

https://dspace.org/

Caring for a child with a tracheostomy in the Gauteng and the Western Cape Provinces of South Africa: caregiver lived experiences

Segev, Aderet

2020
https://hdl.handle.net/10539/30648

Downloaded from a DSpace repository. https://dspace.org/



Caring for a Child with a Tracheostomy in the Gauteng and the Western Cape Provinces of South Africa: Caregiver Lived Experiences.

A Dissertation in Fulfilment of the Requirements of

Masters in Speech Pathology

Presented to

The Department of Speech Pathology and Audiology

School of Human and Community Development

Faculty of Humanities

University of the Witwatersrand

Candidate:

Aderet Segev

Supervisor: Jaishika Seedat

Co-Supervisor: Munyane Mophosho

March 2019

DECLARATION

I hereby declare that this research proposal is on the basis of my own effort. It has only been submitted to the Speech Pathology and Audiology Department at the University of the Witwatersrand. Any contribution made to the research by others has been explicitly acknowledged.



12/03/2019

Aderet Segev Date

ABSTRACT

Introduction: The experience of undergoing a tracheotomy is an emotional journey for both a caregiver and their child. Life change is instantaneous for family members of a child with a tracheostomy as they become responsible for the child both at the hospital and at home. South Africa appears to be a unique context for the current study, with challenges such as limited resources, poverty, diversity of the population, multilingualism, and access to services such as speech therapy. Little is known specifically about the lived experiences of caregivers of children with a tracheostomy in the South African context.

Methodology: To explore the lived experiences of caregivers of the 0-5-year-old paediatric population with a tracheostomy, post hospital discharge, in the Gauteng and the Western Cape provinces of South Africa. The following sub-aims were explored: 1) the experiences of caregivers of children with tracheostomies between the ages of 0-5-years post-hospital discharge, during their transition back into family, home and society. 2) The support systems available to the caregivers. 3) To gain insight into the role of caregivers. A qualitative and interpretative phenomenological approach was employed. Semi-structured, face-to-face interviews were conducted in English & IsiXhosa, using open-ended questions. The study consisted of ten caregivers of children with tracheostomies, who were recruited from two government hospitals in the Gauteng and Western Cape Provinces. The study included caregivers of children of any gender, between the ages of 0-5 years, who had a tracheostomy for at least one month, and had been discharged from the hospital for at least one month. Data was collected over a three month period. Data was transcribed and analysed using thematic analysis.

Results: The experiences of the caregivers appeared to be complex and individually-based. The results confirmed that not only do these experiences include coping with the physical properties of the tracheostomy, but also the medical and emotional experiences. Caregiver roles, the grief process, faith and family support were significant themes that emerged as contributing to the experience of home-based care for the caregivers.

Conclusions: Feelings and attitudes are inseparable from the health condition itself, and thus the insertion of a tracheostomy is not just a medical experience, but rather a combination of concomitant emotional feelings and experiences. The results of this study correlated with the biopsychosocial model of a health condition, illustrating the close connection between one's health, activities and participation within one's context, whereby the diagnosis and insertion of a tracheostomy, contributed to multiple experiences and changes in the lives of the caregivers, specifically in their home, social and family environments. The financial, social, emotional and physical implications expressed by the caregivers suggested that perhaps home-based care is not ideal for caregivers in the South African context.

Implications: Results obtained increase awareness and provide valuable information to nurses, medical practitioners, speech therapists, speech therapy students, as well as amongst caregivers themselves of children with medical conditions, specifically, those with a tracheostomy. Speech therapists have a very important role in advocating success of reintegration back into their family, home, and society, post discharge from the hospital. Faith, religious practice and the grief process can be used as tools to strengthen relationships between patients, families and medical practitioners. The potential benefit of caregiver support groups was emphasized.

Keywords: caregiver, experiences, children, tracheostomies

ACKNOWLEDGEMENTS

Master's has been a wonderful journey and now that it is complete I would like to show my gratitude to all the special individuals in my life. A special thank you to:

- The caregivers who participated in my study. Thank you for your time and sharing your experiences with me.

- My supervisors Dr. Seedat and Dr. Mophosho. Thank you for your support, guidance and insight. Your understanding and patience really made my journey pleasant- exactly how I wanted it to be.

- Prof. Penn. Thank you for encouraging me to do my master's and for believing in me. I wish you could be here to read my research. You are really missed by all.

- My parents and siblings. Thank you for all your love and support over the year. I could have not done it without you.

- My best friends Chanti, Zarreen and Rumaana. It was such a great journey doing masters with you. Your support and encouragement is greatly appreciated.

- The research sites. Thank you for allowing me to conduct my research. A special thank you to Sister Jane Booth for all your help and support.

- My dearest fiancé Menachem. Although you came into my life half way through masters, you really helped me reach the end. I am eternally grateful for all your love and support.

- To my father in heaven Hashem for guiding me, and for showering me with Your love and blessings.

