

■ A Study of the Knowledge of Health Care Providers Regarding Laryngectomy Care

■ Une étude sur les connaissances des fournisseurs de soins de santé auprès des personnes laryngectomisées

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Abstract

Laryngectomized individuals living in British Columbia were surveyed to determine experiences with tracheoesophageal prosthesis (TEP) crises. Subsequently, a questionnaire probing experience, knowledge, comfort level and education on laryngectomy was developed and distributed to front-line health care professionals working in BC. Information provided by patients and front-line health care professionals indicated a need for further education and training of those who may provide front-line services to laryngectomized individuals, specifically TEP crisis management. More than half of the laryngectomized respondents expressed concern about not being able to access the help they require during a TEP crisis. The demographics of specialized health care services suggest that patients living in small and remote areas of the province may have less access to health care professionals who can assist them during a TEP crisis. Fundamental elements of an education program for front-line health professionals are described.

Abrégé

On a sondé les personnes laryngectomisées habitant en Colombie-Britannique pour déterminer comment elles vivent les situations d'urgence reliées à leur prothèse trachéo-œsophagienne. Par la suite, on a élaboré un questionnaire qu'on a distribué aux professionnels de la santé de première ligne de la Colombie-Britannique pour évaluer leur expérience, leur savoir, leur niveau de confort et leur formation à l'égard de la laryngectomie. L'information fournie par les patients et les professionnels de première ligne montre la nécessité d'approfondir la formation et le perfectionnement des personnes qui pourraient offrir des services de première ligne aux personnes laryngectomisées, surtout en ce qui a trait à la prise en charge des urgences affectant une prothèse trachéo-œsophagienne. Plus de la moitié des répondants laryngectomisés ont indiqué être préoccupés par le fait de ne pas avoir accès à l'aide dont ils ont besoin en cas d'urgence affectant leur prothèse. Les données démographiques des services de santé spécialisés indiquent que les patients habitant dans de petites collectivités éloignées de la province auraient encore moins accès à des professionnels de la santé capables de les aider en cas d'urgence. On termine en décrivant les éléments fondamentaux d'un programme d'éducation pour les professionnels de la santé de première ligne.

Key words: laryngectomy, TEP crisis, tracheoesophageal prosthesis, healthcare professional knowledge

Undergoing a laryngectomy is a life altering experience. After the initial trauma of a cancer diagnosis, the laryngectomized individual has to undergo major ablative surgery and subsequently adapt to the anatomical and physiological changes created by the surgery.

In Canada, major head and neck surgeries such as laryngectomy are performed in hospitals with specialized staff and services, typically in the medical teaching hospitals of urban centres (Brown et al., 2000). The specialized human resources, including

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surgeons, physicians, therapists, and nurses, are accessed from the time of diagnosis through to discharge from the medical centre. The team of specially trained professionals in the surgical and rehabilitation centre embraces patients in a safe and supportive environment. Once patients are discharged and return to their community, they may feel less confident about their medical status and access to appropriate services in the event of an emergency.

Allen et al. (1998) found that no clear standards exist for pre- and post-operative services for laryngectomized individuals. Although primary responsibility for post-operative care, education, and counselling was primarily with the surgical facility for the first 6 months, during the 7–12 month postoperative period this responsibility shifted to homecare or to personnel from other facilities. In the 7–12 month period, individuals would likely have returned home, often to areas quite a distance away from their surgical centre.

Several authors have proposed models for an “ideal laryngectomy team” that would allow immediate and direct access, as required, to the appropriate professional on the inter-professional team (Allen et al, 1998; Frowen & Perry, 2000; Gates, Ryan, & Lauder, 1982). Recommended team composition typically includes surgeon; speech-language pathologist (S-LP); lay-laryngectomy advisor; social worker, psychologist, or counsellor; dietician; and audiologist. In addition to providing necessary patient education and resources, the team should develop a plan for all possible circumstances so that the laryngectomy and his/her family always know where to go and who to contact in their community should a need arise. In an Ontario study, findings indicated that patients returning home to smaller centres do not have access to a specialized oncological team care and often they do not have regular access to S-LP services in their communities (Brown et al, 2000).

