

AN EVALUATION OF THE QUALITY OF LIFE IN PATIENTS WITH TRACHEOSTOMY

Nur Dilek Gul¹, Ayise Karadag²

ABSTRACT

Objective: To evaluate the quality of life in patients with tracheostomy.

Methodology: All the patients, who have had tracheostomy operations between 1998-2009 at a University Hospital, Turkey, constitute the population of the study (70 patients). The data have been collected between June -July 2009 by using the Short Form 36 Quality of Life Scale (QoL).

Results: It has been determined that the QoL scores of patients, whose life span with tracheostomy is three months to one year, who have received chemotherapy or radiotherapy, have difficulties in breathing and eating are lower in the various sub-dimensions of the QoL scale. Together with this, it has been determined that the scores of patients who can perform their tracheostomy care independently, have no complications, use esophageal speech, whose sense of smell has not been impaired, and state that their physical appearance has not been affected are higher in the various sub-dimensions the Quality of Life (QoL) scale.

Conclusions: Tracheostomy has a profoundly negative impact on quality of life.

KEY WORDS: Tracheostomy, Quality of Life, Nursing Care.

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INTRODUCTION

One of the surgical interventions made in order to correct the impaired respiratory function is tracheostomy which is usually carried out in larynx cancer. The best treatment option at late stages of larynx cancer is total laryngectomy. Total laryngectomy makes survival possible at a large degree. However, due to its nature this operation leads to the loss of many functions, especially speech.¹ Thus, the impairment of many functions (such as nutrition, respiration, and speaking) and structures by cancers in head-neck region and their treatment has a multi faceted impact on the life of the individual.²⁻⁴ The most commonly emphasized adverse outcome of laryngectomy in the literature is the disappearance of speech function.⁵⁻⁹ However, the presence of problems such as

being unable to smell, loss of respiration from nose, being unable to blow one's nose, problems with straining, the presence of tracheostomy which requires constant care influences individuals as adversely as the loss of speech function does.

As it can be understood from the relevant literature, individuals undergoing tracheostomy are forced to cope with both with cancer occurring in a vital organ and with surgical trauma leading to serious disruption in body image and self esteem. Hence, nurses offering care to patients experiencing problems in important functions experience many problems, particularly in communicating with these individuals. The aim of treatment and nursing care in long term health problems is not only contributing to the prolongation of the patient's life but also planning and implementing what is necessary for individual's leading a high QoL.

QoL has been accorded the place it deserves in nursing discipline and many investigations have been carried out on this issue. There are some studies evaluating the impact of opening stoma on the QoL.^{10,11} Yet, the majority of studies concerning the effect of stoma on QoL involve gastrointestinal system and urinary system stoma. Both our own observations and nursing literature demonstrated that the QoL in tracheostomy, which is a real stoma, has not been considered adequately by nurses.

In literature review, it has been established that studies on QoL in individuals with tracheostomy are quite restricted in Turkey.^{8,12,13} However, care and training of an individual with tracheostomy are among the most important responsibilities of nurses. Nurses encounter many problems regarding the QoL in these patients try to find solutions to these problems. The aim of this study was to determine the QoL in patients with tracheostomy. It is thought that the results that will be obtained from this study will shed light on care, training and rehabilitation programs devised for tracheostomy patients.

METHODOLOGY

Present study was carried out in Ear, Nose and Throat Clinic of Hacettepe University Adult Hospital, which is one of the largest university hospitals in Turkey. The universe of the study comprises 70 tracheostomy patients who underwent tracheostomy between 1998–2009, older than 18 and lived with tracheostomy at least for three months.

In the collection of data, two different forms have been used. 'Demographic characteristics form' was developed by the investigator and includes questions on the demographic characteristics of the patients. Second form is SF-36 QoL scale. QoL was gauged with SF-36 because it is an internationally recognized global measure. SF-36 has previously been validated for use in postoperative patients and in different kinds of cancer trials. It has also been validated in Turkish patients. It includes one multiple-item scale that assesses eight health concepts: physical function, role limitation due to physical problems, social functioning, role limitation due to emotional problems, general mental health, vitality, bodily pain and general health perception. The raw scores are linearly transformed to fit in a range from 0 to 100, with higher scores representing better levels of functioning.

Ethics of the Study:

Before data collection was initiated, written approval was obtained from the hospital where the study was to be carried out. The individuals included in the investigation were informed on the aim of the study and their verbal consent was obtained. All expenses of the study were met by the investigators.

Data Collection:

The study was carried out between 04.06.2009-31.07.2009 with 70 tracheostomy patients treated in ENT clinic of Hacettepe University hospital. Of 70 tracheostomy patients included in the sample, 48 were contacted during hospital admission and 22 through mail. Data collection forms were filled by the patients themselves.

