

Psychosocial Impact and Quality of Life in Tracheostomised Patients and their Primary Care Givers in a Tertiary Care Centre

¹Sreelekshmy S, ²Kouser Mohammadi, ³S M Azeem Mohiyuddin, ⁴Gurappa P Gururaj, ⁵Mohammed K chisty, ⁶Mohan Reddy Matti; ⁷Keerthika Shivaji

¹MS Postgraduate; ²Associate Professor, Otorhinolaryngology and Head and Neck surgeon; ³Professor and Head, Otorhinolaryngology and Head and Neck surgery; ⁴Professor, Psychiatry; ⁵Associate Professor Psychiatry; ⁶Professor and Head, Psychiatry; ⁷Final year MBBS student

Corresponding Author: **Dr Kouser Mohammadi**

Abstract

Background : Airway is the prime priority in basic life support. Tracheostomy is one of the most common procedures done to secure airway, prevent aspiration and provide ventilator support in critically ill patients. The tracheostomised patients suffer from psychosocial problems like fear, anxiety, stress, frustration and communication difficulties. Its impact on patients and their care givers is under reported. This study offers insight into these psychosocial issues in an Indian context, which may contribute to develop strategies to enhance the quality of life in tracheostomised patients. It aims to provide support to alleviate social isolation, reduce stigma, and improve compliance with ongoing treatment. **Methodology :** This observational study was conducted in all tracheostomised patients and their primary care. All tracheostomised patients and their primary caregivers were recruited in the study were followed up for 3 months. Patients were interviewed thrice during follow-up period- on postoperative day (POD)-30, POD-60 and POD-90. Psychosocial status and Quality Of Life (QOL) in patients was assessed by using Perceived Stress Scale (PSS) and World Health organization Quality of life-BREF(WHOQOL-BREF) version Questionnaire. Assessment of stress in caregivers was done by using Kingston Care Giver stress scale (KCGSS). **Results:** The majority of the patients in our study were males (52) compared to females (34). Whereas most caregivers were females (56). Elective tracheostomy was performed in 68 cases, while 18 required emergency tracheostomy. At 30 days postsurgery, 75.59% patients experienced high stress, which decreased to 62.8% at 60 days and further declined to 25.59% at 90 days. This indicates that, as the postoperative period progressed from 30 to 90 days, the proportion of patients with high stress declined. The median scores across all domains-physical, psychological, social, and environmental health-increased over time, with the results being statistically significant ($p < 0.001$). Tube related issues included LRTI(12.7%), tube blockage(11.6%) excessive secretions (15.2 %)accidental decannulation (11.6 %), bleeding from stomal granulations (23.2%) and dysphagia(5.8%). Anger (33.2%), frustration (12.5%), and sleep deprivation (43.2%) were more commonly observed in the first month post-tracheostomy. 4.6% were not socialising to avoid embarrassment and social stigma. Majority of the caregivers were spouses (86.4%) and most of them were females 65.1%. and non-earning members of the family and 45.3% had financial issues. 28% of the caregivers had additional responsibility of contribution to the economy. **Conclusion :** Our study shows tracheostomy greatly impacts patients' and caregivers' quality of life, particularly in rural, illiterate populations. Emergency procedures increase stress due to insufficient preoperative counselling. Stress decreases over time with improved coping. Comprehensive support, including preoperative counselling and caregiver training, is essential to mitigate these effects.

Keywords: Tracheostomy, Caregivers, Psychosocial impact, Quality of life, Stress, Anxiety, Domains, Tube block, counselling, Accidental decannulation.

Introduction

Tracheostomy is one of the most common procedures done to secure airway when it is compromised, prevent aspiration and provide ventilator support in critically ill patients. ⁽¹⁾ It may be done as an elective or emergency procedure and is often lifesaving. ⁽²⁾ However, counseling patients to undergo the procedure and post-operative management are major challenges. Tracheostomy requires life style modifications as it may impair daily activities and cause difficulty in communication. Avoidance of communication and social self-isolation develop due to fear of rejection and humiliation. In patients receiving home care, the maintenance and care of a tracheostomy tube add to the fear and sense of burden not only to the patient but also to the caregivers. ^(3,4,5) Daily tracheostomy care and tube changes carry the risk of bleeding from granulations, with the potential for aspiration, which often leads to panic and anxiety during suctioning and tube re-insertion.

If the caregiver is the family's primary breadwinner, they may become overburdened by the added responsibility of managing tracheostomy care. This can adversely affect their social and personal life, leading to psychosocial issues. While studies have explored the psychosocial impact on tracheostomized patients, the psychosocial well-being of caregivers is often overlooked.

Self-isolation on part on tracheostomized patients is due to difficulty in communication and secretions which leads to consciously avoid social interactions. The psychosocial issues related to tracheostomy can include stress, anxiety, frustration, depression, helplessness, communication difficulties, and social stigma. These problems can lead to decreased socialization not only for patients but also for their caregivers. Patients who have undergone tracheostomy and their caregivers experience a lot of psychosocial problems and feel unsupported and isolated. ⁽⁶⁾ Currently, studies on the psychosocial impact and quality of life in tracheostomized patients are available, but limited literature exists on these aspects in caregivers. This study aims to offer insight into the psychosocial dimensions within the Indian context, contributing to the development of strategies to enhance the quality of life in tracheostomized patients. It seeks to provide support through social groups to alleviate social isolation, reduce stigma, and improve compliance with ongoing treatment.

