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## Effectiveness of Self-Care Education on the Perceived Quality of Life in Adults with a Tracheostomy

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Effectiveness of Self-Care Education on the Perceived Quality of Life in Adults with a  
Tracheostomy

Submitted in Partial Fulfillment of the Requirements for the Degree of Doctor of Nursing  
Practice at the University of Kentucky

By

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Lexington, KY

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## Abstract

**Background:** A tracheostomy is an operative procedure performed to create a stable surgical airway for patients with respiratory compromise due to a variety of clinical reasons. Living with a tracheostomy has tremendous impact on the patient as they experience alterations in their ability to eat, speak, breathe normally, and care for themselves. There is also a potential negative impact to their quality of life. Under ideal circumstances, the tracheostomy is a planned event and education is given to the patient prior to the procedure in an effort to lessen the impact and prepare them to cope with the expected life changes. However, in the acute care hospital setting, placing the tracheostomy has most often not been discussed prior to hospitalization, and frequently patient education is hindered by severity of illness and time constraints of clinical staff. An education initiative to impact self-care knowledge while the patient is still hospitalized is needed and may have a lasting impression on the patients' perceived quality of life.

**Purpose:** The purpose of this project was to examine the impact of an education intervention on the perceived quality of life for adult patients living with a tracheostomy.

**Methods:** This study design was a single sample, longitudinal cohort. The data from a tracheostomy related quality of life questionnaire was evaluated during hospitalization and intended to be re-evaluated at approximately 30 days post-discharge. The data were analyzed for correlation coefficients and via independent samples t-tests.

**Results:** The results of this study indicate a significant difference in tracheostomy related quality of life based on gender, age, and if the procedure was planned prior to hospital admission. Additionally, while not statistically significant, several strong correlations emerged

from the data related to education level and age with various aspects of tracheostomy related quality of life.

**Conclusions:** While limited by small sample size, the findings of this study suggest further research is warranted. Specifically, anecdotal findings indicate variations in tracheostomy care delivery between surgical services and nursing staff, and effort should be made to understand these variations in hopes to standardize and improve care.

## **Acknowledgements**

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Lastly, I would like to thank the UK Healthcare Health Education Center for their support of my project. They graciously provided the tracheostomy care guide and loaned me an iPad for the duration of my project to facilitate patient completion of the quality of life questionnaire.

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## **Background and Significance**

A tracheostomy is a surgically created stoma in the anterior neck to assist in ventilation of a patient with prolonged mechanical ventilation, upper airway obstruction due to a variety of causes such as cancer, inability to protect airway due to neurological disease or brain injury, or trauma. Tracheostomies are one of the oldest known surgical procedures, with evidence of having been performed as far back as 3,600 BC, as portrayed on Egyptian engravings (Rajesh & Meher, 2005). In modern times, many tracheostomies are performed with the ultimate plan of decannulation in mind, however the impact on the patient while the device is in place can be tremendous (Smith et al., 2016).

While there continues to be debate on the initial timing of a tracheostomy in the critical care setting, the procedure is often performed to alleviate issues with long-term laryngeal intubation such as ventilator-associated pneumonia, prolonged sedation, decreased mobility, and damage to oropharyngeal structures (Abril et al., 2021; Andriolo, et al., 2015; Cheung & Napolitano, 2014). Tracheostomies are not without complications however, including but not limited to vocal cord dysfunction, stomal granulation, bleeding, and scarring (Cheung & Napolitano, 2014). Conservative estimates of volume indicate that roughly 85,000 adult tracheostomies occur in the United States (US) yearly, excluding those performed on patients with a head and neck cancer diagnosis (Abril et al., 2021). Others estimate the annual volume to be greater than 100,000, with many requiring discharge to a skilled nursing facility rather than home (Cheung & Napolitano, 2014).

During the calendar year of 2022, the study site agency had 43,211 inpatient admissions. Of those, 1,299 had a diagnosis of a tracheostomy during that encounter.



## **Problem Statement**

Although tracheostomies are a frequently performed surgical procedure, there is little literature to examine the relationship between self-care and quality of life in those living with a tracheostomy (Smith et al., 2016).

## **Context, Scope, and Consequences of the Problem**

Patients with tracheostomies in place experience alterations in the ability to speak, eat, and breathe normally. Moreover, activities of daily living are challenging and alterations in self-perception change social and personal relationships, often for the negative (Mohammadi et al., 2015; Smith et al., 2016). In the acute hospital setting, commonly the tracheostomy is relatively new and the reason for placement may still be of concern. In these instances, educating the patient regarding their tracheostomy may be challenging due to severity of illness (Klein-Fedyshin et al., 2005). While there have been some efforts to close the gap with patient education specific to patients with head and neck surgery indicated tracheostomies, there is little evidence to support the connection between self-care knowledge and quality of life in other patient populations (Gul & Karadag, 2010; Loerzel et al., 2014). Attempts have been made to improve quality of life in adults with tracheostomies by utilizing in-home education via videos (Mohammadi, 2015). Others have found correlation between return of voice and improved quality of life in patients with a tracheostomy (Freeman-Sanderson et al., 2018).

