Original Article

Association between Daily Life Difficulties and Acceptance of Disability in Cancer Survivors after Total Laryngectomy: a Cross-Sectional Survey

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ABSTRACT

Objective: This study aimed to clarify the relationships between the acceptance of disability and daily life difficulties in patients after total laryngectomy. **Methods:** An anonymous questionnaire was mailed to 135 patients who were participating in a self-help group after laryngectomy. The questionnaire included items on personal attributes, daily life difficulties, and acceptance of disability according to the Nottingham Adjustment Scale – Japanese Laryngectomy version (NAS-J-L). Multiple regression analysis was conducted using the NAS-J-L acceptance of disability subscale score as the dependent variable and daily life difficulties as the independent variables. **Results:** Among the 57 respondents, 43 who provided valid answers were included in the analysis (41 men and 2 women; mean age = 67.5 ± 10.6 years). Acceptance of disability was significantly associated with difficulties in defecation (β = −0.409, P < 0.01) and breathing (β = −0.356, P < 0.05). **Conclusions:** Our findings suggested that difficulties in defecation and breathing due to airway alterations influence acceptance of disability after laryngectomy. Therefore, nurses should carefully assess daily life difficulties and patient's ability to perform self-care activities such as defecating and breathing to promote acceptance of disability and facilitate adaptation to daily life after total laryngectomy.

Key words: Acceptance of disability, daily life difficulties, total laryngectomy

Introduction

In Japan, the estimated number of new cases of oral, pharyngeal, and laryngeal cancers is approximately

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24,000 per year as of 2013, with the rate increasing 3.4-fold over the last 3 decades.[1] In patients with advanced laryngeal and hypopharyngeal cancer, total laryngectomy is often selected as treatment with curative intent.[2] Removal of the larynx and creation of a permanent tracheal stoma have profound effects on the patient's ability to talk, feed, drink, smell, breath, cough, and expectorate sputum.[3-6] Patients may also experience functional constipation induced by the lack of glottic closure.[7,8] Laryngectomized patients face multiple difficulties in daily life due to dysarthria, dysphonia, dysphagia, and changes in body image that negatively affect the quality of life (QOL).[3,4,6,9] Thus, laryngectomized patients must acquire new self-care skills and methods of communication to compensate for these functional impairments. However, these patients experience coping difficulties before surgery, and they are at increased risk for inability to cope after surgery.[6] Previous studies reported that some patients exhibit depressive tendencies after laryngectomy,[4,10,11] and the mental health of laryngectomized patients was poorer than that of depressive patients before surgery.[12] According to a study on the psychosocial adaptation of laryngectomized patients, self-acceptance was low and a trend toward anxiety–depression was high in patients who could not accept the loss of voice and who were inadaptable to postoperative lifestyle changes.[13] These psychosocial problems may not become apparent until after hospital discharge, and they are exacerbated over time due to lack of coping skills.[14] A multiplicity of social, environmental, individual, and temporal factors is associated with problems of daily life experienced by patients, as revealed by postoperative lifestyle self-assessments.[15,16] Therefore, it is important to evaluate patients' awareness of postoperative lifestyle changes and potential difficulties following discharge. Patients must cope with these daily life difficulties to help them socially and psychologically adapt to their postoperative life and accept these functional impairments after laryngectomy.[17] To this end, it is critical that nurses facilitate the acceptance of disability when managing daily life difficulties and help patients overcome psychological problems, such as sense of loss and anxiety, to assist them in adapting to daily life after discharge.

Previous investigations on acceptance of disability among patients after laryngectomy have been limited to qualitative analyzes of small samples[6,17-19] or have focused on the patient's ability to accept disability after surgery,[13,20,21] associations with social support[17,21] and body image,[6,19] and differences in the responses of patients who had total laryngectomy and those who had partial laryngectomy.[20,22] However, the relationships between the acceptance of disability and difficulties in daily life following laryngectomy, such as breathing, feeding, defecation, communication with others, and social participation, remain largely unexplored. By clarifying the relationship between the acceptance of disability and daily life difficulties, it is possible to identify the postoperative difficulties in daily life that could interfere with the patient's ability to accept ones disability. Further, nurses will be able to intervene to help patients constructively cope with these issues and adapt positively to postoperative lifestyle changes. Therefore, we performed a cross-sectional study involving laryngectomized patients, and we examined the relationships between acceptance of disability and daily life difficulties to identify strategies that can facilitate adaptation to daily life challenges following laryngectomy.