Objectives

1. To assess the psychological and social effects of tracheostomy on patients and their primary care givers.
2. To assess the quality-of-life following tracheostomy in patients and their primary care givers.

Inclusion Criteria

All the patients who underwent tracheostomy for various reasons like airway compromise, tracheobronchial toilet in Chronic lung conditions, to provide positive pressure ventilation and prolonged mechanical ventilation, etc. at a tertiary care center.

Exclusion Criteria

- Patients tracheostomised for more than 3 months
- Patients with severe head injury
- Patients with neurological deficits
- Comatose patients.
- Tracheostomised patients with a pre-existing psychiatric illness /decreased mental abilities.

Methodology for Data Collection

This observational study was conducted in all tracheostomised patients and their primary care givers, satisfying the inclusion criteria and screened for exclusion criteria during the study period from January 2023 to December 2023. Institutional Ethics committee clearance (SDUMC/KLR/IEC/454), for study was obtained. An Informed written consent from the patients and primary care givers included in the study was obtained. All tracheostomised patients and their primary caregivers in our center who were on regular follow-up for a minimum period of 3 months were recruited in the study. All patients included in this study were followed up for 3 months. Patients were interviewed thrice during follow-up period- on postoperative day (POD)-30, POD-60 and POD-90. Psychosocial status and Quality Of Life (QOL) in patients was assessed by using Perceived Stress Scale (PSS) and World Health organization Quality of life-BREF (WHOQOL-BREF) version Questionnaire. Assessment of stress in caregivers was done by using Kingston Care Giver stress scale (KCGSS).

Analysis & Statistical Methods:

Data analysis included documentation of age, gender, preoperative diagnosis, indications for tracheostomy, predisposing factors (addictions), presence of any co-morbidities, sleep disturbances, swallowing problems, psychological stress like anxiety, depression and effect on social and personal life.

Statistical analysis performed using IBM SPSS version 20.0 software. Categorical variables were expressed as frequency and percentage. Continuous variables were presented by mean \pm Sd or median (Q₁-Q₃). Friedman test was used to analyse the statistical significance of the changes of different domains of QOL at three different follow-up periods (POD-30, POD-60 and POD-90).

Results

Table 1: Distribution of demographic details and tracheostomy tube related issues

<u>Parameters</u>	<u>N (n=86)</u>	<u>%</u>
<u>Gender</u>		
Male	52	60.5
Female	34	39.5

<u>Age</u>		
20-40	15	17.4
41-60	59	68.6
>60	12	13.9
<u>Type of surgery</u>		
Elective	68	79.1
Emergency	18	20.9
<u>Tube related issues</u>		
Lower Respiratory Tract infections (LRTI)	11	12.7
Excessive secretions	13	15.2
Difficulty in swallowing	5	5.8
Difficulty in communication	15	17.4
Bleeding from granulations	20	23.2
Tube block	10	11.6
Accidental decannulation	10	11.6

The majority of the patients in our study were males (52) compared to females(34). Whereas most caregivers were females (56). Of the 86 patients, 68.6% were in the age group of 41 to 60 years, 17.4% in 20 to 40 years age group, and 14% were aged above 60 years. Elective tracheostomy was performed in 68 cases, while 18 required emergency tracheostomy. At POD30,72.1% of patients undergoing elective tracheostomy reported experiencing high stress in contrast to 88.9% of those who underwent the procedure in an emergency context which lasted for 10 to 15 days till the adaptive and coping mechanism got established. The descriptive statistics for each domain of Quality of life is shown in Table 2.

Table 2:Overall Assessment of quality of life in patients using WHOQOL-BREF questionnaire (n=86)

Domain	POD	Mean	Standard Deviation	Median (Q1-Q3)	p value
D-1	30	20.4	11.4	17.9 (10.7-25.0)	<0.001
	60	26.9	18.0	21.4 (14.3-32.1)	
	90	41.6	25.9	32.1 (20.5-61.6)	
D-2	30	20.2	18.4	16.7 (4.2-33.3)	<0.001
	60	22.6	20.3	16.7 (4.2-34.4)	

	90	31.8	25.5	31.3 (8.3-50.0)	
D-3	30	21.5	16.0	16.7 (8.3-33.3)	<0.001
	60	26.6	20.2	25 (14.6-33.3)	
	90	35.9	25.8	29.2 (16.7-58.3)	
D-4	30	25.4	18.6	21.9 (15.6-38.3)	<0.001
	60	28.3	20.5	25 (15.6-40.6)	
	90	37.2	27.0	34.4 (18.8-57.0)	

D1- Physical health domain

D2-Psychological health domain

D3-Social relationship domain

D4-Environmental health domain

Domain 1: Physical Health

The median (Q₁-Q₃) score of the Physical Health domain was 17.9 (10.7-25.0) at 30 days, 21.4 (14.3-32.1) at 60 days, and 32.1 (20.5-61.6) at 90 days with p value<0.001.

Domain 2: Psychological Health

The median (Q₁-Q₃) score of the Psychological Health domain was 16.7 (4.2-33.3) at 30 days, 16.7 (4.2-34.4) at 60 days, and 31.3 (8.3-50.0) at 90 days.

Domain 3: Social Health

The median (Q₁-Q₃) score for the Social Relationships domain was 16.7 (8.3-33.3) at 30 days, 25.0 (14.6-33.3) at 60 days, and 29.2 (16.7-58.3) at 90 days.

