

Sigma's 29th International Nursing Research Congress

Participation of Laryngectomized Patients in Self-Help Groups in Japan: Relationship With Subject Characteristics

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Purpose:

This study aimed to reveal the relationship between participation of laryngectomized patients in self help groups in Japan and subject characteristics from before surgery to 1 year after discharge.

Methods:

We investigated 38 patients who underwent total laryngectomy for surrounding cancers of the larynx. They answered 5 questionnaires in total (before surgery, before discharge, and 3 months/6months/1 year after discharge), and answered all the questions about participating self help groups.

The Questionnaires consisted of basic attributes (age at surgery, sex, treatment methods, employment status before patients underwent laryngectomy and after discharge, participation in self help groups before discharge, conversation with other people in the last month, and participation in community activities after discharge), participation in self help groups, and reasons if not participating in self help groups.

Patients were divided into 2 groups: One was the patients who had an experience of participating in self help groups within 1 year since discharge (hereinafter referred to as “participating group”), and the other was the patients who had never participated in self help groups (hereinafter referred to as “non-participating group”). We calculated descriptive statistics of each group by basic attribute, and overviewed trends by comparing the data of each group.

For ethical considerations, this study was performed with the approval of the Institutional Review Board of the university which the author belongs.

Results:

The average age of all subjects at surgery was 65.8 years old (range, 46-82 years old), including 30 men (78.9%). A total of 38 subjects were divided into 17 patients, the participating group (44.7%) and 21 patients, the non-participating group (55.3%).

More patients received treatment combined with radiation therapy in the participating group (29.4%) than those who in the non-participating group (19.0%).

For employment status, the employment rate in the participating group was at a similar level compared with that of before surgery (47.1%) until 3 months after discharge, and the rate began to decrease afterwards (the employment rate was 23.5% at 6 months and later after discharge). On the other hand, the employment rate in the non-participating group began to decrease at 3 months after discharge (the employment rate was 28.6% at 3 months after discharge) compared with that of before surgery (42.9%).

The proportion of the patients who had already participated in self help groups before surgery was 41.2% in the participating group and 9.5% in the non-participating group, showing a significant gap. For the reasons for not participating in self help groups before discharge: Six out of 10 laryngectomized patients who had not participated in self help groups before discharge in the participating group mentioned "I think I'm going to participate by seeing an opportunity". Afterwards, these patients participated in self help groups in the early post-discharge period. On the other hand, the patients in the non-participating group mentioned other 3 reasons before discharge in addition to "I think I'm going to participate by seeing an opportunity" and "I'm not sure I'll participate": They did not feel well, the venues holding meetings of self help groups were far from home, and the timing was not good for work. These 3 reasons were different from that of those who in the participating group.

For participation in community activities, 17.6% in the participating group and 19.0% in the non-participating group participated in community activities before surgery, showing almost the same proportion. At 3 months after discharge, no patients in the both groups began to participate in community activities. At 6 months after discharge, some patients in the participating group began to participate in community activities (5.9% at 6 months after discharge, and 17.6% at 1 year after discharge). However, no patients in the non-participating group began to participate in community activities even 1 year after discharge.

For conversation with other people, no patients answered "no conversation with other people" at 6 months and later after discharge in the participating group. However, 2 patients (9.5%) answered that they had had "no conversation with other people" even at 6 months and later after discharge. These 2 patients had the same background that they retired at mandatory retirement ages, and they had been trying to communicate with other people by writing and gesture after laryngectomy. One of the 2 patients answered that he was living alone, and he had had almost no conversation with other people before surgery. This patient mentioned like "I don't feel any inconvenience" at any time after discharge. The other patient answered that he was living together with someone and had had a conversation for 30 minutes to 1 hour a day before surgery, but he stopped conversation since before discharge. This patient was thinking to participate in self help groups by seeing an opportunity before discharge. However, he suspended participation at 6 months after discharge because the venues holding meetings of self help groups were far from home. This patient answered "I don't feel any inconvenience by not being able to speak" at 1 year after discharge. This means he was changing his mind about participating self help groups over time.

