding any concerns you may have had about the recovery process	2.7	73
You were given proper education on how to care for your stoma before your surgery	3.6	72
You were given proper education on how to care for your stoma soon after surgery took place	2.5	73
You were given proper education on how to care for your tracheoesophageal puncture (TEP) and voice prosthesis (if you have one) soon after your surgery took place	2.3	60
You were given proper education on how to care for your TEP and voice prosthesis (if you have one) before your surgery	3.4	56
<b>Overall Section Average</b>	2.95	

Table 5: Survey items addressing patient perceptions of their experience pre and post-surgery. Average rating for all items and number of responses are provided (Survey scale: 1=strongly agree, 2=agree, 3=neutral, 4=disagree, 5=strongly disagree).

### Home

The survey questionnaire released showed respondents were, on average, in agreement to neutral (2.56), towards positive statements regarding home care following their procedure.

When breaking down the eight questions of this section, one indicated average agreement with

respondents. In particular, respondents indicated that they felt they could contact members of their care team with any questions post-surgery (2.1). Respondents were on average, in agreement or neutral, when asked about if they were provided with helpful resources regarding care for their tracheoesophageal puncture (2.5) or voice prosthesis (2.6), and that their healthcare providers continued to work as a team to manage the patient's care after they returned home post-surgery (2.4). Respondents trended toward neutral to disagreement regarding their confidence in caring for their stoma (2.7) and TEP (2.7) after going home, that their family was provided with sufficient information to support them (2.7), and that they had sufficient follow-up with healthcare team members (2.7). A table of response data for each item in this section and the overall average rating for all home items can be found in Table 6 below.

### Home

Survey Question	Average Self-Report Rating	Number of Responses
You felt confident about caring for your stoma when you were sent home	2.7	73
You felt confident about caring for your tracheoesophageal puncture (TEP) or voice prosthesis (if you have one) when you were sent home	2.7	59
You were provided with helpful resources to help you and/or a caregiver care for your stoma	2.6	73
You were provided with helpful resources to help you and/or a caregiver care for your tracheoesophageal puncture or voice prosthesis (if you have one)	2.5	63
You felt you could contact members of your care team with questions	2.1	73
You felt family members and/or caregivers were given enough information to support you	2.7	73
You had sufficient follow-up with a speech-language pathologist and other healthcare professionals such as respiratory therapists, dietitians, etc., who helped facilitate alternative forms of communication and helped you navigate changes in breathing, swallowing, feeding, and speech	2.7	73
You felt like your healthcare providers continued to work in a team and jointly manage your care post-surgery	2.4	74
<b>Overall Section Average</b>	2.56	

Table 6: Survey items addressing patients' perceptions of support and education after returning home from their laryngectomy procedure. Average rating for all items and number of responses are provided (Survey scale: 1=strongly agree, 2=agree, 3=neutral, 4=disagree, 5=strongly disagree).

## Personal

Respondents, on average, indicated the highest overall agreement (1.93) with statements regarding personal care and psychosocial adjustment following their procedure. Respondents agreed to strongly agreed, on average, with statements indicating that they had taken sufficient action to properly care for their stoma (1.5) and were comfortable seeking support when they felt it was needed (1.93). Respondents also indicated agreement with statements regarding their own confidence in their ability to compensate for any abilities lost after laryngectomy (2.1), and not being defined by their laryngectomy (2.3). A table of response data for each item in this section and the overall average rating for all home items can be found in Table 7 below.

## Personal Care

Survey Question	Average Self-Report Rating	Number of Responses
You have taken sufficient action to properly care for your stoma	1.5	73
You feel confident in your ability to compensate for any abilities lost	2.1	74
You feel that changes from your total laryngectomy do not define you	2.3	74
You feel comfortable seeking support when you feel it is needed	1.9	73
<b>Overall Section Average</b>	1.93	

Table 7: Survey items addressing patient perceptions of confidence in their own personal care and psychosocial well-being following laryngectomy. Average rating for all items and number of responses are provided (Survey scale: 1=strongly agree, 2=agree, 3=neutral, 4=disagree, 5=strongly disagree).

## Qualitative results

Each respondent provided one tip for others who will be receiving a total laryngectomy at the end of the survey. Eight codes were identified, and each respondent's free response was then

assigned to one or more of the codes. The number of times each code was assigned to respondents' statements was then tallied. Each code and the number of times it was tallied is listed in Table 8.

