

Life with Lost Voice: An Exploration of the Experiences of Patients with Total Laryngectomy

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Abstract

Voice plays one of the most crucial roles in human communication. As total laryngectomy is the surgical removal of larynx and surrounding structures it causes to lose the voice. The purpose of this study is to explore the experiences of patients with Laryngectomy among the members of Laryngectomies' Association of National Hospital of Sri Lanka (NHSL). Purposefully selected 15 patients with laryngectomy were recruited using purposive sampling method for this qualitative phenomenological study. Data was collected during a one month period by using semi structured interviews. Data was analyzed by the thematic analysis method. The study findings revealed that the patients with laryngectomy faced major changes in their lifestyle due to altered airway such as loss of voice, body image concerns, and challenges with eating and communicating. The findings further provided evidences related to the support of the family, friends and health care professionals which was critical for successful transition during the stressful adjusting period. Therefore, exploring experiences of patients with laryngectomy will help to provide better care for them and lead to enhance their quality of life.

Keywords: Experiences, total laryngectomy, laryngectomies.

Introduction

Total Laryngectomy is the surgical removal of the whole larynx and surrounding structures. Partial Laryngectomy, supraglottic laryngectomy, and hemi-laryngectomy are the other main types of laryngectomy. Cancer of the larynx is the most common cause for laryngectomy and total laryngectomy is the final solution that ends

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in most cases (Smeltzer, Bare, Hinkle, & Cheever, 2010). As a result of total laryngectomy, patients mainly experience loss of voice. Loss of voice creates emotional and social changes that may result in withdrawal symptoms and depression. The reactions of the other persons from the society also have a significant impact on these patients' day today life (Happ, Roesch, & Kagan, 2004).

Patients with laryngectomy confront such experiences, because of the increasing amount of cancer situations in respiratory system. More than 450,000 new cases of cancer of the head and neck are diagnosed each year (Donnelly, Gavin, & Comber, 2009). Patients, whose tumors are not eradicated by radiation, generally are subjected to surgery to control the disease (Farrand & Duncan, 2007). Total laryngectomy is undertaken in 50% of those patients (Donnelly *et al.*, 2009).

Patients with total laryngectomy reported mainly the functional and psychological difficulties as their experiences (Noonan & Hegarty, 2010; Risberg-Berlin, Ryden, Moller, & Finizi, 2009; Farrand & Duncan, 2007). The functional difficulties included alteration in swallowing, excessive secretions, speech difficulties, weakness of neck muscles, breathing difficulties and altered energy levels. The psychological concerns included descriptions of depression, regret, and problems with personal resolve.

The study of Bieñ *et al.*, (2008), focused on voice rehabilitation after laryngectomy and found that the methods used for communication verbally in a laryngeal person were very difficult and very important to do in preserving the breath and swallowing. Esophageal speech, dynamic phantom shunt and external pneumatic electric devices were the methods used by researchers. In that, 1078 (64%) were willing to obtain a speaking method. 403 (24%) of the sample would like to have a speaking method after educating them. Ninety seven (5.8%) of them were not willing to use a device due to age, handling difficulties and economic difficulties.

Further Chaves *et al.*, (2012) conducted an observational study with 15 patients, focusing on the limits on quality of life in communication after total laryngectomy. The results showed that the majority compromises the quality of life in communication, but some suggesting good quality of life. It means important limitations of a personal and social nature due to poor communication with their peers. Thus, there is a need for multidisciplinary interventions that aim to minimize the entrapment of negative impact on people

communicating among these patients.

Nakayama *et al.*, (2008) conducted a study in Japan with 50 laryngectomy patients and found many post-operative complications. Respiratory problems were more significant among their complications. According to the authors, the most common cause of air way obstructions or inadequate breathing was intra operative anatomical disfigurations of the throat and pharynx. However, they have not explained how it started, feelings of the patients, when it occurs commonly and how they managed it. A study on physical and psychosocial consequence of total laryngectomy was conducted with 59 patients by Hilgers *et al.*, (1990). They had shown that it is high among the participants who suffered in high sputum production, cough and forced expectoration, needed to clean the airway more than 5 times per day and needed for more frequent stoma care. This interesting study focused strictly on patients' experiences and the findings showed that how it drastically affected the respiratory system.