In this study, key terms were defined as follows. "Daily life difficulties" were defined as difficulties or subjective problems in breathing, feeding, defecation, communication with others, and hobbies due to the impact of laryngectomy. "Acceptance of disability" was defined as a state of recognizing objectively and realistically one's own physical disability. Further, the term described an aggressive living attitude through recognizing that having a disability does not diminish a person's overall value.

Methods

Study design and participants

A cross-sectional study was used to examine the relationships between acceptance of disability and daily life difficulties in patients who underwent total laryngectomy as treatment for perilaryngeal cancer. First, we obtained the permission from a representative of the Laryngectomy Association in Okinawa Prefecture, Japan. Identified participants (n = 135) were all association members who had undergone total laryngectomy. Questionnaires were mailed to prospective participants in August and September 2010. We asked the patients' family members to assist in completing the surveys in cases of limited sight and decreased physical ability. The questionnaires were returned directly by mail. Of the 135 distributed questionnaires, nine did not reach the intended recipients because of incorrect addresses, and nine of the total targeted patients died. Of the 117 investigable patients, 57 patients responded; meanwhile, 14 patients who provided incomplete answers to the questionnaires regarding daily life difficulties were excluded from the study, and 43 patients who provided valid answers for all questions were finally included in the analysis (valid response rate: 36.8%).

Questionnaire

Demographics and personal characteristics

Demographic data and personal characteristics obtained through the survey included sex, age, age at laryngectomy, postoperative years, living arrangement, employment status, hobbies, and communication methods.

Measurement of daily life difficulties

The survey items on daily life difficulties were developed based on the results of previous studies[23,24] and discussions among research members. The questionnaire consisted of 22 items on daily life difficulties after undergoing laryngectomy. Participants were asked to rate their responses using a 4-point Likert scale ranging from 1 (do not agree) to 4 (strongly agree). Higher scores indicated a greater level of difficulty. The validity and reliability of the scale were evaluated through factor analysis. First, exploratory factor analysis was conducted on the 22 items. The item with a factor loading of <0.4 in the preliminary factor analysis was deleted. In selecting factors, a principal factor method was used, oblique factor rotation was conducted using the Promax method, and the factor structure was clarified. Second, Cronbach's alpha coefficient was used to assess internal consistency reliability, and item-total correlation coefficients were examined to determine the item reliability.

Measurement of acceptance of disability

Acceptance of disability was assessed using the "acceptance of disability" subscale of the Nottingham Adjustment Scale, Japanese Laryngectomy version (NAS-J-L),[25] a scale originally developed to measure psychological adjustment following laryngectomy. The reliability and construct validity of the NAS-J-L were previously demonstrated. The acceptance of disability subscale consists of nine items, namely, "Even though my voice is lost, I can do anything for other people," "Even though my voice is lost, I have a variety of possibilities in life," and "I don't feel seriously depressed by losing my voice." These items were rated on a 5-point Likert scale: 1, do not agree; 2, slightly agree; 3, unsure; 4, mostly agree; and 5, strongly agree. Higher scores indicated a greater level of acceptance of disability (range: 5–45). Permission to use the acceptance of disability subscale of the NAS-J-L was obtained from the developer.[25] To ensure the internal consistency and factor structure of the subscale, Cronbach's alpha was calculated, and factor extraction was conducted using the maximum likelihood method. The Cronbach's alpha coefficient for the total score was 0.92, indicating good internal consistency, and one-factor structure was confirmed.