Three of the codes described respondents' statements more often than others. The largest response pattern encouraged future laryngectomy patients to be accepting and positive of the changes resulting from their laryngectomy (31.4% of responses). Following that, 20% of responses suggested establishing and maintaining connections by joining a support group or an online community. Lastly, asking for help regarding care, education, etc., was a common suggestion (17.1% of responses). A total of six statements did not fit any of the codes, and were considered part of the "other" category including: advising that future laryngectomees stay away from research medical centers while another respondent suggested the opposite and asserted that future laryngectomees should choose a comprehensive research center. Other responses included the suggestion to spend a lot of time in the hospital in which surgery and follow-up treatment would occur, find a good speech therapist, be prepared that things might go wrong, and always bring somebody to all medical appointments. The sum of code percentages exceeds 100% due to some responses containing multiple statements

### Tips

Code	Number of Responses	Percentage of Responses
Be Accepting/Positive of Changes	22	31.4%
Establish and maintain connections with other laryngectomy patients	17	24.2%
Ask others for help and support	12	17.1%
Research and educate yourself about your condition	9	12.8%
Other	5	7.1%

Keep hydrated	4	5.7%
Record your voice before you lose it	3	4.2%
Seek out counseling	2	2.8%

Table 8: Codes assigned to respondents' written tips to a future laryngectomy patient.

## Discussion

### Summary of Findings

Overall, the findings in this study were positive regarding satisfaction with healthcare providers' provision of education and support regarding total laryngectomy. Also, respondents overall indicated a generally positive outlook regarding personal changes and psycho-social well-being. That being said, respondents felt neutral or were in disagreement regarding their satisfaction with pre-procedure counseling and education regarding recovery, education about stoma or TEP care prior to surgery, and healthcare providers working in a team.

Post-Diagnosis. Respondents agreed with statements indicating that they understood their laryngeal cancer diagnosis and potential treatment options, and felt capable of making well-informed decisions regarding their own treatment plan. This data is encouraging for researchers or future patients, as it appears that for the subset of patients surveyed, diagnosis information and treatment option were well-understood by patients due to appropriate support and counseling from healthcare providers.

While the overall section average generally indicated that patients agreed with statements regarding education and communication post-diagnosis, respondents, on average, disagreed that their "healthcare providers worked in a team to communicate with [the patient] and one another regarding diagnosis and treatment options." This result is alarming considering that there is a

significant need for multiple allied health professionals and physicians to work together to assess and treat patients with laryngeal cancer, particularly pre and post laryngectomy. Unfortunately, prior research has also indicated that the team approach to laryngeal cancer care may not always be standard (Mehanna, Kong, & Ahmed, 2016).

Pre- and Post-Surgery. In regards to pre and post-laryngectomy counseling and information, respondents indicated overall satisfaction with their care team's ability to answer questions pre-surgery and provide sufficient education about their stoma or voice prosthesis post-surgery. However, respondents were neutral (did not strongly disagree or agree) regarding four of the seven statements in the pre and post-surgery section. Specifically, respondents neither agreed nor disagreed that the education they were provided with prior to their procedure regarding their recovery process, t changes to their communication, respiration, and swallowing, or regarding stoma and tracheoesophageal puncture care was adequate prior to their procedure. Results indicate that respondents did not necessarily feel that they were provided with a great deal of information about the changes that resulted from their procedure in advance of it.

Multidisciplinary guidelines for patient care, such as those developed by Mehanna et al. (2016) may potentially result in improvements in patient perceptions regarding supportive care and practice patterns in these areas in the future. The authors found that originally, patients with recurrent head and neck cancers were "usually treated with palliative intent", in terms of pain management, rather than management of and education about the disease (Mehanna, Kong, & Ahmed, 2016, p. 181). However, educational information about outcomes related to management such as laryngectomy, rather than pain management or end-of-life care may have been beneficial. After a systematic review of literature, the authors found that "the outcomes of

the management of recurrence are not as dire as is widely considered” (Mehanna, Kong, & Ahmed, 2016, p. 181).

Home. Upon going home from the hospital post-laryngectomy, survey respondents did indicate that they were able to contact members of their care team with questions; however, while it appears that laryngectomy patients believed their care team was accessible, the current survey did not ask respondents whether responses to inquiries were provided in a timely manner and sufficiently addressed patient concerns.

Respondents agreed less strongly with statements indicating that caregivers or family members were sufficiently educated to support them post-surgery, that they were confident in caring for their stoma and TEP post-surgery, were provided helpful resources to aid in stoma and/or TEP care, or that follow-up with healthcare providers post-surgery was adequate to allow for confident navigation of functional communication, swallowing, and respiration changes. Perhaps the less enthusiastic agreement with such statements implies that patients could be better supported upon leaving the hospital. In particular, offering “supportive care routinely as part of the management package of all patients” with head and neck cancers is important (Mehanna et al., 2016, p. 181).

