AN EXPLORATION OF THE EXPERIENCES OF PATIENTS WITH LARYNGECTOMY

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INTRODUCTION

Laryngectomy is the surgical removal of part or the whole larynx and surrounding structures. Partial Laryngectomy, supraglottic laryngectomy, hemi-laryngectomy and total laryngectomy are the main types of laryngectomies. Cancer of the larynx is the most common cause for laryngectomy and total laryngectomy is the final solution in most cases (Smeltzer, *et al.*, 2010). Due to this surgery, as a result the patients not only lose a functional part of their body, but they have to live their whole life as a normal person in the society, experiencing a wide range of problems even after completing their treatments.

Patients with total laryngectomy report mainly the functional and psychological difficulties as their experiences (Noonan and Hegarty, 2010). The functional difficulties included alteration in swallowing, excessive secretions, speech difficulties, and weakness of neck muscles, breathing difficulties and altered energy levels. The psychological concerns included descriptions of depression, regrets, and problems with personal resolve. Although patients with laryngectomy live with such experiences, because of the increasing amount of cancer situations in respiratory system, the prevalence of patients with total laryngectomy is increasing all over the world including Sri Lanka. Moreover, there are little or no published studies in Sri Lanka related to this area. Therefore the main purpose of this study was to disclose the experiences of patients with laryngectomy in Sri Lanka. The specific objectives were to identify the physical adjustments with laryngectomy, to discover the psychosocial life of laryngectomized patients, and to explore the factors affecting their psychosocial life.

METHODOLOGY

The study was conducted in the Laryngectomees' Association; the sole community for laryngectomies in the country at the National Hospital of Sri Lanka (NHSL) and it was carried out between December 2013 and January 2014. As the study focus on exploring the day-to-day experiences of participants, to elaborate their fully lived experiences the phenomenological design was used (Basavanthappa, 2007). Purposefully selected 15 laryngectomies who had lost their voice with the surgery and who had more than two years experiences after laryngectomy was recruited for this study. Hence, all of them were using electronic devices for communication. Ethical approval was granted from the ethical approval committee at the NHSL. 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 was assured by securing the information only among the research team and by labeling each patient with a specific code for collected data. Face to face semi structured interviews was conducted for collecting data to maximize the accuracy of the information. A theme list was utilized to guide the interview which lasted for 30 to 45 minutes. Data were analyzed with Hycner's method (Hycner, 1985). According to the steps of transcribing, bracketing and phenomenological reduction of this method, data analysis was carried out to develop common themes. The recorded interviews were 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.

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RESULTS AND DISCUSSION

According to the findings of the study, laryngectomies face various difficulties and these can be categorized into two major facets. Using the generated nine sub themes and two major themes with the analysis process, a model was developed illustrating the laryngectomies' experiences with their new life (Figure 1).

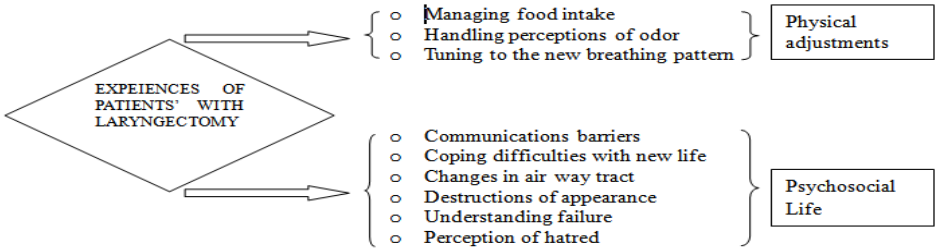

Figure 1. Experiences of Laryngectomy patients.

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 (Noonan and Hegarty, 2010). Participants of the study highlighted that they have 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 (hodi). 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).*

> *"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 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).*

Similar results were found by Beitler, *et al.* (2010), Berlin, *et al.* (2009), and Noonan and Hergerty (2010).

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, and similar findings were obtained from developed and developing countries (Berlin, *et al.* 2009; Chaves,
et al. 2012; Green, Matusiewicz, & Borczyk, 2007).

> *"Nona I can see well. I can here very well. I feel everything as much as you all. But 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).

Difficulties in coping with new life were also a major psychosocial aspect among laryngectomees due to new communication patterns (Dyer and Powell, 2012). Participant C 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)*

Laryngectomees were suffering severe cough, high sputum production and dryness of the respiratory tract when they were coping with 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. Similar findings were reported in many studies (Decotte, *et al.* 2010; Nakayama, *et al.* 2010). 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 Karume….." (Participant E).*

Additionally, the impression of the community for chronically ill patients like laryngectomees is bad (Berlin *et at*., 2009; Chaves *et al*., 2012). From the interviews of participants' perception of hatred in their current life was revealed as;

> *"People in my area use some names such as "old man with a hole on the neck" "robot like seeya" 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)

From the interviewed participants', their experience of difficulties were being understood by others in the society and their hateredness towards them were 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. Nona….. 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).*

Most of laryngectomees 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.

CONCLUSIONS/RECOMMENDATIONS

Most laryngectomies are suffering problems with communication, smelling, breathing swallowing and fear of facing the public. The robotic sound 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 low cost is essential. Laryngectomees 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 be

established through public health nurses and public health inspectors 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 laryngectomy patients, 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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