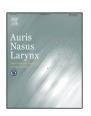
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# A questionnaire to assess olfactory rehabilitation for laryngectomized patients (Provox voice prosthesis users) in Japan

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#### ABSTRACT

*Objective:* We used a questionnaire to investigate olfactory function and the present state of olfactory rehabilitation for laryngectomized patients in Japan.

Methods: This study was conducted using a questionnaire survey. We mailed questionnaires to 190 members of a Japanese laryngectomized patient group (the nonprofit organization YOUSAY-KAI). The survey queried the following items: (1) basic information (age, sex, alaryngeal speech method, etc.); (2) questions about olfactory rehabilitation, such as the individual's experience of olfactory rehabilitation, the number of days from laryngectomy to the start of olfactory rehabilitation, and the location of rehabilitation (i.e., hospital or patient association); (3) free comments; and (4) the self-administered Odor Questionnaire (SAOQ).

Results: We received 121/190 questionnaires by the submission deadline. Of these, 105 questionnaires were valid. All 105 responders used the Provox voice prosthesis as the alaryngeal speech method. Only 4.7% (5/105) of the patients received olfactory rehabilitation in hospitals. Many comments in the free comment column included demands for olfactory rehabilitation such as "I want to know where we can have olfactory rehabilitation" and "I want to have rehabilitation if olfaction recovers." The SAOQ score was significantly higher in the rehabilitation group (mean, 42.5%) compared to the nonrehabilitation group (mean, 22.1%) (p < 0.05). There was no correlation between the SAOQ score and the number of days from laryngectomy to the start of rehabilitation (r = 0.08, p = 0.76)

Conclusion: Patient demand for olfactory rehabilitation is strong, but this therapy is not widely offered to laryngectomized patients in Japan. Notably, the SAOQ scores showed that olfactory rehabilitation may have an effect, even if it is initiated after laryngectomy. We believe that when patients choose voice prosthesis for speech, their olfaction deteriorates unless they undergo olfactory rehabilitation separately from speech rehabilitation. It is therefore necessary to administer olfactory rehabilitation for laryngectomized patients who have never received olfactory rehabilitation, as well as for patients scheduled to undergo laryngectomy.

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#### 1. Introduction

Olfactory function is important for tasting foods, enjoying perfume, or being alerted to hazards such as fire and gas leaks. Laryngectomized patients have permanent tracheostomies on the neck, and the airway and esophagus are anatomically separated. They have various problems affecting speech, bathing, holding heavy things, and blowing their nose. Olfaction is also a major problem, and many patients complain of olfactory difficulties [1-3]. Olfactory rehabilitation is currently provided using two methods. One uses a device that leads inspired air to the nasal cavity through the tube from the tracheostoma to the mouth. The other is the nasal airflowinducing maneuver (NAIM), first described by Hilgers et al. [4], and its effects have been reported in Europe [5–7]. The NAIM is also referred as the "polite yawning technique," as the movement is similar to yawning with the lips politely closed. It enlarges the oral cavity and causes air to flow into the nose.

In Japan, there are few reports regarding olfactory rehabilitation for laryngectomized patients in medical institutions. Rather, many patients first become aware of olfactory rehabilitation in a laryngectomized patient group (YOUSAY-KAI), for which the principal investigator of this study is participating as a volunteer. Olfactory rehabilitation and guidance should be provided at medical institutions rather than laryngectomized patient groups. Unfortunately, olfactory problems and the olfactory function of laryngectomized patients are not well known in Japan, so medical staff do not understand the necessity of olfactory rehabilitation. The aim of this study was to determine whether using a questionnaire survey could clarify the present state of olfactory rehabilitation of laryngectomized patients in Japan and assess whether there are olfaction differences between patients with and without olfactory rehabilitation.

#### 2. Materials and methods

#### 2.1. Questionnaire survey

This cross-sectional study was conducted using a questionnaire survey. We mailed questionnaires and return envelopes to 190 members (i.e., laryngectomized patients) of the nonprofit Japanese laryngectomized patient group YOUSAY-KAI. We received the completed questionnaires from January 2016 to March 2016.

The survey questions covered the following items: (1) basic information (age, sex, diagnoses, type of surgery, experience of radiation therapy [RT], alaryngeal speech method, number of months after voice prosthesis placement, timing of the voice prosthesis placement at the time of cancer surgery [primary placement] or after cancer surgery [delayed placement]), (2) olfactory rehabilitation experience (e.g., experience with olfactory rehabilitation, the number of days from laryngectomy to starting rehabilitation) and location of rehabilitation (e.g., hospital, patient association, or other), (3) free comments, and (4) the self-administered Odor Questionnaire (SAOQ).

#### 2.2. SAOO

The SAOQ was designed by Tsuzuki et al. [8]. It has a high correlation with the T&T olfaction test results (r = 0.592). which are commonly used in Japan, and with the Visual Analogue Scale of smell (r = 0.826) [9]. Proposed by the Japan Rhinology Society, the SAOQ is a self-administered survey consisting of 20 smell-related items: steamed rice, miso, seaweed, soy sauce, baked bread, butter, curry, garlic, orange, strawberry, green tea, coffee, chocolate, household gas, garbage, timber, stercus, sweat, flower, and perfume. Patients answered the SAOO by marking one of four levels for each item: two points when they could smell the odor strongly, one point when they could smell the odor weakly, zero points when they could not smell it at all, and "unknown" (i.e., without any points). For the results, the proportion (percent) of the total score for each item, compared to the full score, was calculated. In this study, we excluded patients who answered "unknown" for more than 11 (>50%) items. Previous studies [10,11] suggest that the olfactory function of normal elderly persons deteriorates with age, and this process is more rapid after age 70. Therefore, we only analyzed SAOQ data from patient younger than 70.

We divided the patients into rehabilitation and nonrehabilitation groups and compared SAOQ scores. In addition, because the rehabilitation group reported the number of days from the laryngectomy to starting olfactory rehabilitation, we examined the data for a correlation between the number of days from laryngectomy to rehabilitation and the SAOQ score.

#### 2.3. Ethical approval

This study was conducted after approval from the ethics review committee We also obtained written informed consent from each participant.

#### 2.4. Statistics

We used Mann–Whitney U tests to analyze SAOQ results between groups. Based on this result, we reviewed the effect of olfactory rehabilitation. We compared the control factors of the two groups, as follows: ages with Welch's t-test; the time after Provox placement with Student's t-test; and sex, diagnosis, type of surgery, experience of RT, and timing of the Provox placement using the chi-square ( $\chi^2$ ) for independence test. We also examined the correlation between the number of days from laryngectomy to olfactory rehabilitation and the SAOQ score rate with Spearman's rank correlation coefficient test. All statistical analyses were performed using SPSS statistical software, version 24 (IBM Corp., Armonk, NY, USA).

#### 3. Results

#### 3.1. Questionnaire collection rate

We received 63.7% (121/190) of questionnaires before the submission deadline. Of these, 105 questionnaires had valid

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