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Original Research Article

Evaluate the impact of quality of life on self image and well being of the tracheostomised patients

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Abstract

Background and Objective: The aim of this study was to evaluate the quality of life in patients with tracheostomy. We will also discuss the relationship between quality of life and patient demographics. The performing of tracheostomy causes alterations in the lifestyle of the individual in physiological, psychological and social aspects. **Methodology:** All the patients, who have had tracheostomy operations between 2017-2019 at a Katuri Medical College &Hospital, constitute the population of the study (70 patients). The data have been collected between October-November 2017 by using Satisfaction with Life Scale Karnofsky Performance Scale were used in the study to assess the quality of life of non ventilated tracheostomy patients. Mean ± standard deviations are given in the results and tables. Kruskall-Wallis H test were used for the statistical analysis. **Results**: In this study there is a significant improvement in the quality of life of the patient when compared to the initial and final assessment of the questionnaire. In this study at the time of first assessment, all the patients (i.e. 52) tracheostomy care was done by nursing staff or by the family members. At the final assessment 42.3% (22 patients) of patients were performing tracheostomy care by them self. In this study at the time of first assessment, 42.3% (22 patients) had no sense of smell and 57.6% (30 patients) had decreased sense of smell and at final assessment, 59.61% (31 patients) had sense of smell, whereas, 40.3% (21 patients) had still decreased sense of smell. In this study at the time of initial assessment, regarding change in physical appearance, 100% (52 patients) had expressed, not liking one's own physical appearance and at the final assessment, 100% (52 patients) are continued to be disturbed from their own physical appearance. In this study regarding feeding, at the time of initial assessment, 42.3% (22 patients) had difficulty in feeding and 57.6% (30 patients) had overcome the initial feeding difficulty i.e. all the patients had initial feeding difficulties. At later stage, 59.61% (31 patients) had no difficulties in feeding, and 40.3% (21 patients) had overcome the initial feeding difficulty at the time of final assessment. 100% (52 patients) experienced problems in respiration initially; significantly it is improved at the final assessment. All patients i.e. 100% (52 patients) had breathing difficulty only in lying down position. At the time of final assessment all patient i.e. 100% are relieved of the swallowing problems. 19.2% had granulation around the stoma and 80.7% had mild cough on and off. **Conclusion**: These findings confirm that tracheostomy has a profoundly negative impact on QOL. Specialized counseling of these patients by a dedicated team may improve QOL significantly.

Keywords: Karnofsky Performance Scale, Quality of life, Tracheostomy, Granulation, Breathing, Swallowing

Introduction

Long-term home mechanical ventilation (HMV) is an increasingly used treatment option for patients with chronic respiratory failure [1, 2]. For this purpose, HMV can be performed either invasively following tracheotomy, or noninvasively using face masks, the latter being the preferred mode [1]. Invasive HMV is only chosen in cases where noninvasive HMV is no longer feasible or sufficient [3]. Here, particularly in patients with neuromuscular disorders (NMDs), invasive HMV should only be electively established after detailed fully informed consent is given for the procedures involved and their potential consequences [3]. In addition, intubation of ICU patients suffering from acute respiratory failure is often accompanied by tracheotomy if mechanical ventilation (MV) has to be applied for a longer period, or if there are foreseeable difficulties with weaning [4]. Even though many patients can eventually be liberated from invasive MV once the acute respiratory failure has been successfully treated, some still require prolonged weaning [4]. In the event that this fails, invasive HMV must once again be implemented [5].Such patients do not usually have the opportunity during stable phases of their disease to decide whether or not they wish to become tracheotomized. While there is increasing evidence that outcome and health-related quality of life (HRQL) are improved in many patients receiving noninvasive HMV [2, 6] the impact of invasive HMV remains especially unclear in patients receiving invasive HMV after an unsuccessful attempt at weaning

- 20+ million members

The present study therefore aimed to assess life satisfaction and patients' perspectives on life and death associated with invasive HMV following unsuccessful weaning in patients with intubation and subsequent tracheostomy that have become necessary to treat acute-on-chronic respiratory failure by carrying out detailed assessments of the specific living conditions experienced by patients in their respective home environments.

- 35+ million publications+ research pr

Study design

- Prospective cohort study.
- Setting: tertiary referral centre.

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- Study period: October 2017- October 2019.
- Fifty (50) tracheostomised patients who are not ventilator dependent.