Mitchell et al. (2013) released 12 consensus statements that pertain to patient and caregiver education, and uniformly agree that ideally education regarding tracheostomy care should happen prior to the surgery. However, in the acute care hospital setting this may be challenging for a variety of reasons, including a previously unplanned tracheostomy procedure prohibiting

pre-operative education, severity of illness, or lack of an available caregiver. Additionally, there are barriers specific to self-care education while the patient is in the hospital. One barrier may include ineffective patient-provider communication where the patient lacks understanding due to complex terminology (Ivynian, et al., 2020). Klein-Fedyshin et al. (2005) cited a lack of time to perform patient teaching as another barrier. Others have reported similar results, with limited time dedicated to patient and caregiver education (Michel et al., 2021; Papadakos et al., 2014). In addition to time constraints, a perception that education was ineffective and difficult to perform in a meaningful way led to demotivation of clinical staff to engage in patient-centric education activities (Lelorain et al., 2017). The challenges of meaningful education exist in a setting where the importance of continuous follow-ups by nursing in order to meet the needs of patients with tracheostomies has been identified (Queirós et al., 2021). Further, patients themselves identified dissatisfaction with the education they received while in the acute care setting (Mohammadi, 2015).

Self-care activities in patients with tracheostomies have broad implications to both the psychosocial and physiological health of the patient. Ideally, patients with tracheostomies in place must be able to manage the device prior to discharge from the hospital setting (Bowers & Scase, 2007). It has been noted that a basic understanding of the disease process necessitating the tracheostomy, as well as device care, are important and can form the basis for self-care activities (Moser & Watkins, 2008). Additional findings support the notion that poor tracheostomy self-care can lead to hospital readmissions due to adverse clinical outcomes (Loerzel et al. 2014; Sefi & Moghaddam, 2018). As such, it is vital to focus time and energy into educating the patient on tracheostomy self-care activities in order to avoid unintended, negative consequences.

## **Current Evidence-Based Interventions/Strategies Targeting the Problem**

There is a large extant body of literature describing the benefits of interventions aimed at early phonation and early decannulation of tracheostomies in efforts to minimize hospital length of stay (Bartow et al., 2018). Much work has been done to outline the standards of care for patients while in the hospital, particularly in the critical care setting (Whitmore et al., 2020). There is also guidance in the form of clinical consensus statements from the American Academy of Otolaryngology-Head and Neck Surgery to guide the clinical care of patients with a tracheostomy both in and out of the hospital setting (Mitchell et al., (2013). It has been identified that self-care autonomy is essential for those with a tracheostomy to promote quality of life, but a direct relationship between self-care education and improved quality of life was not examined (Queirós et al., 2017). There have been attempts at examining the relationship between self-care and quality of life, suggesting that self-care in conjunction with return of speech yield a greater quality of life (Gul & Karadag, 2010). Others have evaluated the relationships between self-care ability, perceptions of health, and activities of daily living (Altinbas et al., 2021). There have been relationships between education and quality of life examined, but were limited to education in the home environment (Mohammadi et al., 2015). While others have examined the impact of self-care education on quality of life in patients with disease processes such as multiple sclerosis, hypertension, chronic hepatitis, and kidney failure requiring dialysis, evidence regarding the association in those with a tracheostomy in place is limited (Ghadam et al., 2016; Hasanpour-Dehkordi et al., 2016; Khademian et al., 2020; O’Shaughnessy, 2014; Sefi & Maghaddam, 2018). Though there is an abundance of clinical guidance on the care of tracheostomy patients, and it is widely recognized that patient education

is an important feature, there is very little literature examining the relationship between self-care education received in the hospital setting and quality of life.

### **Purpose/Objectives**

The purpose of this project was to evaluate the impact of self-care knowledge on the perception of quality of life in adult patients living with a tracheostomy. Specifically, the project had the following goals:

1: Teach 30 patients how to manage tracheostomy care independently and evaluate by return demonstration.

2: Evaluate quality of life in patients during hospitalization and again at 30 days post-discharge to determine impact on quality of life.

### **Overview of the Project Purpose**

The aim of this project was to implement an inpatient education program with the intent of improving self-care knowledge and ability, in an effort to improve perception of quality of life post-hospitalization in adult patients with a tracheostomy.

### **Review of Literature**

#### **Summary of Literature Search**

The following question was created to guide the search of extant literature:

- In adult patients with a tracheostomy, does an inpatient self-care education intervention, compared to standard care, improve perceived quality of life post-hospitalization?

A literature review was conducted using the University of Kentucky Medical Library system, including the databases CINAHL and PUBMED. This review was performed to assess the literature regarding self-care for patients with tracheostomies and establish support for implementing a self-care education program during hospitalization to improve quality of life post-hospitalization for adult patients who have a tracheostomy. The key search terms included ‘tracheostomy’, ‘epidemiology’, ‘self-care’, ‘Orem’, ‘patient education’, ‘nursing time’, ‘quality of life’, and ‘barriers’. A total of 975 articles were identified, 97 of which were reviewed and 29 being found relevant to this study.

### **Gap Identification and Need for Proposed Practice Change**

It is noted that self-care education initiatives aimed at reduction of anxiety related to self-care skill performance are effective for patients with tracheostomies (Loerzel et al., 2014). The researchers note by standardizing the education provided, they were able to observe a significant reduction in trait anxiety as measured by the State-Trait Anxiety Inventory (Loerzel et al., 2014). Others have found a positive correlation between self-care agency and improved perceptions of health in those who have access to routine outpatient care (Altinbas et al., 2021). These studies suggest a connection between self-care knowledge and quality of life, but do not explicitly evaluate that relationship. Investigation is needed to determine the effectiveness of a self-care education initiative on the perceived quality of life of adults with a tracheostomy. The summary suggests that an intervention aimed at improving self-care knowledge and competency has the potential to improve quality life and is supported by a pilot study (Loerzel et al., 2014) and a cross-sectional multisite descriptive study (Altinbas et al., 2021).