Domain 4: Environmental Health

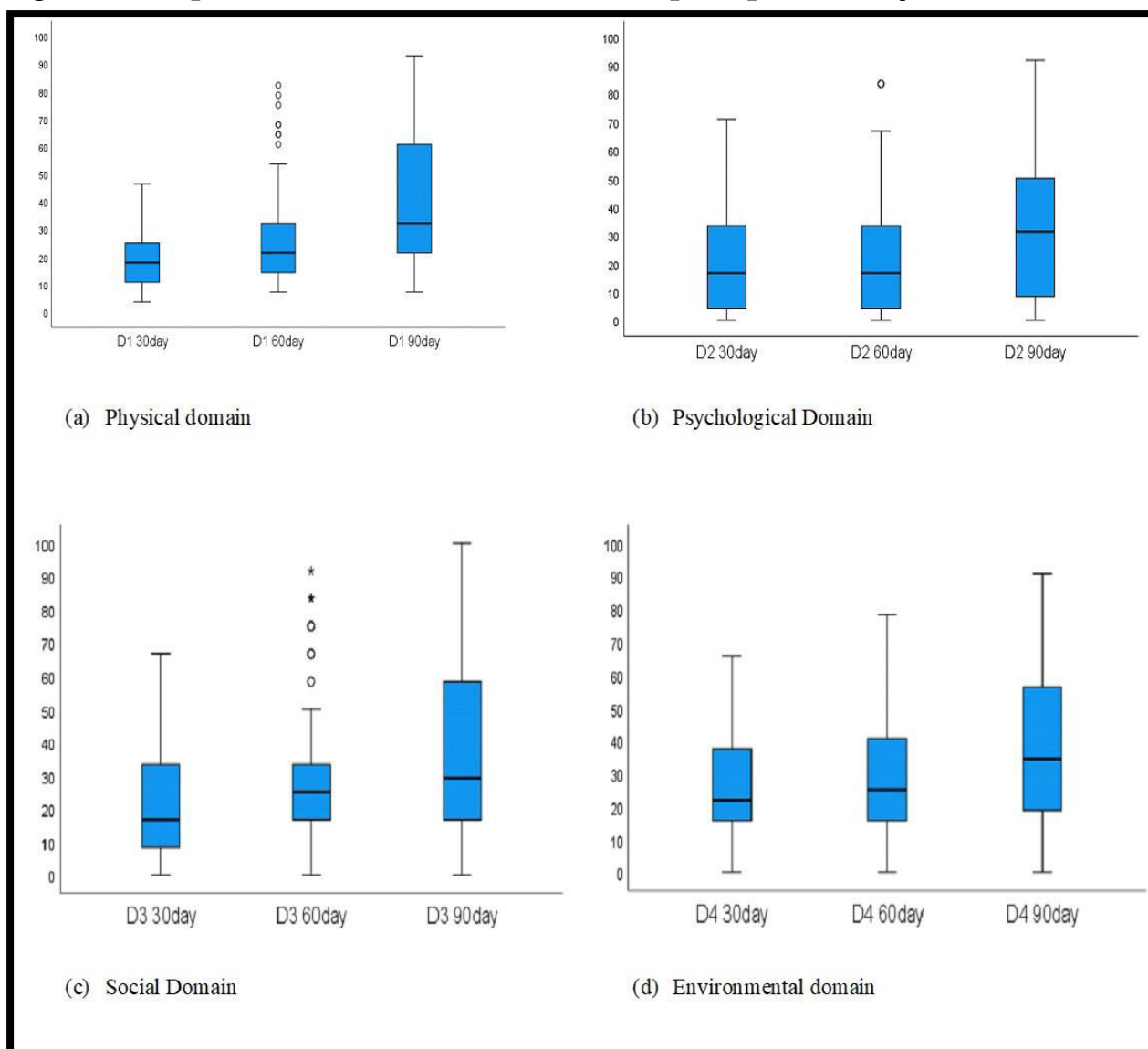
Environmental Health domain, the median (Q₁-Q₃) score was 21.9 (15.6-38.3) at 30 days, 25.0 (15.6-40.6) at 60 days, and 34.4 (18.8-57.0) at 90 days.

The median scores across all domains—physical, psychological, social, and environmental health—increased over time, with the results being statistically significant ($p < 0.001$).

Out of 86 patients, in our study 12.7 % of the patients developed LRTI, 10.4% of patients receiving home care and 1.2% under institutional care experienced tube blockage. 15.2% with increased secretions required frequent suctioning. 4.6 % were not socialising to avoid embarrassment and social stigma as well as need for management of excessive secretions in public. Accidental decannulation was noted in 11.6 %, bleeding from stomal granulations during tube change was seen in 23.2% of our patients. Dysphagia was reported in 5.8% of patients with a cuffed tracheostomy tube and disturbed sleep in 18.7% of patients. Anger (33.2%), frustration (12.5%), and sleep deprivation (43.2%) were more commonly observed in the first month post-tracheostomy. Depression (66.7%) was more prevalent in the second- and third-months post-tracheostomy. We observed that 50-60% of our patients had very poor social interactions. Out of 86 patients 12 patients were professionals, 15 unemployed, 10 self-employed, 49 manual labourers. Majority(58%) of our patients were

daily wage earners and loss of job and employment opportunities were reported in 73% of patients, however 17% were working with tracheostomy tube after POD 60.