Inclusion Criteria

- Patients undergoing elective tracheostomy at this institute.
- Not dependent on any form of assisted ventilation.
- Chronically ill but not requiring urgent or active management for the coexisting disease condition.

Exclusion criteria

- Patients undergoing emergency tracheostomy.
- Patients undergoing tracheostomy elsewhere.
- Patients with primary laryngotracheal complex disease.
- Tracheostomised patient dependent on assisted ventilation.
- The patients selected as per the inclusion criteria formulated were enrolled into the study after obtaining consent (annexure I).Their quality of life is assessed using three international standardized index scales.

Satisfaction with Life Scale,

Karnofsky Performance Scale and living with tracheostomy index scale were used in the study to assess the quality of life of non ventilated tracheostomy patients.

- Patients were administered with a questionnaire once they were able to phonate and were able to communicate with a fenestrated double lumen tube. This was the first day of study.
- Again the patient is assessed on 3rd month / day before Decannulation
- Scoring is given to each and every scale and quality of life is assessed accordingly.

Satisfaction with life scale

The satisfaction with life was developed to assess satisfaction with respondent's life as a whole. The scale does not assess the satisfaction with life domain as health or finances, but allow subject to integrate and weigh these domains in whatever way they choose. Satisfaction with life scale is recommended as a complement to scales that focus on psychological or emotional well being because it assesses an individual's conscious evaluative judgment of his or her life by using the persons own criteria.

This scale is comprised of five questions and each one has seven variables as answers.

- The patients are asked to choose an answer to all the questions.
- Each answer is given a scoring from one to seven. Final score of each patient varies from minimum of five to maximum of thirty five.
- In this scale the patient with low scoring represents the poor quality of life and vice versa.

Satisfaction with life scale [7]

Below are five statements with which you may agree or disagree. Using the 1-7 scale below, indicate your agreement with each item by placing the appropriate number on the line preceding that item. Please be open and be honest in your responding. The 7-point scale is as follows:

1 = strongly disagree
2 = disagree
3 = slightly disagree
4 = neither agree nor disagree
5 = slightly agree
6 = agree
7 = strongly agree

1. In most ways my life is close to my ideal
2. The conditions of my life are excellent.
3. I am satisfied with my life.
4. So far I have gotten the important things I want in life.
5. If I could live my life over, I would change almost nothing.

General Functional Limitations Were Assesse D Using The Karnofsky Performance Scale [8, 9].

This scale index allows patients to be classified as to their functional impairment. This can be used to compare effectiveness of different therapies and to assess the prognosis in individual patients. The lower the Karnofsky score, the worse the survival for most serious illnesses.

- The patient or the attender is asked to choose patient physical status from the options given in the index scale, at that stage of life.
- OVERALL CONDITION "What is your estimate of your overall condition right now, on a scale of zero to hundred. Patient or the attender is asked to choose one variable which suites his physical status at that stage of life
- The index scale has ten variables which are representing the physical status of the individual with a scoring from zero to ten.
- Final score of each patient varies from minimum of zero to maximum of ten.
- In this scale, the patients with high scoring represent good quality of life and vice versa.

Results

Analysis of the various designed Quality of life indicator scales were used in this study which are showing the following results.

In this study, three standardized questionnaire scales were used to assess the quality of life index.

Statistical analysis

- Mean and standard deviation were estimated for all the three functional, psychological and social domains.
- Pared sample T-test was applied to find the level of significance.
- In this study $p<0.05$ was considered as the level of significance.

Table 1: Age Distribution

	N	Minimum	Maximum	Mean	Std Deviation
Age	52	12	12	42.19	15.593
Valid N (list wise)	52	-	-	-	-

Most of the patients fall in the age group of 41-50 yrs.

Table 2: Distribution of Patients According to Sex

	Frequency	Percent	Valid percent	Cumulative per cent
Male	37	71.2	71.2	71.2
Female	15	28.8	28.8	
Total	52	100.0	100.0	100.0

In this study thirty seven patients were male and fifteenpatients were female.