Currently at the study site there is no standardized approach to teaching adult patient’s self-care techniques. Much of the nursing time is spent providing care to the patient including

assessment and intervention, medication administration, and documentation of care. There are several tools available to assist with patient education, including a comprehensive tracheostomy care guide, which was created by a multidisciplinary team comprised of nurses, respiratory therapists, speech language pathologists, chaplains, and health education experts. Unfortunately, this guide is underutilized when teaching the patient self-care techniques based on reports from the Health Education Center (HEC) which distributes the guide. Additionally, each hospital room is equipped with a video based teaching platform called Get Well Network. This platform offers the opportunity for specific education modules to be offered to the patient related to their individualized care needs. However, this tool is also rarely used. Also, a nurse driven care protocol is available as an order set within the electronic health record, although it does not appear to be widely applied per nursing leadership review. Ideally, a standard approach to utilizing these educational tools could be implemented to address the needed self-care education for patients with a tracheostomy.

Clearly there is an opportunity to improve patient education related to tracheostomy self-care. This goal of this project was to implement a standard approach to teaching self-care to adult patients with a tracheostomy in order to improve their perceived quality of life. By creating a standardized approach, optimization of time spent teaching could have the largest impact on a tracheostomy patient's self-care knowledge and the effect of this increased knowledge on quality of life could be examined.

### **Theoretical/Conceptual Framework**

The theoretical framework guiding this project was Orem's Self-Care Deficit Theory (SCDT). The SCDT is comprised of three interrelated theories: the theory of self-care, the self-care deficit theory, and the theory of nursing systems (Nurselabs, 2022). The self-care theory is centered on

the concept that people perform actions to maintain their own health (Nurselabs, 2022). The self-care deficit theory identifies when people are not able to maintain their own care and require nursing intervention (Nurselabs, 2022). The theory of nursing systems is representative of the relationship between the nurse and the person needing care when the self-care requirement exceeds the persons' ability to provide such care (Nurselabs, 2022). This theoretical framework lends itself favorably to this project as it presents a method to identify self-care deficits and provision for nursing to provide that care and education.

## **Methods**

### **Design**

The study design was a single sample, longitudinal cohort as the intent was to measure the same patient at two points in time. Initially, tracheostomy related quality of life (TQOL) was evaluated during hospitalization before the education intervention and intended to be repeated at 30 days post-discharge from the acute care hospital. This study design was chosen in an effort to reduce biases due to confounding from any unknown variable having association with the known variables. The goal of this design was to compare data to determine if a significant difference between the same responders at two points in time existed.

### **Setting**

#### ***Agency Description***

This study was conducted at a large academic medical center in central Kentucky, currently consisting of four short-term acute care hospitals, including a dedicated children's hospital and an inpatient behavioral health hospital, with a total 991 licensed inpatient beds (American Hospital Directory, 2023; UK Healthcare, 2023). Additionally, the hospital system operates over

60 specialty outpatient clinics in central Kentucky and over 60 outreach clinics throughout the Commonwealth. The medical center serves both pediatric and adult populations and is the only Level 1 Trauma center in the state verified for both adults and pediatrics. The medical center is also a Certified Comprehensive Stroke Center, houses a level IV neonatal intensive care unit, and a National Cancer Institute designated cancer program.

During the calendar year of 2022, the agency had 43,211 inpatient admissions. Of those, 1,299 had a diagnosis of a tracheostomy during that admission.

### ***Congruence of Project to Selected Agency's Mission/Goals/Strategic Plan***

The stated mission, vision, and values of the agency center on creating a healthier Kentucky. Included in their mission is a commitment to the pillars of academic health care including research, education, and clinical care. They have a stated commitment to creating a patient-centered environment that allows patients to feel respected and confidently engage in their care to focus on their health. They dedicate efforts aimed at the improvement in the health of all Kentuckians and serve as a resource to many health care systems across the Commonwealth, as well as to the patients themselves. With a stated commitment to partnering with community providers, they offer advanced services with innovative nursing and medical services.

The stated vision of the agency is to become a nationally recognized, top 20 academic health center. Furthermore, the agency has five identified core values that foster a patient centered care environment. These values include diversity, innovation, respect, commitment, and teamwork (UK Healthcare, 2022). The mission, vision, and values reflect the long term aspirations of the organization (Borkowski, 2022). As this study was aimed at increasing self-care knowledge,



each participant received focused education, which is in congruence with the stated goals of the organization.

### ***Description of Stakeholders***

The stakeholders for this study included leadership of the inpatient units where the patients received care, hospital leadership, nursing staff, as well as the patient. Moreover, the principal investigator was a stakeholder as well.

### ***Site-Specific Facilitators and Barriers to Implementation***

There were several facilitators to implementation, including a digital education and engagement system in every hospital room called Get Well Network. This system integrates with the electronic health record and has the capability to allow personalization of the patient education experience based current needs. An additional facilitator is a well-developed tracheostomy care guide available through the health education library. The guide comes as a color printed book in a three-ring binder, with information written through the assistance of health literacy experts and includes professional illustrations. This guide is available free of charge to patients; however, it is the responsibility of the care team to retrieve the guide on behalf of the patient. Currently the guide is only available in English. Additionally, in the electronic health record there is a post-tracheostomy order set covering many of the nursing care actions needed for tracheostomy care, evaluation of patient knowledge, as well as consults to companion services such as respiratory therapy and pastoral care. There were no site-specific identified barriers to implementation of this project.