Statistical analysis

First, descriptive statistics were calculated for all variables included in the study. The Kolmogorov–Smirnov (K-S) test was used to identify the distributions of continuous variables, such as age, postoperative years, each factor score of the daily life difficulties survey, and the NAS-J-L acceptance of disability subscale score. According to the K-S test, these variables were normally distributed. Subsequently, to assess the relationships between the acceptance of disability subscale score and personal attributes expressed in binary variables (e.g., sex, living with relatives or alone, employed or unemployed, with hobbies or without hobbies, use of esophageal speech, or other methods), differences in the mean acceptance of disability subscale score between the two groups were evaluated using a *t*-test. Pearson's correlation coefficients were calculated to assess the associations between the acceptance of disability subscale score and personal attributes expressed as continuous variables (age and postoperative years) and the daily life difficulties score. In addition, to examine whether the acceptance of disability was independently related with these variables, a stepwise multiple regression analysis was performed using the total acceptance of disability subscale score as the dependent variable and personal attributes and daily life difficulties, which significantly correlated with the "acceptance of disability" scores, as the independent variables. The significance level was set at $P < 0.05$ (two tailed) for all tests. All data analyses were conducted using SPSS ver. 20.0 J for Windows.

Ethical approval

Before starting the survey, the methods and goals were explained in writing to a representative of the Laryngectomy Association in Okinawa Prefecture, Japan. All patients were informed in writing of their right to participate in or withdraw from the study, of our guarantee of anonymity and confidentiality of their personal information, and that the return of an answered questionnaire indicated an agreement to participate. This study was approved by the Ethics Committee of the University of the Ryukyus, Japan (approval number: 67).

Results

Demographic and personal characteristics of the participants

The mean age of the participants was 67.5 ± 10.6 years, and 95.3% of the participants were male. Approximately 84% of the participants lived with relatives, 80% were unemployed, and 50% reported hobbies or activities of enjoyment. With regard to their primary method of communication, 25.6% of the participants used esophageal speech, whereas the remainder used other methods such as writing (34.9%) and electrolarynx (23.3%). The total mean acceptance of disability score was 28.9 ± 8.1 (range: 5–45),

and there were no significant differences in scores between the two groups as defined by these demographic and personal variables [Table 1].

Factor analysis of the daily life difficulties scale

A principal factor method was used to estimate the factor loading of the 22 items, and oblique rotation was used for factor rotation using the Promax method. As a result, three items, namely, "It is difficult to eat hot food because I cannot blow to cool it down," "It is hard for me to cough up sputum effectively," and "I catch a cold easily," were removed because of low factor loading (<0.4). Then, another exploratory factor analysis was conducted on the 19 remaining items. Table 2 shows the five factors identified by this factor analysis. The five-factor solution explained 77.7% of the variance in the daily life difficulties score. The five extracted factors were named on the basis of their content as follows: Factor 1, "difficulties engaging in outings and hobbies"; factor 2, "difficulties in defecation"; factor 3, "difficulties with dietary intake"; factor 4, "difficulties in breathing"; and factor 5, "difficulties in communication with others." Internal consistency according to Cronbach's alpha coefficient ranged from 0.79 to 0.90. Corrected item-total correlation coefficients ranged from 0.40 to 0.86. Table 2 also shows the factor mean and item mean scores for daily life difficulties. The mean scores for factors 1–5 were 10.26 ± 4.53 (range: 5–20), 5.21 ± 2.28 (range: 3–12), 7.40 ± 3.00 (range: 4–16), 6.98 ± 2.60 (range: 4–16), and 8.67 ± 2.76 (range: 3–12), respectively.

Table 1: Participant characteristics and total mean score of the acceptance of disability according to groups (n=43)

	n (%)	Acceptance of disability[c]	
		Mean±SD	*P*
Gender[a]			
Male	41 (95.3)	29.4±8.0	0.080
Female	2 (4.7)	19.1±3.2	
Age[b]	67.5±10.6		
Age at laryngectomy[b]	61.2±9.8		
Post-operative years[b]	6.3±6.5		
Living arrangement[a]			
With relatives	36 (83.7)	29.1±7.9	0.740
Alone	7 (16.3)	28.0±9.9	
Employment status[a]			
Employed (contain absence)	9 (20.9)	29.3±11.1	0.915
Unemployed/retired	34 (79.1)	28.8±7.3	
Hobbies or enjoyment[a]			
With hobbies	22 (51.2)	30.5±8.7	0.198
Without hobbies	21 (48.8)	27.3±7.3	
Communication methods[a]			
Use of esophageal speech	11 (25.6)	30.1±10.1	0.589
Other than esophageal speech	32 (74.4)	28.5±7.5	
Writing[d]	15 (34.9)		
Electrolarynx (EL)[d]	10 (23.3)		
Writing + EL[d]	5 (11.6)		
Gesturing[d]	1 (2.3)		
Lip synchronization[d]	1 (2.3)		

