

Short Report

On the Feelings of the Female Family Members of a Laryngectomee

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Abstract

The purpose of this research is to shed light on the feelings of family members who have been taking care of a laryngectomee from the pre-operation stage to the current stage and to gain meaningful suggestions for the practice of nursing support. We conducted an interview with three female spouses and made a qualitative and inductive analysis of the data. The analysis brings out 7 categories and 20 subcategories. The extracted categories are as follows: the female spouses of laryngectomees have the experience of *having an agony accompanying their spouse's daily life struggles with the illness; having a full realization of changes in the situation* such as their spouses' loss of voice after the operation; the female spouses have the feeling of *not wanting others to know their husband's condition; supporting each other among the family members*; and as for their feelings, they feel relief by *sharing with those who have had the same kind of experience*; their husband's condition, the female spouses have the sense of *feeling reassured about their spouse's prognosis*; and moreover, the female spouses are in a state of *being thankful to nurses*. This study has revealed the relief and agony of the spouse of a laryngectomee who strives for better care among the family members in the course of the patient's struggle against the illness and psychological transition, and has uncovered the need for providing firm supports for the spouses of laryngectomees and for providing more opportunities for them to share their experiences.

Introduction

Cancer of the craniocervical (head-neck) region including larynx and pharynx accounts for 5 percent of all cancers. The functions of the craniocervical region include speech, respiration, chewing, swallowing, smell, taste and so on. These functions are vital or are extremely important for leading a social life [1].

A patient who went through the surgical removal of larynx or laryngectomy (henceforth, laryngectomee) is doomed, as a result of this treatment, to lose the organs of speech (henceforth, the loss of voice), which is the most important means of communication [1]. Besides the loss of voice, laryngectomees have to undergo physical, psychological, and social impediments caused by dyspnea (difficulty in breathing), to dysphagia (difficulty in swallowing), the deformation of body image due to tracheostomy (the stoma installation for trachea)²).

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As mentioned in preceding studies on laryngectomees, the acceptance of the loss of voice [3], the acceptance of the deformation of body image [4], and the transition of identity [1,5], and so on have been revealed, but all of these articles focused on the experience of the laryngectomees themselves.

As mentioned above, laryngectomees have a variety of impediments, and lead a life involving struggle with the illness. It is reported in a preceding study that the family members of a laryngectomee are under tremendous mental stress [6]. However, we have not seen any study on the feelings of the family members of a laryngectomee. We can suppose that the family members of a laryngectomee have a trying time and unrest not only for the condition of the disease and its treatment, but also for grief over the loss of voice and for the inner conflict of regaining a means of communication. Therefore, through a qualitative and inductive method, we would like to shed light on the feelings of the family members of a laryngectomee from the time of pre-operation to the current condition.

Research Method

Subjects

Subjects were three female spouses of laryngectomees aged in their 60's and 70's. These laryngectomees went through laryngectomy and lost their organs of speech. They also take part in a Self Help Group (henceforth, SHG) in Prefecture A. The diagnosis the laryngectomees were given was, in one case, middle pharynx cancer and, in the other two, lower pharynx cancer. The number of years after the operation was in two cases, less than a year and, in the other case, 4 years. (Table 1).

Table 1 Profiles of the Subjects

	Age	Relation to a Laryngectomee	Diagnosis	Years after Laryngectomy
A	70s	wife	middle pharynx cancer	less than 1
B	70s	wife	lower pharynx cancer	less than 1
C	60s	wife	lower pharynx cancer	4

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.

We conducted interviews with the subjects at an SHG in Prefecture A. The question topics were “anxiety from the moment of the notification up to the current day”, “feelings about nursing”, “things that were hard and painful”, “people who were supportive and caring”, and so forth. Each interview was about 60 minutes and, with the consent of the subjects, we recorded the interviews by taking notes and using an IC recorder.

Method of Data Analysis

We made a word-by-word transcription out of the recording of the interview. First of all, we classified a unit for our analysis by sorting out a paragraph with a basic sense of meaning. Next, we codified each unit focusing on the feelings of the family members of a laryngectomee. Then, we put the codes in order according to the similarities in meaning, extracted a category, and raised the abstraction level by

repeating this routine of analysis. Whenever we had a doubt about the content of the data, we examined the interpretation of the interview repeatedly.

Assurance of Credibility

The entire process of analysis was conducted by three nursing researchers under the guidance of a supervisor. The categorization was done until the interpretation by the researchers and that by the supervisor precisely concurred. We enhanced the credibility of the analysis by our repeated verifications on the finalized category and the research result.

Ethical Consideration

Prior to the execution of this research, we obtained the approval of the ethical committee at the department of nursing in the school of medical welfare at Kawasaki University of Medical Welfare. We explained to the collaborators both verbally and in writing our research policy as follows; participation based on the free will of participants, freedom of withdrawal at any time, anonymity of participants, the use of the data is restricted to this research only, and no loss of benefits is incurred through non-participation. We conducted the research after gaining their agreement on all the terms of this policy.