Having a basic level of care available in or close to their community gives people a sense of comfort and has been shown to enhance the rehabilitation process. A South African study (Frowen & Perry, 2000) revealed that a higher TEP success rate coincided with a multi-disciplinary team approach and patients consistently being seen by their operating surgeon as well as an S-LP. Allen et al. (1998) also found that patients judged S-LP involvement as an important part of their rehabilitation process.

For Canadians living in rural and remote regions of the country, ongoing access to specialized multi-professional team services may not be feasible. The Ontario study by Brown et al. (2000) highlighted this fact, and anecdotes from our patients in British Columbia reinforce it.

A laryngectomy surgery results in complex anatomical changes, some readily apparent and others less so. The tracheostoma is one of the most obvious changes; it dramatically alters the respiratory tract. Although visible when the anterior neck is not covered, its physiological implications may not be readily apparent to the general public or to health care professionals who are inexperienced

with head and neck surgery. In the case of a respiratory emergency requiring oxygen or resuscitation, it is critical for front-line health care professionals to understand changes in protocol required for a neck breather. Patients express concern about the possibility that uninformed health care professionals may lose valuable resuscitation time when attempting to assist them in a respiratory crisis.

Perhaps less well understood is the purpose and placement of a tracheoesophageal prosthesis (TEP), although it has become the most popular technique for post-laryngectomy voice restoration. Many individuals with a TEP live independently and are able to change and care for their prosthesis without assistance. Even for these individuals, however, crises can occur and having access to a knowledgeable health care professional is crucial for expedient and effective resolution of the problem.

The most common TEP crisis involves difficulty reinserting a dislodged prosthesis. This should be considered a respiratory emergency, because without the protective valve function of the prosthesis, aspiration of food or fluids is possible and, for at least a few hours or days, probable. In this situation, the attending health care professional needs sufficient understanding of the altered anatomy to guide decisions about preventing immediate aspiration and to take stop-gap measures such as inserting a soft rubber catheter into the tracheoesophageal fistula.

Of secondary concern in cases of a dislodged prosthesis is the rapid reduction of the fistula diameter, which, in the absence of intervention, will inevitably close. When the fistula shrinks, it has to be dilated in order for a new prosthesis to be placed. Although this procedure is not particularly painful, it can be uncomfortable for the patient. The process draws on health care resources and requires expertise. Once the fistula closes completely, the patient has to undergo a repeat tracheoesophageal puncture procedure, which entails minor surgery under general anesthetic.

In addition to the time and inconvenience for the laryngectomized individual and the additional health care resources required if an appropriate intervention is delayed, TEP crises can be frightening for the patient. From the moment that the TEP is dislodged, tracheoesophageal speech becomes impossible and an alternate means of communication is required. This means that during the time of crisis, the individual is not able to express his needs to the health care professional or to explain what is happening. For this reason, it is crucial that health care professionals have a basic knowledge of what to do in a TEP crisis. Ideally, every TEP speaker should be able to feel confident that appropriate health care will be available in a crisis.

How knowledgeable and skilled are front-line health care professionals in resolving emergencies such as a TEP crisis? What are the consequences to the patient who lives in a remote area without health care teams who are specialized in laryngectomy care?

Purpose

The main purposes of this study were to determine the level of experience, knowledge, confidence, and skill of a variety of front-line health care professionals who might assist an individual who is experiencing a TEP crisis and to identify gaps in knowledge and skills among front-line health care professionals. Information obtained from both laryngectomized individuals and health care professionals was used to develop a set of guidelines to describe the minimum knowledge that health care professionals require to assist individuals who have undergone a laryngectomy.

Methods

Survey of Laryngectomized Individuals

A survey to determine the occurrence and nature of TEP emergencies and their health-care experiences during crises was developed and disseminated to laryngectomized individuals throughout British Columbia (Appendix A). The questionnaire sent to laryngectomees consisted of two primary questions; both requested a Yes or No answer and both provided opportunities to describe experiences and concerns. Participants were also asked to identify their location.