Conclusion:

Laryngectomized patients not participating in self help groups after discharge are likely to have a less relationship with other people in a workplace or local area which they had before surgery compared with that of the patients participating in self help groups. Especially, this study revealed that laryngectomized patients who had had no conversation with other people over 1 year after discharge were tended to be socially isolated.

It is hard for people other than laryngectomized patients to understand the experiences specific to laryngectomized patients, such as losing their voice, or respiration without nasopharyngeal cavity. Therefore, self help groups would be the only places where laryngectomized patients can share their

experiences and sympathize with other people. In light of this, in order to begin interaction with other people, self help groups would be remarkably useful for laryngectomized patients who lost interaction with the society which they had before surgery. Furthermore, laryngectomized patients in the participating group continued to participate in community activities and have a conversation with other people at 6 to 12 months after discharge. It indicates that participation in self help groups would be helpful for laryngectomized patients to engage in general social activities.

From the above, it is important for medical professionals to assess living conditions of each laryngectomized patient before surgery, and assess the possibility that a patient has less social interaction after discharge. In addition, for laryngectomized patients who are likely to lose interaction with the society, it is important to make an effort actively to connect these patients with self help groups before discharge based on the will of laryngectomized patients. At that time, medical professionals should clarify matters that are likely to hinder laryngectomized patients from continuing to go to self help groups after discharge, and provide support that laryngectomized patients can think about particular measures together.

In this study, we were not be able to capture how laryngectomized patients feel the situation of no interaction with other people, and how the laryngectomized patients who answered "I don't feel any inconvenience by not being able to speak" feel. To reveal them, further investigation will be required.

Title:

Participation of Laryngectomized Patients in Self-Help Groups in Japan: Relationship With Subject Characteristics

Keywords:

Laryngectomized patients, Self-Help Groups and Support for the comeback to normal life

References:

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Abstract Summary:

This study is to reveal the relationship between participation of laryngectomized patients in self help groups and subject characteristics from before surgery to 1 year after discharge. You can get suggestions how you are good by support about the comeback to normal life after the discharge for laryngectomized patients.

Content Outline:

【Objective】

To reveal the relationship between participation of laryngectomized patients in self help groups in Japan and subject characteristics from before surgery to 1 year after discharge.

【Methods】

- 38 patients who underwent total laryngectomy and consented to participate in the study responded to the questionnaire survey.
- The questionnaire was administered before and 3, 6, and 12 months after hospital discharge.
- Survey items : Self-Help Group (SHG) registration and participation status, Reasons for not joining SHG, Basic attributes
- We calculated descriptive statistics of each group by basic attribute, and overviewed trends by comparing the data of each group.

【Results】

- At 3 months after discharge, the employment rate in the participating group is higher than rate in the non-participating group.
- The proportion of the patients who had already participated in self help groups before surgery was 41.2% in the participating group and 9.5% in the non-participating group, showing a significant gap.
- For the reasons for not participating in self help groups before discharge: the patients in the non-participating group did not feel well, the venues holding meetings of SHG were far from home, and the timing was not good for work. These 3 reasons were different from that of those who in the participating group.
- For participation in community activities, at 6 months after discharge, some patients in the participating group began to participate in community activities. However, no patients in the non-participating group began to participate in community activities even 1 year after discharge.
- For conversation with other people, no patients answered “no conversation with other people” at 6 months and later after discharge in the participating group. However, 2 patients (9.5%) answered that they had had “no conversation with other people” even at 6 months and later after discharge.

【Discussion】

- Laryngectomized patients not participating in self help groups after discharge are likely to have a less relationship with other people in a workplace or local area which they had before surgery compared with that of the patients participating in self help groups.
- In order to begin interaction with other people, self help groups would be remarkably useful for laryngectomized patients who lost interaction with the society which they had before surgery.
- It is important for medical professionals to assess living conditions of each laryngectomized patient before surgery, and assess the possibility that a patient has less social interaction after discharge. In addition, for laryngectomized patients who are likely to lose interaction with the society, it is important to make an effort actively to connect these patients with self help groups before discharge based on the will of laryngectomized patients.

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