LIFE AFTER TRACHEOSTOMY: THE EXPERIENCES OF ADULTS IN THE
KUMASI METROPOLIS, GHANA

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Life after tracheostomy: Experiences of adults in the Kumasi Metropolis, Ghana

DECLARATION

I (Bismarck Asare) declare that this thesis is my work produced from research done under the supervision of Dr. Lydia Aziato, School of Nursing, University of Ghana and Dr. Issahalq Duah Mohammed, ENT Department, KATH Kumasi. This thesis has not been submitted in any form for any degree or diploma at any university or other institution of tertiary education. Authors and publishers whose works I have used in this study have been duly acknowledged in the text and list of references.

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DEDICATION

I dedicate this work to the memory of my late parents Mr. Yaw Asare and Mad. Margaret Adutwumwaa for teaching me to be independent all the time. This work is also dedicated to my senior colleague, Alhaji Abdul R. Shaban for his support and encouragement; to my uncle Mr. Boakye Ansah Duah for his continuous prayers on my behalf. Finally, this thesis is dedicated to all adults living with a tracheostomy tube (ALTT) in the Kumasi Metropolis.
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<th>Abbreviation</th>
<th>Full Form</th>
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<tr>
<td>KATH</td>
<td>Komfo Anokye Teaching Hospital</td>
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<tr>
<td>ENT</td>
<td>Ear, Nose, and Throat</td>
</tr>
<tr>
<td>VAS-A</td>
<td>Visual Analog Scale – Anxiety</td>
</tr>
<tr>
<td>ICU</td>
<td>Intensive Care Unit</td>
</tr>
<tr>
<td>US</td>
<td>United States of America</td>
</tr>
<tr>
<td>UK</td>
<td>United Kingdom</td>
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<tr>
<td>WHO</td>
<td>World Health Organization</td>
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<tr>
<td>NHIS</td>
<td>National Health Insurance Scheme</td>
</tr>
<tr>
<td>HNC</td>
<td>Head and Neck Cancer</td>
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<tr>
<td>HRQOL</td>
<td>Health Related Quality Of Life</td>
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<tr>
<td>ALTT</td>
<td>Adults living with a tracheostomy tube</td>
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<td>PLTT</td>
<td>People/persons living with a tracheostomy tube</td>
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ABSTRACT

The use of a tracheostomy tube affects physical and psychosocial life resulting in reduced quality of life. The purpose of the study was to explore the lived experiences of adults with a tracheostomy tube in the Kumasi Metropolis, Ghana. The study used a qualitative exploratory, descriptive design. A purposive sampling method was used, and the data saturation was reached on the ninth participant. The data was analysed using thematic content analysis. Anonymity and confidentiality were ensured. The Thematic Concepts by Foster (2010) was used as a guide for the study. Eight major themes emerged: physical impact, physiological changes, social experiences, psychological experiences, economic constraints, communication dynamics, coping strategies, and support. All the participants experienced pain and impaired functions to carry out their activities of daily living after the surgery. There was difficulty in breathing, dysphagia and altered sense of smell. The adults had altered body image which altered their sexuality and affected their social participation. There were reports of fear and anxiety, depression and suicidal ideations. The participants had challenges with employment due to reduced strength and difficulties with communication. The participants used “speaking valve” or the “finger occlusion method” to communicate and coped with challenges using strategies such as acceptance, resilience and relying on God. They also had physical, financial and social support from family and friends. The possible areas for future investigations identified included an exploration of the support systems for adults with a tracheostomy tube and the attitude of the public towards people living with a tracheostomy tube. It was recommended that the Ministry of Health should extend National Health Insurance Scheme to cover all the healthcare needs of these adults and provide a speaking valve for them at a subsidised cost. There should be counselling and rehabilitation for patients.
CHAPTER ONE

BACKGROUND

1.1 Introduction

According to Hamick (2014) and Serra (2000), the trachea is an extension of the larynx, which measures between 10 and 13cm long in adults. Tracheostomy is a surgical procedure which involves creating an opening into the trachea through the skin of the anterior part of the neck to facilitate breathing (Cheung & Napolitano, 2014; Dawson, 2014). The opening is mostly created at the level of the second and third cartilaginous rings and kept patent by the insertion of a tracheostomy tube. It may be a planned or emergency surgery. It can either be temporary or permanent (Pratt, Ferlito, & Rinaldo, 2008; "Tracheostomy," 2014; Woodrow, 2002). A tracheostomy bypasses the upper airway; this prevents the warming, humidification, and filtration of inhaled air (Barnett, 2012).

Historically, tracheostomy is the first surgical procedure recorded as far back as the first century BC. However, the most popular reference is the description of how Alexander the Great, in the 4th century BC, used his sword to cut open the trachea of a soldier when he was getting choked from a bone lodged in his throat. Aretaeus (2nd century AD) and Galen (2nd to 3rd century AD) wrote that Greek physician Asclepiades of Bithynia performed elective tracheostomy around the 100 BC (Pahor, 1992; Pierson, 2005; Pratt et al., 2008; Walts, Murthy, & DeCamp, 2003).

The indications for tracheostomy include acute respiratory failure with an anticipation of the need for prolonged mechanical ventilation and failure to wean from mechanical ventilation. It is also to maintain the airway in upper airway obstruction, to reduce the risk of aspiration in the airway due to the absence of laryngeal reflexes or ability to swallow. Tracheostomy also provides access to clean the secretions from the tracheobronchial tree (Amusa, Akinpelu, Fadiora, & Agbakwuru, 2004; De Leyn et al.,
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2007; Durbin, 2010; Serra, 2000). The reason for the majority of tracheostomy surgeries are a severe respiratory failure; the need for continued mechanical ventilation (the reason for the majority of tracheostomy surgeries) and traumatic or severe neurologic illness requiring airway, or mechanical aeration or both. Upper airway obstruction is a less common indication for tracheostomy (Cheung & Napolitano, 2014).

Tracheostomy is a life-saving surgical operation performed in the Intensive Care Unit (ICU) as part of a routine management of critically ill patients. It has a high morbidity rate of about 10% of all intubated patients and patients requiring long-term ventilation (Cardone & Lepe, 2010; Durbin, 2010; Freeman et al., 2013; Haspel, Coviello, & Stevens, 2012). However, there is a low mortality rate in both adults and children when performed with the right indication and surgical technique (Freeman et al., 2013; İlçe et al., 2002; Zenk et al., 2009). Comparatively, the incidence of tracheostomy is higher in adults than in children (Wallis, Paton, Beaton, & Jardine, 2011; Zenk et al., 2009). Despite this, tracheostomy in the paediatric age group has been better reported than in adults. The explanation is that the procedure is more challenging and technically more demanding in paediatric patients (Adoga & Ma'an, 2010). It also carries a higher degree of morbidity and mortality in paediatric patients than in the adult population (Adoga & Ma'an, 2010; Daudia & Gibbin, 2006) with a higher morbidity among males than in females because males have increased susceptibility to congenital and acquired disorders (Adoga & Ma'an, 2010).

The procedure represents a significant medical advancement readily available to contemporary physicians (Cardone & Lepe, 2010). There are several benefits associated with tracheostomies. These include less airway dead space and lower airway resistance which potentially reduce the work of breathing and further decrease analgesic and sedative requirements (Durbin, 2010). It also facilitates the prevention of oropharyngeal and
laryngeal lesions, making oral feeding possible and contributes to providing easier and safer nursing care to patients and reduces intensive care and hospital stay (Durbin, 2010; King & Moores, 2008; Shan, Hao, Xu, & Chen, 2013). Tracheostomy is an invasive surgical procedure with numerous possible complications such as bleeding, subcutaneous emphysema, pneumothorax, stoma infection, and sometimes death due to rupture of the innominate artery (King & Moores, 2008; Mallick & Bodenham, 2010; Shah et al., 2012). Tracheal granuloma, tracheomalacia, and tracheal stenosis are also well documented as other complications (Pawar & Suri, 2011; Soudon, Steens, & Touissant, 2008).

Dawson (2014) posits that tracheostomy operation and for that matter, the use of the tube has a high impact on patients. There is a drastic adverse effect on life satisfaction and body-image perceptions due to the prominent disfigurement in the anterior neck (Gilony et al., 2005). Psychological distress and physical indisposition continue to be a major challenge for people who have undergone tracheostomy even months to years after hospitalization (Adhikari et al., 2011; Myhren, Ekeberg, Tøien, Karlsson, & Stokland, 2010; Ringdal, Plos, Ortenwall, & Bergbom, 2010). The issue of self-concept, personal identity, and social integration or social isolation associated with living with the tube, either temporary or permanent can be disturbing and disheartening for any patient and their family (Gilony et al., 2005). There are considerable changes in respiration, nutrition, and communication in people living with a tracheostomy tube (PLTT). There is also a significant reduction in their sense of smell, physical discomfort as well as economic problems which affect their quality of life (Gilony et al., 2005; Gul & Karadag, 2010; Huffman, Emam, & Stevens, 2014). Aside from the fear and panic that accompany dyspnoea and weaning, people give an account of anxiety owing to inaccurate perceptions and delusional memories of living with the tracheostomy tube (Engström, Nyström, Sundelin, & Rattray, 2013).
While individuals with a tracheostomy tube suffer considerable challenges in the aspect of their physical, emotional, and social functioning. It is essential to explore their coping mechanisms for these difficulties. People usually under-report their experience of distress which could result in greater psychological indisposition (Moore, Chamberlain, & Khuri, 2004). Gelinas, O'Connor, and Miller (1998) argue that, most importantly, patients and their caregivers should accept the new life with tracheostomy and not look back to the past life. The reality is that living with a tracheostomy tube brings about a radical change in physical, personal, and social life circumstances and it requires fundamental alterations in self-concept and self-image, social relations, and interactions. Hassanein, Musgrove, and Bradbury (2005) state that clinicians need to assess the way these individuals are coping with the numerous psychosocial effects of tracheostomy because poor coping mechanisms often result in depression. Aarstad, Aarstad, and Olofsson (2008) indicate that neuroticism and an abstention mode of coping lead to a reduced quality of life. Instead, persons who display active coping strategies like creating fun with the problem at hand or engaging in relaxing activities reduce the stress. In addition, individuals who find emotional support from family members or friends (Derks, Leeuw, Hordijk, & Winnubst, 2005) and keep a fighting spirit suffer less depression and have improved quality of life (Hassanein et al., 2005). According to Gelinas et al. (1998), people can cope better when there exist a robust and healthy bond between them and the caregiver and whether there is a good support system available.

There are several studies within nursing and allied healthcare on the physical problems associated with the tracheostomy tube insertion; however, there is a poor description of the lived experiences of adults with a tracheostomy (Foster, 2010). There is a paucity of literature in our local setting regarding the subject (Gilyoma, Balumuka, & Chalya, 2011). Most studies done in this area have concentrated on the surgical technique
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itself, trying to identify which technique is best and has fewer complications while few studies have explored the experiences of people who live with a tracheostomy tube (Akram & Khosrow, 2009). In fact, Gul and Karadag (2010) state that most studies that looked at the experiences of people living with a stoma concentrated on those with gastrointestinal system and urinary system stoma to the neglect of tracheostomy stoma. They continue that, both their observations and nursing literature have demonstrated that the experiences in a tracheostomy, which is also a stoma, have not been studied adequately by nurses. It also seems there are no published studies on the experiences of adults living with a tracheostomy tube (ALTT) in Ghana. Cook, Meade, and Perry (2001) indicate that if clinicians understand the lived experiences of PLTT, they can better appreciate the needs of patients which will enhance their care during the adaptation and rehabilitation processes.

Qualitative methods are uniquely designed to access an emic perspective, to understanding the experience from the viewpoint of those experiencing it (Spiers, 2000). The use of the explorative descriptive method facilitated the study of the experiences of ALTT.

1.2 Statement of Problem

The incidence of tracheostomy has significantly increased in recent times (Mehta, Syeda, Bajpayee, et al., 2015; Mehta, Syeda, Wiener, & Walkey, 2015) across countries (Needham et al., 2005; Vargas et al., 2015). This increase in numbers is due to the presence of complications from prolonged endotracheal intubation which influence the decision to opt for tracheostomy over continued endotracheal intubation (Mehta, Syeda, Bajpayee, et al., 2015; Mehta, Syeda, Wiener, et al., 2015). Other findings that contributed to the increase in the use of tracheostomy included the improvement of care of people who were mechanically ventilated with a tracheostomy. This improvement of care included seduction
requirements, mobility, and oral feeding (Mehta, Syeda, Bajpayee, et al., 2015; Mehta, Syeda, Wiener, et al., 2015; Vargas et al., 2015). The National Confidential Enquiry into Patient Outcome and Death quotes the number of tracheostomies done in the United Kingdom (UK) during 2012 to be about 12000, of which 2546 were adults aged 16 years and above (Wilkinson, Freeth, & Martin, 2015). On average, more than 100,000 tracheostomy operations are done in the United States (US) annually (Yu, 2010). Tracheostomy forms about 9.3% of all Ear, Nose and Throat (ENT) surgeries and 13.4% of all emergency cases at the ENT Department of Komfo Anokye Teaching Hospital (KATH) for the period 2008 and 2013 (KATH Records, 2014).

PLTT experience a drastic reduction in both physical and emotional functioning which leads to worsening self-esteem (Hashmi, Ransom, Nardone, Redding, & Mirza, 2010). The lived experiences of these people are poorly described (Foster, 2010) and unexplored to give any scientific statement. Clinical experience of the researcher, an ENT Nurse at the ENT Nursing School, Kumasi indicates that adults who are living with a tracheostomy tube present with physical, psychological and social problems such as reduced life gratification and body-image.

In addition, literature so far shows that the impact of a tracheostomy on the lived experiences of ALTT seems unexplored in Ghana. These are the reasons that made the researcher conduct a qualitative study with the aim of exploring the experiences of ALTT in the Kumasi Metropolis. There is the belief that the results of this study will add to the literature and inform the care, training and the rehabilitation programmes for PLTT and health care policy related to services for this population.
1.3 The Purpose of the Study

This qualitative study purposed to explore the experiences of adults living with a tracheostomy tube in the Kumasi Metropolis.

1.4 Objectives of the Study

a. To find the physical experiences of adults living with a tracheostomy tube.

b. To examine the physiological experiences of adults living with a tracheostomy.

c. To explore the psychosocial experiences of adults living with a tracheostomy tube.

d. To study the economic experiences of adults living with a tracheostomy tube.

e. To investigate how adults living with a tracheostomy tube communicate.

f. To identify the coping strategies of adults living with a tracheostomy tube.

1.5 Research Questions

a. What are the physical experiences of adults living with a tracheostomy tube?

b. What are the physiological experiences of adults living with a tracheostomy tube?

c. What are the psychosocial experiences of adults living with a tracheostomy tube?

d. What are the economic experiences of adults living with a tracheostomy tube?

e. How do adults living with a tracheostomy tube communicate?

f. What are the coping strategies of adults living with a tracheostomy tube?
1.6 Significance of the Study

The knowledge gained from the experiences of adults living with a tracheostomy tube (ALTT) will enhance better understanding among nurses and other health professionals in providing quality care to meet the needs of ALTT. The reason is that ALTT has different needs other than those limited to the care of the tube and stoma. Findings can assist the development of better rehabilitation programmes to improve their quality of life. It is hoped that the results of the study will serve as resource materials for ALTT to assist them to cope with their new way of life. The study has also assisted in unearthing the need for future investigations in areas such as; the coping strategies of adults with a tracheostomy tube; the attitude of the public towards people living with a tracheostomy tube; the needs assessment of people living with a tracheostomy tube towards the planning of rehabilitation programmes; the clinical viability of the “finger occlusion method” of speaking among people living with a tracheostomy tube. Ultimately, findings of the study will add knowledge to the field of tracheostomy experiences.

1.7 Operational Definitions

Adults: Males and females aged 18 years and above

Experience: What a person living with a tracheostomy goes through.

Tracheostomy: An operation to make an opening into the trachea for breathing (Cheung & Napolitano, 2014; Dawson, 2014).

Thyroiditis: Inflammation of the thyroid gland (Dictionary, 2012).

Thyroidectomy: A surgical procedure to remove all or part of a thyroid gland (Dictionary, 2012).

Family: Parents, spouse, children, siblings and uncles
Polite Yawning: Fast, downward movement of the lower jaw and tongue, while *keeping the lips closed*, to create a subtle vacuum, drawing air into the nasal passages (Hilgers et al., 2000).

**Finger Occlusion Method:** Using any of the fingers to close the tracheostomy tube to enable sound production.
CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

This chapter discusses the thematic concepts used as the framework of reference for the study as well as the review of relevant literature on the experiences of adults living with a tracheostomy tube (ALTT). A search for literature was conducted to explore what was available on the lived experiences of ALTT regarding physical experiences, physiological experiences, psychosocial experiences, economic experiences, mode of communication and the coping strategies of life with a tracheostomy. The electronic databases used to perform the search included: ‘CINAHL’, ‘MEDLINE’, ‘SCIENCE DIRECT’, ‘PUBMED’, ‘GOOGLE SCHOLAR’ and ‘SCOPUS’. The search included keywords and phrases like ‘tracheostomy’, ‘living with’, ‘tube’, ‘life after tracheostomy’. These words were used together with ‘adult lived experience’, ‘physical’, ‘physiological’, ‘psychological’, ‘social’, ‘economic’, ‘communication’, ‘support’, ‘coping’, ‘self-identity’, ‘stigma’. Moreover, qualitative either individually or in combination was also added to get relevant studies on the lived experiences of ALTT.

The search identified several studies on tracheostomy. However, the majority of these studies focused on the surgical procedure, thus trying to determine the technique most appropriate with fewer complications (Lissauer, 2013; Walts et al., 2003) and suctioning technique (Khimani, Ali, Rattani, & Awan, 2015; Moore, 2003). The other studies also concentrated on how to care for the stoma regarding controlling infection, humidification and ensuring that the tubes are clean (Griggs, 1998; Randall, 2014; Woodrow, 2002). Nonetheless, a few studies saw the need to add psychosocial concerns such as altered body image (Adhikari et al., 2011; Myhren et al., 2010), anxiety and depression (Breckenridge, Chlan, & Savik, 2014; Gilony et al., 2005). Communication difficulties were also
identified (Flinterud & Andershed, 2015; Khalaila et al., 2011; Madan, Stadler, Uhrich, Reilly, & Drake, 2011). These findings have generated guidelines on how to care for a person with a tracheostomy tube. However, they lacked the perspectives of the person experiencing the phenomena of living with a tracheostomy tube.

2.2 Guiding Thematic Concepts of reference for the study

The study adopted the thematic concepts (figure 1), developed by Foster (2010) as a guide. Foster developed this thematic concept from the data analysis of a study conducted at a hospital in the UK to provide a graphical description of how tracheostomy has a physical and psychosocial impact from the acute phase of illness through to recovery (Foster, 2010). Living with a tracheostomy tube alters body image, affects verbal communication and impairs swallowing and breathing, impacting negatively on life (Dawson, 2014). Therefore selecting this thematic concept to guide the research questions and analysis was appropriate because it was consistent to a larger extent with the objectives of the study. It also offered a wide scope to explore the study area.

Figure 1: Guiding Thematic Concepts (Foster, 2010)
The thematic concepts have the following major concepts:

a. Necessity for communication
b. Retaining normality
c. Psychosocial discomfort
d. Painful procedures
e. Fear of the unknown
f. Relationships with staff

### a. Necessity for communication

Foster (2010) identifies this theme as core among the experiences of PLTT. He states that verbal communication is a very vital component of our day-to-day interaction with people around us. The findings by Donnelly and Wiechula (2006) support this phenomenon as they state that, the ability to speak is a basic functionality of every human being. Verbal communication allows us to be clear, well understood as well as to be seen and recognised as people. Individuals who lose their ability to communicate verbally lose their identity as a person (Ford & Martin-Harris, 2016; Foster, 2010).