Evaluation of data:

Number, percentages and Mean \pm standard

Table-I: Characteristics of the individual related to living with tracheostomy

Characteristics	N (%)
Person who performs tracheostomy care (n=70)	
Patient him/herself	51 (72.9)
Family members,	7 (10.0)
Getting help when necessary	12 (17.1)
Developing complications(n=51)	
Lung infection	16 (31.5)
Pharyngocutaneous fistula	13 (25.5)
Difficulty in swallowing	13 (25.5)
Bleeding	6 (11.7)
Stenosis	3 (5.8)
Method of communication (n=70)	
Esophageal speech	35 (50.0)
Alternative communication techniques	24 (34.3)
Voice prosthesis	11 (15.7)
Status of experiencing problems in respiration (n=70)	
Experienced problems	21 (30.0)
Did not experience problem	49 (70.0)
Problems in breathing (n=21)	
Obstruction due to accumulation of sputum	15 (71.4)
Shortness of breath	6 (28.6)
Change in the sense of smell (n=70)	
No change	34 (48.6)
Decrease in smelling	20 (28.5)
No sense of smell	16 (22.9)
Difficulty in feeding (n=70)	
Yes	28 (40.0)
No	42 (60.0)
Change in ideas regarding physical appearance (n=69)	
No adverse influence	25 (36.2)
Being disturbed from physical appearance	17 (24.6)
Not liking one's physical appearance	16 (23.2)
Being ashamed of tracheostomy	8 (11.6)
Feeling oneself old	3 (4.4)
Status of effect on social relation (n=70)	
Adverse effect	39 (55.7)
No change	27 (38.6)
Positive effect	4 (5.7)
Psychological problems (n=51)	
Feeling bad	14 (27.5)
Depression	10 (19.6)
Feeling anxious about the future	9 (17.7)
Low morale	8 (15.7)
Fear of recurrence of disease	7 (13.7)
Losing hope of recovery	3 (5.8)
Effect on economic status (n=69)	
Adverse effect	46 (66.6)
No change	23 (33.4)

deviations are given in the results and tables. As QoL scores were found not to be distributed normally, in comparisons between two groups Mann-Whitney U test and comparisons between three or more groups Kruskal-Wallis H test was used. Significance level was set at 0.05 SF-36 QoL scoring was carried out in accordance with the original evaluation.

RESULTS

Detailed information about these patients living with tracheostomy, development of complications, method of communication, problems in breathing, psychological problems and adverse effects on social status besides the comparison of the change scores between the groups is given in Tables-I,II and III.

DISCUSSION

The results of this study carried out on 70 patients with tracheostomy revealed that tracheostomy influences basic human needs formulated in the hierarchy of needs by Maslow and QoL at different degrees (Table-I, Table-II). Consistent with the results reported in the literature, it has been established in the present study that the most basic needs of the patients such as respiration,¹⁴ nutrition,¹⁵ and communication^{8,16,17} are influenced by tracheostomy. Moreover, patients are confronted with changes in physical appearance involved with body

Table-II: Mean Scores of the Subscales of SF-36 (n=70)

Subscales	Mean Score
Physical functioning	64.2 ± 22.1
Role limitation due to physical problems	42.8 ± 27.9
Social functioning	52.5 ± 17.2
Role limitation due to emotional problems	45.1 ± 24.7
Mental health	51.0 ± 17.9
Vitality	43.3 ± 17.1
Bodily pain	46.7 ± 20.0
General health perception	35.1 ± 15.4

image, psychological problems and various complications.¹⁸ Patients experienced economic problems such as decrease in work power, cost of treatment, leaving job, obligatory retirement, working in a passive position⁸ (Table-I).

It has been established that in patients experiencing these problems, QoL is influenced adversely at different subscales (Table-III). However physical functioning and role limitation due to physical problems subscales are the only ones influenced from all variables except for physical appearance. In these two subscales the activities of the individual during daily life (such as sports, shopping, bending, walking etc.) and whether they experience difficulties in carrying out these activities are asked. Therefore, both tracheostomy and cancer treatment influences the daily life of the individual to a large extent. In the literature, it is stated that adverse effects of chemotherapy and radiotherapy influences QoL unfavourably.^{12,19} Vilaseca et al reported that in patients with total laryngectomy, and in patients with larynx cancer chemotherapy and radiotherapy has a negative impact on the QoL in patients.²⁰ Another important result obtained from this study is that patients who carry out tracheostomy care themselves independently and who use esophageal speech method have higher QoL scores in the subscale of physical function. In addition, in the subscales of physical function and role limitation due to physical problems, QoL scores were found to be significantly lower in the group living with tracheostomy for three months to one year than the group living with tracheostomy for 6 - 9 years. Given these findings, it is quite important for health care professionals, who are responsible for the care and treatment of the individual with tracheostomy, to bring the patients to a level where they can assume their self care and to teach patients the best communication methods. Compatible with our findings, Kaya established that in patients with larynx cancer, QoL decreased in the first months after treatment and started to increase from second month on, continuing to increase until 12th month.¹² Hammerlid et al followed patients with head and neck cancers for three