## **Sample**

### ***Target Population***

The target population was adult patients with a tracheostomy in place. All adult patients with a tracheostomy in place were considered regardless of how long the device was in place. The researcher did not want to assume that a patient had sufficient self-care knowledge simply based on device duration. Additional inclusion criterion was based on patient location within the facility. Patients in the Pavilion A care tower were considered potential subjects if they were not in the intensive care unit. An exclusion criterion was related to the ability to read and speak English, as that is the language in which the education materials are currently available. Additional exclusion criteria included those with the inability to participate in education activities, such as acuity, those with a status as a prisoner, and those who were unable consent to participate. The target participant number was 30 participants.

## **Procedure**

### ***IRB Approval***

After completing human subject protection training including the responsible conduct of research and biomedical investigators and key personnel through the University's Office of Research Integrity, the institutional review board (IRB) submission process occurred electronically. Approval under IRB# 80328 was obtained on September 25, 2022. Included in the IRB approval was a waiver of authorization related to HIPAA privacy rules, allowing the principal investigator to review the medical record of potential participants prior to becoming enrolled in the study. Additionally, support was obtained from the Nursing Research Committee at the institution.

### ***Description of Evidence-Based Intervention***

Each potential participant who was approached for consent was offered the tracheostomy care guide regardless of decision to participate. The intervention included utilization of education videos via Get Well Network specifically focused on tracheostomy care. The investigator was present when the videos were viewed in order to answer questions and guide patient through applicable sections within the tracheostomy care guide. The researcher covered key points regarding tracheostomy care for each participant, referencing relevant sections within the care guide, including a description of the type of tracheostomy device which they have in place, an overview of throat anatomy, the importance of hand hygiene when manipulating or cleaning the device, cleaning of the external portions of the device, changing the inner cannula, and techniques for showering to ensure water does not enter through the device. Additionally, topics related to emergency situations were covered including the use of a bag-valve-mask device, the use of supplemental oxygen, and actions to take if secretions plugged the device. Tracheal suctioning was not demonstrated by the researcher as no participants indicated they had been receiving suction routinely. Throughout the time spent one on one with the participant, the researcher encouraged practice of the self-care activities corresponding to the videos and instructions in the care guide. Moreover, the researcher ensured that all potential participants had the post-tracheostomy order set contained within their nursing orders.

### ***Measures and Instruments***

The instrument that was used to assess TQOL is a tool from Smith et al. (2016). Permission to use the tool was granted from the authors. This is a 20 item survey, with all items being Likert type (see Appendix A). The TQOL tool has an overall score range of 20-93, with lower scores indicating better quality of life. Additionally, there were several other variables that were

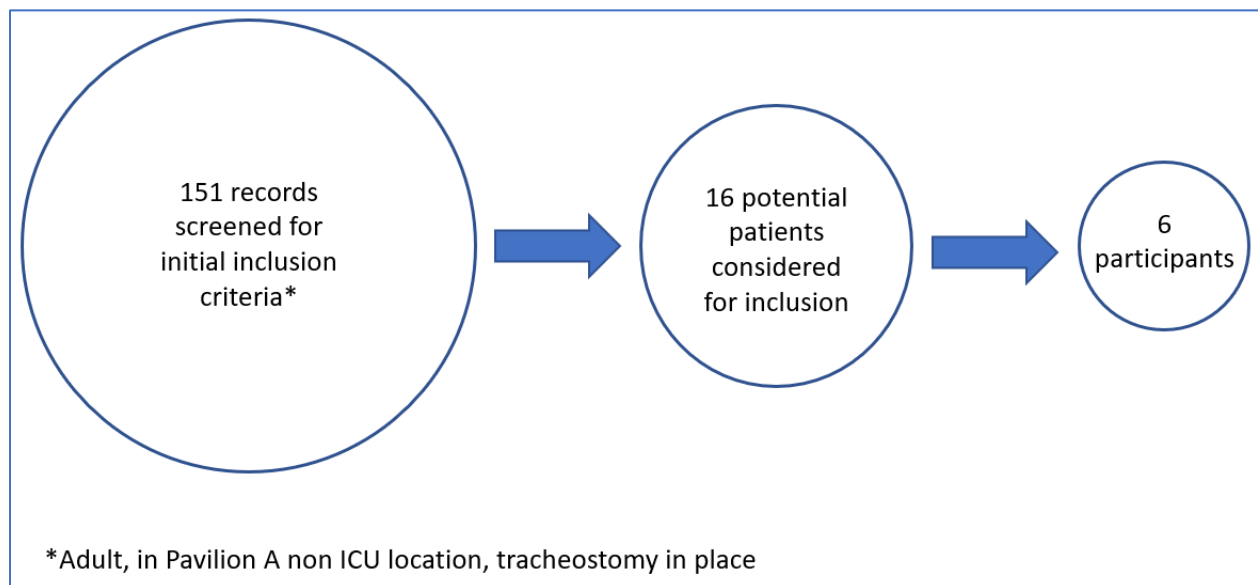
recorded including demographic information such as age, race, gender, educational attainment, income, and if participant will have assistance at home after discharge. Other variables included the primary diagnosis that led to hospitalization and the primary reason for requiring a tracheostomy. Data were collected regarding if the tracheostomy was planned prior to hospitalization, and if planned, was pre-procedure education performed.