The questionnaires were disseminated by mail to approximately 80 laryngectomized individuals through the offices of the surgeons performing the majority of laryngectomy surgeries in British Columbia. Anonymity of the respondents was maintained by requesting that they refrain from including any identifying information, other than location, on the form or the envelope.

Health Care Professionals Questionnaire

A questionnaire was developed to determine level of experience, training, knowledge, and comfort level (confidence) of health care professionals regarding laryngectomy anatomy and special health care needs. To test content validity, 10 health care professionals, five S-LPs, three registered nurses (RN), and two otolaryngologists (OTL), with variable levels of experience with laryngectomy were asked to complete and comment on the draft questionnaire. Nine were completed and returned. Feedback provided by the respondents resulted in minor wording changes to the questionnaire. The most common general comment from respondents was that the questions reminded them how much they had forgotten about laryngectomees and how quickly they had forgotten. This was a common response from S-LPs. One of the RNs who responded said she learned from the questionnaire that there were obviously gaps in the outpatient services that laryngectomized individuals receive.

The final questionnaire consisted of eight questions including knowledge questions and questions about training and comfort level in working with laryngectomized individuals (Appendix B). The questionnaires were sent to 97 facilities province wide, including hospitals and health units. They were addressed generically to emergency physicians and RNs, homecare RNs, and where applicable

S-LPs and OTLs. Along with the questionnaire(s), a pre-addressed and pre-stamped envelope was included. Anonymity of the respondents was maintained by requesting that they refrain from including any identifying information, other than location, on the form or the envelope.

Responses were coded using ordered numeric values for questions 1, 7, and 8; using binary numeric codes for correct (1) or incorrect (0) for questions 2-5; and using binary numeric code for affirmative (1) or negative (0) for question 6. Chi square comparisons were conducted to determine the significance of differences in knowledge question scores by profession, and chi square tests for likelihood ratios were performed to determine linear trends predicting knowledge question performance by experience or professional preparedness.

Results

Survey of Laryngectomized Individuals

Eighteen completed questionnaires were returned. Many of the respondents took the time to write lengthy answers to the questions. Two respondents returned 1-2 page letters sharing stories of numerous crises they had experienced and expressing their concerns about the lack of help they had received and the lack of familiarity their health care providers had regarding laryngectomy. Some individuals left their phone numbers in case there were any more questions, and four people expressed gratitude that the survey was undertaken. As one respondent wrote: *"There is not enough talked about in the media, the public does not have information about laryngectomees or laryngeal cancer, not like other cancers which receive great amounts of attention and publicity."*

Ten of 18 individuals who responded to the questionnaire reported having had a TEP crisis. Of these, four were satisfied with the help they received, three were not, and three were satisfied in the end, after a protracted ordeal. When asked if they had any concerns should a TEP crisis ever happen, 11 out of the 18 respondents replied *yes*, primarily because they would not be able to access help in their community. Other concerns expressed included the increasingly burdensome cost of TEPs, not having anyone in their community with the same "problem," and not having adequate training to care independently for their TEP.

Health Care Professionals Questionnaire

Thirty-six completed health care professionals questionnaires were returned. The respondents included 13 S-LPs, 16 RNs, five physician/surgeons (two of whom were OTLs), and two respiratory therapists (RTs).

The majority (16) of the non-SLP health care respondents were from small and remote communities, estimated to be a minimum of 300 km from the closest city. The majority of S-LP respondents were from large towns and cities.

Because of the similarity of knowledge, skills, training, and small *n* for RTs and S-LPs, the RT responses are reported with those of the S-LPs. Otherwise, responses

were analyzed separately for each profession to determine inter-professional differences.

Experience with laryngectomees seen in the previous five years varied greatly by profession (see Table 1). Of the five physicians/surgeons (hereafter referred to as physicians), three had seen 1–5 laryngectomees, one had seen 10–25, and one had seen more than 25. The two who had more experience were both OTLs. Among S-LPs, eight of 13 had seen 0–10 laryngectomees, two of 13 had seen 10–25, and three of 13 had seen more than 25 laryngectomees. Both RTs who responded had seen more than 25 patients in the previous five years. Of all the professions, RNs had seen the fewest laryngectomees. Nine of 16 RNs had seen no laryngectomees and only seven of the 16 had seen 1–5. None of the RNs in the study had seen more than five laryngectomees in the previous 5 years.