Results

1. The Feelings of the Female Spouses of Laryngectomees

92 codes were gained from the interview. As a result of the analysis, we extracted 7 categories along with 20 subcategories (Table 2). Hereinafter, a category is indicated by ***bold italic***, a subcategory, by *italic*, and a quote from code, by double quotes “ ”. The numerals in parenthesis show the number of codes gained from the interview.

The category ***‘Having an agony accompanying their spouse’s daily life struggles with the illness’*** (21) consists of the subcategories *‘a trying experience accompanying the treatment’* (9), *‘having distrust towards medical staff’* (4), *‘hesitation over the choice of treatment method’* (3), *‘worry over recurrence’* (3), and *‘feeling distress concerning the diagnosis’* (2).

A trying experience accompanying the treatment is the experience of both “the languish for feeling nauseated during radiotherapy or chemotherapy” and suffering the side effects from the treatment. *Having distrust towards medical staff* is the distrust derived from the fact that “the disease was not found in spite of taking a thorough medical check up every year” and the fact that taking regular checkups did not result in earlier discovery of the disease. *Hesitation over the choice of the way of treatment* is a feeling of conflict such as “acceptance of the operation after hesitation” over the price of the loss of voice as the result of the operation. *Worry over recurrence* is the feeling of “fear at each time of a regular check-up”. *Feeling distress concerning the diagnosis* is feeling distress concerning the diagnosis after the symptoms appeared, which is the expression of distress over the period of time when waiting for the confirmation of the diagnosis.

The category ***‘Having a full realization of changes in the situation’*** consists of the subcategories *‘having a full realization of the ordeal of the loss of voice’* (8) and *‘anxiety accompanying changes in the situation’* (5).

Having a full realization of the ordeal of the loss of voice is seen from comments such as “I cried and laughed (with her husband) over the loss of voice”, “because my husband cannot speak (cannot utter speech), it was hard to write ‘sorry’ on a board”, which expresses the full realization of the ordeal of the

Table 2 Feelings of the Female Spouses of Laryngectomees

Category	Subcategory
Having an agony accompanying their spouse's daily life struggles with the illness	a trying experience accompanying with the treatment method
	having distrust towards medical staff
	hesitation over the choice of the way of treatment
	worry over recurrence
	feeling distress concerning the diagnosis
Having a full realization of changes in the situation	having a full realization of the ordeal of the loss of voice
	anxiety accompanying the changes in the situation
Feeling reassured about their spouse's prognosis	feeling the good effects of the treatment
	feeling the joy of recovery
Not wanting others to know their husband's condition	wanting to avoid seeing others and to conceal the husband's condition
	not wanting to talk about the husband's condition
	minding the watchful eyes of neighbors
	feeling a sense of conflict after the husband's condition was known by others
Supporting each other among the family members	recognition of the family's tie afresh
	looking for things that can be done as a family
Sharing with those who have had the same kind of experience	feeling assured upon hearing the same kind of experience
	having got support from those who contracted the same kind of disease as that of husband's while in hospital
Being thankful to nurses	satisfied with nurses' care
	nurses remain concerned
	grateful to nurses who rejoiced together

loss of voice when the subjects closely saw their husbands' painful condition after the loss of voice. The *anxiety accompanying changes in the situation* is revealed from "I attended (my husband) for several days without taking any sleep", which describes the worry over changes after the operation.

The category '*Feeling reassured about their spouses' prognosis*' (6) consists of the subcategories '*feeling the good effects of the treatment*' (6) and '*feeling the joy of recovery*' (3).

Feeling the good effects of the treatment is seen from "though (my husband) cannot speak (he) can eat anything and has become vigorous", which expresses feeling sure of the good results of choosing to keep the eating and swallowing function at the cost of the loss of voice caused by the operation. *Feeling the joy of recovery* is made clear by remarks on the gratefulness to the current condition such as "I have to be thankful for the recovery brought about by the operation" and also seen from "(my husband) recovered

as much as (he) cleaned up (the house for us)", which shows the joy generated by the husband's recovery getting close to his condition before the operation.

The category '**Not wanting others to know their husband's condition**' (12) consists of the subcategories '*wanting to avoid seeing others and to conceal the husband's condition*' (4), '*not wanting to talk about the husband's condition*' (3), '*minding the watchful eyes of neighbors*' (3) and '*feeling a sense of conflict after the husband's condition was known by others*' (2).