Number of day's patients with tracheostomy

As already told above that Patients were administered with a questionnaire once they were able to phonate and were able to communicate with a fenestrated double lumen tube. This was the first day of study and again the patient is assessed on 3rd month / day before Decannulation

Table 3: Distribution of the number of patients with number of days of tracheostomy

No. of Days	No. of Patients
1-10 Days	1
11-20 Days	1
21-30 Days	5
31-40 Days	8
41-50 Days	4
51-60 Days	4
61-70 Days	5
71-80 Days	8
81-90 Days	16

Table 4: Diagnosis of tracheostomy patients

Indications	No. of Patients	Percentage
Polytrauma	19	36.53
Renal Failure	5	9.61
OPC Poisoning	3	5.76
Coronary Artery Disease	3	5.76
Bilateral Abductor Palsy	3	5.76
Seizures Disorder	2	3.84
Subglottic Stenosis	2	3.84
Right MCA BifurcationAneurysm	2	3.84
Septic Shock	2	3.84
Type I Respiratory Failure	2	3.84
Acute Pulmonary Thromboembolism	1	1.92
Bilateral Bronchopneumonia	1	1.92
Bronchial Asthma With Systemic Hypertension	1	1.92
Dengue fever with type 2 diabetes mellitus	1	1.92
Left MCA Infract	1	1.92
Soft Tissue Injury Neck	1	1.92
Viral Encephalitis	1	1.92

Quality of life index 1

Satisfaction with life scale

Patients were asked to choose answers to all five questions which are related to the patient's socio psychological status. Each question has seven variables of answers and has scoring from one to seven depending on the question.A patient with low scoring indicates the poor quality of life and vice versa.In this study, mean initial and final values are 6.67 and 8.17, indicating very poor quality of life at start of study and with significant increase in quality of life at final administration of questionnaire with highly significant P value of 0.000

Table 5: Satisfaction with life scale

	Mean	N	Std Deviation	Std Error Mean
SF-Intial	6.67	52	1.568	217
SF- Final	8.17	52	2.017	280

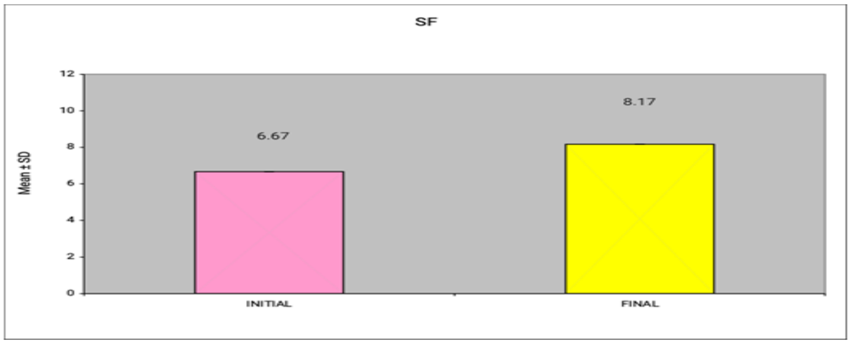


Fig1: Showing initial and final scores of patientsfrom satisfaction with life index scale.

Quality of life index 2

Karnofsky performance scale

The patient's attended or patient himself is asked to choose patient physical status from the options given in the index scale. The scale has 10 variables which are representing the physical status of the individual.

The patient with higher scoring indicates the better quality of life and vice versa.

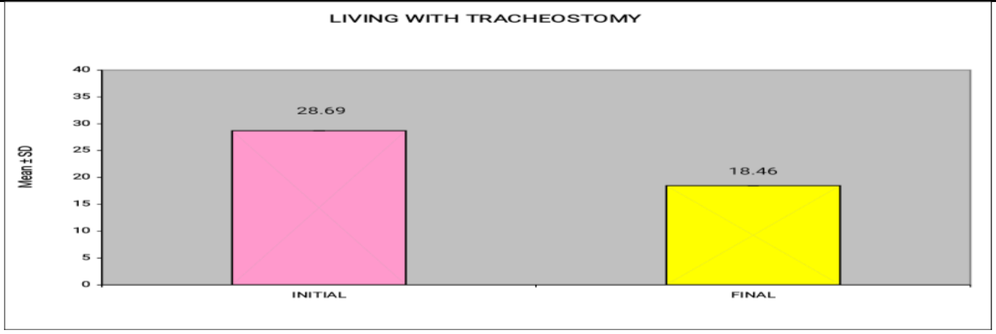
In this study mean initial and final values are 5.94 and 7.56 respectively and indicating very poor quality of life at start of study with highly significant increase in quality of life at final administration of questionnaire significant P value of 0.000

In this scale, at initial administration of questionnaire, all patients expect one (i.e. patient 6) had fallen under category of "unable to work, able to live and care for most personal needs, varying amount of assistance needed".