The knowledge questions yielded additional information (Table 2). Four out of five of the physicians responded correctly to question 2, three of five responded correctly to question 3, and four of five responded correctly to question 5. Twelve out of 16 of the RNs responded correctly to question 2, two of the 16 responded correctly to question 3, and nine of 16 responded correctly to question 5. S-LPs (including the two RTs) had the largest percentage of correct responses to the knowledge questions, 100% responded correctly to questions 2 and 5, and 14 of 15 responded correctly to question 3.

Question 4 probes practical knowledge and targets the primary focus of this study, which is to predict the appropriateness of health care that laryngectomized individuals will receive in the event of a TEP crisis. The responses to this question varied considerably between the professions (see Figure 1). Two of the five physicians (the two OTLs), six of 16 of the RNs and 13 of the 15 of the S-LPs (including the two RTs) responded correctly to question 4.

The results of the knowledge question scores revealed that RNs had the lowest percentage of correct responses on the knowledge questions, including question 4. Chi square statistics revealed interprofessional differences in correct/incorrect response ratios. Significantly lower scores were found for RNs for questions 3, 4, and 5. Significantly higher scores were found for S-LPs and RTs for questions 3 ($p = .0015$), 4 ($p = .0305$), and 5 ($p = .0226$).

Significant chi square tests for linear trend discovery suggested that the more laryngectomees who health care professionals had seen, the more likely they were to give a correct response to questions 3 ($p = .0030$), 4 ($p = .0081$), and 5 ($p = .0048$).

Question 6 probed professional education about laryngectomy and the care of laryngectomized individuals (Figure 2). Three of the five physicians (those who were not OTLs) and 13 of the 16 RNs reported having no specialized education. All of the S-LPs and RTs reported having had specialized education about laryngectomy.

Questions 7 and 8 elicited self-ratings of comfort level and preparedness in working with laryngectomized

Table 1
Laryngectomy Experience by Profession

Question 1: How many laryngectomy patients have you seen in the last 5 years?				
Number seen	RT	S-LP	RN	Physician
0	0	4	9	0
1–5	0	3	7	3
6–10	0	1	0	0
11–25	0	2	0	1
More than 26	2	3	0	1

Table 2
Knowledge Question Responses by Profession

Question 2: A patient who has undergone a total laryngectomy breathes from her/his...					
Profession	RT	S-LP	RN	Physician	Total
Correct	2	13	12	4	31
Incorrect	0	0	4	1	5
Total	2	13	16	5	

Question 3: A TEP (tracheo-esophageal puncture) allows communication between the...					
Profession	RT	S-LP	RN	Physician	Total
Correct	2	12	2	3	19
Incorrect	0	1	14	2	17
Total	2	13	16	5	

Question 4: In the event that the TEP is dislodged, what is the most critical action (i.e. the first step) that must be taken?					
Profession	RT	S-LP	RN	Physician	Total
Correct	2	11	6	2	21
Incorrect	0	2	10	3	15
Total	2	13	16	5	

Question 5: The trachea-stoma leads to the...					
Profession	RT	S-LP	RN	Physician	Total
Correct	2	13	9	4	28
Incorrect	0	0	7	1	8
Total	2	13	16	5	

individuals (Figures 3, 4). Two of the five physicians (the two OTLs) reported feeling very comfortable and completely prepared to work with an individual who has undergone a laryngectomy. The same number (two of five) reported feeling very uncomfortable and not at all prepared. One physician reported feeling not very comfortable and not very prepared. For the S-LP/RT group, seven of 15 reported feeling very comfortable and completely prepared, three of 15 reported feeling fairly comfortable, and five of 15

