Participation of Laryngectomized Patients in Self-Help Groups and Their Motivations for Status Changes

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Purpose:

This study was conducted to clarify the status of participation of laryngectomized patients in self-help groups (SHG) before discharge to 12 months after discharge, and their motivations for its changes.

Methods:

The study population comprised 5 patients who underwent total laryngectomy for perilaryngeal cancer at one facility in the Kinki District of Japan between July 2017 and March 2018, and who consented to cooperate in this study. They were asked to respond to a questionnaire-based survey, and to be interviewed by the author for 30 to 60 min each at five time points: before surgery, before discharge, and 3, 6, and 12 months after discharge. For 2 subjects who had not started the survey at 12 months after discharge as of March 2018, the survey took place for up to 6 months after discharge.

A questionnaire form was used to explore their basic attributes (age at the time of surgery, sex, treatment methods, availability of families living together, employment status, status of involvement in community activities), their status of participation in SHGs, and the reason(s) for non-participation in SHGs. Information about diagnosis, disease stage, surgical technique, and concomitant therapies was also
collected from medical records. After consenting to be interviewed by the author, the subjects were asked about their daily activity status, countermeasures against anxiety and troubles, and their participation in SHGs at various time points. Interview findings were documented by the author after the end of interviews on the basis of notes made by the author during interviews and records of writings by the subjects. Based on responses to the questionnaire and interview findings in combination, we investigated the status of participation of laryngectomized Patients in SHGs and their motivations for its changes.

For ethical considerations, this study was conducted after approval of the institutional review board of the university to which the author belongs.

Results:

Study population outline

The average age of the 5 subjects at the time of surgery was 71.2 years (range 55-87 years), all of whom were male patients. Their breakdown by diagnosis was as follows: laryngeal cancer in 3 subjects (60%) and hypopharyngeal cancer in 2 subjects (40%), including 3 subjects (60%) with stage IV disease. With regard to treatment methods, 4 subjects (80%) underwent total laryngectomy alone and 1 subject (20%) underwent both total laryngectomy and reconstruction surgery with a free jejunal graft. Three subjects (60%) received any concomitant therapy; their breakdown by concomitant therapy was as follows: preoperative radiotherapy for 1 subject (20%), postoperative radiotherapy for 1 subject (20%), and postoperative chemoradiotherapy for 1 subject (20%).

As for preoperative background, all the subjects were living together with their families. Three subjects (60%) were employed, and 2 subjects (40%) were mandatory retirees. One subject (20%) was involved in community activities, including volunteer activity.

Course of participation in SHG

Two subjects (40%) continued to attend SHG meetings after participation. Other 2 subjects (40%) discontinued participation after discharge. The remaining 1 subject (20%) did not participate in SHGs up to 12 months after discharge.

“Motivations” leading to changes in the status of participation in SHG

(1) Subjects who constantly attend SHG meetings after participation

Subjects who constantly attend SHG meetings had been motivated to proactively consider participation after surgery for the reasons of “I want to get reinstated and/or take part in community activities” and “I want to remain able to communicate with other people even after loss of voice” before surgery. However, before discharge, “I don't know SHGs” and “I'd like to wait a restoration of my physical strength” were mentioned as reasons for non-participation in SHGs. Three to six months after discharge, the increased volition “I want to acquire phonation techniques to become able to play social roles” through personal exchange with families, workplaces, and regional people motivated the subjects to constantly attend SHG meetings. In addition, “I will become able to vocalize”, “I'm encouraged by personal exchange with other people”, and “I'm able to be sympathetic with other participants sharing the same experience” by acting together with other SHG members encouraged the subjects to continue participation in SHGs.

(2) Subjects who discontinued participation in SHGs
These 2 subjects joined SHGs not later than 3 months after discharge. After 3 months following discharge, however, they discontinued participation for the reasons of “I feel sick” and “I don’t make progress in phonation techniques even when attending SHG meetings.” Noting their backgrounds, we found that they were distinct from the other subjects in that they underwent highly invasive surgery and postoperative chemoradiotherapy. Furthermore, one of them became unemployed because of aphonia after 3 months following discharge.