### b. Retaining normality

This theme refers to the feelings related to deviations in normal activities such as communication, coughing, swallowing, and diet (Foster, 2010). Additionally, Johnson, St John, and Moyle (2006) describe this theme as a situation where people report of living in an unknown body that does not do its normal functions. The loss of normal body functions whether temporarily or not has a long-term impact on the individual even when the physical discomfort no longer exists (Foster, 2010). According to Johnson (2004), it demands a lot of efforts for PLTT to regain normality. This normality, however, is not equal to the normal life they lived before having the tracheostomy tube, but rather
becoming used to and having control over the most important things in their lives while living with the tracheotomy tube.

c. **Psychosocial discomfort**

Foster (2010) states this concept as the impact of a tracheostomy tube on patients’ daily lives. He states that the stoma at the anterior neck of PLTT and the difficulty in communication associated with having a tracheostomy tube among other challenges, limits tracheostomised persons in their social interactions with other people. These limitations make them withdraw from most social gatherings resulting in social isolation and other psychosocial challenges.

d. **Painful procedures**

This concept relates to the physical sensation of pain which PLTT experience. The dressing of the tracheostomy stoma, suctioning of mucus which accumulates in the tubes and coughing elicit pains (Al Sutari, Abdalrahim, Hamdan-Mansour, & Ayasrah, 2014).

e. **Fear of the unknown**

According to Foster (2010), this concept relates to the fear and anxiety associated with living with a tracheostomy tube as a new experience. Hafsteindóttir (1996) relates this fear to having a hole in the neck and unable to communicate. To be uncertain about regaining normality without using the tube, and whether or not living with the tube is going to be a temporary phenomenon makes patients have a fear of the unknown (Magnus & Turkington, 2006).

f. **Relationships with Staff**

Relationship with staff describes both the positive and negative experiences PLTT have with employees which are related to the care they received rather than the tracheostomy tube specifically (Foster, 2010).
This study applied some of the concepts since the study focused on people who were living at home with a tracheostomy tube. The present study applied the following concepts: Painful procedures, Psychosocial discomfort, Necessity for communication, Fear of the unknown and retaining normality.

In the examination of the related publications, the focus was on a description of the physical experiences, physiological experiences, psychosocial experiences, economic experiences, communication and the coping strategies of ALTT.

2.3 The physical experiences of living with a tracheostomy

The review of studies on the physical experiences of living with a tracheostomy tube on adults’ quality of life identified several challenges. These challenges included pain sensations (Arroyo-Novoa et al., 2008; Khimani et al., 2015; Stotts et al., 2007), reduced strength to undertake daily activities such as bending, walking and lifting (Gilony et al., 2005; Hashmi et al., 2010).

2.3.1 Pain in tracheostomy

The issue of pain is related to the physical presence of pains experienced by tracheostomised persons (Al Sutari et al., 2014; Foster, 2010). It is the commonest experience among people living with a tracheostomy which has an adverse impact on their lives (Ahlers et al., 2008; Li & Puntillo, 2006; Pandharipande, Patel, & Barr, 2014). Studies have shown that the procedure is painful and there is also pain during some nursing procedures such as breathing and coughing exercises (Al Sutari et al., 2014; Pasero, 2003; Siffleet, Young, Nikoletti, & Shaw, 2007). Repositioning (Siffleet et al., 2007; Stotts et al., 2007), as well as tracheal suctioning and stoma dressing (Arroyo-Novoa et al., 2008; Khimani et al., 2015; Moore, 2003) cause pain.
Using a 0 - 10 numeric rating scale, a behavioural tool, and a revised McGill Pain Questionnaire-Short Form, Arroyo-Novoa et al. (2008) measured the link between tracheal suctioning and the experience of pain by conveniently selecting 755 patients who had tracheal suctioning done on them in the intensive care units. The results showed that the intensity of pain was greater during tracheal suctioning (M = 3.96, S.D. = 3.3) than before (M = 2.14, S.D. = 2.8) or after (M = 1.98, S.D. = 2.7) the tracheal suctioning. Although the mean pain intensity during tracheal suctioning was mild, almost half of the patients reported moderate-to-severe pain.

Similarly, Stotts et al. (2007) state that 30% of ICU patients find tracheal suctioning to be an uncomfortable procedure. Applying a scale of 0 - 10, the pain intensity during suctioning of the tracheostomy tube was seven or more. This pain intensity was greater in tracheal suctioning than in other procedures such as wound care, wound drain removal, turning, femoral sheath removal and central line insertion among younger and older adults in Critical and Acute Care Units in acute care hospitals (Stotts et al., 2007). These are great revelations on tracheal suctioning and the associated pain. However, the use of the quantitative method in both studies limited participants in responding to predetermined questions and answers which could be different from their actual experiences of pain during tracheal suctioning. The participants were selected by convenience sampling method which is a non-probability method and thus, the patients who could not participate could have different pain responses and perceptions to suctioning.

To further understand the concept of pain in tracheal suctioning from the patients’ perspective, Foster (2010) used a qualitative phenomenology method to investigate the lived experiences of three tracheostomised patients at the NHS Trust Hospital in the United Kingdom (UK). Two of his participants lived on a tracheostomy tube for 14 and 36 days while the remaining participant was permanent. Findings from the study indicated that
people living with a tracheostomy tube experience painful sensations especially during procedures such as suctioning and dressing of the stoma and while coughing. Although the study offers rich information on the physical effects of adults with a tracheostomy tube, the use of participants who have lived with the tube for only 14 and 36 days gives an experience while in the acute care setting. This finding leaves a gap on people’s experiences in the home/community setting. It is also hard to understand whether the author reached data saturation on the various themes using only three participants.

Although there is an association between pain and suctioning of the tracheostomy tube, Karlsson, Lindahl, and Bergbom (2012) and Moore (2003), identify suctioning as an essential nursing intervention. Suctioning assists to get rid of secretions in the airway and to maintain proper ventilation and oxygenation in patients with a tracheostomy. Hence it is better to have such pains while being suctioned than to suffocate from secretions in the airway (Karlsson, Lindahl, et al., 2012). Sherlock, Wilson, and Exley (2009) state that suctioning should be reserved for patients who are not able to get rid of their secretions because the suction catheter and suction pressure can lead to tracheal damage and most patients find it distressing. Khimani et al. (2015) posit that with adequate knowledge on the pain experiences as well as other challenges associated with tracheal suctioning, health care professionals would be in a better position to enhance the safety of patients with a tracheostomy tube.

2.3.2 Activities of daily living and tracheostomy

According to Isaksson, Wilms, Laurell, Fransson, and Ehrsson (2015) living with a tracheostomy tube decreases strength and the power to work. There is a reduction in a person’s ability to undertake activities of daily living (Gilony et al., 2005; Hashmi et al., 2010) which leads to a decreased quality of life (Gul & Karadag, 2010; Hutzel, 2014).
According to Björklund, Sarvimäki, and Berg (2010) and Molassiotis and Rogers (2012), tracheostomised individuals are unable to undertake everyday functions and activities of daily living. They add that caregivers also express lots of frustration, resentment, and unhappiness.

Gilony et al. (2005) used the Karnofsky Performance Scale (KPS) to measure the influence of a tracheostomy on the quality of life and body image. The authors put 63 participants into three groups: A, 24 cannulated patients; B, 19 patients who have had successful Decannulation and C, 20 non-cannulated patients who were on admission for planned surgeries with no obvious body defects. On the level of physical activities among these three groups of participants, both cannulated and decannulated participants had reduced performance of activities of daily living. These findings widely support other studies that looked at the impact a tracheostomy has on activities of daily living (Gul & Karadag, 2010; Hashmi et al., 2010) of PLTT. However, these were quantitative studies which did not allow participants to provide in-depth explanations to their experiences. Moreover, participants responded to questions based on their experiences in the acute setting but not their lived experiences in the home setting.

Gul and Karadag (2010) identified that a tracheostomy influences activities of daily living which include sports, swimming, shopping, and bending thereby having a profound negative impact on quality of life.

2.4 The Physiological Experiences of living with a tracheostomy

Several physiological functions happen in the human body. These physiological functions keep the body in its normal state. Any deviation in the standard anatomy of the human body affects the human physiology (List & Bilir, 2004). There are structural changes in PLTT (List & Bilir, 2004; Russell, 2005). These structural changes affect
normal bodily functions such as breathing (Karlsson, Bergbom, & Forsberg, 2012), sense of smell (Gul & Karadag, 2010; Huffman et al., 2014) and verbal communication (Flinterud & Andershed, 2015; Madan et al., 2011). It also leads to difficulty in swallowing (dysphagia) (Ceriana et al., 2015; Sharma et al., 2007).

2.4.1 Difficulty in breathing

Studies have shown that breathing is a major concern for PLTT (Gul & Karadag, 2010; Huffman et al., 2014; Karlsson, Bergbom, et al., 2012). According to Karlsson, Bergbom, et al. (2012), the worst experiences of tracheostomised individuals is their inability to breathe. Changes in the anatomy of people with a tracheostomy cause a drastic decrease in the normal warming and humidification of inhaled air (Russell, 2005). A reduced humidification of the inhaled air may result in retention of secretions, impairment of mucociliary clearance, a decrease in cough reflex and also a reduction in the function of the lungs (Clarke, 1995; Conlan & Kopec, 2000; Woodrow, 2002).

Karlsson, Bergbom, et al. (2012) studied the lived experiences of adult intensive care patients who were conscious during mechanical ventilation in the ICU of the Swedish County hospital using a qualitative phenomenological hermeneutic design. The participants reported challenges such as the inability to breath, being voiceless and helpless. These findings impact negatively on the quality of life of patients with mechanical ventilation. Although the study provides rich information on the physical experiences of mechanically ventilated patients which include patients with a tracheostomy, the use of only participants who understand and speak Swedish (Karlsson, Bergbom, et al., 2012) makes it difficult to generalise the findings to other geographical areas.

Difficulty in breathing affects the quality of life of tracheostomised persons (Akram & Khosrow, 2009). It also makes these individuals weak, making them not able to perform
activities that demand much physical strength in addition to activities that would earn them income (Mehnert, de Boer, & Feuerstein, 2013).

2.4.2 Dysphagia

Structural changes in a tracheostomy operation also lead to difficulty in swallowing (Sharma et al., 2007). There is a decrease in elevation of the larynx, oesophageal compression, reduced closure time of the glottis and an obstruction from the cuff of the tracheostomy (Daudia & Gibbin, 2006; De Leyn et al., 2007). These increase the difficulty in swallowing in PLTT (Ceriana et al., 2015; Sherlock et al., 2009).

Sherlock et al. (2009) did a pilot study on the experiences of tracheostomy patients and their opinions on the flow of information at the hospital. The study involved eight patients who had been on a tracheostomy within 12 weeks. Six out of the seven participants who were on oral intake during the period of the interview had dysphagia. Participants had difficulties swallowing food and drink. This finding confirms that PLTT experience dysphagia; however, 12 weeks experience on a tracheostomy is a short time to tell the impact dysphagia will have on the quality of life.

There have been conflicting findings on the association between living with a tracheostomy tube and experiencing aspiration. Some earlier findings identified a link between a tracheostomy and aspiration (Elpern, Scott, Petro, & Ries, 1994; Pannunzio, 1996). However, some new discoveries identified no such association between a tracheostomy and aspiration (Brady, Wesling, & Donzelli, 2009; Leder & Ross, 2010). There is the need to assess the swallowing status as well the airway of these people by speech-language pathologists for appropriate interventions (McGrath & Wallace, 2014; Starmer et al., 2014). The reason is that dysphagia in tracheostomised persons could result in loss of appetite and possible hypoglycaemia (Ganzer, Rothpletz-Puglia, Byham-Gray,
Murphy, & Touger-Decker, 2015; Tsang & Carey, 2015). Knowing the swallowing abilities of these individuals will facilitate the provision of their needed dietary needs the best way possible (Serra, 2000).

2.4.3 Reduced sense of smell and taste

A tracheostomy limits the nasal airflow, leading to an altered sense of smell (Hilgers et al., 2000; Hong, Holbrook, Leopold, & Hummel, 2012; Risberg-Berlin, Rydén, Möller, & Finizia, 2009). The human sense of smell influences well-being and performance and it is directly linked to the quality of life (Huffman et al., 2014; Kennedy, Lewis, Stow, & Sobol, 2016; Tsikoudas, Barnes, & White, 2011). For example, the ability to smell enhances appetite and food choices (Croy, Nordin, & Hummel, 2014; Hays & Roberts, 2006; Mennella, Jagnow, & Beauchamp, 2001). When there is reduced ability to smell, there could be reduced appetite which may later result in loss of weight (Huffman et al., 2014).

A person’s ability to smell means that person is in a good position to perceive possible hazards in the environment. Smelling affects our relationships with others (Doucet, Soussignan, Sagot, & Schaal, 2009; Jacob, Garcia, Hayreh, & McClintock, 2002; Jacob, McClintock, Zelano, & Ober, 2002; Neuland, Bitter, Marschner, Gudziol, & Guntinas-Lichius, 2011). To live with a reduced sense of smell means there will be difficulty in detecting possible hazards in the environment, which is a threat to the person’s safety (Miwa et al., 2001). This feeling of insecurity could lead to anxiety and depression (Croy, Negoias, Novakova, Landis, & Hummel, 2012; Tsikoudas et al., 2011).

Kennedy et al. (2016) did a cross-sectional survey on the ability to smell among 18 paediatric patients living with a long-term tracheostomy (cannulated), persons who had been decannulated after a long-term tracheostomy and individuals who were healthy and
could match the age and sex as controls. The participants of the study had no nasal abnormalities or any other challenge that could destruct the test. The results of the survey suggested that tracheostomy affects the smelling functions of people who are still living with a tracheostomy or have been decannulated. The study provides rich information to affirm the association of a tracheostomy with a reduced sense of smell. However, the use of only paediatric patients presents a need for further studies among adults to enhance a full understanding of the smell phenomenon among a tracheostomy patients.

2.5. The psychosocial experiences of living with a tracheostomy

There are several studies on psychosocial experiences of a tracheostomy. Conclusions from these studies suggest that people living with a tracheostomy have a drastic reduction in psychosocial functioning. This decrease in functioning alters body image, life gratification, and self-esteem (Adhikari et al., 2011; Fingeret, Teo, & Goettsch, 2015). It further impacts greatly on their quality of life (Dawson, 2014; Hashmi et al., 2010). Such psychosocial challenges can be attributed to the prominent disfigurement at the anterior neck (Gilony et al., 2005; Katz, Irish, Devins, Rodin, & Gullane, 2000). Moreover, the inability to communicate properly to enhance successful interpersonal relationships and social interactions is also a setback (Flinterud & Andershed, 2015; Madan et al., 2011).

The obvious psychosocial impact of a tracheostomy that people experience includes; embarrassment and shame (Buhlmann & Wilhelm, 2004; Conroy et al., 2008; Fuchs, 2002). There is also social isolation (Akenroye & Osukoya, 2013; Bessell, Dures, Semple, & Jackson, 2012; Flynn, Carter, Bray, & Donne, 2013) and emotional distress (Adhikari et al., 2011; Ringdal et al., 2010). People experience anxiety and depression (Breckenridge et al., 2014; Engström et al., 2013) as well as suicidal ideations (Cougle, Keough, Riccardi,
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& Sachs-Ericsson, 2009; Phillips & Menard, 2006). Besides, self-concept and sexuality are also affected (Fobair et al., 2006; Gallo-Silver, 2011; Olsson, Berglund, Larsson, & Athlin, 2012).

2.5.1 Altered body image

The term ‘body image’ has been used to conceptualize the psychosocial impact of people’s perception of their bodies. Body image is described as the perception people have of their physical self and most importantly, the perception they believe other people have of them (Grogan, 2007; Phillip & de Man, 2010). These include the perceptions of, and the reactions to how they look, beauty, the state of health, functionality, and sexuality. The concept also incorporates a person’s sense of how their body influences interactions (e.g. how they feel about themselves and other people’s reactions to them), making it a major factor in social and interpersonal relationships (Grogan, 2007; Lubkin & Larsen, 2006; Muth & Cash, 1997).

Altered body image, however, is a state of personal distress, defined by the patient, which indicates that the body no longer supports self-esteem; it is dysfunctional to individuals, limiting their social engagement with others (Fingeret et al., 2015). Altered body image exists when coping strategies are overwhelmed by injury, disease or social stigma (Price, 1995). According to Pelusi (2006), it is not only the changes in physical appearance which makes the patient experience altered body image; a mental image of our appearance does not necessarily match actual body structure, but a change in body image implies that a patient feels changed, physically or psychologically.

Zając et al. (2008) identified a relation between altered body image and low quality of life and relates it to the physical disfigurement (stoma). The face and neck play a major role in an individual’s perception of self (Callahan, 2005). It is in a visually prominent area
of the anatomy, reflecting animation and emotion and serving as a means of communication with others. As a result, Fingeret et al. (2015) state that the presence of a hole in the neck that is kept open by a tube, and through which sputum come out, is likely to reduce the quality of life. Altered body image also leads to high levels of embarrassment and shame (Buhlmann & Wilhelm, 2004; Conroy et al., 2008; Fuchs, 2002). The reason is that the mere realisation of an altered body image makes a person feel shameful and embarrassed in the midst of other people. Most people do not feel comfortable in their current situation, they feel awkward within themselves and would not want to be seen in public because they feel embarrassed by their appearance (Buhlmann et al., 2010).

2.5.2 Social Anxiety and Social Isolation

Facial disfigurement profoundly affects self-concept, social interaction, and emotional well-being (Katz, Irish, Devins, Rodin, & Gullane, 2003). These often result in people feeling isolated and restricted in their social activities (Newell, Ziegler, Stafford, & Lewin, 2004). Studies have shown that people with a tracheostomy exhibit strong signs of social anxiety and social isolation (Aderka et al., 2014; Akenroye & Osukoya, 2013; Bessell et al., 2012; Fingeret et al., 2015; Flynn et al., 2013).

Akenroye and Osukoya (2013) evaluated the social impact of permanent tracheostomy and their management in the Ondo State, Southwest Nigeria. They purposively selected four participants who were all females with ages 65, 50, 43 and 40 years who had lived with a tracheostomy for over 11 years for the study. The authors identified that people living with a tracheostomy had a common challenge of social integration as was indicated by all four participants in the study. The presence of a tracheostomy tube on the neck of people encourages social stigma which prevents them from socially interacting with others. Akenroye and Osukoya (2013) identified that the
families of individuals with a tracheostomy tube were reluctant to accept them home, three (75%) of the four participants stated. The findings by Akenroye and Osukoya (2013) provide significant evidence of the social impact of a tracheostomy. However, the use of only female participants makes it gender bias as the inclusion of males in the study would have made the results richer and generalisable, because the findings as they stand now, may only apply to an all-female population.

Flynn et al. (2013) reviewed reported experiences and views of parents’ whose children has had a tracheostomy tube. Using critical appraisal of qualitative studies guided by the seven criteria outlined in Carter and Goodacre, 10 publications met the inclusion criteria for the study of which six were qualitative and four quantitative. The ages of the children in all the studies were between 2 and 18 years. The authors identified social isolation as a major issue for people living with a tracheostomy. According to the respondents, social isolation can be caused by several factors which include the stigma attached to having a tracheostomy. For a person with a tracheostomy tube to fully partake in any social interaction meant that the people involved understand and accept living with a tracheostomy tube. When this acceptance is absent, the best thing people with a tracheostomy do is to limit their participation in social activities by staying isolated or socialise with few friends and relatives who understand and accept them (Myhren et al., 2010).

People who are socially anxious usually show signs of intense fear most especially when they are going to be exposed to the public (American Psychiatric Association, 2013; Ballenger et al., 1998). According to Bögels et al. (2010), these people mostly exhibit physical and motor symptoms such as blushing, trembling and sweating due to the fear that others are observing their altered body. According to Rumsey, Clarke, White, Wyn-Williams, and Garlick (2004), these symptoms worsen when there are public staring,
name-calling, and unwanted interrogations. These experiences result in appearance-related distress, and make them feel they are not complete, and lead to creating a negative mindset on what they understand about attractiveness (Bessell, Clarke, Harcourt, Moss, & Rumsey, 2010). Individuals with these difficulties may also be socially timid and appear withdrawn or shy (Akenroye & Osukoya, 2013). In some instances, they put up camouflaging behaviours such as wearing clothes with a long neck or hanging extra materials around their neck to cover the tracheostomy tube in order to conceal their defects (Bessell et al., 2012; Flynn et al., 2013).