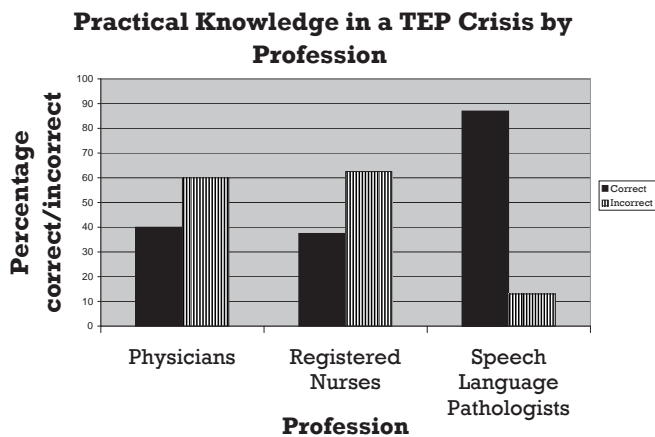


Figure 1. Practical knowledge in a TEP crisis by profession

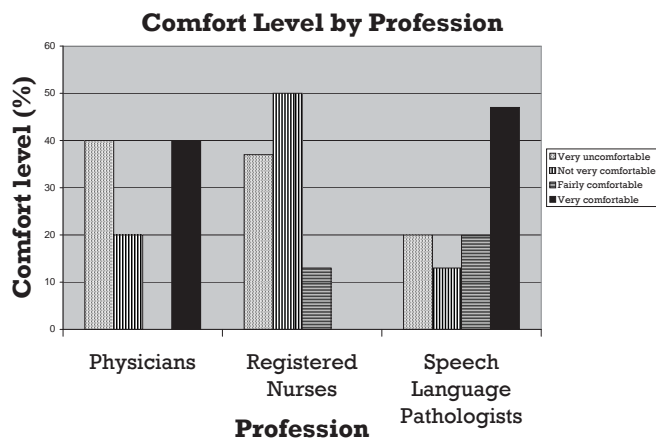


Figure 3. Comfort level by profession

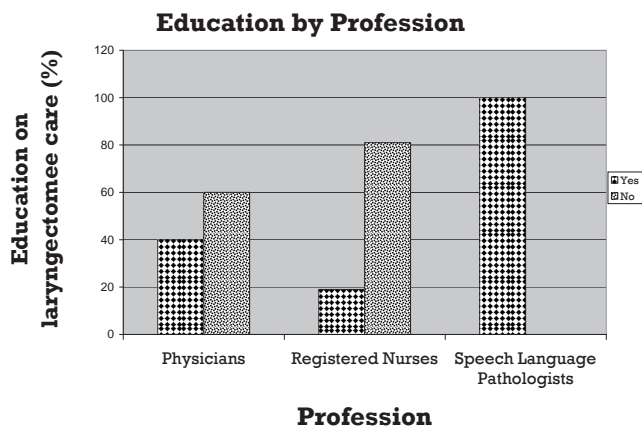


Figure 2. Education by profession

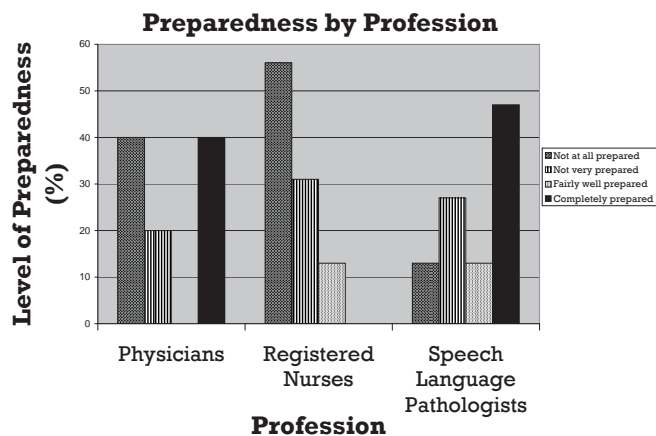


Figure 4. Preparedness by profession

were either very uncomfortable or not very comfortable. Two of 15 responded feeling fairly well prepared, and the remaining six of the 15 reported feeling either not very prepared or not at all prepared. Of the RNs, two of 16 reported feeling fairly comfortable, and 14 of 16 reported feeling either not very comfortable or very uncomfortable. Two of the 16 RNs reported feeling fairly well prepared, and the remaining 14 reported feeling either not very prepared or not at all prepared. No RNs felt very comfortable or completely prepared to work with individuals who have undergone a laryngectomy.