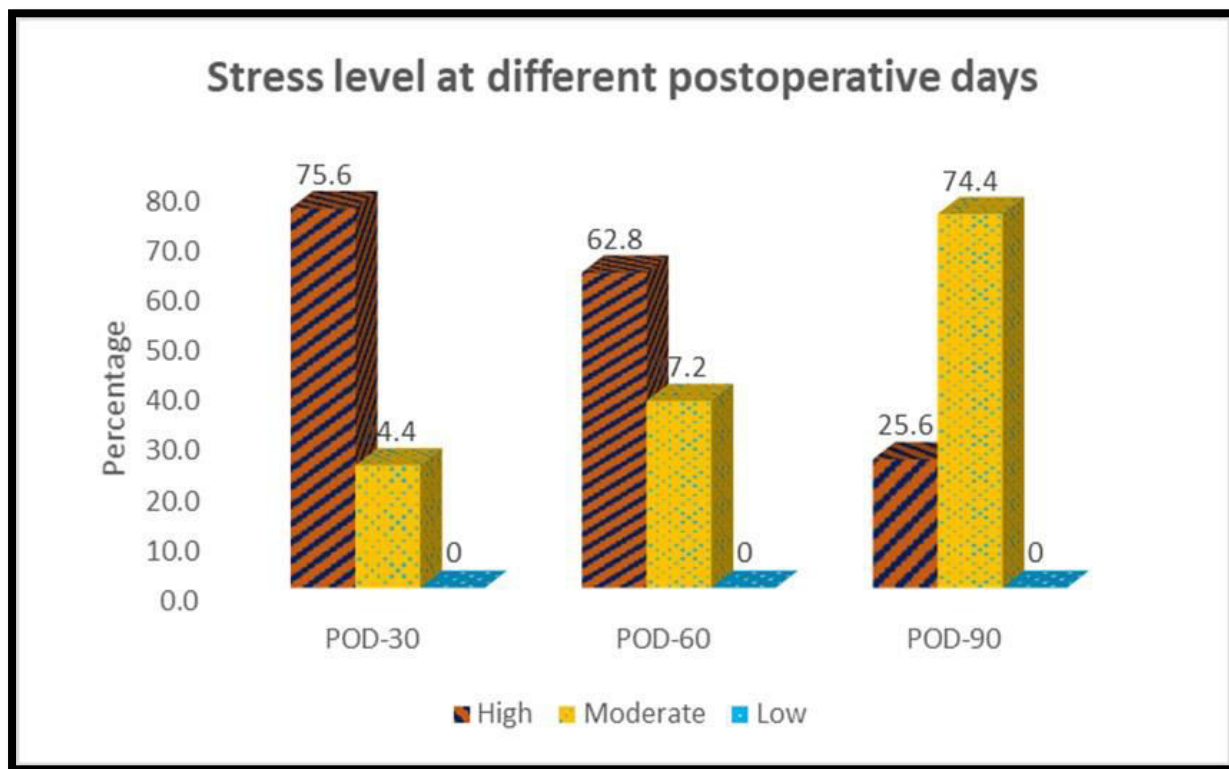
Figure 1: Comparison of all Domains at different postoperative days



Perceived stress scale in patients

At 30 days post-surgery, 75.59% patients experienced high stress, which decreased to 62.8% at 60 days and further declined to 25.59% at 90 days. This indicates that, as the postoperative period progressed from 30 to 90 days, the proportion of patients with high stress declined. However, some level of stress persisted throughout, with a de-escalation from high stress to moderate stress over time as depicted in Figure (2).

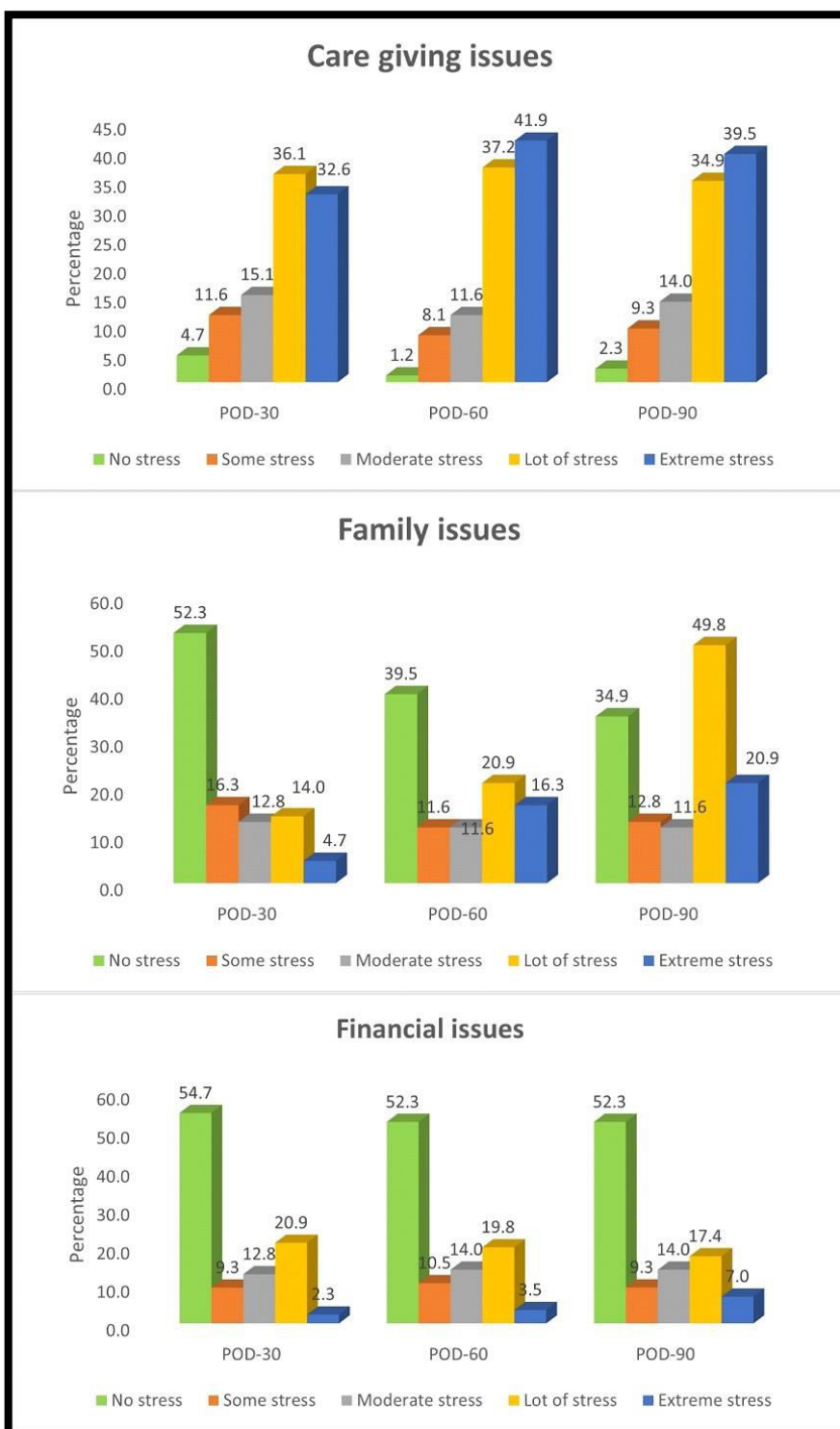
Figure (2): Perceived stress scale in patients