2.5.3 Sexuality

Sexuality has a close association with body image (Salter, 1992). Even though the desire for sexual activity exists in the midst of a significant degree of disability (Schonhofer et al., 2001), many people who live with stomas worry about sexual issues (Nugent, Daniels, Stewart, Patankar, & Johnson, 1999; Persson & Hellström, 2002). Cantlay (2015) indicates that the existence of a tracheostomy tube in addition to difficulty in breathing and an altered voice and appearance may particularly affect sexuality. There is also the loss of the desire for sexual activities such as becoming conscious of the stoma and thinking that one’s partner finds it unattractive (Gallo-Silver, 2011). Many people with physical anomalies and their sexual partners are mostly aware of the contradictions of the body and its exposure in intimate acts when the body and its imperfections are exposed (Olsson et al., 2012). An absence of a body part and various bodily dysfunctions complicate individuals’ social and sexual lives (Fobair et al., 2006).
2.5.4 Anxiety, Depression, Distress, Aggression and Suicidal Ideations

Sharpe, Patel, and Clarke (2011) state that body image disturbance is essential because of its relationship with anxiety, depression, and distress. Breckenridge et al. (2014) studied the influence of a tracheostomy on anxiety in mechanically ventilated adults ICU patients using a secondary analysis of existing data from a large parent study. The study was conducted in the Minneapolis and St. Paul, Minnesota Urban area. Subjects used were from 12 ICUs, between September 2006 and March 2011. The inclusion criteria were; patients aged 18 years and above, alert and participating in their care, able to read and write in English, had an adequate corrected hearing and vision as determined by the ICU nurses’ assessment. A total of 116 patients were used to detect a difference of 13% in the Visual Analog Scale-Anxiety (VAS-A) scores after a tracheostomy placement, with the power of 80% and alpha set at .05. The VAS-A was used to measure patients’ anxiety each day. The findings of the study showed that the daily mean anxiety scores were quite variable among patients with a tracheostomy. Although these results enhance the existing evidence on the association between a tracheostomy and anxiety, the use of patients in the ICU continues to leave a gap on the experiences of people with a tracheostomy in the home.

Chiou et al. (2013) evaluated the link between the level of emotions and health-related quality of life (HRQOL) in well head and neck cancer (HNC) patients post-treatment and to explore their predictive factors using a cross-sectional design between 2008 and 2010 in Taiwan. The authors recruited 73 HNC patients post-treatment, at least one year to complete three survey tools. These tools were; the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire version 3.0 (EORTC QLQ-C30 v.3), the EORTC Head and Neck Cancer Module (EORTC QLQ-H&N35), and the Beck Depression Inventory-II (BDI-II). The results of the study showed that depression is a major problem in patients with Head and Neck Cancer. Depressed Head and Neck
Cancer patients had a significantly poor global health-related quality of life in almost all functioning symptoms.

Björklund et al. (2010) state that people living with a tracheostomy become anxious and depressed mostly because of a reduced ability to fully undertake activities of daily living which are usually used to measure the quality of life of a healthy person. Yanhui et al. (2010) posit that people pay attention to how they look and how they appeal to others. The authors add that this phenomenon is more common in individuals with altered body image than those with no appearance concerns, which usually result in higher levels of depressive symptoms. Buhlmann et al. (2010) provide further evidence that altered body image leads to significant morbidity such as depression. In most instances, these feelings lead people to have negative thoughts such as suicidal ideation and suicide attempts (Cougle et al., 2009). People are unable to live with the stigmatisations attached to altered body image. Some individuals may appear defensive and be dismissive of their appearance which can manifest as aggression usually borne out of the negative response they have received from others (Bessell et al., 2010).

2.6. The Economic experiences of living with a tracheostomy

Studies have shown that the presence of a tracheostomy tube reduces strength and the power to work (Isaksson et al., 2015). According to Mehnert et al. (2013), a PLTT is likely to experience challenges such as reduced strength to work, stopping work, compulsory retirement, and change in job description. In some situations, PLTT changes their routine daily activities both at home and at work (Björklund et al., 2010; Griffiths, Humphris, Skirrow, & Rogers, 2008). This change of activities enables them to meet the demands of everyday life in the midst of the physical inactiveness of living with a tracheostomy tube (Molassiotis & Rogers, 2012; Röing, Hirsch, & Holmström, 2007;
Semple & McCance, 2010). The change in activities also affects their employment because they are unable to do jobs that need physical strength, resulting in reduced income (Steiner, Cavender, Main, & Bradley, 2004).

2.7. The communication experiences of living with a tracheostomy

Communication and specifically verbal communication forms the core aspect of our day to day interactions. The ability to communicate verbally is a fundamental need for every individual (Donnelly & Wiechula, 2006). Speaking enables us to express ourselves, our feelings, and it also allows people to recognize us as humans (Donnelly & Wiechula, 2006). However, studies have shown that a tracheostomy greatly affects the ability to communicate verbally (Flinterud & Andershed, 2015; Guttormson, Bremer, & Jones, 2015; Khalaila et al., 2011). More than 50% of tracheostomised individuals report of reduced ability to verbally communicate (Samuelson, Lundberg, & Fridlund, 2007). Reduced verbal communication is one of the biggest challenges of people living with a tracheostomy (Lewarski, 2005; Sherlock et al., 2009). This reason is that the tracheostomy tube goes below the vocal cords, thus reduce the ability to produce sound. Therefore the act of speaking is inhibited (Woodrow, 2002).

Mostly, the inability to speak leads to psychological discomfort (Karlsson, Bergbom, et al., 2012; Khalaila et al., 2011; Patak et al., 2006). Usually, they exhibit signs of frustration (Flinterud & Andershed, 2015; Johnson et al., 2006) and fear (Khalaila et al., 2011). There is also anxiety, depression, and distress (Engström et al., 2013; Hashmi et al., 2010; Myhren et al., 2010).

Flinterud and Andershed (2015) used a descriptive qualitative design to explain how tracheostomised patients in intensive care communicate and to get a better understanding of their experiences in the perspective of the transitions theory. The sample size was 11
adults who were 18 years or older and could speak the Norwegian language. Findings from the study indicated that PLTT goes through different kinds of psychological experiences trying to communicate. They feel powerless, have upsetting emotions and lose control. Tembo, Higgins, and Parker (2014) posit that being voiceless feels like being imprisoned or being trapped. According to Guttormson et al. (2015) and Laakso, Markström, and Hartelius (2009), inability to communicate verbally affect a person’s well-being, safety, and comfort which affects the quality of life.

Studies have shown that tracheostomised persons adapt the use of a non-verbal form of communication (Barnett, 2012; Flinterud & Andershed, 2015; Grossbach, Stranberg, & Chlan, 2010; Hurtig & Downey, 2008). Usually, they resort to the use of pen and paper, picture and alphabet boards, and techniques such as nodding or shaking their heads as well as eye blink to communicate initially (Barnett, 2012; Grossbach et al., 2010; Hurtig & Downey, 2008). Nonetheless, as indicated by Flinterud and Andershed (2015)’s, study, their ability to verbally communicate improves with time. Techniques such as lip-reading, facial expressions, and more recently, the use of “speaking valves” assist them to achieve successful communication (Barnett, 2012; Flinterud & Andershed, 2015). However, these methods of communication are not all the time effective; speaking valvve are costly and usually prone to breakages, usually leading to stress and frustration (Hashmi et al., 2010; Patak et al., 2006).

2.8. Patients’ coping strategies of living with a tracheostomy

List et al. (2002), define coping as the ability to develop adaptive behaviours or strategies to minimise the experience of stress. Tracheostomised patients experience far-reaching emotional reactions while they find ways to cope with the change in their appearance and present themselves to others. Some individuals can cope well with their
situation, while others become isolated and depressed (Wood & Bisson, 2004). Aarstad et al. (2008) indicate that the inability to develop a good coping mechanism reduces one’s quality of life. However, individuals who show proper coping mechanisms, find emotional support from family members or friends (Derks et al., 2005), and are resilient undergo less depression and have improved quality of life (Hassanein et al., 2005).

In line with the conclusions drawn by Semple and McCance (2010) and Bessell and Moss (2007), people living with a tracheostomy receive psychosocial and everyday support from family and friends. Spirituality alongside the support they get from church gives them a sense of direction, peace, and meaning to life (Semple & McCance, 2010; Spratling, Minick, & Carmon, 2012). Furthermore, emotional support from employers and employees (formal counselling) and working colleagues promotes proper coping (Semple & McCance, 2010). Richardson, Morton, and Broadbent (2015) indicate that tracheostomised persons can cope better when there exists a robust and healthy bond between the patient and the caregiver and whether there is a good support system available. Health care providers are also major players in ensuring that patients with a tracheostomy tube can live a normal life despite their challenges, providing informational, practical, and emotional support to enable them to develop effective coping skills and increasing confidence in social settings (Bessell & Moss, 2007).

A more recent form of coping mechanism identified by Madan et al. (2011) is social media platforms such as Facebook, Twitter, WhatsApp, which have the potential to reduce social isolation and improve peer interaction and communication. It also augments social supports.
2.9. Summary of literature review

The literature reviewed showed that living with a tracheostomy tube comes with physical, physiological, psychosocial, and economic as well as communication stress of which these individuals used different strategies and supports to cope. Most of these findings focused on the patients’ experiences in the acute care setting which make the lived experiences of ALTT in the community/home setting understudied. In addition, most of these findings were from quantitative studies which did not allow participants to provide in-depth explanations to their experiences. These are findings from studies conducted in developed countries. There is a paucity of knowledge on people’s lived experiences after a tracheostomy in the Ghanaian context. In the current study, information about the lived experiences of ALTT was provided. The difficulties associated with Ghanaian adults living with a tracheostomy were explored and described. The belief is that findings from the study will enhance the delivery of nursing care, assist the development of better rehabilitation programmes and add to knowledge in the field of a tracheostomy experiences. In the ensuing chapter, detailed descriptions of the methodology used in the study are shown.
CHAPTER THREE

METHODS

3.1 Introduction

This chapter describes the methods which were used to conduct the study. These include the research design, the study setting, target population, the sampling method and how the data was collected and analyzed. The chapter also discusses the methods that were used to ensure trustworthiness (methodological rigour) as well as ethical considerations.

3.2 Research Design

The study employed qualitative research design. Qualitative research involves an interpretive, naturalistic approach which studies human experiences in their natural environment. Thus, the manner in which people make meaning of the world and the experiences they have in the world (Borbasi & Jackson, 2012; Denzin & Lincoln, 2005; Gergen, Josselson, & Freeman, 2015; Merriam, 2009). The goal of qualitative research is to generate an understanding of a phenomenon from the perspective of the person experiencing the said phenomenon (Spiers, 2000). Specifically, an exploratory descriptive design was employed to explore and describe the experiences of adults living with a tracheostomy (Mayan, 2009). According to Brink and Wood (1997), exploratory, descriptive design explores people in their natural settings, it provides a minimum control of variables, and the end-product of the data collected either aid in theory development or assist in explaining a subject from the people studied.

Therefore this design was desirable to offer rich, comprehensive information from the perspective of people living with a tracheostomy about how adults live with a tracheostomy (Webb, 2011), given the researcher’s clinical experience gained through practice as an Ear, Nose, and Throat (ENT) Nurse.
3.3 Research Setting

The study took place in Kumasi, the capital city of the Ashanti Region and the second biggest city in Ghana. Kumasi is sited in the transitional forest zone and has a distance of about 255.6km from the National Capital, Accra. There are 209 communities in Kumasi, and the metropolis has a population of about 1,975,628. The people in Kumasi are mostly Ashantis. Their primary occupation is trading and farming. “Twi” (Ghanaian local language) is the local dialect shared by almost all people. Kumasi is cosmopolitan in nature and has drawn migrants from all over the country and from abroad. There is a mixed culture in Kumasi; aside from the Ashantis, other ethnic groups have also settled in the city. These include Fantes, Dangomba, Frafra, Hausa, Ewe, Ga-Adangbe, and Krobo.

There are many public and private schools in the metropolis. It also contains one of the nation’s biggest universities (Kwame Nkrumah University of Science and Technology). Both public and private hospital offer health services in the Metropolis. These hospitals include:

- 10 Government Hospitals (1 Teaching Hospital - Komfo Anokye Hospital).
- 160 Private Hospitals/Clinics.
- 3 Quasi-Governments Hospitals.
- 2 Christian Health Associations of Ghana (CHAG) Institutions.
- 18 Private Laboratories.
- 676 Pharmacies.
- 514 Chemical Shops.

The Ear, Nose, and Throat Department at Komfo Anokye Teaching Hospital was the outlet for the recruitment of the participants. The unit is the second largest ENT Department in the country apart from the ENT Department at Korle-Bu Teaching Hospital.
The Komfo Anokye Teaching Hospital (KATH) in Bantama was built in 1940 and became a Teaching Hospital in 1975. The geographical location of the 1000 – bed Komfo Anokye Teaching Hospital, the road network and the business nature of Kumasi make the hospital reachable to all the areas that share boundaries with Ashanti Region and others that are farther away. Referrals come from the three Northern Regions namely, Northern, Upper East, and Upper West Region; Brong Ahafo, Central, Western, Eastern and some parts of the Volta Region. The ENT Department of the hospital came into being in 1963. The Department attends to clients with all kinds of ENT health problems including patients with conditions that call for a tracheostomy. The Department performs close to 78 tracheostomy surgeries annually. The Department also accepts referred cases from neighbouring countries such as Cote d'Ivoire, Togo, Nigeria and other African countries.

3.4 Target Population

The target population for this study was Ghanaian adults living with a tracheostomy in the Kumasi metropolis.

3.4.1 Inclusion Criteria

The inclusion criteria for the study were both males and females who:

a. Were aged 18 years and above or older, because the study was targeted at adults.

b. Had lived with a tracheostomy for at least one year. People with less than one post tracheostomy experience were likely to focus on their intensive care experience and immediate post-operative recovery, which was not the focus of this study.

c. Could speak “Twi” (local language) or English (these were languages the researcher could speak fluently)
d. Gave an informed consent to be participants in the study.

3.4.2 Exclusion Criteria

a. Persons who had extreme difficulty in speaking

b. Individuals with the obvious psychiatric deficit.

3.5 Sample size and sampling technique

The sample size of the study depended on data saturation when successive participants gave similar responses, and no new themes and subthemes emerged (Bernard, 2011; Schensul & LeCompte, 2010). The data reached saturation by the ninth interview. The participants of the study were recruited using purposive sampling method. This approach enabled the selection of individuals who had specific knowledge and experience in the phenomenon under study (Marshall & Rossman, 2014). The sampling technique also allowed only participants who met the inclusion criteria to be recruited to provide the rich information on their experiences on living with a tracheostomy. The ENT Department at the Komfo Anokye Teaching Hospital was the outlet for recruitment. Adults who have lived with a tracheostomy for at least one year and accessed care at the ENT Department were recruited.

A formal permission was sought from the head of the ENT Department with an introductory letter from the School of Nursing, University of Ghana, which stated the purpose of the study. The researcher used multiple strategies to identify and recruit participants with the support of two ENT Nurses and the nurse-in-charge of the department. The researcher had an interaction with these three staff to brief them on the purpose of the study as well as the inclusion and exclusion criteria and gave them the information sheet which contained the complete information about the study. The contact number of the
researcher was made available to the nurses for notification of potential participants. The researcher reached such potential participants on the phone, explained the study to them, answered all questions bothering them and subsequently screened them for eligibility. The researcher then met the potential participants who showed interest at a mutually convenient time and place, completed consent form and conducted the interview.

3.6 Pre-testing of Data Collection Tool

The semi-structured interview guide was pre-tested with two adults who met the inclusion criteria in the Accra Metropolis using Korle-Bu Teaching Hospital as the point of recruitment. The goal was to determine if the guiding questions and wording were appropriate and comprehensible and to practice explaining the study, and completing informed consent procedures. The practice interview also enabled the researcher to improve his interviewing skills.

3.7 Data Collection Tool and Procedure

The data collection was from January to April 2016. The researcher used individual interviews as the primary data collection tool. These in-depth interviews employed a semi-structured interview guide with open-ended questions (Appendix B) to solicit information from each participant. During and after completion of informed consent (Appendix C), the researcher established rapport with the participants and also gained their cooperation which allowed them to share their lived experiences freely on a tracheostomy tube. This rapport building occurred while completing a basic demographic profile (Appendix A) which assisted in reducing participants' anxiety through answering easy questions about themselves.
The researcher started the interview with a grand tour question “Tell me about your experiences on living with a tracheostomy”. Grand tour questions opened up discussions and allowed participants to choose a convenient way to begin (Mayan, 2009). Furthermore, any unclear responses from the participants were also be clarified when necessary while asking for follow-up information during the interview (Leedy & Ormrod, 2001; Mayan, 2001, 2009). Following this question, the researcher used probes to explore their experiences and perceptions about changes and adaptations after a tracheostomy.

During the interview, the researcher wrote brief notes to keep track of ideas for later exploration; he observed verbal and nonverbal behaviours as observation included some degree of interaction between the researcher and the environment or the people being observed (Dewalt & Dewalt, 2011). The interviews were audio-taped and transcribed verbatim (Mayan, 2009). The in-depth interviews were conducted at participants’ places of choice, i.e., their home or workplace to certify that they were comfortable during the process. The researcher did all the interviews in Twi (local dialect). The interviews lasted between 45 to 70 minutes.

As data collection and analysis progressed, and as the researcher learned more about the participants’ experiences of living with a tracheostomy, interview questions evolved and focused on issues and concepts important to the participants’ experience rather than the concepts that he identified as essential before the start of the study (Mayan, 2009).

3.8 Data Management

Interviews were audio-taped and the observations made on participants formed part of the field notes which were taken to complement the audio-recording. Participants were assigned letters in a chronological manner (A to Z) according to the order of the interview. Researcher transcribed verbatim each recorded interview immediately after the interview.
A replay of the audiotape was done to ensure accurate transcription and to reduce error and omissions as much as possible. During the transcription, pseudonyms were used to replace the letters. Each transcription was saved as a different file and put in a folder with special identification. The researcher kept the hard copies of the interviews under lock and key in the office. Additionally, participants’ demographic characteristics were separated from the hard copies. Electronic copies of the transcriptions were kept in a folder on a password protected computer hard drive to ensure that data was secure and safe.

3.9 Data Analysis

Data analysis was done simultaneously with data collection using thematic content analysis technique to identify important themes and patterns in the data. The process of data analysis in this study involved identifying, coding and categorizing the primary patterns in a data. It involved organising and integrating narrative qualitative information according to the emerging themes and concepts (Mayan, 2001; Miles & Huberman, 1994). The researcher spaced out individual interview sessions to enable simultaneous data collection and analysis, to follow the tenets of inductive inquiry. The researcher booked no interview until the recorded interviews were transcribed and coded.

The researcher familiarized himself with the data by listening and reading and re-reading the transcripts several times, noting down initial ideas after each interview. The researcher then generated the preliminary coding by noting interesting ideas, words or concepts. This open-coding included labelling section of text that were important to the research questions. The researcher used in vivo coding which involved labelling participants own words with labels to remain close to the data and to preserve the vitality of the meaning. Categories were formed by merging similar codes and using encompassing labels. Comparison of categories continued and the researcher examined the relationships
between categories. The researcher identified themes, which were underlying ideas that seemed related to all data. The researcher discussed the coding and data analysis with a supervisor to have a better data analysis.

3.10 Methodological Rigour (Trustworthiness)

Rigour is a critical component of a qualitative study. (Speziale, Streubert, & Carpenter, 2011). According to Aroni et al. (1999), rigour is the process of showing reliability and proficiency in a qualitative study and a demonstration of the validity of the research procedure. Morse, Barrett, Mayan, Olson, and Spiers (2002) posit that a qualitative study which lacks rigour is not credible and would not impact knowledge. It is, therefore, essential that reliability and validity be adequately employed when conducting research. Consequently, trustworthiness, composing of credibility, transferability, dependability, and confirmability has been chosen as the criteria which are equal to reliability and validity to ensure rigour in a qualitative study (Guba & Lincoln, 1981, 1982; Lincoln & Guba, 1985). Situated in these are other methodological strategies such as audit trail, member checks when coding, categorizing or confirming results with participants, peer debriefing, and negative case analysis to ensure rigour in qualitative studies (Guba & Lincoln, 1982). The researcher applied the criteria above to ensure trustworthiness in the study.

Credibility, according to Merriam (1998) and Guba and Lincoln (1981) tells how reliable the findings of the study are to reality. According to Lincoln and Guba (1985) ensuring credibility is one of the most vital components in ensuring trustworthiness. The researcher purposefully recruited participants who met the inclusion criteria and were able to provide in-depth information on their experiences after the tracheostomy to achieve credibility. The researcher also employed iterative questioning skills and probes to elicit
detailed data from participants. Member checks were also carried out in the form of iterative verification to verify the accuracy of the data and by continuing analysis (Morse et al., 2002) at the end of the interview session. The researcher also ensured that each interview was transcribed and analysed (coded) before the next interview was conducted. Researcher again ensured that a second person experienced in qualitative research did independent coding. The two codings were compared to reduce disparities and also to present participants realities as much as possible.