Personal. Respondents’ average agreement with positive statements about psychosocial health and resilience post-laryngectomy was stronger than for any other section of the survey. The results of this section are encouraging, as it appears that patients feel positive about their identity and ability to compensate for lost function and engage in self-care. According the National Multidisciplinary Guidelines for Recurrent Head and Neck Cancers in the United Kingdom, “patients often have significant symptoms, and should be offered best supportive care interventions regardless of the intent of therapy” (Mehanna, Kong, & Ahmed, 2016, p. 189).

This supportive care may facilitate some of the positive personal outcomes acknowledged by patients here.

### **Implications**

Overall, the results of this survey indicate a possible need for improvements in pre- and post-procedure counseling and education regarding recovery as well as stoma and TEP care, the provision of support to patients when navigating physiological changes post-surgery, and support for patients' caregivers. These results may be reflective of the way in which laryngeal cancer care is approached by both research and medical professionals. In particular, "the literature pertaining to patients after laryngectomy is based largely on the ideology of the biomedical model, which tends to disregard the significance of the experience and impact of the illness, concentrating instead on symptoms as indicators of disease or tolerance of disease" (Noonan & Hegarty, 2010, p. 284). This focus on managing laryngeal cancer with total laryngectomy versus focusing on the impact of this management approach, may have led to some of the response patterns found in this survey. Noonan and Hegarty (2010) suggest that patients should be given an opportunity to describe their experiences with laryngeal cancer and laryngectomy in their own words; which may, in turn, facilitate better education about stoma and TEP care as well as physiological challenges pre- and post-surgery.

Unfortunately, the consequences of inadequate support and education for total laryngectomy patients may be quite problematic. Specifically, patients that turn to the internet to seek out information may not be reliable. For example, research reviewing a collection of sites discussing laryngectomy home care and physiological changes post-surgery, etc. found that the majority were not accredited (controlled by a medical source) (Pothier & Pothier, 2009). If a laryngectomy patient turns toward the internet to fill holes in their education about their

laryngectomy and the information they access is unreliable, problems during recovery might result. Such problems are likely to be prevented by more thorough education from patients' own healthcare providers.

A potential remedy to misinformation accessed electronically may be an online self-care education program to support patients after total laryngectomy created by a reliable source. Jansen et al. (2016) studied the effects of one such program which was comprised of two different sections: self-help (independent) exercise, relating to stoma use, and self-help education, relating to stoma care. It was found that the "usage rate of the self-help care education program was good and patients were satisfied with the application" (Jansen, et al, 2016, p. 3). Patients were "coached on a weekly basis by their speech therapist or nurse practitioner/specialist via e-mail or telephone." (Jansen, et al, 2016. p. 3). It was determined that while the online educational section was beneficial, the self-help exercises required in-person guidance from care team members.

Researchers in Ireland discovered through a systematic review of research that pre-operative counselling for total laryngectomy patients remains variable (Fitzgerald & Perry, 2015). According to information found, most current research on this topic relies on expert opinion rather than good research evidence and often has poor methodological quality. While literature on this topic remains limited, "there are nevertheless clear, persistent reports by patients and [caregivers] of shortfalls in clinical practice that need to be addressed by rigorous research studies" (Fitzgerald & Perry, 2015, p. 15). This provides further evidence that while counseling and education for total laryngectomy patients may not currently be adequate, current research needs to better describe and understand its particular shortfalls.

Another important outcome that might ultimately be improved with better education and supportive care is laryngectomees' communicative participation. Bolt, Eadie, Yorkston, Baylor, & Amtmann(2016) examined variables significantly associated with communication in everyday activities and communicative participation for patients following head and neck cancer. The results from this study suggested that “communicative participation in adults with [head and neck cancer] is associated with self-rated speech severity, cognitive function, whether or not a person has undergone total laryngectomy, and time since diagnosis” (Bolt et al. 2016, p. 1146). This results are important for future clinicians who are providing education to total laryngectomy patients. When providing proper education to total laryngectomy patients, clinicians and healthcare providers need to take into consideration the patient's ability to understand and comprehend education given to them.

### **Limitations of Current Methodology**

In the current study, a total of seventy-four participants responded to the survey. Given that the total number of respondents is small, it is difficult to determine if this data is generalizable to other total laryngectomy patients in the United States. Further, statistical analysis was not completed to determine if there was a pattern of answers by geographical location of procedure, age, or gender. Such additional analyses may provide information as to whether patients perceive their care and experience with laryngectomy differently depending on these factors.