Wanting to avoid seeing others and to conceal the husband's condition is seen from comments such as "I do not want to make contact with others or go out", which expresses a desire not to let other people know about the husband's loss of voice and the accompanying agony by avoiding contact with others. *Not wanting to talk about the husband's condition* is seen from "I do not want to talk about what happened to my husband", which expresses the feeling that they don't want to concern anyone with the loss of their husband's voice. *Minding the watchful eyes of neighbors* is seen from "I do not want to talk to people other than family members because others have to make a great effort giving sympathy over the disability in speech", which expressed the feeling of anxiety over how the husband's loss of voice affects others' minds. *Having a feeling of conflict after the husband's condition was known by others* is seen from comments such as "though everybody now knows about it, I still do not want to talk about it" and "when getting used to the situation that others know about it, I came to wish my husband would talk about it through electricity (electronic larynx)", which expresses a feeling of conflict.

The category '**Supporting each other among the family members**' (10) consists of the subcategories '*Recognition of the family's ties afresh*' (6) and '*looking for things that can be done as a family*'.

Recognition of the family's tie afresh is seen from comments such as "(my daughter) let me take a rest and it was a great help" and "I count on my children or brothers when I want to talk", which expresses the physical and mental support from family members who care about the subjects. *Looking for things that can be done as a family* is seen from comments such as "I took care of my husband in cooperation with nurses" and "I gathered information by talking to other patients", which expresses the fact that the subject did whatever they could to care for their husbands and collected information to support the laryngectomees.

The category '**Sharing with those who have had the same kind of experience**' (12) consists of the subcategories '*feeling assured upon hearing the same kind of experience*' (8) and '*having got support from those who contracted the same kind of disease as that of husband's while in hospital*' (4).

Feeling assured upon hearing the same kind of experience is seen from comments such as "I got cheered up because of the good atmosphere with (my husband's) fellow sufferers at the meeting" and "I am being taught what I don't understand", which expresses the fact that those who were in the same situation talked about their worries and helped each other to solve their problems. *Having got support from those who contracted the same kind of disease as that of husband's while in hospital* is seen from comments such as "I was able to stay cheerful and was not depressed because the patients who contracted the same kind of disease as my husband's were in the same room", which expresses the fact that spending time together with the patients suffering from the same kind of disease reduces the feeling of worry.

The category '**Being thankful to nurses**' (14) consists of the subcategories '*satisfied with nurses' care*' (9), '*nurses remain concerned*' (3) and '*grateful to nurses who rejoiced together*' (2).

Satisfied with nurses' care is seen from comments such as "nurses gave proper care of the hole when taking a shower without showing any reluctance" and "nurses did very well always and worked with a smile", which expresses the satisfaction with care not only in terms of skills but also in terms of response and attitude.

Nurses remain concerned is seen from the expressions of nurses such as "is there any problem you have?", from which the subjects felt the nurses' compassion. *Grateful to nurses who rejoiced together* is seen from

“(nurses) expressed their joy over the recovery”, which expressed the feeling of rejoicing over the attitude of nurses who supported the trying treatment and shared the joy of recovery with the patients and the family members.

Discussion

The spouses of cancer patients, from the time of the notification, felt full of pain, which was derived from the same process the patients of cancer experienced including feelings of regret, anger, resignation, and self-reproach [8]. The spouses also felt *an agony accompanying their spouse's daily life struggles with the illness* all through the time of the appearance of symptoms, the confirmation of the diagnosis and treatment and during life after being discharged from hospital. They had a feeling of conflict over the choice of treatment as expressed in “I had a feeling of conflict over the choice of the loss of voice caused by the operation or the loss of strength caused by anti-cancer drugs”, and had a feeling of conflict over their husband's survival and keeping the vocal cord function.

They had the feeling of worry over recurrence of the cancer after being discharged from hospital as expressed in “I have fear concerning the results of regular check-ups every time” and “no worry after 5 years”. In the process of treatment and recuperation of cancer, unexpected recurrence and metastasis occurs. It is reported that the 5-year survival rate for larynx cancer is 70 percent and that for pharynx cancer is 40 to 60 percent [9]. In addition, the spouses of the patients have to face uncertainty over the unexpected life of recuperation for cancer after the hospital treatment [8]. The spouses of laryngectomies in this research have also spent days of feeling worry over the recuperation process and the worsening of the condition and they have shared with their husbands the trying experience of the side effects of the treatment and the undergoing of another operation. Above all these, the patients lost the organs that produce speech, one of the most important means of communication, and the spouses, together with the patients, had the feeling of agony by sharing the situation of *having a full realization of the changes in the situation* as they experienced “crying and laughing together” and “feeling misery over the husband's disability in speech”. Also, the female spouses had the sense of *feeling reassured about their spouse's prognosis* when they felt the effectiveness of the treatment and assured of the prolongation of life at the cost of the operation accompanying the loss of voice as expressed in “I have to be thankful for (my husband) regaining health”. It is reported that the family members of a patient share the trying experience of both physical and psychological pain, and that affects the mental health or hygiene of the family members [10, 11]. From this point of view, it can be inferred that the spouses of laryngectomees have to face more of the agony in sympathizing with the pain of laryngectomees who experience the feeling of loss caused by the loss of their voice, and it is made obvious that the family members should be provided with nursing just as the patients are. In living with laryngectomees and struggling together with the disease, the spouses are satisfied with the nurses' conduct and care. They are *thankful to the nurses* as expressed in their mention of concerned nurses' queries such as “is there any problem you have?” and “(nurses) expressed their joy over recovery”. It is reported that at the actual scene of medical treatment in general, the care support given to a patient depends on the physical condition of the patient, and despite the needs and the health principles of the patient, the chances are high that the source and type of support is determined according to the type and degree of disease [12]. Also, most of the initiative of nursing is to be put in partnership during this chaotic period [13]. The role of nurses is to give necessary support even though it is not asked for [14]. The result of this research indicates that the subjects were satisfied with the nurses' care and they were given not only physical support, but also emotional support. The patient's experience of contracting cancer and receiving treatment is also enormous for the family members, and it takes a large