Transferability describes how applicable the findings of a study are in other settings (Guba & Lincoln, 1981; Merriam, 1998). The researcher gave a thick description of the setting, the design of the study as well as the sample size and the method of data collection. The inclusion and exclusion criteria of the study, as well as the number and length of data collection sessions and the period used to collect the data, were described.

Dependability describes the replicability of the study by another researcher (Guba & Lincoln, 1981). To ensure dependability, the researcher wrote in detail the research process which included the design and its implementation, data gathering as well as evaluation of the success of the research methodology for future replication by another researcher (Shenton, 2004). This procedure assisted in establishing the proper application of the research process.

Confirmability in the qualitative study shows how objective the researcher is. It is the process of ensuring that the findings are the specific experiences and ideas expressed by the participants and not the preferences of the researcher (Patton, 1999). The researcher made sure that the results of the study reflected the participants’ experiences and perspectives, and not the researcher’s preferences by keeping a reflective journal of the researcher’s biases and assumptions. The researcher also kept an audit trail which showed how the data was collected, analysed and processed to get the findings of the study.
3.11 Ethical considerations

The researcher obtained ethical approval from the Institutional Review Board at the Noguchi Memorial Institute for Medical Research, University of Ghana. A permission was sought from the ENT Department of the Komfo Anokye Teaching Hospital, Kumasi with an introductory letter from the School of Nursing, University of Ghana and a copy of the ethical approval. Participants were given the information sheet which outlined the purpose and objectives of the study. Any potential benefits and risks were explained to participants in Twi (local dialect). The researcher then did a follow-up to get their intention either to participate in the study or not. Potential participants who accepted to take part in the study were given a consent form to sign. For participants who had challenges reading and writing, the researcher translated the consent form into Twi for them in the presence of a witness after which both the witness and the participant were made to sign or thumbprint the consent form. Researcher informed the participants that they had the option of not answering a question if it was sensitive, to pause or stop the interview or to withdraw from the study even after signing the consent form without any consequences. The researcher assured participants of the safekeeping of the data.

The researcher ensured confidentiality by assigning letters to participants in a chronological manner (A to Z) according to the order of the recruitment. Pseudonyms were used to replace the letters when quoting participants in the findings chapter or any publications. Participants were made aware that all the data and documents including the audiotapes, consent form would be kept under lock and key in researcher’s office for at least five years of the study. Additionally, participants’ demographic characteristics were separated from these documents. The soft copies of the transcriptions were kept in a folder with a password on researcher’s hard drive to ensure that data was secure and safe.
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The researcher anticipated minimal risks; however, participants’ reflections on their experiences could at times be distressing. The researcher arranged for an ENT counsellor/social worker to provide counselling services for participants when necessary. No participant was referred to the counsellor since participants were able to control their emotions while sharing their experiences. The participants were assured of anonymity during publications of aspects of this study.

Participants did not have any direct benefits, however, their experiences shared would assist to enhance the delivery of quality nursing care to people living with a tracheostomy tube.
CHAPTER FOUR

FINDINGS

4.1 Introduction

This chapter gives a description of the results of the data gathered from the various participants of the study on their experiences of living with a tracheostomy tube. Both common and unique experiences of all the participants are presented. Using thematic content analysis, eight themes were identified. They are physical experiences, physiological experiences, social experiences, psychological experiences, economic experiences, communication experiences, coping mechanisms and support. The main themes and their sub-themes are presented with verbatim quotations from the participants using pseudonyms. The Thematic Concepts and the objectives of the study were used to analyse the data. The descriptions of the background of the participants as well as the thematic findings of the study are also presented in the following sections.

4.2 Description of the study population

The study population was nine adults, of which eight were females and one, male, aged between 42 and 57 years. One was in his early forties, three in their late forties, another three in their early fifties and two in their late fifties. The average age of the participants was 50 years. Regarding their educational background, three of the participants had no formal education, four were middle school leavers, and the other two had tertiary education. Regarding their employment statuses, four of the participants were not working during the time of the interview. Out of these four, one was a trader, one, a farmer and the remaining two were secretaries before they had the tracheostomy tube. The remaining five participants were still working at the time of the interview. One was a farmer, another one was a teacher, and one a cleaner with the remaining two being traders.
Six of the participants were married, two were widows, and one was not married. Only one of the participants had no child, the remaining eight had children with ages ranging from 1 to 5 years. One participant had eight children, but only four were alive. Eight of the participants were Christians with one, a Muslim.

The participants spoke several languages such as Twi, Dagomba, Frafra, Grusi, Hausa, Fante, Ga, and English. All the participants spoke Twi aside their native languages. The participants’ years of experience in living with a tracheostomy tube ranged between one year four months and 32 years. All the participants were living permanently on the tracheostomy tube. Seven of the participants had their tracheostomy tube as a result of post-thyroidectomy complications (cut of recurrent laryngeal nerve), and the remaining two had upper airway obstruction. Two of the nine participants had their tracheostomy surgeries planned while the remaining seven were operated as emergency cases. The residential locations of participants were in and around the Kumasi Metropolis. All the participants accessed healthcare at the Komfo Anokye Teaching Hospital.

4.3 Organisation of themes and Thematic Concepts

Thematic Concepts (Foster, 2010) was used as a guide this study. There are six major constructs in the thematic concepts which provide a graphical description of how tracheostomy has a physical and psychosocial impact from the acute phase of illness through to recovery; necessity for communication, retaining normality, psychosocial discomfort, painful procedures, fear of the unknown, relationships with staff. This study, however, applied five of the constructs in the thematic concepts since the focus of the study was people who were living with a tracheostomy in the community. The findings of the study were organised according to the constructs of the thematic concepts together with the objectives of the study as; physical experiences, physiological experiences,
psychosocial experiences, economic experiences, communication experiences and coping strategies.

**Table 1: Summary of Themes**

<table>
<thead>
<tr>
<th>THEMES</th>
<th>SUB-THEMES</th>
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<tbody>
<tr>
<td>Physical experiences</td>
<td>Painful experience</td>
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<tr>
<td></td>
<td>Impaired activities of daily living</td>
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<tr>
<td>Physiological experiences</td>
<td>Difficulty in Breathing</td>
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<tr>
<td></td>
<td>Dysphagia</td>
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<td></td>
<td>Reduced sense of smell</td>
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<tr>
<td>Social experiences</td>
<td>Altered body image</td>
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<td></td>
<td>Social isolation</td>
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<td></td>
<td>Altered sexuality</td>
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<tr>
<td>Psychological experiences</td>
<td>Fear and anxiety</td>
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<td></td>
<td>Depression</td>
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<td></td>
<td>Suicidal ideation</td>
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<tr>
<td>Economic experiences</td>
<td>Work Challenges</td>
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<td></td>
<td>Reduced income</td>
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<tr>
<td>Communicate experiences</td>
<td>Mode of communication</td>
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<td></td>
<td>Challenges with verbalisation</td>
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<tr>
<td>Coping mechanisms</td>
<td>Acceptance of situation</td>
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<td></td>
<td>Resilience,</td>
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<tr>
<td></td>
<td>Spiritual</td>
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<tr>
<td>Support</td>
<td>Family,</td>
</tr>
<tr>
<td></td>
<td>Friends support</td>
</tr>
</tbody>
</table>
In the quest to answer the first research question: “What are the physical experiences of adults living with a tracheostomy tube,” one theme emerged; “physical experiences of a tracheostomy tube” with corresponding sub-themes. These are presented in the following paragraphs.

4.4 Physical Experiences of living with a tracheostomy

This theme describes the physical effects associated with living with a tracheostomy tube. It was realised that living with a tracheostomy tube was physically discomforting with a particularly painful experience immediately after the surgery. The pains emanated from the surgery itself, during bending, while coughing and when swallowing. Usually, the pains were treated with medications especially when it resulted from infections. However, some were allowed to resolve on their own as participants did not know which drug to take to address the problem. Living with a tracheostomy tube led to reduced strength leading to difficulty in performing activities of daily living such as cooking, washing and sweeping as well as challenges in mobility like bending, climbing and lifting items. The sub-themes identified for the physical impacts were painful experiences and impaired activities of daily living. These are described with verbatim quotations.

4.4.1 Painful Experiences

One of the major physical experiences of a tracheostomy tube among participants was pain that made it difficult to do anything. Participants indicated that the pain was severe in the initial stages after the surgery, and it usually subsided later in life.

“So when I was fully conscious, I saw that my neck and throat had become heavy, and I felt so much pain, but what could I do?” (Aba);

“I felt some pains and heaviness in my throat and on my neck. I wanted to lift my head, but the pains were so much. The nurses told me to relax}
and not to raise my head. I felt so much pain; the pains were unbearable that I even cried” (Mansa).

“Right now there is no pain, but when it was freshly done, it was painful” (Aba); “When I came home, actually, I did not feel the pains” (Becky);

“It was painful at first, but it is not painful now” (Sussy).

Participants indicated that the causes of the pain included the surgery itself (site of the operation), swallowing, piercing of the tube especially when they bent.

“It pained me, the location of the operation (pointed to the right lateral side of neck) pained me very much mostly on swallowing” (Nsiah).

“Oooh sometimes the tube chokes me, and I try to straighten it. It pierces and hurt when I bend down, and that makes it very painful” (Aba).

There were also chest pains from excessive coughing and pains when the stoma became infected.

“Whenever I cough, I have chest pains. When the inner tube become blocked, and I remove it, it was painful initially. I had to remove it gradually, yet I was able to wash it frequently. Coughing causes many pains” (Becky).

“….again when there is an infection, it is painful, but when the infection resolves, there is no pain” (Sussy).

However, most of the participants stated that suctioning or cleaning of the tube was not painful

“Suctioning was not painful. It was rather walking around that was difficult” (Becky); “Usually suctioning was not painful” (Aba).

Some participants used medications to treat the infections and resolve the pains.

“I go for a check-up, and I am given some medications for the infections and pains. The doctor told me to report anytime I have any infection” (Sussy).
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One of the participants did not report to the hospital or take any drugs. She endured the pains till it subsided on its own because she did not know which drug to take to relieve the pains.

“I did not do anything. I did not take any drugs because I did not know which drug I had to take to resolve the pain. So I could have the pain for 2 or 3 days, but I would not do anything. I always endured the pain till it subsided” (Akua).

4.4.2 Impaired activities of daily living

Participants indicated that the tube had reduced their strength, they easily got tired making them unable to performance activities of daily living.

“Now I am not fit, you may think I am fit when you see me, but when I am at home, I am unable to do anything” (Nsiah);

“I do not have enough strength now, my brother. The least activity I do, I get tired, and it is as if I am short of breath” (Mansa); “I am unable to do things quickly if I do it quickly, I have difficulty in breathing unless I rest for a while. So I usually don’t rush when I am doing something” (Akua).

All the participants indicated difficulties in doing routine activities such as bending, talking, sweeping, carrying or lifting items, climbing hills or stairs, walking briskly or exercising.

“I am unable to do any other thing like sweeping. I cannot bend down and sweep. As the tube is in, it is like a pen….. So anytime I bend, it hurts my throat” (Nsiah).

“I am unable to talk for a longer period. I usually get exhausted when I talk for a longer time. I do not have enough strength now” (Sussy).

“I was not having any such difficulties before I did the surgery. These days if I want to lift something, like a bucket with water to go and bath, I have to seize breathing for a while before I am able to lift the bucket. Because of the tube, I am unable to do this (tries to bend down)” (Adiza).

“You see, now my strength has reduced, I am not as strong as I was initially. The work I doing at first, I cannot do it now because I do not
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have the strength to work. You see this hill, (pointed to a small hill in front of her house) I almost die anytime I climb it. This little hill, it is not this one alone oooh, any hill at all, I cannot climb with ease. Unless I stop and rest severally, I cannot ’continue climbing” (Akua).

Some participants indicated their difficulty in undertaking household chores like washing their dirty clothes. This was because most of the participants felt dizzy and or had waist pains in their attempt to stand to do these activities.

“I am unable to wash. I do not know, but I get so tired of washing just a single cloth. The strength has reduced. I am unable to wash the clothes of my children. If I wash one cloth, I sweat profusely; it will surprise you” (Akua).

“I cannot even stand to do anything. As soon as I stand, I get waist pains. It was not like that at first before the surgery. I cannot stand to do anything, for instance, standing to wash, I cannot do it. I get dizzy anytime I stand, and I always feel like I am falling” (Nsiah).

Some participants also indicated cooking as a major challenge for them especially the females. This was due to weakness and difficulty in getting closer to fire. Usually, it led them into difficulty in breathing which made them felt uncomfortable.

“I find it tough to go near the fire, so cooking for my husband and children has become a burden for me. Thankfully, my husband has been very supportive. Most of the time he does the cooking and the children also assist” (Mansa).

“Even my cooking at home is a problem. Usually, I sit in one place and order for the items to cook” (Akua).
In the quest to answer the second research question: “What are the physiological experiences associated with adults living with a tracheostomy tube,” one theme emerged; “physiological experiences of a tracheostomy tube” with corresponding sub-themes. These are presented in the following paragraphs.

4.5 Physiological experiences of living with a tracheostomy

Living with the tracheostomy tube affected some physiological functions of the participants. It was identified that most of the participants were given the tracheostomy tube because of difficulty in breathing that emanated from complications of thyroidectomy.

Participants, therefore, became relieved initially of difficulty in breathing after they were given the tube. However, most of the participants reiterated that their exposure to dust and high scented substances resulted in difficulty in breathing. Participants were also afraid of getting aspirated from eating and drinking. Eating dried, roasted, fried and hard foods, as well as drinking soups, were major concerns for most participants. There were difficulties in controlling where these foods would pass, and most participants had the difficult task of creating a “support base” in the throat with their tongues to prevent aspirating the foods eaten. The ability to smell also reduced among several of the participants especially when the cover of the tube was taken off. Odour from the tube was sometimes not perceived unless participants were prompted. The sub-themes found included difficulty in breathing, dysphagia and a reduced sense of smell. These are described with verbatim quotations.
4.5.1 Difficulty in breathing

Breathing was a major concern to all the participants. Most of the participants had difficulty in breathing from post thyroidectomy complications which necessitated the tracheostomy operation.

“(Wiped tears from her eyes, occluded the tube and started to talk) I had a goitre, and I was operated; afterwards, I had difficulty in breathing because there was a problem with a nerve in my neck, so I was given the tube to aid me breath” (Mansa).

Given this, most of the participants indicated they were relieved of difficulty in breathing after they were given the tube although some were told the tube was going to be inserted temporarily.

“Yes I felt relieved because I was able to breathe well when the tube was inserted” (Becky);

“I was suffering initially with breathing, so I was not surprised when I woke up to see the tube. The doctor informed me that he was going to give me the tube for the time being and later he will remove it, so I felt it was a good thing for me because I was able to breathe afterwards” (Aba);

“My breathing is better than after the thyroidectomy when the tube was not there. The tube has again reduced the noisy breathing” (Sussy).

All the participants still had problems with their breathing while living with the tracheostomy tube.

“Awww, since I was given the inner tube, my breathing is not like how it was before, (takes in air and covers the tube) before I was given the inner tube, my breathing was better than how it is now” (Aba);

“There is difficulty in breathing. As you already know, this is not your natural breathing that God gave you, it is now artificial, and so your breathing will not be normal” (Adiza);

“The breathing is not as good as before I was given the tube” (Sussy).
Factors that contributed to the difficulty in breathing with the tube included intolerance to dust and high scented items. The exposure to dust made participants cough extensively and even coughed out blood and had difficulty in breathing.

“Sometimes I have difficulty in breathing especially when I come in contact with high scented items. Anytime I came in touch with great scented perfumes; I become breathless. If it happens while I am in traffic, I have to sit close to the window so that I can get enough air or else I will have problems with breathing” (Nsiah).

“Now that I have the inner tube in my throat if I am doing something, it does not like dust, so if dust gets into me, I suffer a lot. I suffer, and it makes me cough, cough severely and you will see that I even cough out blood” (Kwasi).

Accumulation of mucus in the tubes also resulted in difficulty in breathing.

Now too, with the inner tube, if I make the least mistake, and it blocks because I did not wash it, it becomes difficult for me to breath. Someone who does not know me may think I am asthmatic. Meanwhile, I do not have asthma” (Aba).

4.5.2 Dysphagia

Difficulty in swallowing was another major challenge for the participants. Most participants were afraid of getting choked whenever they ate. There were times participants had to take out the inner tube before they could eat.

“Yes there is a problem with swallowing, you have to be very careful else you will get choked. The food will pass through where food is not supposed to pass. That is how I see it, and it is same when you are drinking soup. So you have to get a “support base” in your throat. At times when I put soup in my mouth, I have to block my throat with my tongue else when it enters where it is not supposed to pass, I am in trouble” (Becky);

“Yes, the surgery has affected me in many ways. Even if I wanted to eat, I had to take out the inner tube” (Nsiah).
Participants’ biggest challenge was eating dried, roasted, fried and hard foods.

“Eating too dried foods could choke you, you always have to be careful, or when you are drinking soup, and you do not take your time, you can aspirate it; you will cough. So you have to take your time anytime you are eating” (Adiza).

“In the beginning, I was told not to eat hard foods, as it is dry and can choke me. So I was taking liquid diets and light soup” (Adoma).

“….for instance, roasted or fried yam, if there is not enough water in it, you have to take your time and chew till it gets very soft before you can swallow it well else it will choke you when swallowing. Even during chewing, I do not know if there is a hole there or not; if you do not use your tongue to support it, you can get choked” (Kwasi).

4.5.3 Reduced sense of smell

Some of the participants complained of reduced ability to smell. Detecting odour on themselves was a challenge unless someone prompted them.

“My sense of smell has reduced, it is not like before I was given the inner tube. Sometimes someone has even to tell me I have a bad odour on me because I am unable to smell it myself” (Aba).

“Yes, the presence of the tube has reduced my sense of smell. If you are not careful, you cannot detect the scent of anything; for instance the bad smell of something. Even now I used perfumes with caution else my nose will be blocked. There are a lot of issues ooh” (Akua).

“Sometimes you are unable to smell anything, and I do not know why. Even when you get an infection, there is a bad odour around you. There are times that I do not even perceive it myself. Usually, my husband is the one that tells I smell unpleasant. So I can say the way I smell has also been affected” (Mansa).
However, one of the participants did not have any problem with her sense of smell. She was able to detect any scent including good and bad ones.

“*My sense of smelling has not changed in any way; it is my vocal cords that have a problem. I can smell everything. I am even able to smell when there is an odour in the tube*” (Adoma).

In answering the third research question: “What are the psychosocial experiences of adults living with a tracheostomy tube?” two major themes emerged; social experiences and psychological experiences. These are presented in the following paragraphs:

4.6 **Social experiences of living with a tracheostomy**

The physical presence of the tube on the neck altered participants’ body image and made them “*look different*” and “*incomplete*”. The tube was very obvious in the neck. The position of the tube changed the way participants wore clothes. They were restricted in the kind of dresses they put on especially when they had to go for social gatherings. This prevented most participants from taking part in social activities either at church or home because they could not withstand how much people stared at them. Additionally, the odour from the tube also prevented participants from going into public gatherings. In situations where participants had to attend these programmes, other clothing materials were used to “*cover the neck*” to reduce being stared at. Usually, participants preferred to stay indoors. The sexual life of the participants was also affected. Participants felt “*unfit*” and “*unattractive*” to engage in sexual activities. The participants who were not married bemoaned that, most suitors got interested in them, but they got scared when they saw the tube. They lost hope in marrying. It was identified that both the married and unmarried participants had sex once in a while. The sub-
themes identified are altered body image, Social Isolation, and Altered Sexuality. These are described with verbatim quotations.

4.6.1 Altered Body Image

All the participants indicated that the physical presence of the tube altered their appearance and body image. They looked different, incomplete and felt bad.

“You see, when you have this (points to the tube) on your neck, it makes you look different... I feel sorry; I feel terrible. It is like you are not even a human being. You feel incomplete, and you feel weird as well. My brother, it is not easy for me at all” (Mansa).

Most participants indicated that the tube had changed their mode of dressing. The position of the tube restricted them in wearing certain kinds of dresses and putting on ornaments.

“It has changed the way I dress. I would have put on a necklace if I dress up, but with this, on my neck, I cannot put the necklace on” (Akua);

“It has affected my dressing and how I see myself severely. Even now if you are going to sew a dress, you are careful of the style; there are some dresses that you cannot wear now. You cannot wear dresses that can have contact with the tube” (Adoma).