Both of the two S-LPs who responded incorrectly to question 4 rated themselves as not very comfortable and not very prepared.

Chi square statistics suggest that the higher the professional's knowledge self-ratings was, the more likely he/she was to respond correctly to questions 3 ($p = .0004$), 4 ($p = .0211$) and 5 ($p = .0133$).

Discussion

The present study investigated the knowledge of health care providers regarding laryngectomy care. Among the most intriguing results were the relatively low performance on knowledge questions and the low self-ratings for comfort and knowledge by the front-line health care professionals,

(non OTL) physicians and RNs, compared to S-LPs and RTs. As has been noted in other regions of Canada (eg., Brown et al., 2000), teams of professionals specializing in the care of laryngectomized individuals tend to be focused in urban centres, and specialized medical/S-LP services typically are not available in smaller centres. S-LPs providing services in remote regions of BC tend to work as itinerants, and if practicing locally, work out of schools or public health clinics, primarily with children. The apparent knowledge advantage of the S-LPs may be of little practical consequence if they are not positioned to assist laryngectomized individuals at the time of a crisis.

If S-LPs in outlying and rural areas are not the professionals serving the laryngectomy population, who is and do they have the education/training to be able to deliver the care needed? During a respiratory crisis, front-line health care professionals are most likely accessed in local hospitals and health clinics. In rural or outlying areas, doctors and nurses are the front-line health care professionals, and therefore they are the ones dealing with situations such as TEP crises. In urban centres, S-LPs experienced in TEP management may be more accessible. The majority of the RN and physician/surgeon respondents in this study lived and worked in small and remote communities. This geographical situation no doubt puts a constraint on the

number of laryngectomized individuals in the community to whom a health care professional might be exposed, and the results of our statistical analysis suggest that experience in this area predicts textbook and practical knowledge.

Assuming basic textbook and practical knowledge are prerequisites for appropriate intervention, many front-line professionals may not have sufficient education and training to ensure effective and timely service for laryngectomized patients in a crisis, and the service gap that is implied is most likely to affect individuals living in smaller and more remote areas of the province. In this study, fewer than half of the front-line health care professionals (RNs and physicians) had any special education in laryngectomy care. In a recent survey of S-LPs, 94% of the respondents believed there is a need for more formal education/training in the area of head and neck cancer, including laryngeal cancer (Beaudin, Godes, Gowan, & Minuk, 2003).

Study limitations and Future Research

A primary limitation of this study was the small sample size. Survey research by mail typically exposes itself to selection biases that can be difficult to control. Although only a small number of former patients responded, their comments mirror those heard from clinicians and laryngectomized individuals who are seen frequently through our provincial resource program. The predominance of professional respondents from small and remote centres of BC may reflect a specific concern or curiosity about this population. This provides a starting point for future research and professional education targeting specific professional groups. The low numbers of physician/surgeon responses must be considered when interpreting the results. The low response rate from non-SLP health care professionals practicing in urban centres may reflect the assumption that special problems are typically dealt with by specialized professionals and teams. Patients living in or close to centres with specialized head and neck teams tend to rely on those professionals at times of TEP crisis.

Conclusions

Information provided by patients and front-line health care professionals indicated a need for further education and training by those who may provide services to laryngectomized individuals, specifically TEP crisis management. More than half of the laryngectomized respondents expressed concern about not being able to access the help they require during a TEP crisis. Professional teams and S-LPs who have specialized knowledge and experience in TEP management tend to be located in urban centres and are therefore inaccessible to those living in remote regions, which leaves a service gap for smaller centres and puts the responsibility on RNs, physicians, and other health care professionals who may not have the necessary specialized training about laryngectomy offered in their professional curriculum.