To determine if any patterns based on geographical location can be captured, a relatively equal number of respondents from the Northeast, Southeast, Southwest, Midwest, and West regions of the United States could be recruited and compared in future surveys. Further, within each geographical location, recruiting participants from a variety of hospitals might be useful.

Responses from individuals who have received care from medical research centers, university hospitals, or private hospitals might be compared to potentially identify trends in practice patterns by hospital facility, size, resources, and practitioner training.

### **Recommendations for Future Research**

The results of this study should be interpreted with caution due to its limitations, but should encourage further research into the lack of proper and informative education from the onset of the laryngeal cancer diagnosis to immediately after and several months post-laryngectomy. Specifically, a longitudinal study following the patients over time to from post-diagnosis to post-laryngectomy surgery may provide information about practice patterns, patient education, and caregiver and healthcare provider support over time.

### **Conclusions**

This study found agreement, on average, with statements regarding respondents' satisfaction with post diagnosis education, education about stomas or tracheoesophageal punctures following total laryngectomy, and accessibility of laryngeal cancer care team members post-laryngectomy. Similarly, respondents indicated strong agreement with statements regarding their own personal care and self-acceptance following total laryngectomy. While these findings are encouraging, this study also found average disagreement or a lack of agreement or disagreement in regards to statements indicating education provided by the healthcare team and home care recovery following a total laryngectomy. Specifically, respondents felt neutral or were in disagreement regarding pre-procedure counseling and education regarding recovery, education about stoma or TEP care prior to surgery, and healthcare providers working in a team. These particular areas deserve additional attention in order to support patients with laryngeal cancer pre and post-laryngectomy.

## Appendix A

### Demographics

Age:

Sex:

Years Post-Laryngectomy:

State Procedure Done in:

Medical Center Procedure Completed (if known):

Form of Alternative Communication:

### Post-Diagnosis Questions

Survey questions addressing patient perceptions post-diagnosis (Survey scale: 1=strongly agree, 2=agree, 3=neutral, 4=disagree, 5=strongly disagree).

1. You had sufficient understanding of your laryngeal cancer diagnosis
2. Your healthcare providers discussed all the treatment options available for your cancer
3. You felt you were well-equipped to make decisions about your own treatment
4. Your healthcare providers worked in a team to communication with you and one another regarding your diagnosis and treatment options

### Pre- and Post Surgery

Survey questions addressing patient perceptions post-surgery (Survey scale: 1=strongly agree, 2=agree, 3=neutral, 4=disagree, 5=strongly disagree).

1. You were given sufficient information about what recovery would be like prior to your total laryngectomy
2. You had sufficient pre-operative counseling with your surgeon, speech-language pathologist, and other healthcare providers to discuss changes to your communication, swallowing, and respiration
3. Your healthcare providers counseled you regarding any concerns you may have had about the recovery process
4. You were given proper education on how to care for your stoma before your surgery
5. You were given proper education on how to care for your stoma soon after surgery took place
6. You were given proper education on how to care for your tracheoesophageal puncture (TEP) and voice prosthesis (if you have one) soon after your surgery took place
7. You were given proper education on how to care for your TEP and voice prosthesis (if you have one) before your surgery

### **Home**

Survey questions addressing patient perceptions on home care (Survey scale: 1=strongly agree, 2=agree, 3=neutral, 4=disagree, 5=strongly disagree).

1. You felt confident about caring for your stoma when you were sent home
2. You felt confident about caring for your tracheoesophageal puncture (TEP) or voice prosthesis (if you have one) when you were sent home
3. You were provided with helpful resources to help you and/or a caregiver care for your stoma
4. You were provided with helpful resources to help you and/or a caregiver care for your tracheoesophageal puncture or voice prosthesis (if you have one)
5. You felt you could contact members of your care team with questions
6. You felt family members and/or caregivers were given enough information to support you
7. You had sufficient follow-up with a speech-language pathologist and other healthcare professionals such as respiratory therapists, dietitians, etc., who helped facilitate alternative forms of communication and helped you navigate changes in breathing, swallowing, feeding, and speech
8. You felt like your healthcare providers continued to work in a team and jointly manage your care post-surgery

### **Personal**

Survey question addressing patient perceptions of self-confidence (Survey scale: 1=strongly agree, 2=agree, 3=neutral, 4=disagree, 5=strongly disagree).

1. You have taken sufficient action to properly care for your stoma
2. You feel confident in your ability to compensate for any abilities lost
3. You feel that changes from your total laryngectomy do not define you
4. You feel comfortable seeking support when you feel it is needed

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