### ***Data Collection***

From an initial screening of the electronic health record, in accordance with IRB approval, a total of 151 potential participants were identified based on initial inclusion criteria of adult with a tracheostomy in Pavilion A non-ICU locations (see Figure 1). Of the initial 151, a total of 16 patients met inclusion criteria and were evaluated for inclusion in the study. Of the total 16 patients considered for inclusion, 6 consented to participate.

**Figure 1**

### ***Participant Review and Inclusion***



Upon identification of potential participants, the researcher first contacted the primary medical service responsible for the care of the patient to obtain permission to approach the patient for consideration of participation. Once permission was obtained from the medical provider, the researcher communicated with the primary nurse responsible for the care of the patient in order to coordinate a time appropriate for the researcher to approach the patient. After agreement was made between the nurse and researcher, the researcher approached the patients in their hospital room inviting them to participate in the voluntary study. The researcher explained the purpose of the study, the purpose of the TQOL survey, as well as an explanation of the risks and benefits of participation. Patients were reassured that participation was voluntary and would not affect their hospital treatment plan.

Of the 16 patients who were approached to participate, seven declined participation and declined accepting the tracheostomy care guide. Three declined participation but accepted the care guide. Two indicated desire to participate but cited fatigue and requested to participate another day. In this instance, the researcher followed up with those potential participants the following day but was unable to consent either. One had been decannulated in the early morning due to excessive bleeding and the other had been discharged by the time the researcher had returned. Of the six who agreed and were consented to participate, two already had a tracheostomy care guide at bedside. A total of an additional four participants were consented and given the tracheostomy care guide by the researcher.

All six consented participants completed the initial TQOL survey on an iPad while they were inpatients. The survey was created through the internet electronic platform Qualtrics. Each participant responded to a unique survey link provided by the researcher. The initial survey included the 20 items from the Smith et al. TQOL tool, as well as demographic questions related

to education level, income level, and if assistance would be available at home. The data obtained from the surveys were kept secure in a de-identified file.

Each participant was emailed a second survey link containing the same 20 TQOL questions approximately 30 days after discharge. Each participant was emailed a total of two times soliciting completion of the repeat survey. No participants completed the second survey.

### ***Data Analysis***

Descriptive analysis was performed on demographic data. The continuous variable age was evaluated and presented as a mean and standard deviation. Categorical variables race, gender, education level, income level and if patient has assistance available at home were evaluated and presented as numbers and percentages. The intended plan for data analysis including evaluating the change in TQOL over time via linear regression analysis and/or repeated measures analysis was unable to be performed as no participants returned the second survey. As many variables were collected in the data set, evaluation of the impact of a variety of predictors on TQOL was also performed.

In order to facilitate analysis, in addition to total TQOL score (20 questions), three subscales were created based on like question groupings for physical activity, social activity, and tracheostomy care. The physical activity subscale is a composite mean of two related questions. The social activity subscale is the mean of three related questions. The tracheostomy care subscale is the mean of two related questions. Pearson's product moment correlation was used to evaluate the relationship between age and total TQOL score, physical activity, social activity, and tracheostomy care subscales. Spearman's correlation was used to evaluate the relationship between income level and total TQOL score, physical activity, social activity, and tracheostomy

care subscales. Independent sample t-tests were also evaluated to examine the relationship between the variables gender and if the tracheostomy was planned prior to hospitalization with total TQOL score, physical activity, social activity, and tracheostomy care subscales.

## **Results**

### **Demographics and Findings**

The average age of the participants was 53.7 years (SD=15.8, see Table 1). The majority of the participants described themselves as white (83.3%) and over half of the participants were female (66.7%). The distribution of education level among participants included high school graduates (33.3%), some college (33.3%), 2 year degrees (16.7%), and those with 4 year degrees (16.7%). The majority of the participants reported income less than \$25,000 (83.3%).

Additionally, the majority of the participants reported that they will have assistance at home after discharge from the hospital (83.3%). A small portion of the participants had the tracheostomy planned prior to hospital admission (33.3%), however none received pre-procedure education (0%).

The participants were admitted to the hospital for a variety of reasons including motor vehicle collision (16.7%), gastrointestinal bleed (16.7%), ischemic stroke (16.7%), heart failure (16.7%), and cancer of the tongue (33.3%). While admission reason varied between participants, half received an unplanned tracheostomy due to acute respiratory failure. Other indications for the tracheostomy in the participant population included ECMO and heart transplant (16.7%) and selective neck dissection with partial glossectomy (33.3%, see Table 2).

Total TQOL scores in the study population ranged from 32-56 (Mean = 43.8, SD = 9.2). The physical activity subscale ranged from 1 - 4, on a 5 point scale, with a mean of 2.17 and a

standard deviation of 1.1. The social activity subscale ranged from 1 - 4 on a 5 point scale, with a mean of 2.2 and a standard deviation of 1.1. The tracheostomy care subscale ranged from 1.5 - 4.5 on a 5 point scale, with a mean of 2.9 and a standard deviation of 1.4.

There was a strong negative correlation between age and total TQOL score however statistically non-significant ( $r = -.716$ , with  $p = .11$ ). Participants in this study who were younger tended to have a higher TQOL score, indicating poorer quality of life, whereas those who were older tended to have a lower TQOL score, indicating better quality of life. A limitation to the significance is the small sample size ( $n=6$ ). There was a non-significant, moderate negative correlation between age and physical activity ( $r = -.478$ ,  $p = .38$ ). A limitation to the significance again is small sample size ( $n=6$ ). There was a non-significant, moderate negative correlation between age and tracheostomy care ( $r = -.484$ ,  $p = .52$ ). A limitation related to sample size had an impact on significance ( $n=4$ ). There was a statistically significant, strong negative correlation between age and social activity ( $r = -.193$ ,  $p = .03$ ). Participants who were younger tended to have a higher social activity score, indicating a poorer quality of life.