Table-III: Comparison of the change scores between the groups

Subscale	Duration of living with tracheostomy	Chemotherapy	Radiotherapy	Complication	Communication method	Breathing	Smelling	Nutrition	Physical appearance									
Physical function	9.96 ^a	0.019 ^b	135 ^c	0.036 ^b	123 ^c	0.020 ^b	287 ^c	0.009 ^b	20.204 ^a	0.000 ^b	250.5 ^c	0.001 ^b	10.5 ^a	0.005 ^b	291 ^c	0.000 ^b	378 ^c	0.370 ^b
Role -physical	11.176 ^a	0.011 ^b	135 ^c	0.031 ^b	51 ^c	0.000 ^b	232 ^c	0.001 ^b	7.145 ^a	0.028 ^b	187 ^c	0.000 ^b	6.56 ^a	0.038 ^b	376.5 ^c	0.009 ^b	424.5 ^c	0.801 ^b
Social functioning	2.848 ^a	0.416 ^b	164 ^c	0.110 ^b	134 ^c	0.030 ^b	446 ^c	0.600 ^b	0.890 ^a	0.641 ^b	383 ^c	0.082 ^b	0.39 ^a	0.821 ^b	544.5 ^c	0.591 ^b	417 ^c	0.720 ^b
Role -emotional	3.917 ^a	0.271 ^b	152 ^c	0.055 ^b	144 ^c	0.037 ^b	374.5 ^c	0.115 ^b	0.456 ^a	0.796 ^b	410.5 ^c	0.148 ^b	12.6 ^a	0.002 ^b	391 ^c	0.010 ^b	307.5 ^c	0.041 ^b
Mental health	2.728 ^a	0.435 ^b	181.5 ^c	0.217 ^b	189.5 ^c	0.277 ^b	447.5 ^c	0.623 ^b	3.645 ^a	0.162 ^b	372.5 ^c	0.067 ^b	2.10 ^a	0.349 ^b	431 ^c	0.058 ^b	340.5 ^c	0.155 ^b
Vitality	1.544 ^a	0.672 ^b	111.5 ^c	0.011 ^b	146 ^c	0.058 ^b	395.5 ^c	0.237 ^b	4.428 ^a	0.109 ^b	288 ^c	0.003 ^b	3.28 ^a	0.194 ^b	298.5 ^c	0.000 ^b	421 ^c	0.768 ^b
Bodily pain	1.341 ^a	0.719 ^b	71 ^c	0.001 ^b	137.5 ^c	0.039 ^b	412.5 ^c	0.336 ^b	2.011 ^a	0.366 ^b	265 ^c	0.001 ^b	2.75 ^a	0.253 ^b	338 ^c	0.002 ^b	315.5 ^c	0.075 ^b
General health perception	2.012 ^a	0.570 ^b	164.5 ^c	0.121 ^b	171 ^c	0.153 ^b	329 ^c	0.039 ^b	2.407 ^a	0.300 ^b	310.5 ^c	0.009 ^b	2.96 ^a	0.228 ^b	250 ^c	0.000 ^b	386 ^c	0.433 ^b

^aKruskall - Wallis H ^bp value ^cMann - Whitney U

years and determined that that QoL was reduced markedly after operation and adaptation process started after third month and starting from 12th month patients were adjusted to their new way of life, approaching their preoperative levels of QoL.⁴

Loss of voice developing after total laryngectomy is the most important and leading problem with larynx cancer operations.^{8,16,17} Some patients refuse operation with the fear of losing speech function as being unable to talk leads to many losses in personal, social or economic aspects.⁹ Voice rehabilitation after total laryngectomy enables these patients to regain their speech skill and to communicate hence, coping with their psycho-social problems.¹⁶ Esophageal speech is swallowing of air and keeping this air at the superior side of esophagus and enunciating words using this air. A voice of much higher quality than other methods can be obtained through this training.⁹ In the study conducted by Makitie et al, it has been reported that speech rehabilitation enhances the QoL for the patient.²¹ More than half of the patients included in the study stated that after tracheostomy their sense of smell decreases or completely disappeared (Table-I). Following total laryngectomy, hyposmia and anosmia may develop in the majority of patients. Similarly, Tas et al reported that individuals undergoing total laryngectomy experience a large rate of smelling disorders after operation⁸, and Hanna et al established that in patients that underwent total laryngectomy, changes in smelling and taste sense have a adverse impact on QoL.¹⁹ The fact that patients are disturbed with their physical appearance, that they do not like themselves and feel ashamed are signs of the changes caused by tracheostomy in body image. This perception of a change in physical appearance may lead to emotional and psychological problems in patients.

CONCLUSION

It has been established in the present study that patients who live with tracheostomy experience problems in respiration, nutrition and communication. Moreover they undergo

changes in sense of smell and perceptions of physical appearance and had various complications and psychological problems. Their economic status was also influenced adversely. These problems experienced by individuals with tracheostomy influenced QoL at different dimensions. Specialized counseling of these patients by a dedicated team may improve QoL significantly.

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