Kingston care giver stress scale

The proportion of caregivers experiencing extreme stress due to caregiving responsibilities, family, and financial issues showed an increasing trend from postoperative day 30 to day 90 as illustrated in Figure (3).

Figure (3): Distribution of variables of Kingston Caregiver Stress Scale at different points of time.



In our study majority of the caregivers were spouses (86.4%) and most of them were females 65.1%. and non-earning members of the family and 45.3% had financial issues. 28% of the caregivers had additional responsibility of contribution to the economy.32% of caregivers in home care settings felt insecure about tracheostomy tube care,15%of care givers were apprehensive about dislodged or blocked tube. 75% of primary caregivers also reported

restrictions in their daily activities due to extended responsibilities. 19% of caregivers expressed dissatisfaction due to limitations in leisure and recreational activities. 8% reported change in their relationship with the spouse or relatives. Caregiver fatigue and burnout was reported in 23%.

Discussion

Tracheostomy is a lifesaving procedure indicated for airway obstruction and chronic respiratory conditions in critical care settings. ⁽¹⁾ Depending upon the underlying disease, tracheostomy tube dependence can be either temporary or permanent and it carries its own inherent risks and consequences. Literature indicates that complication rates associated with tracheostomy range from 6% to 66%. ^(7,8,9) Patients not only encounter significant tracheostomy tube related problems but also psychosocial challenges. The range of tracheostomy tube-related issues includes susceptibility to lower respiratory tract infections (LRTIs), excessive coughing, difficulty in swallowing, temporary loss of voice, challenges with bathing, bleeding from granulation tissue, risks from mucus plugs and crusts obstructing the tube, and accidental decannulation. These problems compromise the quality of life and also adversely impact the patient's psychosocial well-being. ^(4,10,11)

Conversely, caregivers also endure significant physical and emotional stress. Managing tracheostomized patients is a formidable challenge, necessitating constant vigilance at the patient's bedside. Key responsibilities include regular suctioning of secretions and periodic tube changes, especially for those receiving care at home rather than in a clinical environment. The abrupt change in roles and responsibilities also impacts the financial and psychosocial well-being of both the patient and the caregiver. This study was performed to document the psychosocial impact of tracheostomy on patients requiring tracheostomy for 3 months and their caregivers.

The majority of our patients were males (52) aged 41 to 60 years, with most of them bread winners of the family as well. These findings align with the study conducted by Kumar V. ⁽¹²⁾

In our study, patients undergoing emergency tracheostomy experienced a higher proportion of stress (88.89%) compared to those undergoing elective procedures (72.06%). Increased stress in emergency cases is likely, due to the urgent nature of the procedure and the associated acute circumstances with no adequate time for mental preparation. Research by Hasmi, Barnett, and McCornick et al. has highlighted that targeted stress management strategies—such as comprehensive preoperative counselling, opportunities to meet with tracheostomized patients in advance, and allowing sufficient time for decision-making—can significantly enhance understanding and acceptance of the surgery in an elective setting. ^(3,13,14)

The risk of lower respiratory tract infections is high as tracheostomy bypasses upper airway compromising warming, filtering and humidification of air. The inhaled air directly reaches the lower airway leading to drying of the epithelium thereby contributing for increased

mucous production and reduced ciliary activity in the dry mucosa. Cough reflex is also impaired with pooling of secretions above the tracheostomy tube with risk of aspiration in uncuffed tube.⁽¹⁵⁾ In our study 12.7 % of the patients developed LRTI.