Findings of the descriptive study done by Risberg-Berlin *et al.*, (2009) identified the effects of total laryngectomy on olfactory function, health-related quality of life, and communication. Patients who were successfully rehabilitated concerning olfaction and communication, had an overall feeling of good and less mental distress. It showed that the demand for successful rehabilitation is helpful to patients with laryngectomy to overcome these barriers.

According to the literature, even most of the researches addressed to the patients undergoing laryngectomy surgery were focused on the inpatients treatment and recovery process. Little has been studied after they reintegrate into the community. Among these, most studies were done in developed countries than developing countries. However, in the Sri Lankan context, literature related to patients with laryngectomy has not been adequately identified. As Sri Lanka is a developing country with limited resources and specific cultural groups, their experiences of patients with laryngectomy may be significant and of paramount importance. Hence, the main purpose of this study was to explore the experiences of patients with Laryngectomy among the members of Laryngectomies' Association of National Hospital of Sri Lanka (NHSL).

Methodology

A qualitative phenomenological design was utilized in this study. It is best to explore the day to day lived experiences of participants and it recognized how people perceive and talk about their experiences (Hancock, 1998; Lester, 2007; Marriam, 2009). A qualitative

approach is also important to understand how people make sense of their experiences (Merriam, 2009).

Study Settings and Participants

The participants of this study were patients with total laryngectomy from the Laryngectomies' Association; the sole community for patients with laryngectomy in the country at the National Hospital of Sri Lanka (NHSL). The study was carried out between December 2013 and January 2014. Fifteen patients who had lost their voice with the total laryngectomy surgery were recruited using purposive sampling method. Thirteen males and two females who had more than two years experiences after total laryngectomy surgery were considered as inclusion criteria for this selection. The patients with speaking valves were excluded from the study. All of them were using electronic devices after this surgery for communication with others. Willingness to discuss their own feelings and ability to sign an informed consent were also considered as they were able to share their experiences related to their new life with laryngectomy.

Ethical Consideration

Ethics approval was granted from the ethical approval committee at the NHSL and administrative clearance was also obtained from the NHSL authorities. All participants were kept fully informed of the purposes, benefits and potential risks of the study. Written informed consent was obtained from each voluntary participant notifying them of the ability to withdraw from the study at any time without any penalty. Anonymity and confidentiality were assured by securing the information only among the research team and by labeling each patient with a specific code for collected data.

Data collection

The research tool was a theme list that facilitated to conduct face to face semi structured interviews in their mother tongue. It was validated by using reviewed literature and finalized with expert opinion (Polit & Beck, 2013). A translator was used for Tamil and Muslim patients (Polit & Beck, 2013). A theme list was utilized to guide the interview which lasted for 30 to 45 minutes. Theme list or inventory of topics helped to cover all relevant issues such as physiological difficulties as well as psychological discomforts that required investigating. On the other hand, this theme list did not have direct questions but it acted as a reminder or a guide

regarding the topics that needed to be considered while interviewing by the interviewer. Supplementary questions such as “*What; How; and Can you.....*” were added in order to encourage participants to describe their experiences in more detail (Burns & Grove, 2005). To maintain the consistency and accuracy of the data, first author conducted the all interviews.

Family members or friends were not presented during the interviews, which allowed participants to talk freely about their experiences without bias. The researchers were able to explore their most valuable experiences during the interview avoiding confusion of participants. Mental stressors and physical tiredness of participants were minimized by providing a calm and quiet environment, flexibility of time and respecting them. Interview skills like keeping silent, listening, making encouraging noises (e.g.: ‘Mmmm’) and looking interested (Boyce & Neale, 2006) were maintained during the interviews. The high quality audio and video tape recorders were used for collecting data to maximize the accuracy of the information. The researchers were more concerned about the nonverbal clues used by the participants (Polit & Beck, 2010). The participants’ body language and comfort level were observed closely during the interview process.