[a]*t*-test, [b]Mean±SD (Standard deviation), [c]Range of score 5-45, [d]Ways of except of esophageal speech

Item mean score of the acceptance of disability subscale

Table 3 shows the mean scores of the nine items on the acceptance of disability subscale (range: 1–5). The highest rated item was "Even though my voice is lost, I can do anything for other people (3.63 ± 1.13)," whereas the lowest rated item was "I am satisfied with my abilities, and I am not distressed even the loss of voice (2.74 ± 1.24)."

Factors associated with acceptance of disability

As shown in Table 4, a positive correlation was observed between the acceptance of disability and time after surgery (r = 0.310, P < 0.05). Negative correlations were observed for difficulties engaging in outings and hobbies (r = –0.326, P < 0.05), difficulties in defecation (r = –0.530, P < 0.001), difficulties with dietary intake (r = –0.357, P < 0.05), and difficulties in breathing (r = –0.494, P < 0.01). In multiple regression analysis, the variance inflation factor was 1.129, and no multicollinearity was observed. Difficulties in defecation (β = –0.409, P < 0.01) and breathing (β = –0.356, P < 0.05) were significantly and negatively related to the acceptance of disability scores with an adjusted coefficient of determination of 0.362 (P < 0.001).

Discussion

The study results implied that difficulties in defecation and breathing due to a permanent tracheal stoma impede the acceptance of disability, and acceptance of disability after laryngectomy was related to difficulties in defecation and breathing. Self-evaluation of functional impairment and daily activities following laryngectomy provides patients the confidence to adapt to postoperative lifestyle changes and confers a sense of control over their daily lives,[19] increasing the feeling of self-efficacy.[5] In addition, it has been reported that patients regain their confidence by coping with various physical problems and difficulties in daily life, which in turn promotes the awareness of positive changes,[26] thereby increasing the sense of fulfillment in postoperative life and promoting self-acceptance.[7,13] Thus, nurses should comprehensively assess problems related to daily life, promote self-care of permanent tracheal stoma and self-health management, and provide adequate education and give continuous support to patients to enhance their self-care ability and feelings of satisfaction with their daily lives after discharge from the hospital. Furthermore, regular nursing support through home visits and outpatient services may increase patients' awareness of self-control regarding daily life difficulties and promote the positive acceptance

Table 2: Factor mean score, item mean score and exploratory factor analysis of the daily life difficulties scale (*n*=43)

