

Short Report

On the Feelings of Pharynx and Larynx Cancer Patients — Focusing on Female Patients—

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Abstract

This study makes explicit the feelings of female laryngectomees through the qualitative and inductive analysis of interviews with three laryngectomees who participate in a Self Help Group (henceforth, SHG). As a result of the analysis, we have extracted 4 categories with 21 subcategories. The 4 categories identified are *'demanding a treatment with proper conviction and assurance through adequate informed consent'*, *'being in agony as a laryngectomee and in the process of acquiring a new voice'*, *'SHG functions as a place for getting emotional support'*, *'not at first accepting the fate of receiving a trying treatment, finding a meaning in life, supported by people around them and by nurses who draw out the self-care abilities in them'*. The results of this study suggest that this particular form of nursing care should satisfy the following qualities: the continuous administration of informed consent, high level of understanding of a laryngectomee's agony and struggles for acquiring a new voice, fulfill the role as a liaison with SHG, and provide care support enabling laryngectomees to find a meaning in life.

Introduction

People with progressive pharynx or larynx cancer must endure an operation treatment that removes their pharynx and larynx along with the vocal cords (henceforth, laryngectomee). They end up losing their organs of speech unexpectedly. Moreover, the changes in the body image combined with the difficulty in breathing and swallowing and the setting up of the bronchitis stoma leads laryngectomees further into psychological, social and physical distress [1].

It is essential, therefore, that nurses should have a full understanding of the patients who undergo surgical removal of the pharynx (henceforth, laryngectomy) from various perspectives including physical, psychological and social points of view. However, the number of studies on laryngectomees is very small when compared with research on other cancer patients. Thus, it is hard to say that nurses have a sufficient perception of laryngectomees.

The largest impact among the secondary impediments a laryngectomee experiences is the loss of the organs of speech. Speech is the main means of self-expression for a human, and losing it is more unbearable than losing a person who is closely related [2,3]. The loss of the organs of speech is that of the means of communication, so it is reported that the loss leads patients into social isolation, making them feel

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loneliness, humiliation, anxiety and shame [4,5]. Therefore, acquiring a substitute vocal organ conditions or determines the life of a laryngectomee. The training for acquiring a substitute vocal organ is provided mainly at Self Help Groups (henceforth, SHG). SHGs, enhance friendship and welfare among their members by promoting the mutual instruction and learning among the fellow sufferers of the same disease. It is also reported that SHGs, not only provide speech training, but also play a role of reducing anxiety over death or relapse by giving an opportunity to learn about living with cancer [6]. It is further reported that SHGs function as a place for mental support; reducing members' anxieties about how their physical condition is perceived by others as well as themselves, and providing healing solitude by making friends with fellow sufferers [7]. However, the research on laryngectomees available so far does not take sexual distinction into consideration [1,8]. Indeed, there is no study at all that describes the feelings of female laryngectomees.

The purpose of our study is to shed light on the feelings of female laryngectomees and to draw out implications from them for future nursing practice.

Research Method

Subjects

Three subjects who went through laryngectomy and lost their organs of speech were chosen for this study. The three have been participating in an SHG in Prefecture A. The choice of the subjects was made and approved by the president of the SHG upon our request. The subjects chosen currently live in the local area and go to the hospital once in 1 to 3 months. They all gave us their consent to take part in our research after we gave them a thorough explanation of our research purposes, methods, and policies for the protection of their privacy. Furthermore, we explained to them both verbally and in writing that participation is completely voluntary and guaranteed that they preserve the right to leave the research process at any time and that there will be no affect at all on the medical treatment they will receive from then on. As for the collection of data by voice recording, we received the subjects' agreement at each recording session. The subjects came under all of the following conditions:

- Being a laryngectomee
- Currently living in the local area
- Able to communicate through speaking or writing
- Being in a stable mental condition, without an experience of consulting a doctor of psychosomatic medicine or psychiatry or a clinical psychotherapist, without taking medication for mental illness or depression
- Not suffering from dementia

Method and Location of Data Collection

Data was collected throughout June 2006 at an SHG in Prefecture A. The research was based on a qualitative and inductive model.