At final administration of questionnaire, more than 50% of the patients i.e. (27 patients) fall under category of "able to carry on normal activity and to work, no special care needed" showing a significant improvement of quality of life while comparing with values of initial administration.

Table 6: Karnofsky performance scalePaired Samples Statistics

		Mean	N	Std. Deviation	Std. ErrorMean
Pair 1	KARNOFSKY - INITIAL	5.94	52	.873	.121
	KARNOFSKY - FINAL	7.56	52	.777	.108



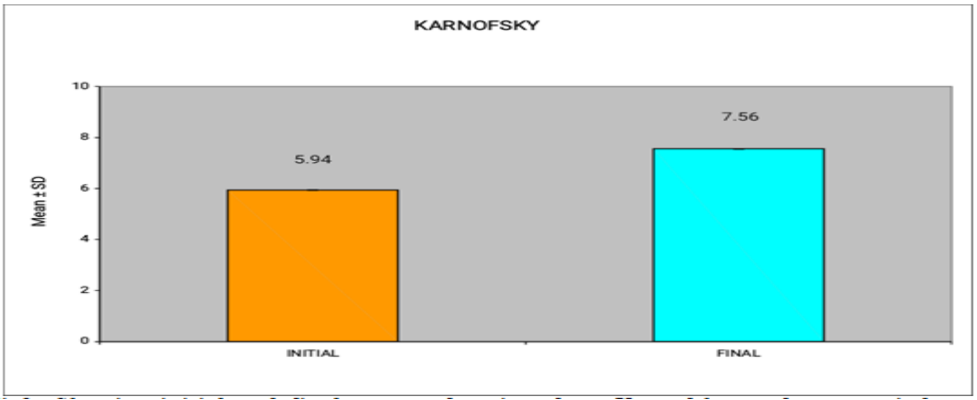


Fig2: Showing initial and final scores of patientsfrom Karnofsky performance index scale.

Quality of life index 3

Living with Tracheostomy

This scale represents with questions corresponding to the functional, psychological and social aspects of the patients. This scale is composed of 11 questions with three answers to each one.

In this scale, a patient with higher scoring indicates the poor quality of life and vice versa.

In this study mean initial and final values are 28.69 and 18.46 respectively which indicate very poor quality of life initially and with high significant increase in quality of life at final administration of questionnaire with significant P value of 0.000

Table 7: Living with Tracheostomy

Paired Samples Statistics

		Mean	N	Std. Deviation	Std. ErrorMean
Pair 1	LIVING WITH TRACHEOSTOMY -INITIAL	28.69	52	2.005	.278
	LIVING WITH TRACHEOSTOMY -FINAL	18.46	52	1.448	.201

Fig3: Showing initial and final scores of patientsfrom Living with Tracheostomy index scale.

Table 8: Mean Value and P Value of Patients

	Initial	Final	P value
Satisfaction with life	6.67	8.17	0.000
Karnofsky performancescale	5.94	7.56	0.000
Living with Tracheostomy	28.69	18.46	0.000

Discussion

It has been established in the present study that the most basic needs of the patients such as respiration, nutrition, and communication etc are influenced by tracheostomy.

Moreover, patients are confronted with changes in physical appearance involved with body image, social, psychological problems and various complications.

Gilony D et al reported in a study that, reduced scores after tracheostomy indicated an overall diminished quality of life and changes correlated with personality traits. Decannulated patients exhibited slight improvement indicating an incomplete psychosocial recovery [10].

In this study there is a significant improvement in the quality of life of the patient when compared to the initial and final assessment of the questionnaire.

In this study Quality of Life (QoL) scores were found to be significantly lower in initial days in the patients living with tracheostomy. After three months scores improved significantly showing improved QOL.

Nur Dilek et al reported in a study that patients, who can perform their tracheostomy care independently, were having higher QoL scale and on the other part more than half of the patients stated that after tracheostomy their sense of smell decreases or completely disappeared [11].

In this study at the time of first assessment, all the patients (i.e. 52) tracheostomy care was done by nursing staff or by the family members. At the final assessment 42.3% (22 patients) of patients were performing tracheostomy care by them self.