Factor/item	Mean	SD	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5
Factor 1 : Difficulties engaging in outings and hobbies (α = 0.90)	10.26	4.53					
19. I do not feel like going out because it is difficult to communicate with others	2.07	1.10	0.92	0.10	-0.08	0.01	0.05
20. I do not like going outside because I am bothered by the appearance of my permanent tracheal stoma	1.77	0.92	0.79	0.20	-0.18	-0.05	0.05
18. I frequently stayed home instead of going out.	2.07	1.10	0.78	0.26	0.03	-0.11	0.06
21. I feel that I can not derive enjoyment from hobbies than before laryngectomy	2.07	1.10	0.75	-0.09	0.13	0.25	-0.07
22. I feel that it is difficult to engage in hobbies than before laryngectomy	2.19	1.10	0.62	-0.11	0.27	0.11	-0.04
Factor 2 : Difficulties in defecation (α = 0.88)	5.21	2.28					
16. I often have a sense of abdominal fullness because of constipation.	1.72	0.83	0.08	0.92	0.13	-0.09	-0.01
17. I tend to be constipated more often than before laryngectomy.	1.70	0.86	0.09	0.79	-0.03	0.23	-0.06
15. It is difficult for me to defecate because I can not strain due to the lack of glottic closure	1.79	0.86	0.21	0.72	-0.05	-0.12	-0.01
Factor 3 : Difficulties with dietary intake (α = 0.81)	7.40	3.00					
5. I feel that I derive no pleasure from meals.	1.84	0.95	-0.03	-0.01	0.95	-0.05	-0.04
4. It takes time for me to have a meal because I can not swallow a lot of food at a time.	2.02	0.94	0.16	0.05	0.80	-0.06	0.07
1. It is difficult for me to swallow food	1.83	0.95	0.51	-0.02	0.61	-0.02	-0.07
3. I feel that I have a decreased sense of taste.	1.70	0.89	-0.39	0.14	0.45	0.25	0.10
Factor 4 : Difficulties in breathing (due to airway alternations) (α = 0.79)	6.98	2.60					
10. I have momentary difficulty breathing because I get water in the permanent tracheal stoma while taking a bath.	1.93	0.88	0.28	-0.33	-0.06	0.80	-0.01
13. I sometimes have a bloody sputum.	1.37	0.66	-0.15	0.29	-0.07	0.76	-0.21
9. I often have momentary difficulty breathing	1.79	0.86	0.10	-0.06	0.05	0.69	0.12
12. I often have sticky sputum because of low humidity in the trachea	1.88	0.88	-0.04	0.36	-0.03	0.56	0.22
Factor 5 : Difficulties in communication with others (α = 0.85)	8.67	2.76					
6. I feel that it is difficult to communicate with family members	2.44	1.03	-0.27	0.01	0.17	0.01	0.89
8. I feel that it is difficult to answer the phone	3.35	1.07	0.18	-0.04	-0.04	-0.07	0.78
7. I feel that it is difficult to communicate with others	2.88	0.96	0.22	-0.06	-0.14	0.07	0.75
Rotation sums of squared loadings			4.63	3.04	3.49	3.41	3.09
Proportion of variance (%)			33.49	14.77	11.91	10.16	7.35
Cumulative proportion of variance (%)			33.49	48.26	60.17	70.33	77.68

α: Cronbach's α, SD: Standard deviation

Table 3: Item mean score of the acceptance of disability subscale (*n*=43)

	Mean	SD
Acceptance of disability (α = 0.92)		
Even though my voice is lost, I can do anything for other people	3.63	1.13
Even though my voice is lost, I have a variety of possibilities in life	3.51	1.20
I don't feel seriously depressed by the loss of voice	3.30	1.23
Even though my voice is lost, I can do what I want, and I can become a person I want to be	3.26	1.22
Even if there is somethings I can not do and person who have voice can do it, I do not mind	3.23	1.24
Even though my voice is lost, I feel that my life is meaningful	3.19	1.20
Even though my voice is lost, I do enjoy a variety of things	3.21	0.90
I rarely feel discomfort about the loss of voice	2.84	1.19
I am satisfied with my abilities, and I am not distressed even the loss of voice	2.74	1.24

α: Cronbach's α, SD: Standard deviation

of disability, thereby facilitating the adaptation to daily life after laryngectomy.

Constipation decreases the QOL of patients following laryngectomy.[8,27] Although laryngectomized patients considered constipation as the most troublesome symptom, they often do not inform healthcare workers about this issue because they are not sufficiently aware of its importance.[8,27] Ugur *et al.*[8] reported that functional constipation was more prevalent among laryngectomized patients and that colonic transit time was significantly prolonged in patients aged >65 years than in control patients aged <65 years who had not undergone laryngectomy. They also identified the factors contributing to the risk of constipation after surgery, such as age, changes in diet and defecation habits, stress and depression, immobility, and lack of glottic closure. Patients often do not recognize these causes.[8] Therefore, nurses should evaluate the problems related to defecation habits and constipation using appropriate assessment tools and provide appropriate advice to patients regarding postoperative diets and rehabilitation of bowel function.