A series of person-to-person interviews were carried out with the subjects who voluntarily agreed on giving us their cooperation. The place where the interviews were conducted was a room with the complete protection of privacy. The room was not in the facilities of the SHG and was designated by a representative from the SHG. At the time of interviewing, proper measures were taken to prevent the conversation from being heard. The inquiries we made to the subjects concerned their profiles and backgrounds (such as age, diagnosis, time after laryngectomy, way of communication, and so forth) and "their feelings from the moment they first felt the symptom to the present", and we asked them to talk freely on the topic. The

profiles and backgrounds were obtained through lip-reading and gestures by the subjects themselves. We made it a rule that each subject had one interview only and took enough breaks during the interview, taking into account the reduction of physical burden on the subject. In the course of conversation, we let them communicate not only through the artificial larynx or the speech production by esophagus but also through lip-reading and writing. When subjects communicated by lip-reading and gestures, we confirmed our understanding by talking to them sufficiently whenever we were not able to figure out what they were trying to communicate. With the clear consent of the subjects, the interview was recorded on an IC recorder.

Method for Data Analysis

We made a word by word transcription out of the recording of the interview and the notes we took during the interview. Initially, after repeatedly reading the transcription from the interview including lip-reading and gesture communication, we classified a unit for our analysis by sorting out a minimum paragraph. Next, we codified each unit focusing on the feelings of female laryngectomees. And then, we put the codes in order according to similarities in meaning, extracted a category, assessed and reassessed until the classification rendered an accurate description of the data, and raised the abstraction level by repeating this routine of analysis. Whenever we were unsure about the nature of the data or classification, we gave careful consideration to the interpretation of the interview repeatedly. The entire process was done by three nursing researchers under the guidance of a supervisor. The categorization was done until the interpretation made by the researchers and that made by the supervisor concurred precisely. We enhanced the credibility of the analysis by giving a proper verification on the finalized category and the research result.

Among the nursing researchers, one has more than 5-years experience in working at the department of otorhinolaryngology at a hospital as well as a 5-year experience in qualitative research, another has 3-years experience in qualitative research, and another has 35-years experience in qualitative research and 7-years experience as a supervisor. This study was carried out under the guidance of this supervisor.

Ensuring the accuracy of the final results and the category names enhanced the credibility of the result. Furthermore, the results of the analysis were shown to all the subjects and they were asked to verify the accuracy of our understanding in the analysis of the interview and its content. Concerning subjects who were not able to make enough speech sound, we presented the results of this study to them, asked them to verify the content and thus enhanced the credibility of the result.

Definitions of Terms

- 1) Laryngectomee: someone who has lost the organs of speech because of the surgical removal of the larynx (laryngectomy) due to developing a malignant tumor on the pharynx and/or larynx
- 2) Feelings of laryngectomees: the mind (cognition, emotion, sensation, perception and so forth) of a laryngectomee, who has lost the larynx as the result of laryngectomy

Fellow sufferers: other individuals who fell victim to the same disease and went through laryngectomy; the term bears the connotation that they not only had the same kind of experience but also can understand each other because they passed through the same kind of ordeal.

Ethical Considerations

Prior to the execution of this research, we asked for approval from the ethical committee at the department of nursing in the school of medical welfare at the Kawasaki University of Medical Welfare. We

explained it both verbally and in writing to the president, the vice president and directors of the SGH and gained the consent to carry out the research and record the interactions during the interviews. We carefully respected the protection of privacy, and the interview was conducted in a separate room under the direction of a representative from the SHG.

We also explained the purposes and the methods of our research, the policy of free participation and free withdrawal at any time, even in the middle of the interview. We further made sure that whatever part of the interview a subject did not want us to use will never be dealt with in the research and will never be shown anywhere. In addition, we made it clear both verbally and in writing that whether or not a subject participates in the research in no way affects the benefit of a subject; we ensure the confidentiality of the identity of the subject and the content of the interview; and that the result of the research should be reported to the subjects. We then informed them that all the recordings would surely be kept in a locked place and be disposed of completely upon the completion of the research.