Data analysis

Qualitative data, collected on the digital recorders during the interview, were analyzed according to thematic analysis (Hycner, 1985). For this, several steps of Burns and Grove (2005) have been followed such as transcribed into text with several reviews, clustered, coded according to their common features, and derived sub themes followed with general themes. To maintain the validity of the study, each transcription was reviewed by interviewers to come to an agreement on the extracted themes. Member checks were done to maintain the trustworthiness of the study.

Findings

The 15 participants were interviewed for this study. Participants were above 35 years and below 80 years. From that 13 were Sinhalese, one was Muslim and one was Tamil. All participants were literate and represent below provinces eastern, central, north central, north, and western. According to the findings of the study, laryngectomy patients face various difficulties and these can be categorized into two major themes. Using the generated nine sub themes and two major themes with the analysis process, a model was developed illustrating the laryngectomy patients’ experiences with their new life (Figure 1).

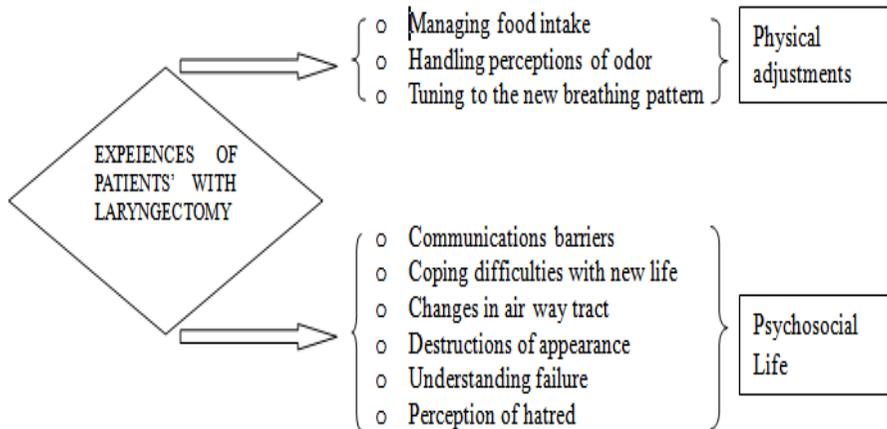


Figure 1. Experiences of patient with laryngectomy

Physical Adjustments

Whatever the type of laryngectomy that the patients had undergone, all of them experienced physical changes after the surgery such as difficulties of food intake, difficulties in smelling, and especially difficulties in breathing due to loss of the larynx or the vocal tube. Participants of the study highlighted that they had to face various problems with physical changes such as difficulties of swallowing, smelling and breathing after a laryngectomy surgery. However, these were regulated by themselves with time. While such personal changes are often difficult to express, the interviews reflected a variety of personal impacts on this as;

“I often eat rice with much gravy. I want more curry. I don’t like to eat at cafeterias and outside hotels or restaurants. Because if something occurs; I mean cough or respiratory problem it is a big issue. So I drink a milk packet and go home to eat. If the cough starts I can’t manage it alone. Need others help” (Participant M).

Patients experienced difficulties with odor. They were not in a position to feel the odor. One participant expressed handling perception of odor like this;

“After this operation sometimes I don’t feel some fragrances such as my perfume or some foods. But I don’t worry. Though I can’t smell I can do so many things?” (Participant B).

After the laryngectomy surgery most of patients were suffering from breathing difficulties adjusting to new life. Such feeling of turning to new breathing pattern was expressed as follows;

“After one month I could breathe effectively without the help of oxygen machine.... Step by step I used to tolerate and ignore some difficulties like coughing, nasal discharges and high frequency in breathing patterns.”(Participant A).