With regard to the analysis of patient's QOL after laryngectomy, results showed that coughing and dyspnea are the major symptoms affecting QOL.[11,27,28] In patients who underwent laryngectomy, impaired pulmonary function is a reflection of the sum of presurgical damages, mainly from smoking and effects of the primary disease, and changes due to nonphysiological postlaryngectomy airway conditions.[29,30] These disadvantageous changes

Table 4: Factors associated with the acceptance of disability ($n=43$)

	Acceptance of disability	
	r	β
Age	0.194	-
Postoperative years	0.310*	0.156
Daily life difficulties		
Difficulties engaging in outings and hobbies	-0.326*	-0.101
Difficulties in defecation	-0.530***	-0.409**
Difficulties with dietary intake	-0.357*	-0.121
Difficulties in breathing	-0.494**	-0.356*
Difficulties in communication with others	-0.258	-
Adj.R^2		0.362***

r: Pearson's correlation coefficient, β: Standard partial regression coefficient, Adj. R^2: Adjusted coefficient of determination. *P<0.05, **P<0.01, ***P<0.001

adversely affect pulmonary function.[30,31] Moreover, 40%–70% of laryngectomized patients in other studies complained of breathing difficulties.[5,9,23,24,27] In our study, only a few participants complained of breathing difficulties based on the relatively low mean score of the item "I often have momentary difficulty breathing." However, Trzcieniecka *et al.*[11] reported that breathing disorders were significantly correlated with depressive symptoms. Thus, laryngectomized patients who complain of breathing difficulties should be carefully assessed, both physically and psychologically, as it is necessary to consider the possibility that depression may be disguised as breathing problems.

Regarding the relationship between postoperative years and acceptance of disability, results showed that the state of acceptance improves over time.[22] The present findings suggest that this does not hold for all patients following laryngectomy. Thus, nurses should observe patients' response in the immediate and later postoperative periods. In a qualitative study of Japanese patients who underwent laryngectomy,[17-19,26] patients expressed desires to be beneficial to their family members, to perform tasks for other people, and to fulfill social functions such as resuming work. In this study, social factors, such as living arrangements, employment status, hobbies, and communication methods, were not significantly associated with acceptance of disability. Regarding the effect of laryngectomy on patients' QOL, previous research showed that physical function was the most important factor affecting patients' psychological condition, whereas the psychological condition was the most important factor affecting patients' social function.[11,32] It was also stated that the management of physical symptoms, social reintegration, participation in enjoyed activities, and vocational issues following laryngectomy may represent significant barriers to achieving optimal QOL.[33] Therefore, nurses should continuously assist patients in managing daily life difficulties associated with physical functional changes, following laryngectomy, as well as psychosocial aspects such as social participation and support system to improve patients' QOL.

Limitations and implications

This study had several limitations. First, the results are based on a small sample size, which may hamper the generalizability. In addition, the study sample was confined to Japanese patients in a self-help group, and thus, the findings may not be applicable to other patients. Therefore, it is necessary to examine patients in other regions, particularly those not participating in self-help groups. Second, the reliability and validity of the daily life difficulties survey must be validated in future studies. Third, additional studies, including illness-related information, such as clinical indicators (e.g., type of diagnosis and treatments and cancer stage) and background information (e.g., personality and social support status) should be conducted. Finally, a longitudinal study tracking the effects of nursing interventions on daily life problems and self-care management on the acceptance of disability is needed to identify the most effective strategies.

The findings of this study can be applied to laryngectomized patients to develop self-care strategies needed to prevent and to manage the daily life difficulties that hamper the acceptance of disability. In particular, nurses should pay attention to daily life difficulties in defecation and breathing both in the immediate and later postoperative periods. Further research is required to develop long-term educational programs following laryngectomy and to verify the efficacy of these programs for enhancing the self-care ability of patients to adapt to postoperative lifestyle changes.

Conclusion

The present study found that the acceptance of disability after laryngectomy is related to difficulties in defecation and breathing. Therefore, appropriate assessments and nursing interventions should be provided to help patients acquire the necessary self-care abilities to cope with daily life problems. Nurses must promote patient's ability to manage the daily life difficulties, positive acceptance of disability, and adaptation to daily life after laryngectomy.

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Conflicts of interest

There are no conflicts of interest.

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