The minimum you should know about emergency care for patients with laryngectomies and tracheoesophageal prostheses: A short tutorial

Two practical objectives of this study were to determine the need for education and training among front-line health care professionals so they can deliver appropriate care to individuals who have undergone a laryngectomy and to develop minimum knowledge and skill criteria to ensure timely and effective care in a TEP crisis. It is also the goal of this special issue of the *Canadian Journal of Speech-Language Pathology and Audiology* to educate the readership about different aspects of head and neck cancer. We are including the following text to acquaint you with some of the fundamentals of TEP surgery and care. Like other front-line health care professionals, you should have a fundamental understanding of laryngectomy surgery, implications for breathing and speech, voice rehabilitation surgery, and implications and procedures for crisis intervention. We also recommend that you seek some practical training in this area, even if you do not necessarily expect to work frequently with laryngectomy patients.

1. Anatomical Changes.

Following a laryngectomy, individuals breathe solely through the tracheostoma in their neck and not at all from their nose or mouth. In the case of an emergency where oxygen is required, the oxygen must be placed over the tracheostoma and not over the nose or mouth.

The majority of individuals who have undergone a laryngectomy in the past two decades have also had a tracheoesophageal puncture, which is a minor surgical procedure to restore voice. This procedure creates a fistula between the upper back wall of the trachea and the esophagus, effectively pairing the air and food pipes for the purposes of supplying pulmonary airflow to a voice source in the esophagus (crico-pharyngeus muscle). A TEP is a small device that is inserted into the fistula. The TEP keeps the fistula patent and acts as a two-way valve, keeping food and fluid out of the trachea while allowing air to flow into the esophagus to create voice. In the event that the prosthesis valve is no longer effective or is dislodged or removed, anything that is swallowed will travel through the fistula and go directly into the trachea and lungs (aspiration). Within a few hours, the tracheoesophageal fistula will begin to shrink. Eventually it will close completely if nothing is inserted in it to keep it patent. If the fistula is left open, aspiration is inevitable until the fistula is completely closed, which could take several days.

2. Practical knowledge

If a TEP is dislodged (falls out or is pulled out), it is crucial that the fistula be occluded as soon as possible. For various reasons, it may not be possible to re-insert the TEP or to insert a new one; in any instance, the TEP should only be inserted by an individual who has training in the procedure. In this situation, a soft rubber catheter of similar diameter to the prosthesis must be inserted through the fistula and several inches into the esophagus to prevent

aspiration. The distal end is taped to the neck to ensure the catheter will stay in place. The goal of the catheter is to prevent food and fluid from leaking out of the fistula and into the lungs; this is best achieved with a catheter that is slightly larger than the prosthesis diameter.

TEPs need to be replaced periodically, typically when the two-way valve begins to fail and cause aspiration. If an in-situ TEP is leaking sufficiently to cause aspiration, it should be removed by pulling the prosthesis away from the fistula site and out of the stoma, from the external tab, if there is one. If there is no tab, the prosthesis should be grasped firmly using a hemostat (not forceps) that can be locked onto the prosthesis and pulled away from the fistula site and out of the stoma. While removing a TEP, the utmost care must be taken that the TEP does not fall into the trachea! After safely removing the TEP, a catheter should immediately be inserted into the open fistula to keep the fistula patent and to prevent aspiration.

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Appendix A

Questions for Laryngectomees with Tracheoesophageal Prosthesis (TEP)

1. Please tell us where you live: _____
2. (a) Have you ever had a TEP "crisis"? (Example, your TE prosthesis falls out, you're home alone, and you can't get it back in.)
(Circle): Yes No

(b) Please describe the "crisis" (What type of problem you were experiencing, what you did, where you went for help, who helped you, the outcome):

- (c) Were you satisfied with the help you received? (Circle): Yes No
3. (a) Do you have any concerns that you will not be able to access the help you need in your community in the event of a TEP "crisis" (whether or not you've already experienced a TEP crisis)?
(Circle): Yes No

(b) If yes, please describe your concerns:

Thank you for taking time to complete this questionnaire. You may mail or fax it to:
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Vancouver, BC, V5Z 1M9
Fax #: 604-875-5382