4.6.2 Social Isolation

All the participants reiterated that the tube was very obvious on their neck, and people stared at them anytime they went out.

“The tube is very visible; it is very obvious to others that I have a problem going out with it” (Mansa).

“Eii! In the beginning, I was so disheartened. Someone could look at me till he hits an object before he would stop staring at me. Everywhere I went, people looked at me; at church, market everywhere, people stared at me” (Aba).
Most of the participants indicated that they socially isolated themselves from most public activities because of the odour from the tube.

“For me, ever since I had the tube, I have seized to patronize any public events. Truthfully I do not go to public places or gathering; I am truthful. (Chuckled, chuckled again) Usually, I do not feel right; you would not feel fine in yourself” (Sussy).

“Sometimes I am unable to go into the public, especially when there is an odour in the tube. My guilty conscience will even make me move from the crowd or isolate myself from the public” (Becky).

In situations where participants had to go, they covered their neck with other clothing materials to prevent the embarrassment from staring.

“All the time I covered my neck with the “hijab.” It is embarrassing going into the public with this tube because people will ask: “Why, what is wrong with her, what’s that in her neck.” Hmmm, it is pathetic” (Akua).

“I mostly wear shirts these days because those are the ones that can cover the tube a bit. Whenever I put on a shirt, I have to button to the neck, so it covers the tube a bit; either than that, I had to cover it with something, else people will look at you” (Kwasi).

4.6.3 Altered Sexuality

All the nine participants both married and unmarried complained of diminished interest in sexual activities.

“Honestly, since I was given the tube, I have lost interest in having sex, because it is tiring; but you cannot also stay unconcerned about your husband” (Becky);

“Ahh my sexual relationship with my husband - that one has diminished tremendously” (Nsiah);
Participants indicated they were unfit to engage in sexual activities. Hence they engaged in sexual activities once in a while.

“You do not have strength, so you cannot be having sex often. Your strength is low” (Akua); “...Ooh that one, once in a while I have sex” (Aba).

“Once in a while then, we make love. However, like to be doing it continuously, no! I cannot because there is not enough strength” (Kwasi).

Most of the participants echoed that the presence of the tube made them look unattractive. The participants who were not married had lost hope of marrying because they felt unattractive to suitors. Most suitors were scared of the tube so they could not approach them to talk about marriage.

“I have not married again. After my husband’s death, I have not remarried, but even with this tube in my neck, who will be interested in marrying me? If someone sees me with this tube in my neck and having difficulty breathing and talking, he will not even be interested in me. So now I do not have a husband, I am not married and since my husband’s death about 5 years now, I have never had sex” (Sussy).

“Ooh men are interested when they see me, but because of the tube, they are afraid. As I have been operated on with the inner tube in my neck, they get scared, so it is part of the reason why I am not married” (Aba).

However, participants who were married indicated that their partners understood their situation and empathised with them. The partners did not worry them with sexual activities often.

“Mmmmm, it is ok, (chuckles), it is not regular, but it is ok. My husband is fine with it because he knows the situation I am in” (Becky);

“My wife copes with it. That is why I said she has been very supportive and cooperative. You know, it is not every woman that will understand you like that, but she takes it like that. She has never complained. She knows I will give out my best if I had the strength” (Kwasi).
4.7 Psychological experiences of living with a tracheostomy

Most participants became anxious and depressed in their current state. Some participants were given the tracheostomy tube temporarily. However, unsuccessful weaning from the tube made participants live on the tube permanently. They had therefore lost hope in becoming normal again. Most of the participants were afraid of not knowing what was going to happen while they lived with the tube. There were also fears of dying and leaving children behind. Participants were disturbed going through these challenges and out of frustrations entertained the idea of committing suicide. The sub-themes identified are fear and anxiety, depression and suicidal tendencies. These are described with verbatim quotations.

4.7.1 Fear and Anxiety

Some of the participants initially thought they were going to live with the tube temporarily, but they had to live with it permanently due to unsuccessful weaning process. This made them sad.

“Oooh, I was there. I stayed at the ward for some time; I stayed for almost one month. Initially, I was told by the doctors that the tube would be removed after some time. However, here I am, six years now, and I am still living with it” (Mansa); “They tried, the doctors tried to remove it when I was in the ward. Initially, they covered it, but anytime it was covered; I had the difficulty in breathing. So they could not remove it, and I had to live with it” (Adiza).

The majority of the participants were anxious and had lost hope of becoming normal again. Participants had a fear of not knowing what will happen to them next while living with the tube.

“...since then no one had attempted to remove the tube because I suffered when the tube was removed. So I do not know whether the nerve will get to its normal state or not, I do not know” (Akua).
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“The Doctor told me I was only going to live with it for 6 months when it was 6 months, he did not say anything, one year time he did not mention anything. So in the second year when we went there, he stated that with this operation, when the nerves are cut, it cannot be repaired in Ghana unless outside. Who will send me outside the country for it to be repaired”? (Becky).

Some participants were even afraid they were going to die to leave their children behind.

They were disturbed going through such challenges.

“Eiii, my brother, you have this thing in your throat (points to the tube) you would be afraid. Whether you are going to live, whether you are going to die, you do not know. Meanwhile, my kids are very young, and I do not know what will happen to me, so that is what makes me sad...Eii!, (shook her head severally and continued to talk) it is not easy, (shook the head again) it is not easy (wiped tears from her eyes with her cloth and continued to talk) when you wake up in the morning, you become sorrowful” (Akua).

“It is very disturbing. Some people can stare at me till they run into an object before they stop watching me. When it happens like that, I get morose. Everywhere I go, people look at me; at church, market, everywhere, people stare at me” (Aba).

4.7.2 Depression

Participants bemoaned that it was depressing and disturbing having numerous challenges ranging from difficulty in verbal communication, difficulty in breathing, change in appearance and eating as well as reduced strength while living with the tube.

“It is sad and disturbing... (Wiped her tears with a tissue and continued to talk). Everything about me has changed now. I am living an almost new life full of challenges; A new life where eating is even a problem because you are afraid you will aspirate the food. I am unable to express my feelings when something disturbs me. You are always indoors because you are shy to go out... It disturbs” (Becky).

“Now, I am unable to talk much; there is difficulty breathing, even my appearance has changed, and I do not have enough strength because I get tired easily for doing the least activity. It worries me a lot, (looked
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saddened), it is as if you are not even a human being.....it makes me cry sometimes” (Sussy).

“There are times I want to add my voice to something but my situation does not allow me. It is very depressing at times” (Mansa).

4.7.3 Suicidal Ideations

Participants were disturbed going through these challenges and out of frustrations entertained the idea of committing suicide.

“Sometimes you feel like crying; you become so frustrated and so worried. You get sad and feel so lonely that if you are not careful, you will commit suicide” (Mansa).

In answering the fourth research question: “What are the economic experiences of a tracheostomy on adults living with a tracheostomy,” one main theme emerged; economic constraints. This is presented in the following paragraphs.

4.8 Economic experiences of tracheostomy

Living with the tracheostomy tube brought economic hardships to most of the participants. The tube reduced participants’ strength and made them unfit to work. Most of the participants changed their jobs; some lost their jobs while others did not get employed because employers saw them as unfit for the jobs. Most of the participants especially those who were unemployed had little hope of gaining employment. Participants who were engaged in trading lost customers because of their difficulties in verbally communicating. These led to much financial hardship as participants could not take care of themselves and their families. They also had financial difficulties assessing health care. The sub-themes included work challenges and reduced income. These are described with verbatim quotations.
4.8.1 Work Challenges

Most of the participants complained the tube had reduced their strength to work. Four of the participants had to stop their jobs because of reduced strength.

“Oooh, after the surgery truly job has been a big problem for me. I was a government worker. I was working at Ghana Pioneer Aluminium Factory, so the money I had from that work is what I used for the surgery. However, after the surgery, if I tell you I have been working, I will be lying to you, I do not work” (Aba);

“I started work after the first surgery. I was going to work at Kuntenase. When I got to the station, I had to take “dropping” because I could not walk. So my boss told me to take rest on days I felt I could not come. I used to work thrice every week, but now I do not go anymore. I have stopped the work” (Nsiah).

“Mmmmm, that is what I have been saying. Unlike initially when I could go to the farm and work, now I am unable to go. For two years now, I have not gone to farm. I am always at home. I am unable to do anything, anything I do, no matter how small it is, I become exhausted” (Sussy).

Some participants indicated they felt dizzy walking in the sun. Due to this, they could not do the normal trading they used to do.

“Oooh now I am home ooh, I am even unable to go to the store. The reason is if I walk under the sun, I get dizzy, and I am unable to see anything... I do not like heat, so I am unable to do any work or job” (Adiza).

Getting a new job was also a challenge for participants who were either not employed or stopped the work they were doing before the tube was inserted because employers felt they were unfit to work.

“I searched and searched, but I did not get any job to do. If I get a job, I will be very glad, but I do not know whether it is because of the tube I have in my neck or what. When I told employers I needed a job, they usually stared at me for a long time and afterwards said to me, there was no job. Sometimes when I got back home from the unfruitful job
search, I asked myself “is it because of the tube in my neck that is why I do not get a job to do?” So that is what I sometimes think” (Aba).

Some participants changed their jobs and others had to reduce the number of employment they had because of the tube.

“The thing is, I had been a professional teacher for almost 17 years until I had the tube in my throat but now I cannot teach (started tearing, wiped the tears with her cloth and began to talk again). Initially, I was given a different task to be doing. I was asked to be recording marks and writing reports. Later, I was sent to our district education office to be doing documentations, and that is where I work now” (Mansa).

“This is the same work I was doing (Chemical selling), but I was doing some others aside. Initially, I was working with the Health Insurance; but after being given the tube, I was unable to do that work again because of tiredness. So when it happened like that, (chuckles), I went there and told them I could not do the job anymore because it was very tiring” (Becky).

“It has reduced the way I used to work. I was a trader, and I still am a merchant, but I am unable to work as before. Now there is no strength; there is not enough force. I used to go far for trading, but now I am unable to do so” (Akua).

Some participants especially those who were engaged in trading lost most of their customers as well as revenue because they were unable to communicate well verbally with the customers.

“…when someone comes to buy something because he or she fail to hear you, that person will even leave. Usually, they tell you “I am coming, or I am unable to hear you.” Even now, some people have difficulty hearing what I say, so they will tell you “I am coming” but they leave and never returned. So it affects you, your finances” (Becky).
4.8.2 Reduced income

Participants indicated they were faced with many challenges getting money to take care of themselves and their families.

“No money comes from anywhere because I am not working (hehehe, she laughed)” (Nsiah).

“(Remained silent, sobbed and cleaned the tears, continued to talk). As I sit here now, if you ask me even GH¢5, I cannot get it for you, GH¢5, I cannot get it for you (remains silent for a while, wipes her tears) I do not have it. There are times I go hungry the whole day without food; it is as if I am fasting” (Aba).

“My husband who was taking care of me is dead. Moreover, even this my son (points to her son), I was working and taking care of him in school, but now there is no money. He has even completed Senior High school, but he owes the school, so we have not been able to go for his results” (Sussy).

Attending reviews and taking care of the tube was a challenge for most of the participants.

“So as I live now, it is hard for me. Even taking care of the tube, buying gauze and tape all the time is an issue for me. Money is also needed to visit the hospital for review monthly. So life is difficult for me” (Sussy).

“Additionally, I have to take care of myself and the tube, change the dressings and buy drugs among others. So your finances will go down. For my salary, I still get it but it is not enough for me, and I cannot do any other job unless the one that will allow me to sit only at one place” (Mansa).

>Your finances will go down (smiled, spoke with some difficulty, took in some air, then continued) because you cannot do any other work. I usually went to work late and had to close early. This reduced the amount of money I made in a day” (Becky).

All the participants wished the tube would be removed to enable them to work to take care of themselves and their families.

“If they do not remove this tube, how will I survive, I am unable to work, what will I do, how will I be able to buy these items? (Remained silent,
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wiped her face and continued to talk) I do not have any money to take care of my son. Had it not been this sickness, I would have been able to do some small work to at least to take care of him. With this tube on my neck, I cannot farm to get money to take care of him and myself” (Sussy).

“So if it can be taken off, I will be euphoric. I want to regain my strength and do things the way I used to do them” (Mansa).

In answering the fifth research question: “How do adults living with a tracheostomy tube communicate?” one major theme emerged; Communication experiences. This is presented in the following paragraphs.

4.9 Patients’ communication experiences on living with a tracheostomy

Communication was a major challenge for all participants. Most of the participants had difficulty verbally communicating with the tube. Participants indicated production of speech was not possible at the initial stages of the tube insertion. However, they gradually regained their voice usually about a month or two later. It was identified that during hospitalization, participants used sign language and wrote on papers to communicate when they could not produce speech. Participants who were not educated had many difficulties writing to express their needs to the health personnel on the ward.

Some participants used “speaking valve” when they regained their voice before their voice could be heard. Participants who could not afford the speaking valve used their finger to occlude the tube to talk. However, talking without putting the finger on the tube left participants with rib pains.

There were other challenges associated with verbal communication. Participants were unable to speak for a longer period; they got exhausted whenever they talked for a long time. The spiritual life of some participants was also affected. Participants who had certain responsibilities at church before the tube insertion were unable to do so again.
Things such as reading the Bible at church, and singing at church were all affected, and participants indicated it had an adverse impact on their spirituality. The sub-themes included mode of communication and challenges with verbalization. These sub-themes have been described with verbatim quotations from participants.

4.9.1 Mode of communication

Most of the participants indicated that when the tubes were freshly inserted, they could not have verbal communication.

“After the operation, I became “dumb.” I was not talking (Aba); Immediately after the operation, I was unable to talk” (Sussy).

They resorted to the use of non-verbal cues like sign language and writing on papers with a pen to communicate.

“...so initially, after the surgery when I was in the Ward, whenever I needed something I will do a sign to get me understood. Whenever a nurse or a doctor asked me a question, there were pens and papers that I used to write my “broken English” to them, and they understood me” (Aba).

“The voice to talk was not coming at all. I was using signs; sometimes I wrote to communicate (Becky).

“Oooh, I was using signs to communicate. When the tube is inserted freshly you will not be able to talk so the only way out is to use sign language” (Adiza).

However, participants bemoaned that it was difficult using nonverbal cues to communicate because some of them could not even read and write and it was not everyone who could read what they wrote.

“I could not do anything, whatever I wanted to do, I had to write it, and it was not everyone that could read what I wrote. So it was not easy (chuckles)” (Becky).
“Life was difficult for me when I had not regained my voice. There were times I went somewhere, and because I could not talk, I had to do signs or write on paper. Meanwhile, I could not write well what I wanted to say so it was not good, not good. When it happens like that, you do not feel like going where you want to go” (Adoma).

Participants gradually regained their voices within a week or two after the surgery.

“Yes, I initially struggled to speak, but the speech became better gradually. So it was like that till about 2 weeks after the surgery when I realised I was gradually regaining my voice until I was discharged and now by God’s grace, I can speak” (Aba).

“As you get better than, your voice also gets better. The doctor told me they did not cut anything in my throat” (Adiza).

Participants indicated that when they regained their voice, they still had to either use “speaking valves” or their fingers to occlude the tube anytime they were talking. They stated that anytime the tube was not occluded while talking, only air came out instead of voice and they got rib pain when they did that.

“I use a “speaking valve,” so if I put it on the tube, I can talk well but if the valve is off, I am unable to talk” (Adiza).

“The doctor told me to be putting my finger on the tube when I am speaking. So anytime I put my finger on the tube, my talking is fine, but if I take off my hand, it is only air that comes out” (Sussy).

“By God’s grace, I can speak now. However, if I need to talk, I have to put my finger on the hole of the inner tube (she directs her left index finger to show me how she covers the inner tube). However, if I do not put my finger there, I find it difficult to talk and anytime I do so, I get pains in my ribs” (Aba).

4.9.2 Challenges with verbalization

Most of the participants indicated that there were challenges associated with the regained verbal communication. The majority of the participants stated that they could not talk for
a longer period. They could not engage in long conversations, anytime they did that, they got exhausted and had to pant for breath because they had to cover the tube to talk.

“There is tiredness all the time. When you speak for a while, you get tired, and you are unable to breathe, but when you take off your hand from the tube to take in some air too, you cannot talk” (Becky).

“The thing is, you get tired easily for talking for a long time. You are unable to engage in long conversation” (Mansa).

“Now I do not have problems with speech when I put my hand on it. It is only that when I talk for a while, I get tired” (Sussy).

Some participants revealed that their spiritual life was also affected, particularly the performance of activities such as Bible reading and singing at church.

“My inability to communicate has affected me very much. At first, before the insertion of the tube, I was a Bible reader at church, now I cannot do it anymore, I was a chorister, I cannot sing again. All these affect me spiritually. I am someone who loves singing, but now I cannot sing anymore. When it happens like that (chuckles) it gets me worried….sometimes I try to sing but the voice does not come” (Becky).

“Yea, I was a singer, but now I cannot sing, and it worries me so much…usually, I get worried a lot looking at myself as I cannot sing like I used to. When I go to church, I do not have any voice to sing, so I just sit and look on” (Sussy).

In answering the sixth research question: “what are the coping strategies of adults living with a tracheostomy tube? Two major themes emerged: coping mechanisms and support. These are presented in the following paragraphs.

4.10 Patients’ coping mechanisms while living with a tracheostomy tube

Participants of the study reiterated how they coped with the challenges they encountered while living with the tracheostomy tube. Most of the participants indicated that they accepted the fact that they were going to live permanently with the tube because
they knew before the surgery was done that, it was either they had the tube or died. Some also indicated that once they were not dead and were still alive, it meant that they had to be content because some other people did the operation and died. Given these, they were not shy of their situation. They developed the strong mentality and strong will to live. Other participants also indicated that they were encouraged when they saw other PLTT who were also doing very well anytime they came to the hospital. The majority of the participants also indicated that they depended on spiritual support to survive. The prayed to God and He supplied them with their needs through people. The sub-themes identified are Acceptance of the situation, resilience, and spirituality. These are described with verbatim quotations.

4.10.1 Acceptance of situation

Most of the participants knew and accepted their situation even before the tube was inserted. They were therefore not surprised to see the tube in their neck.

“I was not surprised. I knew I was going to have something in my neck, and I knew that was the only way for me to survive. When I became conscious, I used my hand to feel the tube in my throat, and I realised I was able to breathe, so I was ok with it” (Becky).

Some of the participants also indicated that they have realised nothing would change, so they have accepted the situation.

“Yes! Initially, I was disturbed that someone like me who was very active and able to talk my mind on anything as long as I wanted, couldn’t do it now. However, now I have realised that is how it is going to be, so I have taken it like that” (Sussy).

Some participants indicated they were not shy of their situation anymore because people around them knew they were normal. They were in that state because of sickness.

“I am not shy. Anyone who knew me knows that this was not how God created me. This is because of illness, so I am not shy” (Nsiah).
4.10.2 Resilience

Most of the participants indicated that they no longer paid attention to what people said about their current situation but rather concentrated on whatever they did.

“In the beginning, I was so discouraged... however, later I realised I was making a mistake, so I decided that I not be going to pay attention to anyone. I saw that people looked at me, but I did not pay attention to them” (Aba).

“Eii!.....They stared at me seriously. However, in all these, I did not care because I came to worship God” (Kwasi)

Some participants felt there was no need to worry because other people had the same operation but died, so they had to be grateful to be alive.

“Ooh me, I feel I am ok. Someone did it once but did not talk and died. So if I am living, then it is grace. I do not listen to what people say” (Nsiah).

Some of the participants developed the strong mentality and a strong will to live when they saw other people who were on tracheostomy doing very well anytime they came to the hospital for review.

“...So when I come to the hospital, and I meet other people who have the tube and are doing well, it encourages me that all is well. My people have not seen it before, so they pity me” (Sussy).

4.10.3 Spirituality

All the nine participants indicated that they also got inspiration from God. They relied on and prayed to God to assist them in all things. They believed God answered their prayers and provided their needs through people.

“It is all God’s doing. Honestly, when I get lorry fare, I go for prayers. Sometimes I give GH¢1 offering but it is from my heart, and God knows I do not have much money. So if I get something small, then I go, I go for
prayers. So had it not been prayers, it would have been tough (still sobbing)” (Aba).

“God is God because He gives me hope to live all the time. With my kids and the finances unstable, God gives me food to eat because He is God. God will do it, and He is faithful to His words, God has done it” (Akua).