There was non-significant weak negative correlation between income level and total TQOL score ( $r = -.393$ ,  $p = .44$ ). There was a very weak, non-significant correlation between income level and physical activity ( $r = .133$ ,  $p = .8$ ). There was a strong, non-significant correlation between education level and total TQOL score ( $r = .736$ ,  $p = .09$ ). There as a weak, non-significant correlation between education level and physical activity ( $r = -.313$ ,  $p = .55$ ). Again, small sample size impacted the overall significance of these correlations ( $n=6$ ). There was no correlation between income and social activity ( $r = 0$ ,  $p = 1$ ).

Independent samples t-tests were performed on the data and compared gender with the total TQOL score, physical activity, social activity, and tracheostomy care subscales. Male



participants reported an average TQOL score of 54.5, whereas females reported a lower average score of 38.5 (see Table 3). This indicates a reported better quality of life in the female participants included in the study. This finding was also a statistically significant finding ( $t = -4.093$ ,  $p = .015$ ). Females also scored lower averages on the subscales for physical activity, tracheostomy care, and social activity. There was a significant difference between males and females for the social activity subscale as well ( $t = -4.025$ ,  $p = .028$ ). Independent samples t-test was also performed and compared if the tracheostomy was planned or unplanned with the total TQOL score, physical activity, social activity, and tracheostomy care subscales (see Table 4).

### **Discussion**

The first aim of this study was to teach 30 patients self-care activities and evaluate their knowledge via return demonstration. This was unable to be achieved due to several factors including small sample size and inability to evaluate patient self-care due to participant hesitation. Primarily, only six participants consented to participate. Additionally, every patient was reluctant to perform any self-care activities on themselves. Self-care ability has been recognized as a key factor to a successful transition to life with a tracheostomy (Queirós et al, 2016). It has been noted that education can be difficult due to severity of illness, which may have been a factor in this study (Klein-Fedyshin et al., 2005). It has also been noted that a well-developed relationship between the patient and nurse can impact patient outcomes; however, due to the timing of this study, this was limited (Hartweg & Metcalfe, 2022). The researcher was able to guide participants through the Get Well network videos and educational guide to begin education with the patients. It is believed by the researcher that each participant gained a portion of knowledge from the interactions, and in one case, the participant made notes in the care guide as instruction occurred.

As Orem's theory of self-care relies on the concept that people maintain their health through performing health focused actions, it is likely the barrier to self-performance in this study is grounded in a combination of patient fatigue, and possibly, poor timing on the part of the researcher. The participants had been relying on the nursing staff to meet their care needs at the time of interaction with the researcher, supporting the self-care deficit portion of Orem's SCDT. While it is certainly appropriate to have nursing intervention and care in the hospital setting, and is supported by Orem's self-care deficit theory when the patient cannot care for themselves, it is also important for the patient to become an active participant in their care to the extent possible (Hartweg & Metcalf, 2022). As noted by Bowers & Scase (2007), it is important for patients to be able to maintain their tracheostomy device prior to discharge home. It is possible that the patients were not nearing discharge when interacting with the researcher, and thus had not yet progressed to independent self-care activities. Gul & Karadag (2010) note patients who are able to self-perform care activities have been shown to have better quality of life, thus the lack of self-performance likely had an impact on their total TQOL scores. Again, severity of illness may have impacted the engagement of the patients in the performance of self-care activities (Klein-Fedyshin et al., 2005).

Orem's theory of nursing systems also calls for a supportive-education system where the patient should learn to perform self-care activities related to deviations in health (Nurselabs, 2022). Actions related to achieving normalcy when there are deviations in health include understanding and learning to cope with the effects of treatment measures, seeking assistance when appropriate, and carrying out therapeutic measures (Hartweg & Pickens, 2016). In this study, the participants were hesitant to participate and lacked engagement in their own care. This was evidenced by those who consented to participate not engaging in self-care actions with

the assistance of the researcher, as well as those who did not consent to participate. There were seven potential subjects that not only declined participation, but declined the tracheostomy guide resource to aid them in their self-care.

The second aim of this study was to evaluate self-care education on the quality of life in adult patients with a tracheostomy in place. It is noted that those with a tracheostomy report a diminished quality of life (Gilony et al., 2005). Unfortunately, as no study participants returned the repeat survey, the researcher was unable to determine the effect of the self-care education the patients received in the hospital. Possible reasons why the participants failed to return the second survey may include discharge to another facility leading to inability to access email or simply choosing to no longer participate.

### **Implications for Practice, Education, Policy, and Research**

Through the initial identification and approach for consent to participate of potential participants, the researcher discovered an interesting detail. Of potential participants who were approached for inclusion, whose admitting service of record was Otolaryngology (ENT), all had the educational booklet referenced in nursing orders, had the booklet at the bedside, and the post-tracheostomy order set active in their medical record. This indicates one surgical service at the hospital is aware of these resources and are using them to a degree. This was not noted of any other primary admitting service. Interestingly, of the potential participants on the ENT service who had the booklet, none indicated that staff had begun using it with them at the point of interaction with the researcher.