Psychosocial Life

The function of making sounds is performed by the larynx and the vocal cords. When a person loses parts or all of these structures, it can cause difficulties or they can lose the ability to speak. As a result, communication barriers were the main psychosocial experiences reported.

“I can see well. I can here very well. I feel everything as much as you all. But I feel no need to live without my voice” (Participant A).

“I can’t express my feelings to my wife as it is. Also I can’t go close to my children as I wish. I live with all these sorrows till my death. The biggest sadness was my wife also can’t understand me. I have a big fear that I will try to think of suicide again if I have to face intolerance further. It is only fear I have. I don’t like to do so” (Participant A).

“It was a dam shame than the inability to speak. I didn’t prefer to talk even with you madam. Actually some looks at us very unpleasantly when we talk with this machine. People are not interest in this rough voice. Just like a Robot. When we talk others look at us specially. Those days I thought even to suicide. I felt no point to live without the voice” (Participant B).

Difficulties in coping with new life were also a major psychosocial aspect among patients with laryngectomy due to new communication patterns. They might get angry as they were not in a position to communicate well with their family members. Participants reported this as;

“Those days I was so aggressive. Even the family members couldn’t understand what I say. One day I threw my plate and it was broken. My daughter was also injured with this incident.” (Participant H)

“I went to a shop to buy some goods. When I just get on to the

shop the owner shouted on me and asked to his helper, give something to this beggar and ask him to don't come again. There is no more to give you again. Madam, I can't speak properly. That is true. But I can hear very well. What will think if you were me? I felt so sad. But I pretend I was deaf and I wrote my need in a paper and gave it with money. He was upset. Then he did his job and smile with me. But that was not the thing should be happened.” (Patient B).

Patients with Laryngectomy suffered severe cough, high sputum production and dryness of the respiratory tract when they were coping with the new life. Furthermore, they were dealing with the problem of coughing and also the problem with their out ward appearance influencing their lifestyle. They always sought to cover it with modifications to their dresses. Participants revealed this situation as;

“I am always covering my neck with this handkerchief and I always bring this papers (showing paper tissues) in my pocket to clean this (showing his neck opening, which is full of secretions)” (Participant N).

“Earlier, always I used to wear trouser and T-shirt. But now I have to use this towel to cover this opening. So I can't wear any types of T-shirts. The neck button is needed to cover the lower part of the neck with this handkerchief. So many things have to think before wear, eat, and go somewhere. This is our fate.....” (Participant E).

Additionally, the impression of the community for chronically ill patients like patients with laryngectomy is poor. From the interviews of participants' perception of hatred in their current life were revealed as;

“People in my area use some names such as “old man with a hole on the neck” “robot man” and “man speaking with machine”. I do not like to go out because of these names”. (Participant J).

“When we talk with this machine young crowd and high class ladies cover their ears with fingers and looks at us like as animals” (Participant C and Participant J).

Participants were also worried about the inability to express their feelings. They highlighted that it was a big problem and a negative experience after surgery. So the interviewed participants' experiences of difficulties were being understood by others in the society and their hatredness towards them was revealed as;

“Can I speak as they do? But anyone doesn't understand it. It is o.k. if we have any advantage by explaining our difficulties. Do you think will they help us with even ten rupees? No never. They just asked for their interest and fun. If we meet on the next day they even don't know who we are. That's the way (Participant B and Participant F).

“I went to take few documents from our one of the government office and that man told me to come on next day because his spectacles were forgotten in somewhere. Man told me I can't understand your language perfectly. So you have to write it sometimes. But today I can't read your words without my specs. Come.... Come.... on tomorrow. I will try. Then what can I do without scolding him? Is this the way the society was care on us. But this is a Buddhist's country” (Participant H).

The patients with laryngectomy have a negative impression of society. So they try to hide from the society due to above factors and their special needs such as semisolid food requirements, severe cough during meals and slow oral intake of foods.