Results

1. Attributes of the Subjects

The attributes of the three subjects are shown in Table 1. 110 codes were gained from the interviews.

Table 1 Attributes of Subjects

	Age	Diagnosis	Years after Laryngectomy	Way of Communication
A	80s	Larynx Cancer	1	Electronic Larynx
B	70s	Unknown	9	Electronic Larynx
C	70s	Lower Pharynx Cancer	1 (and 10 months)	Electronic Larynx

2. On the Feelings of Female Laryngectomees

The 4 categories of feelings of female laryngectomees extracted were:

- *‘Being in agony as a laryngectomee and in the process of acquiring a new voice’*
- *‘Not at first accepting the fate of receiving a trying treatment, finding a meaning in life through the support of people around them and nurses who draw out the self-care abilities in them’*
- *‘SHG functions as a place for getting emotional support’*
- *‘Demanding a treatment with their proper conviction and assurance through adequate informed consent’*

There are also 21 subcategories determined in the process of our analysis (Table 2.). Hereinafter, a category is indicated by ***‘bold italic’***, a subcategory, by *‘italic’*, and a quote from code, “non italic”. The numerals in parenthesis show the number of codes gained from the interview.

- 1) The category ***‘Being in agony as a laryngectomee and in the process of acquiring a new voice’*** (35) consists of the subcategories *‘cannot decide on receiving the treatment of laryngectomy’* (4), *‘acquired a means of communication’* (4), *‘the preparation period was long because the period of having to sustain pain was long’* (1), *‘suffering conscious symptom after laryngectomy’* (11), *‘being one who experienced laryngectomy’* (11), *‘having had an operation other than laryngectomy’* (2), and

Table 2 The Feelings of Female Laryngectomees

Category	Subcategory
Being in agony as a laryngectomee and in the process of acquiring a new voice (35)	cannot decide on receiving the treatment of laryngectomy (4)
	acquired a means of communication (4)
	the preparation period was long because the period of having to sustain pain was long (1)
	suffering conscious symptoms after laryngectomy (11)
	had to be hospitalized (2)
	being one who experienced laryngectomy (11)
	having had an operation other than laryngectomy (2)
Not at first accepting the fate of receiving a trying treatment, finding a meaning in life through the support of people around them and nurses who draw out the self-care abilities in them (49)	seeking nursing care that develops an ability of self-caring that an individual needs (15)
	having had a period of good progress (2)
	being unable to accept the current condition of the illness (3)
	having had to take the risk of receiving a treatment that results in the loss of the organs of speech (5)
	being glad to have had the treatment after all (1)
	going to have to acquire a self caring ability that I need (6)
	to live with the support from surrounding people (10)
	becoming fearful of talking to others (7)
Demanding a treatment with their proper conviction and assurance through adequate informed consent (8)	being glad to have/meet a reliable doctor (2)
	wanting to trust what a doctor says (3)
	having had a desire to be given an explanation from the patient's standpoint (3)
SHG functions as a place for getting emotional support (12)	looking forward to going to SHG (2)
	participated in SHG after discharged from hospital (4)
	can receive mental support by taking part in SHG (6)

had to be hospitalized' (2).

- 2) The category ***'Not at first accepting the fate of receiving a trying treatment, finding a meaning in life through the support of people around them and nurses who draw out the self-care abilities in them'*** (49) consists of the subcategories *'seeking nursing care that develops an ability of self-caring that an individual needs'* (15), *'having had a period of good progress'* (2), *'being unable to accept the current condition of the illness'* (3), *'having had to take the risk of receiving the treatment that results in the loss of the organs of speech'* (5), *'being glad to have had the treatment after all'* (1), *'going to have to acquire a self caring ability that I need'* (6), *'to live with the support*

from surrounding people' (10), and *'becoming fearful of talking to others'* (7).