amount of time for the family members to come to terms with the meaning of it. The shock, even though it is diminished, repeatedly falls upon the family members often caused by a tiny trigger [14]. Also, it is pointed out that the most critical and trying stages for the patient are the time when the patient is notified of the necessity of laryngectomy, the time when a patient recognizes what happened to the patient's body after the operation, and the time when a patient is discharged from hospital where they had necessary protections of all kinds and must now look after themselves [16]. From this perspective, it is suggested that, there is not only a need for providing the specific physical care in the course of the appearance of the symptom and the process of the treatment, there is also a necessity for the nursing care to meet the needs of the feelings of laryngectomees and their family members.

The laryngectomees, as the result of the loss of voice have difficulty in expressing themselves and keeping company with others. As mentioned above, this is one of the most critical and trying stages, when they cannot feel they are understood by their friends, even though they successfully went through the operation and resumed an ordinary life [16]. It is made clear that those who lost the ability of communication in the course of their life can feel alive and at ease when they can feel assured of being understood by others in human relationships [16]. Also, in this research, we are able to see the attitude of the family members in that they try to understand the feelings of laryngectomees as much as they can. They helped laryngectomees' treatment and recuperation only among the family members, and they talk to each other only among the family members as expressed in "I do not want to talk to people other than family members because others have to make a great effort giving sympathy over the disability in speech". In research on the emotional instability of the family members of cancer patients, it is made clear that caregivers limited the subject of communication [16] and closed communication was seen in general. As a result of this research, it is found out that although the communication is limited within the family members, the spouses recognized that they were being supported by other family members.

The spouses and the family members did whatever they could to care and treat the laryngectomees and to gather information on the disease and the process of it. It is made clear that in research on the family members of a cancer patient in the terminal period, that the family members feel a strong tie and assurance with the patient through giving care to the patient [16]. Also, it is described by Nojima that the family members are the indispensable resources for a patient [19]. Therefore, it can be inferred that to support the patient with the collective power of the family members with the proper recognition of each of the roles of the family provides the power to overcome the situation not only for the patient, but also for the family members.

The spouses and the family members were supported by the fellow sufferers of the patients and their families, and had the feeling of certainty over the same kind of experience. It points out that there occurs the feeling of security in the environment where cancer patients are not uncommon and where the patients and the family members can share information on treatment and recuperation [8]. The laryngectomees especially have the feeling of agony over having tracheostomy (the stoma installation for trachea), the difficulty in communication due to the loss of voice and so on. The family members who support the patients also share the same feeling, so their sharing of worry and the trying experience can serve to assist the cooperative life of treatment and recuperation. From this view point, it is made clear that the support provided by a chance for the fellow sufferers and their family members to meet is necessary.

This research sheds light on the feelings of the family members of laryngectomees. However, it is hard to say that the subjects here can serve as representatives of family members of laryngectomees as a whole. The number of the subjects who belonged to the SHG and participated in this research was only three, which qualifies the results of this research to some extent. What we have to do from now is continue to survey while increasing the number of subjects.

Conclusion

As we have shown to be the case, the feelings of the family members of laryngectomees include the experience of *having an agony accompanying their spouse's daily life struggles with the illness* and *having a full realization of the changes in the situation*. And the female spouses have the feeling of *not wanting others to know their husband's condition* and they are in the practice of *supporting each other among the family members*. They feel relief by *sharing with those who have had the same kind of experience* and the female spouses have the sense of *feeling reassured about their spouse's prognosis*. Moreover, the female spouses are *thankful to nurses*. It is suggested that we need to understand the situation of the female family members of laryngectomees where they have the feeling of agony and relief over the mental condition and transition of the patients and over the support given by the family members and that providing the support for them to share the feelings and the experiences among them is a necessity.

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Supplementary Note

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