It is believed by the researcher that this could be an area of interest for future study. Understanding the differences between provider knowledge and utilization of these health

resources could inform on how to improve widespread adoption of the resources. It is noted in the literature that patient education programs are time consuming, thus understanding a particular team's approach to resource utilization would be beneficial to streamlining patient education (Papadakos et al., 2014; Porter, 1998).

Another interesting detail which was not part of the formal study included the serendipitous discovery that the nursing staff lacked awareness of the tracheostomy care guide's existence. Anecdotally, staff mentioned not knowing the guide was available on demand from the HEC or that the patient had been given one from their medical team, as in the case of the ENT patients. Also, many staff were unaware of the post-tracheostomy order set which is authorized to be entered into the medical record as a nurse driven protocol. An order set such as this increases nursing autonomy by allowing the nursing staff to be active in the nursing interventions that they perform for their patients.

It is believed by the researcher that this lack of knowledge on the part of the nursing staff likely impacts nursing care and ultimately patient outcomes. Further research is suggested to formally evaluate nursing knowledge of existing health resources and implement a nursing focused education initiative. Full awareness and utilization of all available health resources would certainly benefit the patient, as sufficient knowledge on the part of the nursing staff would yield easier identification and management of any issues (Mungan et al., 2019). It is certainly possible that variations in knowledge among nursing care staff yield variations in tracheostomy care delivery to the patient (Mungan et al., 2019). It is noted that nurses are key in delivering information and providing resources to patients to ensure better outcomes (Kang, 2002). As such, the nursing staff and patient population would benefit from an education initiative aimed at increasing knowledge and standardizing care.

Future initiatives should also include addressing the results of this study. Additional research is needed to fully explore the correlation between age and TQOL. Of particular note is the strong correlation between age and the social activity subscale. When fully understood, interventions could be developed that are aimed in improving this aspect of quality of life in those hospitalized with a tracheostomy. Recreation therapy has been shown to be effective in pediatric populations and could be replicated in adult populations (Hoag et al., 2022).

There were differences in the reported quality of life between males and females in this study. Additional research is needed to understand the relationship gender has on quality of life. As the sample size was very small, it is difficult to make assumptions based on the results of this study alone. Also, differences were reported in those who had a planned tracheostomy and those who did not have a planned tracheostomy. To better understand the relationship between planned versus unplanned and quality of life, this researcher suggests supplemental research to also include qualitative investigation as well.

### **Limitations**

The primary limitation of this study is the small sample size and lack of repeated measures data. While 151 patients were screened for participation, ultimately only six consented and completed the initial survey and education and none completed/returned the second survey.

The initial aims of teaching patient's self-care techniques and evaluating via return demonstration were limited by several factors. One factor was patient fatigue and lack of desire to perform self-care actions. Another limiting factor was the lack of an anatomical teaching model to demonstrate self-care activities. While not part of the original study design, as patients

were reluctant to perform self-care activities, it would have been beneficial to have an anatomical model to demonstrate self-care actions to the patients.

### **Conclusion**

The intended design of the study was not realized due to lack of repeated measures data. However, as the data that were collected indicate, there are several correlations worthy of additional investigation. Associations between several predictor variables and the subscales of the TQOL tool, while not statistically significant in this study, suggest that knowledge could be gained with a larger sample size to inform nursing practice in the future. Significant findings related to gender and planned versus unplanned procedure warrant further scrutiny and research with a larger sample size as well, and could inform on future practice in the development and implementation of interventions aimed to improve certain aspects of quality of life for those groups who reported lower quality of life in those domains.

Anecdotal findings related to utilization of existing hospital resources by certain medical teams lends itself favorably to future research and could form the basis for the standard adoption across medical teams. Standardization would benefit the patient immensely as variations in care would therefore be minimized. Lastly, incidental findings related to nursing knowledge also is worthy of more inquiry.

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## Tables

**Table 1**

*Sociodemographic characteristics of the study sample (N=6)*

<b>Variable</b>	<b>Mean (SD) or n (%)</b>
Age	53.7 (15.8)
Race/ethnicity	
White	5 (83.3%)
Black	1 (16.7%)
Gender	
Female	4 (66.7%)
Male	2 (33.3%)
Education Level	
High School Graduate	2 (33.3%)
Some College	2 (33.3%)
2 Year Degree	1 (16.7%)
4 Year Degree	1 (16.7%)
Income Level	
Less than \$25,000	5 (83.3%)
\$50,001 – \$80,000	1 (16.7%)
Assistance at Home	
Yes	5 (83.3%)
No	1 (16.7%)
Planned tracheostomy	2 (33.3%)
Education prior to tracheostomy	0 (0%)

**Table 2***Admission and tracheostomy reason of the study sample (N=6)*

<b>Variable</b>	<b><i>n</i> (%)</b>
Admission Reason	
Motor vehicle collision	1 (16.7%)
GI Bleed	1 (16.7%)
Ischemic stroke	1 (16.7%)
Heart failure	1 (16.7%)
Cancer of the tongue	2 (33.3%)
Tracheostomy Reason	
Acute respiratory failure	3 (50%)
ECMO and heart transplant	1 (16.7%)
Selective neck dissection and partial glossectomy	2 (33.3%)

**Table 3***Means, standard deviation, and comparisons by gender (N=6)*

	Males (n=2) <i>Mean (SD)</i>	Females (n=4) <i>Mean (SD)</i>	t value   (p – value)
Total TQOL score	54.5 (2.1)	38.5 (5.1)	4.093* (.015)
Physical Activity	2.8 (1.8)	1.9 (0.9)	.877 (.43)
Tracheostomy Care	4 (0.7)	1.8 (0.4)	4.025 (.057)
Social Activity	4 (0)	1.8 (0.5)	4.025* (.028)

\*p&lt;.05.