“It is God who is taking care of me. Usually, I pray to God for His Grace and He has never disappointed me” (Sussy).

4.11 Support while living with a tracheostomy tube

Living with a tracheostomy tube posed lots of challenges. Mostly people living with the tube needed support to survive. All the participants in the study indicated that they got various forms of support from spouses, family, friends, and children in undertaking some of these activities. It was realised that most of the participants depended on their spouses and relatives for financial and emotional support as well as support in undertaking activities of daily living. Nonetheless, some of the participants indicated that some forms of support waned with time. Additionally, not all the participants were lucky to get these supports. The sub-themes are family, friends, and spiritual supports. These are described with verbatim quotations in the following paragraphs.

4.11.1 Family support

Most of the participants stated that their family (spouses, children, mothers, fathers, uncles) lent their support in undertaking most of these household chores.

“Oooh, it is ok; my family supports me. They do not allow me to do anything at home; like washing and others, they do it. Whenever we went somewhere, like the village, for instance, we used to go to the farm together; but now, they do not allow me even to go when I ask to go with them. They tell me to stay at home” (Becky).
However, some of the participants indicated they did not get any assistance to undertake some of the household chores; they rather hired people to do those activities for them.

“I always hire someone to wash them for me” (Akua).

Some of the participants were also supported financially by their family members.

“I sometimes get financial assistance from family especially my mother. My daughter too is not working but she is married, so when she gets some money, she sends some to me” (Sussy).

“It is only my mother who supports me. I have children, so my mother sells the shea butter and gives me the proceeds to take care of myself and my kids. So she supports me” (Akua).

Some of the participants lamented that the financial supports from family members had decreased over time. Life, therefore, had become unbearable for them and their families.

“Ooh at first, my uncle was supporting me, but he is out of a job now, so if I say I have anyone who supports me, then I am lying...as I sit here now if you asked me even GH¢5, I cannot get it for you, (Remained silent for a while, wiped her tears) I do not have. It is a generous person who gives me money to prepare some meal so that we will all eat; that is all. It has been like that till you came to meet me” (Aba).

“When I got sick, my father died. You know when it gets so difficult initially they will support, but now that it seems I am a bit strong, who will support? If someone will support you, it is just like giving you GH¢2 to buy something like bread. If I am going to the hospital, I cannot go and ask my relatives for assistance. They will say they do not have any money” (Sussy).

Participants also indicated they got emotional support from their families especially their husbands and children.

“My husband has been very supportive. He supports me a lot. He is my main source of support and inspiration. He does most of the things for me” (Mansa).
“Now my children have seen how it is, so it is not surprising to them anymore. So if I am unable to do something I used to do before the tube was inserted, they do not get surprised because they know my situation now. So they have taken it to be normal, and they encourage me a lot” (Becky).

4.11.2 Friends’ support

Some of the participants also indicated that their friends sometimes also gave them emotional and financial assistance.

“My friends at church also sympathise with me. They sometimes pay me visits and give me some encouragement” (Nsiah).

“I have friends who also come around to visit. Whenever they come around, they give me some money. Usually, I use it for transportation to the hospital for review and other expenses” (Sussy).

“Sometimes my friends also come around. They usually come on weekends to see me” (Mansa).

4.12 Summary

The findings above were based on the data collected from adults who are living with a tracheostomy tube in the Kumasi metropolis. The findings indicate that ALTT have different kinds of experiences ranging from physical, physiological, psychosocial and economic, communication to coping. They experienced pain from the operation itself when they bend and cough as well as during stoma infection. Majority sought for medical treatment for the pain they experienced while others did not seek for any treatment because they could not afford the cost of health care.

The majority of the participants had reduced strength which made them unfit to do any job to earn income. However, some had to change jobs or stop the work they were doing because the tube made them incapable of doing the job they were doing before they had the tube resulting in lots of financial constraints.
Participants had a problem with swallowing, breathing and smelling which compromised their quality of life. The majority of the participants felt different because the tube made them look incomplete and reduced their self-image. They preferred to stay indoors and isolate themselves from most social activities because of how people looked at them. These made them anxious, depressed and at times they entertained suicide ideas.

Additionally, most of the participants used nonverbal cues like sign language and writing on papers to communicate when the tube was freshly inserted because they had no voice in the initial stages after the surgery, however, those who could not read and write to express themselves became frustrated and lived in apathy. As they gained their voices, they either used ‘speak valves’ or occluded the tube with their finger to talk. Most of them had problems doing some kinds of activities like singing and reading the Bible at church, reducing their spirituality.

Participants received support from their family members in undertaking some activities of daily living like washing, cooking. Others received financial assistance from family members, friends and generous individuals for survival. Participants used various kinds of coping strategies to survive. These included; acceptance, resilience and relying on God to cope.

Most of these findings were in line with the constructs in the thematic concepts used as a guide for this study. However, since this study was done among ALTT in the community rather than patients in the ICU, some of the findings such as economic constraint and support emerged as new discoveries. These results are discussed in detail in the next chapter.
5.1 Introduction

The study aimed at exploring the experiences of adults living with a tracheostomy in the Kumasi Metropolis. The study explored different kinds of experiences after in-depth interviewing of nine adults with tracheostomy tubes. The study had the following objectives:

a. to describe the physical impact of adults living with a tracheostomy tube
b. to examine the physiological changes associated with adults living with a tracheostomy tube
c. to explore the psychosocial experiences of adults living with a tracheostomy tube
d. to study the economic impact of tracheostomy on adults living with a tracheostomy tube
e. to investigate how adults living with a tracheostomy communicate
f. to identify the coping strategies of adults living with a tracheostomy tube.

Eight main themes emerged from the analysis of the experiences of adults living with a tracheostomy in the Kumasi Metropolis based on the thematic concepts by Foster (2010) and the objectives: physical experiences, physiological experiences, social experiences, psychological experiences, economic experiences, communication experiences, coping mechanisms and support. These key findings are discussed in relation to existing studies subsequently.

5.2 Physical experiences of living with a tracheostomy

The physical experiences among adults living with a tracheostomy tube (ALTT) identified in this study included painful experiences and impaired activities of daily living. Pain is a subjective and an unpleasant sensory and emotional experience arising from an
actual or potential tissue destruction or described regarding such damage (Breivik, 2002; Leeson, Gulabivala, & Ng, 2014). In the present study, the experience of pain was due to sensory and actual tissue damage arising from the surgical procedure itself and the discomfort from the tube in the performance of certain activities. All the participants in the study complained of the pain they experienced at the site of the surgery as well as on swallowing when they became conscious after the surgery. This is consistent with several studies which also identified the association of tracheostomy surgery and pain (Al Sutari et al. 2014). According to Al Sutari et al. (2014), the experience of pain from the tracheostomy surgery and the physical presence of the tracheostomy tube are well-known among tracheostomised individuals. Freeman (2011) also identified in her study that people who have undergone a tracheostomy surgery usually have pains on swallowing mostly at the initial stages after the surgery which reduces their nutritional requirements. Considering that there is difficulty in speaking in the early stages after the tracheostomy surgery (Flinterud & Andershed, 2015; Madan et al., 2011), the ability to express the pain experienced is hindered (Foster, 2010). ALTT, therefore, become exasperated, and they express it in anger (Magnus & Turkington, 2006). The only option left for them is to be quiet and endure the pains they experience (Karlsson, Bergbom, et al., 2012). The reduction in nutritional requirement can lead to hypoglycaemia since they may not be able to meet their nutritional requirement. Therefore, nurses need to assess the nutritional demands of such individuals and meet the requirements through other means like taking of light diet and intravenous fluids since those may be tolerable; hence the prevention of possible hypoglycaemia (Ganzer et al., 2015).

In the current study, the pain subsided later, especially when the incisional wound healed. However, participants had pains whenever they coughed. This is consistent with studies by Al Sutari et al. (2014) and Siffleet et al. (2007) which indicated that breathing
and coughing exercises cause pain in people living with a tracheostomy. Additionally, stoma infection and movement of the tube on bending were identified to be other factors which caused pain among the adults living with a tracheostomy in the Kumasi Metropolis. This finding is also in line with the findings by McCormick et al. (2015) that, stoma infection and the dressing of the stoma cause pain in tracheostomized adults.

Contrary to the study by Arroyo-Novoa et al. (2008) who described suctioning of the tracheostomy tube to be painful, the findings of the current study showed that suctioning was not painful. This difference may have resulted from the fact that participants might have forgotten their experiences while they were in the intensive care unit since this present study used tracheostomised adults who were at home and did no suctioning. The commonest way of cleaning the tube is to take the inner tube off, clean and reinsert, hence suctioning is not practised amongst them (Barnett, 2012; Russell, 2005).

The efficient management of postoperative pain is inadequate in most continents and even in the United States and Europe, studies have shown that there is the need for improvement (Apfelbaum, Chen, Mehta, & Gan, 2003; Benhamou et al., 2008; Francis & Fitzpatrick, 2013). Studies have also shown that nurses worldwide lack the requisite knowledge in postoperative pain management (Abdalrahim, Majali, Stomberg, & Bergbom, 2011; Francis & Fitzpatrick, 2013; Wang & Tsai, 2010; Yava et al., 2013). This situation is similar to the Ghanaian nurses’ (Aziato & Adejumo, 2014), although there is the belief that nurses have their subjective understanding of pain and see pain as a distasteful sensation (Aziato, Akorfa, Dedey, & Clegg-Lamptey, 2016).

The most significant activity in improving postoperative pain management is to administer nonopioid analgesics such as NSAIDs, acetaminophen (White, 2005). These analgesics contribute to improving sleep, reducing delirium and agitation (Gélinas, 2007), as well as reducing the high rate of post-traumatic stress disorders that are associated with
the experience of pain (Granja et al., 2008). It will also assist to achieve quick resumption of normal activities of daily living (Eng, 2011; White et al., 2007) which will assist to improve patients’ quality of life. Therefore adults undergoing a tracheostomy surgery should be given adequate preoperative education on the experience of pain on awakening from the anaesthesia. Potent analgesia should be provided and administered to facilitate the pain management (Abdalrahim et al., 2011). Proper education during discharge with emphasis on how assuming certain body positions could reduce tube movements (which cause pain) should be a priority.

Impaired performance of activities of daily living was one of the physical experiences of ALTT in the Kumasi Metropolis. Impaired activities of everyday life is a situation where a person is unable to perform all their daily activities due to reduced strength, immobilisation, restrictions in movement, lack of motivation and pain (Chiang, Wang, Wu, Wu, & Wu, 2006; Elvir-Lazo & White, 2010). In the current study, all the participants complained of reduced strength and easy fatigability which made it difficult for them to undertake activities of daily living. Consistent with these findings, other studies have reported that PLTT have reduced capacity to participate in activities of daily living (Foster, 2010; Hashmi et al., 2010).

Among the activities identified in the current study which participants were unable to do included bending, talking, sweeping, carrying or lifting items, climbing hills, walking briskly or exercising. Cooking and washing were also affected. Participants felt dizzy and had waist pains when they stood to wash or cook. This is consistent with the findings by Gul and Karadag (2010), which indicated that living with a tracheostomy tube affects one's performance of activities such as swimming, bending, climbing, talking as well as any other activity that needs physical strength; this greatly affects their quality of life. These findings indicate that adults living with a tracheostomy have a lot of functional limitations.
Hence, the need to provide support in undertaking some of these functions to assist improve their quality of life and to reduce possible frustrations and depressions (Björklund et al., 2010; Lang, France, Williams, Humphris, & Wells, 2013). As Howren, Christensen, Karnell, and Funk (2013) suggests, the provision of social support, especially from family members and friends, will positively influence the quality of life of individuals with a tracheostomy.

In the current study, the impaired performance of activities of daily living from reduced strength impacted on the economic status of the participants. Consistent with this finding, Isaksson et al., (2015) reported on the central concern of a reduction in work power in the literature. At times, tracheostomised adults changed their normal daily activities both at home and at work (Björklund et al., 2010; Griffiths et al., 2008). This change of activities is to enable them to meet the physical impairments that result from living with a tracheostomy tube (Molassiotis & Rogers, 2012; Röing et al., 2007; Semple & McCance, 2010). This change in activities leads to reduced income because most of these adults are unable to undertake jobs requiring physical strength (Steiner et al., 2004). Coupled with the high cost of living and tube care (Hyde et al., 2015), these individuals need financial support. They also need retraining in less difficult jobs to earn a living (Björklund et al., 2010; Steiner et al., 2004; Verdonck-de Leeuw, van Bleek, Leemans, & de Bree, 2010).

From the findings on the physical challenges of the tracheostomy tube in the current study, it can be concluded that ALTT have physical challenges. The experience of pain from the surgery itself, when swallowing, during breathing and coughing, piercing of the tube on bending as well as during stoma infections is stressful enough for these adults. Reduction in strength to perform activities of daily living impact on their quality of life. Their inability to perform strenuous activities including working to earn an income is very frustrating taking into account the rising cost of living and health care.
5.3 Physiological experiences of living with a tracheostomy

This aspect discusses the defects of bodily functions of the ALTT in the Kumasi Metropolis in Ghana. The human body performs different physiological functions which assist in keeping the body in an active state. Any artificial change in the human structure is likely to affect the physiology of the body. The tracheostomy surgery interrupts vital bodily physiology (List & Bilir, 2004) such as, disruption in the ability to breath, swallow, speak, and taste which cause tremendous discomfort (Björklund et al., 2010; Funk, Karnell, & Christensen, 2012). The physiological changes of the ALTT were: difficulty in breathing, dysphagia and a reduced sense of smell.

The structural changes that occur in tracheostomised individuals result in a reduction of the natural warming and humidification of inhaled air (Russell, 2005). The decrease in the humidification leads to retention of secretions, impairment of mucociliary clearance, decrease cough reflex and reduction in lung function (Conlan & Kopec, 2000; Woodrow, 2002) resulting in difficulty in breathing (Gul & Karadag, 2010; Huffman et al., 2014). In the current study, difficulty in breathing was a major challenge for all the participants.

The findings of the present study further revealed that difficulty in breathing from post thyroidectomy complication was the common indication for the tracheostomy surgery for most of the participants. This finding affirms the study by Cheung and Napolitano (2014) which identified the most common indications for a tracheostomy to include acute respiratory failure, the need for prolonged mechanical ventilation and trauma to the throat requiring mechanical ventilation. These adults were therefore relieved when the tube was inserted (Durbin, 2010; Haspel et al., 2012). However, accumulation of mucus in the tube, intolerance to dust and high scented items resulted in excessive coughs and difficulty in breathing which reduced their quality of life. Akram and Khosrow (2009) state that difficulty in breathing is a major challenge for tracheostomised adults and this
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physiological dysfunction affects their quality of life. Additionally, the difficulty in breathing made most people weak rendering them incapable of undertaking any strenuous activities including those that could earn them a living (Mehnert et al., 2013). Therefore, adequate education before discharge on the tube care and the avoidance of high scented items and dust will assist to reduce an excessive cough and the resultant difficulty in breathing.

The act of swallowing involves the passage of food and drink that has been chewed or broken into smaller pieces in the mouth through the throat into the stomach. Interruption at any stage of the process or a disruption in the structure of the throat can lead to difficulty in swallowing (dysphagia) (Sharma et al., 2007). In tracheostomised adults, a reduction in laryngeal elevation, oesophageal compression, reduced glottis closing time, and obstruction from the cuff of the tracheostomy tube cause difficulty in swallowing (Daudia & Gibbin, 2006; De Leyn et al., 2007; Russell, 2005; Serra, 2000). Findings from the present study showed that adults living with a tracheostomy tube had difficulty in swallowing (dysphagia). In line with this finding, other surveys have also reported of the difficulty in swallowing as a common phenomenon among tracheostomised adults (Ceriana et al., 2015; Foster, 2010; Serra, 2000; Sherlock et al., 2009).

Further findings from the current study indicate that there is the feeling of aspiration and the sensation of getting choked while swallowing especially soup, dried, roasted, fried and hard foods. However, there are conflicting findings in the literature on the impact of the tracheostomy tube and aspiration. While earlier findings suggest a link between a tracheostomy tube and aspiration (Elpern et al., 1994; Pannunzio, 1996), some recent findings disapprove of this linkage (Brady et al., 2009; Leder & Ross, 2010). To confirm the non-association of the tracheostomy tube and aspiration, Leder and Ross (2010) identified no significant change in aspiration between pre and post tracheostomy situations.
However, it was identified that people who need tracheostomy are likely to experience swallowing disorders after the surgery (Sherlock et al., 2009). Therefore there is the need for more collaborative work to include the speech-language pathologist to assess the swallowing function and the airway of people who are tracheostomized before discharge (McGrath & Wallace, 2014; Starmer et al., 2014) to verify these individuals’ ability to swallow without getting aspirated.

Dysphagia in tracheostomy may certainly lead to loss of appetite, possible hypoglycaemia, and a resulting weight loss. The reason is that food serves as a fundamental and physiological need, providing energy and nutrients for the body to enhance growth and vitality (Ganzer et al., 2015; Tsang & Carey, 2015). The inability to eat as a result of dysphagia will derail the sustenance of life (Klinke, Hafsteinsdóttir, Thorsteinsson, & Jónsdóttir, 2014). Hence, ALTT should be educated and encouraged to follow proper dietary requirements (Serra, 2000).

Another physiological challenge that compounded the lives of ALTT was the reduced sense of smell. The smelling process relies so much on the flow of air through the nasal cavity as well as odorant binding and stimulation of an associated chemosensory receptor (Kaupp, 2010; Patel & Pinto, 2014). Both conductive and sensorineural defects can alter the process of smelling (Hong et al., 2012). Studies have shown that surgical procedures such as laryngectomy and tracheostomy lead to a conductive dysfunction of the nose by limiting nasal airflow, hence causes a reduction in the sense of smell (Hilgers et al., 2000; Hong et al., 2012; Risberg-Berlin et al., 2009). It was evident in the current study that the ALTT had reduced the sense of smell. This finding confirms other studies that, living with a tracheostomy tube impact negatively on the ability to smell (Huffman et al., 2014; Kennedy et al., 2016; Tsikoudas et al., 2011).
Furthermore, in the present study, participants had difficulty detecting odour on themselves unless someone prompted them. The ability to smell has a significant influence on our health and behaviour. Reduced sense of smell is detrimental to the quality of life of adults living with a tracheostomy (Hummel & Nordin, 2005; Neuland et al., 2011; Nordin, Blomqvist, Olsson, Stjärne, & Ehnhage, 2011). For instance, studies have shown that the ability to smell influences eating lifestyles and improve nutritional intake by enhancing appetite and food choices (Croy et al., 2014; Hays & Roberts, 2006; Mennella et al., 2001). Therefore, interruption in the sense of smell could reduce appetite and further lead to loss of weight (Huffman et al., 2014). Smelling also facilitates the detection of possible hazards in our surroundings and as well influences interpersonal relationships (Doucet et al., 2009; Jacob, Garcia, et al., 2002; Jacob, McClintock, et al., 2002; Neuland et al., 2011). The reduced ability to smell implies that the safety of ALTT is at stake (Miwa et al., 2001). These individuals are susceptible to developing anxiety and depression (Croy et al., 2012; Tsikoudas et al., 2011).

Therefore, preoperative education for patients who are undergoing a tracheostomy surgery should include education on the physiological changes (Tsikoudas et al., 2011). There is also the need for proper evaluation of the olfactory status of tracheostomised persons post-surgery for counselling, and where needed, rehabilitated with the “polite yawning” technique (Hilgers et al., 2000; Hong et al., 2012).

5.4 Social experiences of living with a tracheostomy

In this study, ALTT had different social implications which included: altered body image, social isolation, and altered sexuality. The human face and neck are critical in an individual’s self-identification (Bradbury, 2012; Callahan, 2005) because it is the most prominent part of the human structure serving as a channel of interaction with others.
Therefore any changes in this nomenclature alter the body image of the individual resulting in reduced self-esteem (Caravati-Jouvenceaux et al., 2011; Krouse et al., 2009). The reason is that body image as explained by Phillip and de Man (2010) is the impression people make of their physical appearance and the impression they trust others have of them. These include how they see themselves and how others see them regarding their look, attraction, their health as well as how their bodies aid them to interact with people (Grogan, 2007; Lubkin & Larsen, 2006). In the current study, the physical presence of the tube altered the appearance and body image of ALTT making them look different and incomplete. This finding is congruent with numerous studies of the change in body image of tracheostomised adults (Callahan, 2005; Fingeret et al., 2015; Rhoten, Murphy, & Ridner, 2013; Sherlock et al., 2009; Teo et al., 2016). In related studies, Dawson (2014) and Katz et al. (2003) affirm that living with a tracheostomy tube results in high incidence of altered body image as a consequence of the noticeable mutilation at the anterior part of the neck. According to Callahan (2005), the human face enhances an individual’s self-identity and as well serve as a means of interaction since it is the most visually prominent part of the human body. Therefore, the presence of a visible hole at the anterior part of the neck which is kept patent with a tube, through which mucus passes will likely alter the body image and quality of life (Fingeret et al., 2015; Zając et al., 2008).