Discussion

The study findings showed both positive and negative experiences of patient with laryngectomy. There were two main themes which were derived from the qualitative data of the patients with laryngectomy with relation to physiological and psychological experiences.

These patients have no choice related to their difficulties. However, they want to learn how to live with the effects of laryngectomy surgery which results in a disruption between the upper and the lower airways causing changes in smelling, breathing, swallowing and the loss of a normal voice (Risberg-Berlin *et al.*, 2009; Green *et al.*, 2007; Chaves *et al.*, 2012).

The participants experienced the challenges in finding support and information on self-management of day today airway issues integrating to the new life. They gradually adapted to a new breathing pattern with high frequency in breathing, nasal discharge and coughing. Beitler, *et al.* (2010), Risberg-Berlin, *et al.* (2009), and Noonan and Hergerty (2010) identified these difficulties in breathing

influence on living with an altered airway. The current study further revealed that these changes have significant impact on the patient, their families and the social life of family members.

These study findings described the negative impact of loss of smell and its effect on eating. Dropkin (1997) also concluded that a total laryngectomy produced significant changes in factors related to eating. It can affect nutritional intake and quality of life. The findings of the study further highlighted that swelling, dry mouth, high sputum production interfere with their usual eating patterns (Decotte *et al.*, 2010; Nakayama *et al.*, 2010).

The study findings have revealed that the communication was the major challenge for the patient with laryngectomy. The biggest fear for them was facing the public as well as maintaining interrelationship with others (Risberg-Berlin, *et al.* 2009; Chaves, *et al.*, 2012; Green, *et al.*, 2007). They felt angry when they could not communicate properly. Laryngeal cancer is rare for a small community, and patients can feel very isolated and alone when they are the only patient with these challenges. Participants of this study further highlighted that the experiences alter their new life and negatively affected their quality of life (Risberg-Berlin, *et al.*, 2009; Chaves, *et al.*, 2012; Green, *et al.*, 2007).

According to the study findings, patients with laryngectomy experienced high sputum production and dryness of the respiratory tract. Furthermore they were dealing with the problem of coughing. With these all difficulties their out ward appearance influenced their lifestyle. As people look at them in a different way, they always sought to cover it with modifications to their dresses (Decotte *et al.*, 2010; Nakayama *et al.*, 2010).

Patient with laryngectomy often complain about negative attitudes of others upon them, which may cause poor quality of life (Nakayama & Okamoto, 2008). Body image also affects the emotional status of the patients. It appears due to the influence by others' negative attitudes, and bad expressions. This type of attitudes may have increased their physical symptoms. Similarly, their social activities also seem to be diminishing due to these negative attitudes of the community. It may cause poor quality of life after laryngectomy (Dyer & Powell, 2012).

Conclusion

Most patients with laryngectomy suffer problems with communication, smelling, breathing, swallowing and fear of facing of the public. The robotic sound which comes out from the device that the participants use for communicating with others is the major barrier and the biggest fear for them in facing the public as well as maintaining interrelationship with others. Therefore, developing more versatile speaking devices for a low cost is essential. Patients with laryngectomy often complain about a negative attitude of others upon them. Emotional status of the patients appears to be influenced by others' negative attitudes, bad expressions, and these attitudes may have increased their physical symptoms. Similarly, their social activities also seem to be diminishing due to these negative attitudes of the community, which may cause poor quality of life after laryngectomy. Therefore, it is recommended that educational programs need to be established through health care workers to improve awareness among the general public regarding cancers of the larynx since it will help with early diagnosis of cancer. It is also important to ensure the public awareness on this surgery, its consequents and especially for the benefit of prospective patients with laryngectomy, regarding what to expect and how to manage the physical and psychosocial changes after laryngectomy. This will improve their quality of life and will create a harmonious living status for patients with laryngectomy within the society. Moreover, further research on the topic is needed to expand and corroborate the findings of this study, to make better improvements in laryngectomy patients' quality of life, and developing comparatively better speech devices for them.

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