**Table 4***Means, standard deviation, and comparison by planned status (N=6)*

	Planned (n=2) <i>Mean (SD)</i>	Not Planned (n=4) <i>Mean (SD)</i>	t value   (p – value)
Total TQOL score	54.5 (2.1)	38.5 (5.1)	4.093* (.015)
Physical Activity	2.8 (1.8)	1.9 (0.9)	.877 (.43)
Tracheostomy Care	4 (0.7)	1.8 (0.4)	4.025 (.057)
Social Activity	4 (0)	1.8 (0.5)	4.025* (.028)

\*p&lt;.05.



## Appendix A

### Tracheostomy QOL Questionnaire

#### 1. Pain

- I have no pain/discomfort
- There is mild pain/discomfort not needing medication
- I have moderate pain/discomfort- requires regular medication (not narcotic)
- I have severe pain/discomfort controlled only by narcotics
- I have severe pain/discomfort not controlled by medication

#### 2. Appearance

- I have not noticed any changes in my appearance
- The change in my appearance is minor
- The change in my appearance bothers me, but I have not changed my daily activities because of my appearance
- I feel slightly disfigured by my appearance and limit my activities because of my appearance
- I feel significantly disfigured and cannot be with people because of my appearance

#### 3. Physical Activity

##### *i. Exercise tolerance*

- There has been no change in my ability to exercise
- I am able to do the same amount of exercise, but I am more tired
- My exercise tolerance has decreased, but I am still able to do my daily activities
- I do not have the energy to do my daily activities
- I am usually in a bed or in a chair and house-bound

##### *ii. Limitations to moving neck- implications in daily life*

- Tracheostomy does not limit my neck movement
- Tracheostomy limits my neck movement to a minor degree
- Tracheostomy limits my neck movement, but I am still able to do my daily activities without difficulty
- Tracheostomy limits my neck movement, and it prevents me from doing some of my daily activities
- I am unable to move my neck because of the tracheostomy

4. Swallowing

- I never have difficulties with swallowing
- I occasionally have difficulties with swallowing (less than once a week)
- I often have difficulties with swallowing (1-6 times per week)
- I have difficulties with swallowing on a daily basis
- I always have difficulties with swallowing

5. Communication

*When plugging my tracheostomy tube:*

- People have no difficulties understanding my speech
- People occasionally have difficulties understanding my speech
- People understand my speech half of the time
- More often than not, people do not understand my speech
- I am unable to speak

6. I feel anxious when I'm out in a public setting because of my tracheostomy

- Not at all
- Occasionally
- Half of the time
- Often
- All the time

7. Social Activity

*i. Does having a tracheostomy limit your social activity with friends and strangers?*

- Not at all
- Occasionally
- Half of the time
- Often
- All the time

*ii. Does having a tracheostomy limit your interaction with your family?*

- Not at all
- Occasionally
- Half of the time
- Often
- All the time

*iii. How easy is it to conceal your tracheostomy?*

- People never notice my tracheostomy
- People rarely notice my tracheostomy
- People notice my tracheostomy about 50% of the time
- People almost always notice my tracheostomy
- People immediately notice my tracheostomy

8. Tracheostomy care

*i. How much time are you spending daily on tracheostomy care?*

- 5 minutes or less
- 5-15 minutes
- 15-30 minutes
- 30 minutes to 1 hour
- more than an hour

*ii. How easy is it to clear/cough up secretions?*

- Always able to clear secretions
- Able to clear secretions half of the time
- Often unable to clear secretions
- Occasionally unable to clear secretions
- Never able to clear secretions completely

9. Problems with Tracheostomy

*i. How often do you have problems with your tracheostomy tube falling out?*

- I never have difficulties
- I occasionally have difficulties (less than once a week)
- I often have difficulties (1-6 times per week)
- I have difficulties on a daily basis

*ii. How often do you have problems with plugging of your tracheostomy tube?*

- I never have difficulties
- I occasionally have difficulties (less than once a week)
- I often have difficulties (1-6 times per week)
- I have difficulties on a daily basis

*iii. How often do you have problems with granulation formation?*

- I never have difficulties
- I occasionally have difficulties (1-2 episodes)
- I often have difficulties (3-5 episodes)
- I continually have difficulties (>6 episodes)

*iv. How often do you have bleeding associated with your tracheostomy?*

- I never have difficulties
- I occasionally have difficulties (less than once a week)
- I often have difficulties (1-6 times per week)
- I have difficulties on a daily basis

*v. How often do you have problems with a malodorous smell associated with your tracheostomy?*

- I never have difficulties
- I occasionally have difficulties (less than once a week)
- I often have difficulties (1-6 times per week)
- I have difficulties on a daily basis

*vi. How often do you require suctioning?*

- I never have to use the suction
- I occasionally use the suction (less than once a week)
- I often have to use the suction (1-6 times per week)
- I use the suction on a daily basis

*vii. If you cap, how often does the cap fall off?*

- I never have difficulties
- I occasionally have difficulties (less than once a week)
- I often have difficulties (1-6 times per week)
- I have difficulties on a daily basis

10. Overall, I am \_\_\_\_\_ satisfied with my tracheostomy.

- Very satisfied
- Somewhat satisfied
- Indifferent
- Somewhat unsatisfied
- Very unsatisfied