(3) Subject who did not participate in SHGs

Although he was considering participation in SHGs before discharge, this subject was highly anxious about daily activities after discharge, such as meals and reinstatement, so that he was reluctant to participate in SHGs for the reason of “I have no room in my heart to consider participating in SHGs.” Thereafter until 12 months after discharge, the inability to comfortably take meals due to treatment-related dysphagia and loss of gustatory sensation, as well as impatience for reinstatement and other factors led to the lack of room in his heart to consider participating in SHGs.

In addition, 3 to 6 months after discharge, “I'm unlikely to get relaxed in SHGs because all members are older than me” and “I don't want to contact other people because I feel a handicap due to loss of voice” were also mentioned as reasons for being reluctant to participate in SHGs.

This subject did not actually join SHGs. However, his wish “I want to be able to communicate with other people even after loss of voice” became evident at the occasion of reinstatement 12 months after discharge. Furthermore, he was “recommended by my attending physician to participate in SHGs.” These facts motivated the subject to begin proactively considering participation in SHGs.

Conclusion:

Motivations for participation in SHGs mentioned by the subjects who constantly attended SHG meetings, i.e., “I'm encouraged by personal exchange with other participants” and “I'm glad to have my thought understood by other participants sharing the same experience”, reconfirmed that SHGs served as opportunities for peer support that not only helps patients acquire substitute voices after experiencing aphagia, but also provides mental healing through personal exchange among participating members.

In addition, personal exchanges with other people at workplaces, local communities, and elsewhere after discharge motivated the subjects to acquire phonation techniques for playing social roles, and led to their continued attendance in SHG meetings. Therefore, if provided early after discharge to allow the subjects to continue their activities in which they have been involved from before, support is expected to lead to their participation in SHGs and continued employment and community activities, thus resulting in a good outcome of promoted social rehabilitation for laryngectomized Patients.

On the other hand, 1 subject was reluctant to participate in SHGs for the reason of physical deconditioning during the entire period before discharge to 12 months after discharge. Noting his and other subjects’ backgrounds, we can conjecture that they are likely to lose personal exchanges with other people since they have difficulty even with going outside and finding jobs. In addition, there seemed insufficient efforts of medical professionals to raise laryngectomized Patients’ awareness of information about SHG activities before discharge. Based on these findings, we conclude that it is important for medical professionals to accurately assess the influences of the time course of recovery from surgical invasion and postoperative concomitant therapies on patient daily activities, and to provide both mental and physical support for laryngectomized Patients to live stable daily activities after discharge, in order to allow them to restore social activities without missing the chance, while taking into account their wishes. It is also important to understand, before surgery, how laryngectomized Patients want to spend time in their life after discharge, and to provide patients with specific information about the support that will be available by participating in SHGs as a helpful approach to realizing their hopes.
Title:
Participation of Laryngectomized Patients in Self-Help Groups and Their Motivations for Status Changes

Keywords:
Laryngectomized patients, Self-help Groups and To promote social rehabilitation

References:


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Abstract Summary:
The purpose of this study is to clarify the status of participation of laryngectomized patients in self-help groups before discharge to 12 months after discharge, and their motivations for its changes. This study shows a suggestion about how to support the promoting social rehabilitation for laryngectomized Patients.

Content Outline:
• The purpose of this study is to clarify the status of participation of laryngectomized patients in self-help groups (SHG) before discharge to 12 months after discharge, and their motivations for its changes.

• In five laryngectomized patients, we investigated the status of participation in SHG, their motivations for its change, and their background by the questionnaire and the interview each at five time points: before surgery, before discharge, and 3, 6, and 12 months after discharge.

• In results, following things were clarified; 1) “Motivations” leading to participation in SHG were “I want to get reinstated and/or take part in community activities”, “I want to remain able to communicate with other people even after loss of voice”, and so on, and 2) “I don’t know SHGs”, “I’d like to wait a restoration of my physical strength”, and so on were mentioned as reasons for non-participation in SHGs.

• Based on these findings, it is important for medical professionals to assess the influences of the time course of recovery from surgical invasion and postoperative concomitant therapies on patient daily activities, and to provide both mental and physical support for laryngectomized Patients to live stable daily activities after discharge. It is also important to provide patients with specific information about the support that will be available by participating in SHGs as a helpful approach to realizing their hopes.

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