Findings of the study identified that the position of the tube restricted these adults in wearing certain kinds of dresses and putting on ornaments. This finding is similar to the results of Bodenham et al. (2014) which stipulates that living with a tracheostomy tube comes with numerous restrictions ranging from a change in physical appearance, change in dressing to change in daily activities. These limitations reduce people’s self-esteem and quality of life (Howren, Christensen, Karnell, & Funk, 2013; Pereira da Silva, Feliciano, Vaz Freitas, Esteves, & Almeida e Sousa, 2015; Wells et al., 2015). These limitations lead
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to numerous psychosocial challenges (Brown & Randle, 2005; Paul, 2010). Adequate
counselling and close monitoring in addition to social support will support to improve the
lives of these individuals and contribute to reducing possible psychosocial challenges
(Howren, Christensen, Karnell, Van Liew, & Funk, 2013). These will assist because
dissatisfaction in the body image of people living with a tracheostomy increase with time
with no evidence of adjustment (Sharpe et al., 2011).

One of the social impacts of living with a tracheostomy tube that emanated from
altered body image was social isolation. Studies show that there is a close link between
altered body image and social isolation (Aderka et al., 2014; Coles et al., 2006; Kelly,
Walters, & Phillips, 2010; Pinto & Phillips, 2005). This link often limits individuals with
altered body image in playing active roles in social activities (Newell et al., 2004).
Consistent with what literature reports, ALTT reported the tube was very prominent on
their neck and made people stare at them anytime they went out. They added that they
socially isolated themselves from public activities because of the odour they had from the
tube which increased the staring from the public. This finding confirms previous studies
which reported that people living with altered body image especially from facial
disfigurement suffer social isolation (American Psychiatric Association, 2013; Katz et al.,
2003) from the fear of being looked at by others (Bögels et al., 2010). These experiences
result in the feeling of incomplete, and the creation of negative impression about
themselves (Bessell et al., 2010) further leading to more psychological distress (Sharpe et
al., 2011).

It was also identified that participants covered their neck with other clothing
materials to hide the tube and reduce public embarrassment when it became necessary they
had to attend gatherings. Studies have shown that PLTT find ways to disguise themselves.
They wear clothes with necks or hang extra materials around their neck to cover the tube,
feeling comfortable in public (Akenroye & Osukoya, 2013; Bessell et al., 2012; Flynn et al., 2013).

The participants of the study had an alteration in their sexuality. They experienced diminished sexual activities because they felt unfit to engage in frequent sexual activities. In addition, participants stated that the tube made them look sexually unattractive. Studies have shown that living with a tracheostomy affects sexuality (Batıoğlu-Karaaltın, Binbay, Yiğit, & Dönmez, 2016; Schonhofer et al., 2001). The presence of the tube, with the associated difficulty in breathing and loss of voice as well as a change in appearance, reduce the desire for sexual activities (Cantlay, 2015; Coelho-Marques, Wagner, De Figueiredo, & d'Avila, 2006; Persson & Hellström, 2002).

Participants who were not married or had lost their partners felt they looked unattractive to win the attention of suitors. Those who were married indicated their partners understood they were unfit to engage in sexual activities. According to Gallo-Silver (2011), people become aware of their altered appearance and accept that their partners find them sexually unattractive which further reduce their desire for sexual activities. Sexual gratification is considered to be an integral part of life fulfilment; lacking it will most likely lead to psychosocial problems such as low self-esteem, depression, and anxiety and lessen the quality of life (Batıoğlu-Karaaltın et al., 2016; Hoole, Kanatas, & Mitchell, 2015). It is, therefore, important to provide psychosocial support and also involve partners of people who are to undergo a tracheostomy surgery during preoperative preparation and follow-up care (Batıoğlu-Karaaltın et al., 2016; Offerman, Pruyn, de Boer, Busschbach, & Baatenburg de Jong, 2015). Specific programmes on sexual counselling will also be useful (Öztürk & Mollaoğlu, 2013).
5.5 Psychological experiences of living with a tracheostomy

This aspect describes the psychological experience of ALTT. These were fear and anxiety, depression and suicidal tendencies. The current findings showed most of the participants initially thought they were going to live temporarily on the tube but had to live with it permanently due to unsuccessful weaning process. They were anxious and had lost hope of regaining normality. There was also the fear of not knowing what could happen to them next while living with the tube. Studies have shown that tracheostomised individuals experience fear and anxiety (Howren, Christensen, Karnell, & Funk, 2013; Molassiotis & Rogers, 2012).

For instance, majority of Magnus and Turkington (2006) participants recounted being unsure how long they were going to live on the tracheostomy tube, clearly depicting their fear of the unknown. Living with the tracheostomy tube was a new experience for all the participants. This new experience came with its fear of the unknown. Additionally, participants were anxious living with a new appearance, having difficulty in breathing and speaking. These were enough to have them entertain the fear of the unknown and anxiety about the uncertainty of regaining normality. However, Breckenridge et al. (2014) state that healthcare professionals should not believe they can best detect the existence and severity of patients’ anxiety. They should not assume that psychological challenges like anxiety reduce after the tracheostomy placement. Hence, there is the need for healthcare professionals to employ evidenced-based strategies such as communication methods, supportive measures, preventive care and other complementary treatments to ease patients’ anxiety in both pre and post tracheostomy stages.

Another psychological impact identified in the current study was depression. Participants were depressed because they encountered several challenges. They indicated that the tube had affected almost every aspect of their lives so much so that, they no longer
lived like normal human beings. These make them depressed. The numerous challenges associated with having a tracheostomy tube result in depression and distress (Sharpe et al., 2011). About 15 to 50% of PLTT experience depression in their disease trajectory.

In a related study, Chiou et al. (2013) established that living with a tracheostomy tube with the associated change in appearance, speech and breathing results in depression. According to Buhlmann et al. (2010) and Yanhui et al. (2010), depression is more prominent among people with alteration in body image than those with no appearance challenge. Flinterud and Andershed (2015) and Karlsson, Forsberg, and Bergbom (2012) indicate that being voiceless after a tracheostomy is very depressive, considering the inability to communicate even the feeling of pain for immediate remedy. They added that most people only have the option of enduring the pain and hoping that, their facial expression of the discomfort would be recognised by health professionals as soon as possible. In most situations, the feeling of depression leads to suicidal ideations (Cougle et al., 2009).

In the current study, suicidal ideations were one of the psychological experiences on ALTT tube in the Kumasi Metropolis. Most of the participants became frustrated from the countless challenges they encountered from having the tracheostomy surgery. These frustrations made them entertain the idea of committing suicide. Suicidal ideation is the deliberate idea people have of ending their lives, which include either planning in detail or having the slightest thought of killing oneself rather than killing oneself (Phillips & Menard, 2006). This is congruent with other studies which show that persons with chronic depression are more likely to commit suicide (Haisfield-Wolfe, McGuire, Soeken, Geiger-Brown, & De Forde, 2009). Furthermore, Cougle et al. (2009) indicate that having a tracheostomy tube with the associated physical and psychosocial challenges lead to suicidal ideations. In a related study, Kam et al. (2015) identified that patients with health
problems related to the head and neck are three times likely to commit suicide in the whole US population. It is not surprising that adults with a tracheostomy tube had suicide ideations because they experienced physical symptoms such as pain and impaired activities of daily living and psychosocial challenges including; altered body image, social isolation, altered sexuality, fear and anxiety, and depression. All these predicaments in which participants fond themselves could lead to suicidal ideations. It is, therefore, necessary that these adults be given the needed social support through strict monitoring and counselling (Howren, Christensen, Karnell, Van Liew, et al., 2013).

5.6 Economic experiences of living with a tracheostomy

The present study identified economic constraints among adults with a tracheostomy which included work challenges and reduced income. According to Mehnert et al. (2013), living with a tracheostomy tube facilitates economic challenges such as reduction in work power, the cost of health care, leaving a job, compulsory retirement and change in employment structure. Results of the current study showed that adults with a tracheostomy had challenges with verbal communication and reduced strength to work, hence some stopped working, and others changed their jobs while some reduced the number of employment they had. There was a challenge of getting new jobs for participants who were either not working before the tracheostomy or stopped their work after the tracheostomy. Meanwhile, studies have shown that good economic status of an individual reduces physical disability, reduces psychosocial distress, and improves health-related quality of life (Gul & Karadag, 2010; Mehnert, 2011).

Also, the current study identified that tracheostomised adults had the arduous task of getting money to take care of themselves and their families. In some instances, attending the review and taking care of the tube served as a huge challenge for them. Most of the
participants wished the tube would be removed to enable them work. This finding affirms findings in other studies that poor economic status of people living with a tracheostomy tube affects their health seeking behaviour and their health standing and reduce their quality of life (Mehnert, 2011; Öztürk & Mollaoğlu, 2013; Steiner et al., 2004; Verdonck-de Leeuw et al., 2010). However, it was identified in the current study that the participants had support from family members and friends. In line with this finding, studies have shown that the provision of support from caregivers have positive influence on patients recovery and life thereof (Howren, Christensen, Karnell, Van Liew, et al., 2013).

5.7 Patients’ communication experiences of living with a tracheostomy

This section talks about the issues related to communication among ALTT. These were; mode of communication and challenges with verbalization. Verbal communication is a basic human physiology and a fundamental need for every individual. It plays a major role in our daily interactions, supporting us to express ourselves and our feelings as humans (Donnelly & Wiechula, 2006). However, living with a tracheostomy tube affects this fundamental physiology tremendously (Flinterud & Andershed, 2015; Gutormson et al., 2015). In the current study, most participants complained of difficulty in speaking at the initial stages of the tube insertion. This finding is consistent with numerous studies on the reduction in verbal communication after a tracheostomy (Flinterud & Andershed, 2015; Karlsson, Forsberg, et al., 2012; Khalaila et al., 2011; Sutt, Cornwell, Dunster, Spooner, & Fraser, 2014). For instance, Samuelson et al. (2007) posit that more than 50% of people who undergo a tracheostomy have reduced ability to communicate verbally within the initial stages after the surgery. Related studies have also shown that verbal communication is one of the biggest challenges of people who live with a tracheostomy tube (McCormick et al., 2015; Schindler et al., 2012; Sherlock et al., 2009).
However, participants in the current study resorted to the use of non-verbal cues specifically sign language and writing on papers to communicate. Findings from other related studies indicate that tracheostomised persons adopt a non-verbal form of communication such as the use of pen and paper, picture, and alphabet boards, nodding or shaking of heads and eye blinking to communicate (Barnett, 2012; Grossbach et al., 2010; Hurtig & Downey, 2008).

The participants in this study lamented that the use of these non-verbal methods of communication was very frustrating due to weakness and inability to read and write. In line with this finding, Foster (2010) indicates that the use of non-verbal methods of communication is also frustrating due to inability to write, either because of poor coordination or physical weakness. In a much same way, Johnson et al. (2006) state that weakness impairs patients’ non-verbal communication. Most tracheostomised patients quit trying to communicate and become apathetic when these non-verbal methods of communication are not effective (Kraaijenga et al., 2016; Schindler et al., 2012). Therefore, there is the need for other alternative and efficient means of communication between health professionals and tracheostomised patients who are voiceless; because when there is ineffective communication between a nurse and a non-vocal patient due to poor understanding, lack of clarity and uncertainty occur (Carroll, 2007).

In the current study, participants regained their voice. However, they still had to either use “speaking valve” or their finger to occlude the tube when talking. They stated that anytime the tube was not occluded while talking, only air came out instead of voice, and they get pain in their ribs. This finding is congruent with the findings by Flinterud and Andershed (2015) that, tracheostomised persons gradually regain their ability to communicate verbally with time. Furthermore, related findings also indicate the use of “speaking valves” assist adults with a tracheostomy tube to have successful verbal
communication (Barnett, 2012; Chandrasekhar et al., 2013; Hess, 2005; Pandian et al., 2014). However, studies have shown that this method of communication is not very reliable, it is costly and usually prone to breakages leading to stress and frustration for people with a tracheostomy tube (Hashmi et al., 2010; Patak et al., 2006). The use of the finger to occlude the tube while talking was not identified in the literature; probably, it is not a clinically accepted method of verbal communication for tracheostomised persons. Further research could be done to assess its potential usage and benefits; it may be a better alternative especially for those patients who cannot afford the cost of the speaking valve.

In the current study, the participant had challenges when they regained their voice. They got exhausted and had to gasp for breath whenever they talked for a longer period. They could not engage in longer conversations. This finding confirms findings in other studies that people who live on tracheostomy are unable to speak for longer periods due to reduced strength and exhaustion (Björklund et al., 2010; Molassiotis & Rogers, 2012). Participants in the current study had difficulty in undertaking some activities like reading of the Bible and singing at church, impacting on their spiritual life. Various studies have identified the impact of living with a tracheostomy on all aspects of life including spirituality (Cantlay, 2015; Fingeret et al., 2015; Flinterud & Andershed, 2015; Isaksson et al., 2015) including spirituality (Allmon, Tallman, & Altmaier, 2013; Falsetti, Resick, & Davis, 2003). However, Cole, Hopkins, Tisak, Steel, and Carr (2008) noted that spiritual decline impacts negatively on coping, hence the need to encourage tracheostomised people on spiritual growth to enhance their coping.

The current study identified that inability to have effective verbal communication resulted in lots of psychosocial discomforts expressed in the form of apathy, anxiety, depression and social isolation. Some participants even had to change their jobs due to a disruption in verbal communication. Studies have shown that inability to speak leads to
psychosocial distress. Usually, there is frustration and fear (Johnson et al., 2006; Khalaila et al., 2011), anxiety, depression, and distress (Engström et al., 2013; Myhren et al., 2010). There is also interruption with work (Björklund et al., 2010; Griffiths et al., 2008; Molassiotis & Rogers, 2012; Röing et al., 2007) and social isolation (Aderka et al., 2014; Kelly et al., 2010). These affect the quality of life of ALTT (Batıoğlu-Karaaltın et al., 2016; Hutzel, 2014).

5.8 Patients’ coping mechanisms of living with a tracheostomy

The mechanism of coping refers to the adaptation of strategies to minimise the experience of stress (List et al., 2002). It is normal for individuals who experience stressful situations such as living with a tracheostomy tube to learn ways to cope with their new life (Wood & Bisson, 2004). According to Derks et al. (2005), people living with a tracheostomy tube use strategies to cope with the stress associated with the tube. In the current study, most of the adults living with a tracheostomy accepted their situation. Most of the participants knew and accepted their situation even before the tube insertion because they knew tracheostomy was their last resort for survival. Although they were not comfortable with their current situation, they realised nothing would change, so they accepted the situation. Other studies have also identified the use of acceptance to cope with stressful situations (Birkeland & Natvig, 2009; Thumala Dockendorff, 2014). For instance Lang et al. (2013) state that individuals identify successful coping by accepting the current situation and seeing the new life as better rather than worse. In the end, they learn to be positive and have a healthy life rather than be in the state of chronic denial and get worse.

Another coping strategy adopted by the adults living with a tracheostomy in this study was being resilient. Participants no longer paid attention to what people said about their current situation. They developed the strong mentality and strong will to live when
they saw other tracheostomised individuals doing better in life. In line with this finding, Aarstad et al. (2008) report that people who develop positive attitudes towards their situations have better coping than those who think negative of themselves. In other words, the individuals who develop active coping strategies (Derks et al., 2005) and have strong mentality cope well, are less depressed and live improved lives (Hassanein et al., 2005; Sherman, Simonton, Adams, Vural, & Hanna, 2000).

The current study also identified spirituality as another coping strategy for tracheostomised adults. All the participants stated that they got inspiration from God. They relied on and prayed to God to support in all things. According to de Guzman et al. (2012), this method of coping is called religious coping. Studies have shown that people use religious coping mostly in critical situations where there seems to be no hope (Bagheri-Nesami, Rafii, & H. Oskouie, 2010; de Guzman et al., 2012; Semple & McCance, 2010; Sturz & Zografos, 2014). In confirmation of these studies, the literature states that religious coping improves psychological well-being (de Guzman et al., 2012). Moreover, instead of grieving over a normal life that lost forever, it is better to believe in God for his support to cope with the new life (Sherman et al., 2000; Spratling et al., 2012). Participants found solace in God through faith and prayers that in the midst of the difficulties, they believed they served a living God, who came to their rescue anytime they needed His assistance.

People living with a tracheostomy receive different kinds of social supports from various sources (Bessell & Moss, 2007; Semple & McCance, 2010). In the current study, participants received most of their social supports from their family members (spouses, children, mothers, and siblings) and their friends. The kinds of support they received ranged from emotional, financial to physical. Participants had support from spouses and children in undertaking most of the physical activities they could not do: washing, cooking and lifting items. They received emotional support as well as financial assistance from their
spouses and children for their health care needs. This finding is congruent with the study by Richardson et al. (2015) that, the presence of family and friends to provide social support is useful to PLTT. The availability of social support has also been linked with general and disease-specific quality of life in people living with a tracheostomy tube and thus, assist to decrease the feeling of distress (Howren, Christensen, Karnell, Van Liew, et al., 2013; Zarzycka, Kobos, Czarnecka, & Imiela, 2015). Furthermore, social network sites such as Facebook could assist to reduce social isolation and enhance peer interaction. In addition, the creation of an online community for people living with a tracheostomy could augment their social welfare (Madan et al., 2011). Social support has numerous advantages to individuals living with a tracheostomy tube, hence the need to encourage its use.

5.9 Discussion of the Guiding Thematic Concepts

Finally, findings of this study to some extent support the Thematic Concepts by (Foster, 2010), which sought to give some knowledge of how the various aspects of tracheotomised patients’ experience interconnect and make meaning with each other. The different themes in the framework link to each other, and although they are grouped into principal components, reflecting various aspects of the tracheostomy experience (Dawson, 2014), they still do not stand as independent components. This study found the interconnections to be relevant because living with a tracheostomy tube impact on the whole life of the individual, not just an aspect of it. For example, living with the tube leads to difficulty in breathing and speaking as well as a change in appearance (Flinterud & Andershed, 2015; Huffman et al., 2014; Teo et al., 2016). Difficulty in breathing results in weakness and incapacitation in undertaking strenuous activities which include those that can bring income (Isaksson et al., 2015; Mehnert et al., 2013). The change in appearance together with challenges with speech results in other psychosocial problems like social
isolation, anxiety, and depression (Chiou et al., 2013). Speech problems also affect employment and reduction in income (Isaksson et al., 2015; Mehnert et al., 2013). Therefore, the experiences people get while living with a tracheostomy tube do not stand alone, but they relate to each other to make up their whole lived experience.

However, there are still some aspects of the experience that are missing from the themes mentioned by Foster (2010). For instance, the impact of a tracheostomy on employment, the support people get and the strategies they use to cope with these challenges of living with a tracheostomy which this study highlighted, are missing in Foster’s work. These additional findings could partly be due to the differences in the study settings. The current study’s setting (home setting) explores more into the tracheostomised persons’ lived experiences because these experiences do not end in the ICU but transcend into the home setting. However, this study found the constructs of the Guiding Thematic Concepts as very useful in exploring the experiences of adults living with a tracheostomy.
CHAPTER SIX

SUMMARY AND CONCLUSION

6.1 Introduction

This chapter provides the summary and conclusion of the study. It highlights the implications for nursing practice, education, research, and policy. The researcher also presents the experience acquired in the study together with recommendations.