- 3) The category **'Demanding a treatment with their proper conviction and assurance through adequate ICs'** (8) consists of the subcategories *'being glad to have / meet a reliable doctor'* (2), *'wanting to trust what a doctor says'* (3), and *'having had a desire to be given an explanation from the patient's standpoint'* (3).
- 4) The category **'SHG functions as a place for getting mental cares'** (12) consists of the subcategory *'looking forward to going to the SHG'* (2), *'participated in SHG after being discharged from hospital'* (4), and *'can receive mental care by taking part in SHG'* (6).

Discussion

In this study, we aim to unveil the feelings of female laryngectomees, having conducted interviews with three female laryngectomees who participate in SHGs. We extracted 4 categories along with 21 subcategories from the data. Based on the categories drawn out here, we would like to give some consideration to the problems in the practice of nursing support.

Concerning the category **'Being in agony as a laryngectomee and in the process of acquiring a new voice'**, as one subject commented,

"... it (laryngectomy) is rarely seen in women. And cigarettes and liquor, I don't take them at all. In spring, in summer... I only sip a little beer... I was kind of shocked at falling victim to this illness."

Here we can see the shock of how unexpected the disease was. Due to the fact that the subject led a healthy life free from the habits generally considered to be the cause cancer, the subject gave a horrified reaction like "why me?" This emphasizes the patient's difficulty in understanding the reason for contracting a completely unexpected disease after receiving the shocking notification of it [9]. This also emphasizes the tendency for a patient to develop posttraumatic stress disorder (henceforth, PTSD) after receiving the shocking notification [10]. In the midst of such a psychological state of mind, the female laryngectomees we interviewed underwent radiotherapy for a long period of time before they had laryngectomy. Subsequently, they were notified of their having to receive laryngectomy that results in the loss of voice, as they recalled, "... (losing my voice made me feel) this must be the end of my life, I thought". It should be obvious from this perspective that the female laryngectomees experienced the sudden loss of their pre-established identity [11,12]. Besides being unable to understand why they had to contract this particular cancer, they had to go through laryngectomy, which accompanies the 'worse-than-death' ordeal of losing your voice. Also, it can be inferred that they needed a certain amount of time before they were able to give the acceptance to laryngectomy since they had radiotherapy, which keep the organs of speech intact, for a long time.

"(Whenever I talked to a nurse about my hesitation in having laryngectomy) I felt quite assured by the nurse who listened to me without saying anything." commented one subject. She talked about the nurse who helped her have the confidence to decide on the methods of treatment by herself. The nurse shared her painful feelings with her and spent time together with her enabling her to choose a way to live by herself. Nursing aid is based on trustworthy relations with patients. Okaya pointed out that a patient's trust in a nurse is derived from a nurse's attitude, paying attention and respect to a patient [13]. Also, Benner showed the importance of a committed patient-nurse relationship to the foundation of nursing aid [14]. Nursing that goes closely with female laryngectomees should be in great demand.

The female laryngectomees then decided to receive laryngectomy, but were suffering the secondary impediments such as pain in pharynx and difficulty breathing. These painful symptoms persist after laryngectomy, so they had to bear the unbearable agony. Just as they said "The nurse came immediately to check up on me when I let them know I felt a little bad. I was so glad." "I wish we had a hospital that

performs an aspiration for us at any time,” they wanted a quick fix to ease their appearing symptoms. The pain discourages the will to fight against the illness, and the symptom of the difficulty in breathing has them bear the association so much as to die [15]. Furthermore, physical care is the care of touching a patient’s ego itself [16]. It is very important for nurses to keep this always in mind. In particular, the laryngectomees lose their voice, so nurses should provide them proper care in response to their feelings.

Moreover, while they said they were able to meet a reliable doctor, the female laryngectomees were in need of a concrete explanation from their points of view, as they expressed in *‘Demanding a treatment with their proper conviction and assurance through adequate ICs’*. As described above, the female laryngectomees had to spend a long time before they were notified of laryngectomy, and they were deeply perplexed as to why they had to develop such a disease even though they did not smoke. The degree of acceptance after laryngectomy is one of the key factors that determine quality of life (henceforth, QOL) [17], and it has been reconfirmed that the practice of satisfactory IC is very important to this process. In this respect, nurses as well as doctors are required to understand more of the situations the female laryngectomees are in; that they need care support for their determination on laryngectomy, for their change in physical and psychological state and for the assurance of satisfactory IC.