Excessive secretions requiring regular suctioning can be uncomfortable and distressing and its management in public leads to feelings of embarrassment. This results in social withdrawal and isolation. To avoid embarrassment and social stigma patient tries to hide tracheostomy tube by using high collars or scarfs in public places. Gilony et al, reported that patient's identity and self-perception is compromised leading to personality changes and altered self and body image.⁽¹⁶⁾

The tracheostomy tube itself acts as a foreign body, which induces increased mucus production. The increased viscosity of the mucus leads to formation of mucus plugs and crusts, resulting in frequent blockage of the tracheostomy tubes. This led to frustration and dissatisfaction among patients and caregivers. According to Nyanzi et al, the most common complication was tube obstruction (52.6%), whereas McCormick et al. reported mucus plugging only in 18.2% of cases.^(14,17) In our study, 10.4% of patients receiving home care experienced tube blockage, a rate significantly higher than the 1.2% observed in those under institutional care. This discrepancy may be attributed to the superior hospital care and the use of mucolytics. Also, in home care the depth to which the suction catheter is introduced into the tracheostomy tube is an issue as many of the caregivers feel insecure to pass it across the tracheostomy tube due to cough and end up clearing only the upper part of the tube. This can be overcome by, education and training of family caregivers to recognize issues related to a dislodged or blocked tube.^(3,8,10,14,15)

A tracheostomy tube particularly with a cuff, affects the ability to swallow by disrupting both mechanical and physiological mechanisms.⁽¹²⁾ Due to the splinting effect of the tracheostomy tube on the larynx and the compression of the oesophagus by a cuffed tracheostomy tube, patients often experience difficulty in swallowing. This issue is particularly prevalent during the first two weeks following the tracheostomy. In our study, 5.8% of patients with a cuffed tracheostomy tube reported dysphagia, in contrast to 3.9% observed in a comparable study.⁽¹⁷⁾ The majority of our patients (86.2%) were transitioned to an uncuffed tube two weeks post-tracheostomy after ruling out aspiration. The compression effect on the oesophagus was alleviated to some extent by using uncuffed tubes and Ryle's tube feeds (33.2%). Dietary modifications and reliance on feeding tubes compromise social interactions, such as family meals and dining out, impairing the sense of normalcy and overall well-being. Research by Gul and Karadag et al showed that over 50% of the patients also had diminished or complete loss of sense of smell following tracheostomy which further added to their distress.⁽¹⁸⁾ However, we did not assess for sense of smell in our study.

Communication is fundamental to daily life and the maintenance of interpersonal relationships. The temporary loss of voice during the initial phase leads to profound communication difficulties, resulting in feelings of isolation and loneliness. Patients may struggle to engage in social interactions. Flinterud, Andershed, and Laakso et al. reported that the inability to express needs and emotions leads to frustration, exhaustion, helplessness, and a sense of disconnection.^(19,20) This lack of effective communication was

even higher in our patients as most of them were illiterate and could not write their feelings or requirements this communication barrier leads to emotional stress.

A multidisciplinary approach improves patient satisfaction by reducing the time needed to restore speech.⁽⁶⁾ The problem of temporary voice loss can be minimized to an extent by using speaking valves, fenestrated tracheostomy tubes, and speech therapy. Family caregivers also assumed the additional role of facilitator and interpreter for tracheostomized patients.⁽²⁰⁾ All patients in our study were encouraged to undergo early speech therapy. Among them, 82.6% of patients who had an uncuffed tube or deflated cuff were able to phonate using the finger occlusion technique. This was complemented by alternative methods of communication such as lip reading, writing, using hand gestures, picture boards, or electronic devices. Despite the availability of these alternative methods, they were rarely utilized.

Home care of a tracheostomized patient is often perceived as burden by both the patient and the primary caregiver, typically a spouse.^(3,4,5) Family caregivers frequently expressed frustration and dissatisfaction with the transition to home care and the coordination of healthcare visits.⁽¹⁴⁾ This challenge can be minimised through strategies that provide periodic support and reassurance from healthcare professionals. Adequate training and counselling of the caregivers is essential for home care of the patients. Garner et al, reported that 47% of otolaryngologists did not follow any standardised tracheostomy discharge protocol for training of caregivers.⁽²¹⁾ As per McCormick et al survey only 48% felt 'very prepared' at discharge and 11% were not trained prior to discharge.⁽¹⁴⁾

In a study by Rossi Ferrario et al, in addition to tracheostomized patients, 75% of primary caregivers also reported restrictions in their daily activities. Among them, female caregivers and primary caregivers of patients who had a tracheostomy for less than 14 months duration experienced greatest stress.⁽⁵⁾ The responsibility of tracheostomy care led to fear, anxiety, and insecurity. The majority (77.7%) of caregivers in our study particularly spouses experienced extreme stress due to the decision-making responsibilities regarding cleaning and change of tube and they felt increased pressure and resentment without adequate preparation or support. Caregiver issues included feelings of being overworked and overburdened, which compromised daily commitments, other household responsibilities, and social obligations. Some also reported changes in their relationship with the spouse or relative, feelings of being trapped and restricted by caregiving responsibilities, a lack of confidence in providing care, and worries regarding the future care needs of the patient.

In our study, all patients developed some form of psychological problem, with the stress of the underlying disease being a major contributory factor. Anger (33.2%), frustration (12.5%), and sleep deprivation (43.2%) were more commonly observed in the first month post-tracheostomy. Depression (66.7%) was more prevalent in the second- and third-months post-tracheostomy. Additionally, compromised sleep was often due to discomfort and the sensation of a foreign body (18.7%) from the presence of the tube, as well as increased secretions (15.2%) that required frequent suctioning. Suicidal tendency was noted in one of our patients following alcohol withdrawal. Withdrawal symptoms like anxiety, agitation, and severe mood disturbances coupled with psychological distress due to tracheostomy

tube contributed to heightened suicidal contemplation. These findings emphasize the need for comprehensive monitoring and support addressing both the physical and mental health of such patients.