In this study at the time of first assessment, 42.3% (22 patients) had no sense of smell and 57.6% (30 patients) had decreased sense of smell and at final assessment, 59.61% (31 patients) had sense of smell, whereas, 40.3% (21 patients) had still decreased sense of smell.

It has been determined that the scores of patients who can perform their tracheostomy care independently, have no complications, and state that their physical appearance has not been affected are having better QoL. 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.

In this study at the time of initial assessment, regarding change in physical appearance, 100% (52 patients) had expressed, not liking one’s own physical appearance and at the final assessment, 100% (52 patients) are continued to be disturbed from their own physical appearance.

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.

Reza Shaker et al reported in a study, though the vocal cords close completely during swallowing in patients with tracheostomy, their duration of closure is significantly shorter compared with normal volunteers. Coordination of deglutitive vocal cord kinetics, apnea, and submental electromyography was altered in patients with tracheostomy [12].In this study regarding feeding, at the time of initial assessment, 42.3% (22 patients) had difficulty in feeding and 57.6% (30 patients) had overcome the initial feeding difficulty i.e. all the patients had initial feeding difficulties. At later stage, 59.61% (31 patients) had no difficulties in feeding, and 40.3% (21 patients) had overcome the initial feeding difficulty at the time of final assessment.

Patients experienced economic problems such as decrease in work power, cost of treatment, leaving job, obligatory retirement, working in a passive position, it has been established that in patients experiencing these problems, QoL is influenced adversely.

At the time of intial assessment, 100% (52 patients) expressed adverse effect on the economy status. At the time of final assessment, 96.1% (50 patients) expressed advese effect on the economy status and 3.8 % (2 patients) expressed that is bearable.

Dean R Hess et al reported in a study, Facilitating Speech in the Patient with a Tracheostomy that the ability to speak is an important aspect of the quality of life for patients with a tracheostomy. A variety of techniques to achieve this are available for either mechanically ventilated or spontaneously breathing patients. Teamwork between the patient and the patient care team (respiratory therapist, speech-language pathologist, nurse, and physician) can result in restoration of speech in many patients with long- term tracheostomies [13].

In this study the mode of communication, of all patients at the time of both initial and final assessment is by closing inner tube of a fenestrated tube (all 52 patients were on sheiley Tracheostomy tube).

Cihakova I et al reported in a study that, significant changes after tracheostomy were encountered in the evaluation of satisfaction with individual life themes [14].

Tracheostomy therefore certainly deteriorates the quality of life of the patients but not to such extent that the life would become unbearable. Moreover, the results indicate that men tolerate the presence or sequel of tracheostomy somewhat better than women, quite possibly due to the unpleasant cosmetic consequences of tracheostomy for women.

There was also a decrease in satisfaction with the spiritual and intellectual life, hobbies, job, and family [14].

In this study patients had problems in respiration, breathing difficulty due to sputum obstruction. They also had depression and had lost hope of recovery with social effect.

100% (52 patients) experienced problems in respiration initially; significantly it is improved at the final assessment. All patients i.e. 100% (52 patients) had breathing difficulty only in lying down position.

100% (52 patients) experienced difficulty in breathing initially, due to obstruction of sputum; significantly the same is improved at the final assessment. The entire patients i.e. 100% (52 patients) had Shortness of breath on and off.

All patients had complications due to tracheostomy, 36.5% (19 patients) had developed difficulty in swallowing, 40.3% (21 patients) had granulation around the stoma, and 23% (12 patients) had cough at the initial assessment of study. At the time of final assessment all patient i.e. 100% are relieved of the swallowing problems. 19.2% had granulation around the stoma and 80.7% had mild cough on and off.

Kaya et al established that in patients, QoL decreased in the first months after treatment and started to increase from second month on, continuing to increase until 12th month [15].

Conclusion

All tracheostomy patients had poor quality of life with compromise on respiration, nutrition, and communication. Problems experienced by individuals with tracheostomy, influenced quality of life in different dimensions. The score for satisfaction of life index improved over the period of time as evidenced by the score at the initial and final assessment which was statistically significant. Tracheostomy influence changes in physical appearance involved with body image, social, psychological problems and various complications. There is a significant improvement of performance in patientsat the finalassessment compared to the initial assessment, 51.5%of patients were able to take care of themselves without help.

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