6.2 Summary

This qualitative study explored the lived experiences of ALTT in the Kumasi Metropolis, Ghana. The study has largely proven that living with a tracheostomy tube presented with lots of physical, physiological, psychosocial and economic challenges. There was pain from the surgery, during coughing and on swallowing which these adults could not report due to their inability to produce speech freshly after the surgery. This situation they found themselves in mostly resulted in anger and frustration. The reduced ability to talk, difficulty in breathing, and dysphagia impaired the performance of activities of daily living with a direct effect on employment. Some of the participants were not employed; others had changed jobs, and some had reduced the number of employment due to the tracheostomy tube. Participants complained of a change in appearance and body image, reduced self-esteem and altered sexuality. Due to this new look, participants socially isolated themselves from most social activities or had to put up a camouflage behaviour (cover the tube with extra clothing) to be a part of these social events. Participants lived in fear and anxiety wondering if the tube will ever be taken off. Owing to these challenges of life with a tracheostomy tube, they became depressed, even to the point of harbouring suicidal ideation.
This study identified that a few ALTT used “speaking valve” to speak. However, the majority of the participants used “the finger occlusion method” to talk because they could not afford the cost of the speaking valve. In the midst of all these difficulties, participants employed strategies such as acceptance, resilience, and reliance on God to cope with them. They also gained physical, financial and emotional support from friends and family members.

6.3 Implications for Clinical Nursing Practice

Findings of the current study bring to the fore issues that must be addressed to improve the quality of life of ALTT. These results have implications for nursing practice. Understanding the lived experiences of adults with a tracheostomy tube can support nursing, and medical practitioners provide efficient care to meet the health needs of these individuals. Results of the study indicated that living with a tracheostomy tube has an effect on all aspects of the person’s life: physical, physiological, psychosocial, and economic and communication. Most of these challenges are new experiences to adults living with a tracheostomy and worsen their plight. Therefore, nurses should intensify the preoperative preparations and education, emphasis on the many problems associated with living with the tube such as pain, reduced strength, difficulty in breathing and speaking, change in appearance and the associated emotional challenges. Knowing about these problems before the surgery will assist these adults to have a better transition into their new life with the tracheostomy.

Patients have difficulty in speaking in the initial stages of the surgery. In most situations, these patients are unable to utilize the call systems provided to them for communication. Therefore, nurses should assess the communication needs such as the ability to read and write before the surgery and provide non-verbal communication tools.
that will be suitable for the patient. This requirement assessment will assist to reduce the frustrations patients go through when they are unable to communicate their complaints to the health staff. To lessen the incidence of possible hypoglycaemia from painful and difficulty in swallowing, nurses ought to assess the nutritional needs of the patients after the surgery and provide adequate nutrition through other means such as giving light diets and IV fluids. Nurses should also critically observe patients after the surgery for the possible experience of pain and institute proper pain management for these adults; since most of them are unable to communicate verbally. Moreover, care of the tube and suctioning should be done tactfully to reduce pain and prevent infection.

The challenges of living with the tube at home far outweigh those experienced while at the hospital. Therefore, nurses should ensure proper counselling and education on tube care, the need for review, avoidance of high scented items and dust to reduce coughing and difficulty in breathing as well as activities that are likely to cause pain before discharge. The relatives and partners of these patients should be involved in the preparation before discharge on the need to provide adequate physical, emotional, financial and social support. There should be close monitoring of these adults in their homes. There is the need to watch for the effect of a tracheostomy tube on their job and income and possible challenges such as depression, and suicidal tendencies.

Finally, nurses should ensure that there are proper rehabilitation programmes for these adults to support improve their quality of life.

6.4 Implications for Nursing Education

Nursing education is core in enhancing the knowledge of nurses in providing quality care to adults who have to undergo or have undergone a tracheostomy surgery. Nurses play a major role in the preoperative preparation, inter and intraoperative treatment as well as
post-operative care. Nurse link up with other members of the health team in the provision of all the needed support for these patients and spend more time with them than other members of the health team. Therefore, nurses’ understanding of what constitute quality nursing care in achieving the quality of life for these patients should be a priority.

Although there is an established ENT Nursing School in Ghana that train specialist ENT nurses to render this needed care, the capacity of this institution should be built regarding infrastructure and equipment to enhance the training of these specialist nurses. Additionally, the aspect of the curriculum for training general nurses at the core level which deals with courses or topics on ENT should be given the needed attention. Tracheostomy care should be taught by ENT nurse specialists who have adequate knowledge in the care of patients with ENT health problems. General Nurses will get a better understanding of caring for patients with a tracheostomy since general nurses are the cadre of nurses who mostly care for these patients in the wards.

In the interim, training on continuous professional development (CPD) for nurses should include aspects of ENT nursing care; specifically, care of tracheostomised persons so that it will equip all groups of nurses on at least the basic health needs of these individuals living with a tracheostomy tube.

6.5 Implications for Policy

The results of this study suggest the formation of a National Association of Tracheostomised Persons. With this association formed, the large number of active persons who have been rendered inactive and mostly dependent on their family members will be identified and given the needed rehabilitation so that their individual knowledge, professional skills, and productivity will not go waste but rather, make them resourceful to the nation.
The government should support in providing a speaking valve which is always in short supply. Also, there should be a waiver on the cost of the speaking valve since most of these individuals have been rendered jobless due to living with a tracheostomy tube. Hence their inability to afford the high cost of these speaking valves has made them resort to the non-clinically approved “finger occlusion” method as identified in this study. Additionally, the various policies such as Livelihood Empowerment Against Poverty (LEAP), which support people within the poverty bracket should be extended to people living with a tracheostomy since they are also a suffering but unrecognised group of individuals who depend on the benevolence of philanthropists and family members.

The policy on the National Health Insurance Scheme should be planned to cover all the treatments that PLTT receive. If possible, they should be registered free of charge on the scheme since most of them are unable to attend reviews to care for the tube because of lack of finances which further reduces their quality of life.

6.6 Avenues for Future Research

From the results of this study, many prospective studies could be conducted. For example, the main themes that emerged out of this study can be further studied to gain a thorough understanding of their experiences. More studies can be done in the following areas:

a. The physical impact of adults living with a tracheostomy tube.

b. The physiological challenges of adults living with a tracheostomy tube.

c. The Psychological experiences of adults living with a tracheostomy tube.

d. The Social experiences of adults living with a tracheostomy tube.

e. The economic constraints of tracheostomy on adults living with a tracheostomy tube.
f. The communication dynamics of adults living with a tracheostomy tube.

g. Coping strategies of adults living with a tracheostomy tube.

h. The lived experiences of adolescents with a tracheostomy tube.

i. The attitude of the public towards people living with a tracheostomy tube.

j. Needs assessment of people living with a tracheostomy tube towards the planning of rehabilitation programmes.

k. The clinical viability of the “finger occlusion method” of speaking among people living with a tracheostomy tube.

6.7 Field Experiences/Reflections

The experiences gained during this study can be described as rich and revealing. The researcher made new friends during the research. This study allowed the researcher to see the realities of living with a tracheostomy tube in the home setting. The study additionally gave the researcher the chance to learn what adults living with tracheostomy endure and their everyday needs at home. The emotional state of the researcher in those moments of the study was that of empathy. The physical and psychosocial miseries shared by these adults, and the financial constraints which were very obvious from their physical appearance, rendered the researcher very emotional. The researcher had to shed some tears at a point during the interview and even had to give some financial support to some participants as they had not eaten the whole afternoon.

The general attentiveness of the researcher, the encouraging responses, and the emotional facial expressions made the participants open up to share more of their experiences. The researcher felt participants’ pain and suffering from their voices and although they had challenges with speaking for long, these participants were still ready to share their experiences, because they felt it was an opportunity for people to hear how they
Life after tracheostomy: Experiences of adults in the Kumasi Metropolis, Ghana

were suffering since it was their first time of going through such interview after their tracheostomy surgery.

The study was touching. Both researcher and participants depicted several emotional responses during the study. The researcher was surprised at the kind of revelations participants were making on their lives with the tracheostomy tube. It was realised that the study gave adults living with a tracheostomy tube the opportunity to share their experiences on living with a tracheostomy tube. The researcher observed that participants looked relieved and happy after sharing their story. It seemed they were glad they had the chance to tell their story. An indication to them that someone cared about them.

The study has brought a drastic change of the researcher’s attitude towards people living with a tracheostomy tube. The researcher has developed a more empathetic feeling for people living with a tracheostomy tube. The researcher before the study, saw people living with a tracheostomy tube as individuals who only had a physical challenge due to the presence of the tube on their neck. It was identified that, although these individuals with a tracheostomy tube look well and happy on the outside, inwardly, they go through a lot of challenges which they hardly get people to share with.

6.8 Limitations of the Study

This study contributed to the understanding of the experiences of adults living with a tracheostomy in the Kumasi Metropolis. However, it has some limitations. Only adults were used for this study; there is the possibility that people in different age groups may have different experiences. One other constraint of the study was identifying the correct locations of the participants. Most of the addresses of the participants were difficult to locate. The researcher had to drive around trying to locate participants’ residences leading to increased cost of transportation and communication. The interviews that were conducted
at participants’ homes were interrupted by family members. Those that were done at participants’ workplaces were also interrupted by customers. These interruptions affected the flow of the stories. Despite all these limitations, the findings should be seen as a support to an ongoing effort to fill the gap in the non-existing literature on the experiences of adults in Ghana living with a tracheostomy tube.

6.9. Conclusion

This study can conclude that living with a tracheostomy tube had a physical impact in areas of painful experience and impaired activities of daily living in the lives of adults living with the tracheostomy tube. Physiologically, there were challenges with breathing, swallowing and the sense of smell. Living with a tracheostomy also had psychosocial challenges: there was an alteration in body image which altered these adults’ sexuality and further got them socially isolating themselves from public activities. Participants, therefore, became anxious, depressed and even had suicidal ideations.

Living with a tracheostomy also affected the economic status of these adults. The change in appearance, the difficulty in breathing and speaking either made these adults stop the work they were doing, change their work schedule or reduce their workload. This dwindled their income and contributed to financial hardship in the midst of high cost of living and healthcare. The communication aspect of these adults was also affected. At the initial stage, these adults relied on non-verbal cues but later resorted to using either speaking valve or “finger occlusion” method before they could speak. However, they could not partake in some activities like singing and reading of the Bible which they were doing before the tracheostomy tube insertion.

Despite all these challenges, acceptance of the situation, being resilient and relying on God, as well as available support from family and friends, assisted them to cope with
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life. In all, the Guiding Thematic Concept by Foster used as a guide to this study was useful in identifying the interrelatedness of the various aspects of the experiences of living with a tracheostomy tube. Even though some aspect of the experiences were lacking taking into consideration the experiences of people with a tracheostomy residing in a community, it was a useful guide.

6.10 Recommendations

Based on the results of the study, the ensuing recommendations were made:

6.10.1 Recommendation to Nurses and other Health Professionals

a. Nurses should collaborate with other health professionals and patients’ relatives to enhance proper preoperative counselling and education before the surgery.

b. Nurses should ensure proper pain assessment and management during the immediate post-surgery stage since patients have difficulty communicating their pain.

c. Nurses should assess the nutritional needs of the patient with tracheostomy and encourage them to follow proper dietary requirements.

d. Nurses should provide high-quality nursing care to prevent stoma infection.

e. Nurses should prepare patients and relatives adequately on tube care and the provision of social support while at home.

f. Nurses should ensure that patients have access to the needed care during follow-up visits.
6.10.2 Recommendation to the ENT Department/Komfo Anokye Teaching Hospital

a. The heads of the ENT Department should liaise with the hospital management to provide adequate speaking valves and at a subsidised price for tracheostomised persons.

b. There should be a collaborative work which will bring on board all needed specialists such as the nutritionist and speech-language pathologist to assess the patient before discharge.

c. The leadership at the ENT Department together with the hospital management should establish proper rehabilitation and counselling programmes for people living with a tracheostomy.

d. The hospital management in collaboration with the ENT department and other agencies should conduct further studies to assess the clinical viability of the “finger occlusion method” of speaking and as well promote its usage among people living with a tracheostomy tube.

6.10.3 Recommendation to the Ministry of Health/Ghana Health Service

a. Health facilities should make it a policy that, there should be proper airway assessment for all patients who are to undergo thyroidectomy surgery.

b. There should be a collaboration with agencies to ensure an adequate supply of speaking valves at a subsidised price.

c. National Health Insurance package should be extended to cover all medical treatments of people living with a tracheostomy tube and possibly, free registration for them.
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doi: 10.1017/S0022215115000158


APPENDICES

Appendix A: Background information of Participants

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<tr>
<th>Pseudonyms</th>
<th>Age</th>
<th>Type Of Surgery</th>
<th>Sex</th>
<th>Edu. Background</th>
<th>Occupation</th>
<th>Marital status</th>
<th>Number of children</th>
<th>Nationality</th>
<th>Religion</th>
<th>Languages spoken</th>
<th>No of years of experience</th>
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<tr>
<td>Madam Nsiah 001</td>
<td>50yrs</td>
<td>Planned</td>
<td>F</td>
<td>Tertiary</td>
<td>Unemployed</td>
<td>Married</td>
<td>3</td>
<td>Ghanaian</td>
<td>Christian</td>
<td>Twi, English</td>
<td>3years</td>
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<td>F</td>
<td>Middle Sch.</td>
<td>Unemployed</td>
<td>Not married</td>
<td>0</td>
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<td>Christian</td>
<td>Fante, Ga, Twi</td>
<td>23years</td>
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<td>Middle Sch.</td>
<td>Trading</td>
<td>Married</td>
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<td>Ghanaian</td>
<td>Christian</td>
<td>Twi, English</td>
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<td>None</td>
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<td>Married</td>
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<td>Muslim</td>
<td>Twi, Hausa, Dagomba</td>
<td>9years</td>
</tr>
<tr>
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<td>F</td>
<td>Middle Sch.</td>
<td>Unemployed</td>
<td>Widow</td>
<td>2</td>
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<td>Christian</td>
<td>Twi</td>
<td>3years</td>
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<tr>
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<td>Middle Sch.</td>
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<td>Christian</td>
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<td>Widow</td>
<td>4A; 4D</td>
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<td>Christian</td>
<td>Twi, Frafra, Grusi</td>
<td>1year, 4months</td>
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</table>
Appendix B: Interview Guide

Interview Guide

Section 1: Background Information

Code number: .....................

1. Age (years): .................................................................
2. Level of Education: ..........................................................
3. Occupation: .................................................................
4. Place of residence: .........................................................
5. Marital status: ..............................................................
6. Number of children: ......................................................
7. Nationality: .................................................................
8. Religion: ........................................................................
9. Languages spoken: .........................................................
10. How long have you been living with the tube? ....................
11. Was your tube insertion a planned one or emergency? ......

Section 2: Experiences

Main question: Please can you tell me about your experiences on living with tracheostomy?

Sub-questions (probe where necessary)

1. What made you have a tube on your neck?
   Probes:
   - So what happened next?

2. Please tell me about how you felt when you realized you had a tube in your neck?
   Probe:
   - So what happened next?
   - So what did the nurses and/or Doctors tell you?
3. Please tell me, how it feels to live with a tube in your neck?
   Probe:
   - Sputtering, Pain
   - Breathing
   - Sense of smell
   - Ability to undertake daily activities like shopping, sweeping, running, etc.

4. Please tell me, how you communicate with others
   Probe:
   - Lip reading
   - Nodding of head
   - Writing on paper
   - Use tablet
   - Talks with tube
   - Uses speech valves

5. Please share with me how you have been managing your life
   Probe:
   - Work
   - Social activities
   - Family/Family support
   - Financial issues
   - Community (spirituality, friends)
   - Marriage (sexuality)

6. Please can you share with me a typical day of your life whilst living with a tube in your neck?
   Probe:
   - What difficulties do you encounter

7. Is there anything else you would like to talk about?
Appendix C: Consent Form

NMIMR-IRB CONSENT FORM TEMPLATE

Title: Life after Tracheostomy: The Experiences of Adults in the Kumasi Metropolis

Principal Investigator: Bismarck Asare

Address: Department of Adult Health, School of Nursing, College of Health Sciences, University of Ghana, P.O. Box LG 43, Legon, Accra, Ghana.

General Information about Research

The objective of the study is to explore life after neck tube insertion. The study will explore the physical effects, the psychosocial impact, the communication issues as well as the coping strategies associated with living with a tube on the neck.

If you decide to take part in this study, you will meet with the researcher and have a conversation with him for a period of between 45 minutes to 1 hour in either “Twi” or English language. A second conversation may be arranged if necessary. The conversation will be about the things you go through whilst living with a tube on your neck. You will be asked to sign or thumb print a consent form as appropriate.

Possible Risks and Discomforts

It is not expected that being in this study will be harmful to you, however you may feel emotional about telling your story. When that happens, the researcher will refer you to someone who will talk to you to relieve you of your emotions without any financial cost to you.

Possible Benefits

The study may not have any direct benefits for you at the moment, however your experiences shared may enhance the delivery of quality nursing care to people living with tube in the neck.

VALID UNTIL
12 NOV 10

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Confidentiality

The conversation will be recorded on tape and later written in words. Your name will not be recorded. An odd number and fake names will be given to your conversation.

The only people that will know about our conversation will be the researcher supervisors. All information that has your name on it will be kept under lock and key at a separate place from the written information for 5 years after the study.

Compensation

You will not receive any payment for participating in this research. However, if the researcher is to meet you anywhere outside your place of work or home for the interview, you will be given an amount of GHS 10.00 as transportation.

Voluntary Participation and Right to Leave the Research

Participating in this research is purely voluntary. You are free to leave the study at any point during the study even after you have agreed to be part of the study. Such withdrawal will not have any effect on any health service that you require from health care providers.

Contacts for Additional Information

If you have any questions or concerns about the research now or later, please contact:

The researcher:
Bismarck Asare, M.Phil Nursing (student), Department of Adult Health, School of Nursing, College of Health Sciences, University of Ghana, P. O. Box LG 43, Legon, Accra, Ghana.
0243158805/0206644465, macekar94@gmail.com

VALID UNTIL
12 NOV 2016

APPROVED DOCUMENT
Or his supervisor:

Dr. Lydia Aziato, Department of Adult Health, School of Nursing, College of Health Sciences, University of Ghana.

0244716686 / 0208552719 aziato1@yahoo.com

Your rights as a participant

This research has been reviewed and approved by the Institutional Review Board of Noguchi Memorial Institute for Medical Research (NMIMR-IRB). If you have any questions about your rights as a research participant, you can contact the IRB Office between the hours of 8am-5pm through the landline 0302516438 or email addresses: irb@noguchi.mim.com.org
VOLUNTEER AGREEMENT

The above document describing the benefits, risks and procedures for the research title Life after Tracheostomy: The Experiences of Adults in the Kumasi Metropolis has been read and explained to me. I have been given an opportunity to have any questions about the research answered to my satisfaction. I agree to participate as a volunteer.

Date ___________________________ Name and signature or mark of volunteer

If volunteers cannot read the form themselves, a witness must sign here:

I was present while the benefits, risks and procedures were read to the volunteer. All questions were answered and the volunteer has agreed to take part in the research.

Date ___________________________ Name and signature of witness

I certify that the nature and purpose, the potential benefits, and possible risks associated with participating in this research have been explained to the above individual.

Date ___________________________ Signature of Person Who Obtained Consent

VALID UNTIL 12 NOV 2016
Appendix D: Introductory Letter

December 2, 2015

The Head
Department of ENT
KATH
Kumasi

Dear Sir/Madam,

INTRODUCTORY LETTER

I write to introduce you Bismark Asare, an MPhil Year II student of the School of Nursing, University of Ghana, Legon. He is conducting a research on “Life after Tracheostomy: The Experiences of Adults in the Kumasi Metropolis”.

I should be most grateful if you could kindly assist him with the information that he may require.

Thank you.

Yours faithfully,

Dr. Lydia Azale
Sr. Lecturer
Appendix E: Ethical Clearance

ETHICAL CLEARANCE

FEDERALWIDE ASSURANCE FWA 00001824
NMIMR-IRB CPN 035/15-16
IRB 00001276
IORG 0000998

On 13th November, 2015, the Noguchi Memorial Institute for Medical Research (NMIMR) Institutional Review Board (IRB) at a full board meeting reviewed and approved your protocol titled:

TITLE OF PROTOCOL: Life after tracheostomy: The experiences of adults in the Kumasi Metropolis

PRINCIPAL INVESTIGATOR: Bismarck Asare, MPhil CAND.

Please note that a final review report must be submitted to the Board at the completion of the study. Your research records may be audited at any time during or after the implementation.

Any modification of this research project must be submitted to the IRB for review and approval prior to implementation.

Please report all serious adverse events related to this study to NMIMR-IRB within seven days verbally and fourteen days in writing.

This certificate is valid till 12th November, 2016. You are to submit annual reports for continuing review.

Signature of Chair: ____________________________
Mrs. Chris Dadzie
(NMIMR – IRB, Chair)

cc: Professor Kwadwo Koram
Director, Noguchi Memorial Institute
for Medical Research, University of Ghana, Legon