The episodes of tube change exacerbate anxiety and fear in both patient and care giver. Similar observations were made in the study done by Katja Laakso et al, in which the patients reported physical discomfort due to presence of tube itself and the basic tracheostomy tube care is frightening.⁽²⁰⁾

Bleeding from stomal granulations during tube change was seen in 23.2% of our patients in contrast to only 10.7% patients in a study by Cormick et al and 11.8% by Nyanzi D J et al.^(14,17) The exuberant granulations not only occlude airway but also results in haemorrhage and risk of aspiration during tracheostomy tube change. Difficulty in tube repositioning either due to stomal collapse or stomal stenosis carries threat of creating a false tract. The collapse of stoma during tube change results in drop in saturation inducing a panicky situation. Accidental decannulation was noted in 11.6% in our study compared to 17.6% of patients by Cormick et al. and, 17.1% by Nyanzi D J et al.^(14,17)

Routine daily activities like bathing and showering are cumbersome as there is risk of water accidentally entering the tracheostomy tube and causing coughing or choking episodes. The need for assistance with bathing fosters a sense of dependence on caregivers. Patients develop sense of worthlessness and loss of autonomy.

In our study most of the patients had high stress level in the first month, which showed a declining trend with the passage of time. Patients interviewed in the first (75.59%) and second month (62.8%) had more stress levels compared to third (25.59%) month. This could be due to development of potential improvement in stress management or coping mechanism over time.

The quality of life in the physical health domain (D1) showed a rising trend over time from a median score of 17.9 to 32.1 (p value <0.001), which can be attributed to awareness about the disease, understanding the importance of undergoing treatment and improved response to treatment.

According to study by Hashmi et al, tracheostomised patients scored worse on both physical and mental health, while there was a minor improvement in physical health following tracheostomy, mental health worsened. In contrast, in our study a progressive improvement in psychological health domain (D2) overtime (median score of 16.7 to 31.3, p value <0.001) was observed.

Research by Gul and Karadag showed that 55% of participants reported negative effects on social relationships. We observed an overall improvement of social relationship (D3) domain scores overtime, which was statistically significant (median score of 16.7 to 29.2, p value <0.001)⁽¹⁸⁾

It was observed that, among the three determinants of the social domain, there was improvement in personal relationships and support from friends. However, no consensus could be reached regarding sexual life. Our assessment on social domain was curtailed to an extent, as the patients were reluctant to disclose details on sexual life as it is considered as a taboo in this part of the world with a conservative society. In our study, two

patients separated from their spouse. The likely reason could be due to the medical condition compounded by presence of a tracheostomy tube, which strained their intimate relationships.

Environmental health (D₄) showed a moderate improvement over time. Financial strain is augmented by employment issues due to loss of voice which limits job opportunities requiring verbal communication.⁽¹⁸⁾ Majority (58%) of our patients were daily wage earners and loss of job and employment opportunities were reported in 73% of patients, Due to restrictions in physical activities, lifting heavy weights and exposure to dusty environment. When the primary earning member of a family undergoes a tracheostomy, the entire family dynamics can shift dramatically. This necessitates redistribution of responsibilities, often creating significant stress and adaptation for all family members. The primary caregiver may also have to balance new job responsibilities along with the existing duties.

In addition to financial responsibilities, the primary caregiver is expected to adapt to the increased care needs of a tracheostomized member. It includes specific skills and constant attention to manage tasks such as suctioning secretions, tracheostomy care and monitoring for potential complications. The caregiving role is often taken on by the spouse, who balances caregiving duties along with other household responsibilities. In our study majority of the caregivers were females, mainly spouses (86.4%). This can lead to caregiver fatigue and burnout. The primary caregiver might neglect their own health and well-being.

In our study, majority of the caregivers were spouses and siblings and majority were females 65.1% and all were non-earning members of the family and 45.3% had financial issues. Study by Gul and Karadag showed that 66% reported adverse impacts on their economic position. Additionally, the need for constant care, and the physical limitations imposed by the condition and frequent medical visits also contributes to overall emotional stress.

In a study by Rossi Ferrario et al, 84% of patients avoided social contact. The lack of leisure activities and the inability to attend social functions significantly impact the quality of life for tracheostomized patients.⁽⁵⁾ Fear of coughing episodes, difficulty in communication, and the physical discomfort associated with managing secretions can discourage patient participation in recreational activities and impose travel constraints. We observed that 50-60% of our patients had very poor social interactions. Similar observations of social withdrawal were reported by Foster A, Gilony, and Barnett M.^(3,10,16)

Overall, these findings highlight persistent and severe issues across physical, psychological, social, and environmental domains, emphasizing the need for comprehensive, multidisciplinary interventions for these patients.

Limitation of the Study

The findings of this study cannot be generalized to all tracheostomized patients and their primary caregivers, as it was conducted in a single tertiary hospital located in a rural district's head and neck department. The study population predominantly consisted of illiterate individuals with limited familiarity with digital services. We recommend conducting a multicentric study across different hospitals, incorporating a larger and more

diverse cohort from both rural and urban areas. This study should include patients with various pathologies necessitating tracheostomies, allowing for a broader spectrum of findings concerning both patients and their caregivers.