Also, the female laryngectomees managed to alleviate the feeling of loss caused by the actual loss of voice by reacquiring the ability for self-caring, as one of them said “I am glad that the nurse taught me how to remove sputum.” In this respect, the practice of nursing for the female laryngectomees, the importance of the reacquisition of the ability for self-caring, has been indentified.

Furthermore, as to the female laryngectomees’ negative feeling towards the treatment, it has been found that negative feeling can be improved by finding a meaning in life thanks to the support from surrounding people including nurses. Generally, it is assumed that a patient with a positive and active disposition shows a better progress of prognosis [18]. Therefore, it is suggested from the description *‘not at first accepting the fate of receiving a trying treatment, finding a meaning in life through the support of people around them and nurses who draw out the self-care abilities in them’* that it is important for nurses to provide care, keeping in mind the following: nurses should bring out a positive attitude and action in the female laryngectomees by creating a human environment where people understand the female laryngectomees well, their difficulty in communication because of the loss of voice as well as their agony in their change of appearance [19].

At the SHG they started to take part in after they were discharged from hospital, the female laryngectomees were in the process of acquiring a new method of speaking after laryngectomy, and the group functions as a place for them to get emotional support over and above the training for speech production: “Everybody is very kind, and they let me spend time with them as if they were my dear old friends” “I feel tension when I have to talk to people in general, but I feel relief when I come to this gathering” “Hospitals cure a disease but they do not cure our mental disease” “I am most grateful to the SHG for the emotional support” are genuine comments from the female laryngectomees.

It is reported that a lot of patients suffered a feeling of inferiority and fear after they were released from hospital [20]. As mentioned above, it is pointed out that at the SHG the patients can share information and feelings with their fellow sufferers, alleviate fear about the reappearance of cancer and death, get rid of inferiority complexes of feeling like a disabled person, and heel the feeling of isolation [7,8]. For a female laryngectomee of advanced age, it is suggested that *“SHG functions as a place for getting emotional support”* where they can open their hearts among fellow sufferers and get comforted from the growth of the feeling togetherness.

This study focused only on three female laryngectomees who participated in the SHG in Prefecture A and the limited nature of this study qualify its findings. We need to give careful consideration before we make any generalizations based on. However, it is quite meaningful to shed light on the feelings of female laryngectomees, for the first time bringing light on their struggle to find meaning in life with the care support from fellow sufferers and surrounding people, including nurses. In order to develop this research we need to conduct research in other areas of their lives and to increase the number of subjects so as to draw out the generalization of the research results.

Conclusion

Based on our research making explicit the feelings of female laryngectomees we found that , they desire to choose a treatment with their proper conviction and assurance through adequate informed consent. They want to have satisfactory explanations from medical staff from the time they started to feel the symptoms and desired to receive treatment free from the feeling of insecurity. At the SHG they began to participate in after being discharged from hospital the laryngectomees found themselves in agony and in the process of acquiring a new voice. Providing not only the training for production of speech, the SHG functions as a place for getting emotional support. This provides mental support to the female laryngectomees, and it is shown that the laryngectomees, who could not at first accept the fate of receiving a trying treatment, eventually find meaning in life in virtue of the support they receive from people around them and nurses who draw out the self-care abilities in them. As an implication from this study, therefore, it is suggested that this particular form of nursing care should satisfy the following qualities: continuous administration of informed consent, a deep understanding of a laryngectomee's agony and struggles in acquiring a new voice, fulfill the role of a liaison officer with the SHG, and the care support for laryngectomees to find meaning in life.

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Postscript

Part of this study was reported at the 27th Conference of Japan Academy of Nursing Science and at the 1st Korea Japan Joint Conference on Community Health Nursing.

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