Conclusion

Our study shows that tracheostomy has a significant impact on the quality of life and psychosocial well-being of both patients and their primary caregivers. The challenges were encountered across physical, psychological, social, and environmental domains. Stress levels were more after emergency tracheostomy as there was inadequate time for preoperative counselling and mental preparation. The stress levels declined noticeably in patients due to better coping mechanism and improved stress management over time. Caregivers also faced substantial emotional and practical burdens, affecting their overall quality of life. These insights highlight the necessity for a comprehensive support system, including preoperative counselling and training, addressing both patient and caregiver needs to enhance their quality of life and mitigate the psychosocial impact of tracheostomy. The stress levels are even more pronounced in a rural, illiterate populations like in our area.

Appendices

WHOQOL-BREF Questionnaire

Domain Name	Question No	Questions
General	1	How would you rate your quality of life?
Physical Health	2	How satisfied are you with your health?
	3	To what extent do you feel that physical pain prevents you from doing what you need to do?
	4	How much do you need any medical treatment to function in your daily life?
	10	Do you have enough energy for everyday life?
	15	How well are you able to get around?
	16	How satisfied are you with your sleep?
	17	How satisfied are you with your ability to perform your daily living activities?
	18	How satisfied are you with your capacity for work?
Psychological	5	How much do you enjoy life?
	6	To what extent do you feel your life to be meaningful?
	7	How well are you able to concentrate?
	11	Are you able to accept your bodily appearance?
	19	How satisfied are you with yourself?
	26	How often do you have negative feelings such as blue mood, despair, anxiety, depression?
Social	20	How satisfied are you with your personal relationships?

Relationships		
	21	How satisfied are you with your sex life?
	22	How satisfied are you with the support you get from your friends?
Environmenta 1	8	How safe do you feel in your daily life?
	9	How healthy is your physical environment?
	12	Have you enough money to meet your needs?
	13	How available to you is the information that you need in your day-to-day life?
	14	To what extent do you have the opportunity for leisure activities?
	23	How satisfied are you with the conditions of your living place?
	24	How satisfied are you with your access to health services?

Perceived Stress Scale

Questi on No.	Question	Never (0)	Almost Never (1)	Someti mes (2)	Fairly Often (3)	Very Often (4)
1	In the last month, how often have you been upset because of something that happened unexpectedly?	0	1	2	3	4
2	In the last month, how often have you felt unable to control the important things in your life?	0	1	2	3	4
3	In the last month, how often have you felt nervous and "stressed"?	0	1	2	3	4
4	In the last month, how often have you felt confident about your ability to handle your personal problems? (Reverse Scored)	0	1	2	3	4

5	In the last month, how often have you felt that things were going your way? (Reverse Scored)	0	1	2	3	4
6	In the last month, how often have you found that you could not cope with all the things you had to do?	0	1	2	3	4
7	In the last month, how often have you been able to control irritations in your life? (Reverse Scored)	0	1	2	3	4
8	In the last month, how often have you felt that you were on top of things? (Reverse Scored)	0	1	2	3	4
9	In the last month, how often have you been angered because of things that were outside of your control?	0	1	2	3	4
10	In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?	0	1	2	3	4
<p>Perceived Stress Scale Scoring</p> <p>Scores ranging from 0-13: Low stress</p> <p>Scores ranging from 14-26: Moderate stress</p> <p>Scores ranging from 27-40: High Perceived stress</p>						

Kingston Caregiver Stress Scale

Feeling no stress 1	Some stress 2	Moderate stress 3	A lot of stress 4	Extreme stress 5		
Care giving issues						
To what extent...						
1	Are you having feelings of being overwhelmed, overworked, and/or overburdened?	1	2	3	4	5
2	Has there been a change in your relationship with your spouse/relative?	1	2	3	4	5
3	Have you noticed any changes in your social life?	1	2	3	4	5
4	Are you having any conflicts with your previous daily commitments (work/volunteering)?	1	2	3	4	5
5	Do you have feelings of being confined or trapped by the responsibilities or demands of care giving?	1	2	3	4	5
6	Do you ever have feelings related to a lack of confidence in your ability to provide care?	1	2	3	4	5
7	Do you have concerns regarding the future care needs of your spouse/relative?	1	2	3	4	5
Family issues						
To what extent						
8	Are you having any conflicts within your family over care decisions?	1	2	3	4	5
9	Are you having any conflicts within your family over the amount of support you are receiving in providing care?	1	2	3	4	5
Financial issues						

To what extent						
10	Are you having any financial difficulties associated with care giving?	1	2	3	4	5

Affiliations:

¹Sreelekshmy S- Postgraduate, Otorhinolaryngology and Head and Neck surgery, Sri Devaraj URS medical college, Kolar, Karnataka, India

²Kouser Mohammadi, Associate Professor, Otorhinolaryngology and Head and Neck surgery, Sri Devaraj URS medical college, Kolar, Karnataka, India

³S M Azeem Mohiyuddin, Professor and Head, Otorhinolaryngology and Head and Neck surgery, Sri Devaraj URS medical college, Kolar, Karnataka, India,

⁴Gurappa P Gururaj, Professor, Psychiatry, Sri Devaraj URS medical college, Kolar, Karnataka, India

⁵Mohammed K chisty, Assistant Professor, Psychiatry, Sri Devaraj URS medical college, Kolar, Karnataka, India

⁶MohanReddy Matti, Professor and Head, Psychiatry, Sri Devaraj URS medical college, Kolar, Karnataka, India,

⁷Keerthika Shivaji, Final year MBBS Student, Sri Devaraj URS medical college, Kolar, Karnataka, India

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