TABLE OF CONTENTS

DECLARATION ..... **ii**

ABSTRACT ..... **iii**

ACKNOWLEDGEMENTS ..... **iv**

TABLE OF CONTENTS ..... **v**

LIST OF TABLES ..... **x**

LIST OF FIGURES ..... **xi**

LIST OF ABBREVIATIONS ..... **xii**

TERMINOLOGY ..... **xiii**

CHAPTER 1: INTRODUCTION **1**

1.1. Problem Statement & Rationale for the Study 1

CHAPTER 2: LITERATURE REVIEW **4**

2.1. Introduction & Definition of a Tracheostomy 4

2.2. Tracheostomy Indications & Decannulation 6

2.3. Tracheostomy Complications & Challenges 8

2.4. The Tracheostomy Multidisciplinary Team 10

2.5. Home-Based Care and the South African Context 13

2.6. Family and Caregiver Experiences 16

2.7. Paediatrics: 0-5-year-old Age Group 18

2.8. Quality of Life 19

2.9. The Grief Process 20

2.10. Third-Party Disability 21

2.11. Summary 22

2.10. Theoretical Framework 23

CHAPTER 3: METHODOLOGY 25

3.1. Aims of the Study.....25

3.1.1. Primary Aim of the Study.....25

3.1.2. Sub-Aims of the Study. 25

3.2. Research Design.....25

3.3. Site Description.....26

3.4. Participants.....28

3.4.1. Participant Description.....28

3.4.2. Sampling Strategy & Sample Size. 31

3.4.3. Selection Criteria. 32

3.4.4. Rationale for the inclusion criteria for the caregivers' participation in the study. .33

3.5. Research Instrument.....35

3.6. Pilot Study.....35

3.7. Data Collection & Procedure 37

3.8. Overall Research Procedure.....39

3.9. Data Analysis 41

3.10. Triangulation & Trustworthiness 43

3.10.1. Credibility.....44

3.10.2. Transferability/Generalisability. 45

3.10.3. Confirmability. 45

3.10.4. Reliability. 45

3.11. Ethical Considerations 46

CHAPTER 4: RESULTS & DISCUSSION 49

4.1 Sub-Aim One 50

4.1.1. Caregiver Feelings towards the Tracheostomy. 50

4.1.2. The Grief Process. 54

4.1.3. Third-Party Disability. 59

4.2. Sub-Aim Two 64

4.2.1. Faith. 64

4.2.2. Family Support. 70

4.2.3. In-Hospital Tracheostomy Training. 74

4.3. Sub-Aim Three 76

4.3.1. Tracheostomy Training and Care. 76

4.3.2. Providing Financial Stability. 82

4.3.3. Home-Based Care. 85

4.4. Latent Theme: Caregiver Hospital Experiences 88

CHAPTER 5: CONCLUSIONS & IMPLICATIONS 91

5.1. Conclusions 91

5.2. Implications of the study 96

5.2.1. Clinical and Theoretical Implications....96

5.2.2. Policy Implications....100

5.2.3. Implications for Further Research....100

5.3. Limitations of this Study....102

REFERENCES....105

APPENDICES....120

Appendix A: Biographical Information....120

Appendix B: Semi-Structured Interview Open-Ended Questions....121

Appendix C- Participant Information Sheet....122

Appendix D- Participant Consent Form....125

Appendix E- Audio-Recording Consent Form....126

Appendix F- Research Site HOD Request for Permission....127

Appendix G- Research Site CEO Request for Permission....129

Appendix H: Distress Protocol....131

Appendix I: Participant Descriptions....132

Appendix J: Biographical Participant Data....135

Appendix K: Themes of the Study....136

Appendix L: Approval of Title Change....137

Appendix M: University of the Witwatersrand HREC Medical Clearance Certificate....138

Appendix N: University of Cape Town HREC Medical Ethics Clearance....139

Appendix O: Red Cross War Memorial Children's Hospital Clearance Letter....140

Appendix P: Chris Hani Baragwanath Academic Hospital Clearance Letter.....141

Appendix Q: Chris Hani Baragwanath Academic Hospital Speech Department HOD Clearance Letter 142

Appendix R: Turnitin Report 143

LIST OF TABLES

Table 3.1. Participant and child biographical information 29

Table 3.2. Caregiver and child duration of hospital stay 30

Table 3.3. Caregiver employment status..... 31

Table 3.4. Outline of the Research Procedure..... 39

Table 4.1. Outline of themes that emerged in relation to the aims of study 50

Table 4.2. Public reactions towards the child with the tracheostomy..... 60

Table 4.3. Excerpts from participant interviews in relation to the tracheostomy training..... 75

LIST OF FIGURES

Figure 2.1. Tracheotomy 5

Figure 2.2. Tracheostomy 5

Figure 2.3. The biopsychosocial model of a health condition (WHO, 2007) 24

Figure 3.1. Phases of Thematic Analysis- According to Braun & Clarke (2006) 43

Figure 4.1. The stages of the grief process. 55

Figure 4.2. Caregiver support systems. 71

Figure 4.3. Caregiver roles in taking care of their child with a tracheostomy. 79

LIST OF ABBREVIATIONS

CHBAH- Chris Hani Baragwanath Academic Hospital

FTT- Failure to Thrive

HBC- Home-Based Care

HPV- Human Papilloma Virus

ICF- International Classification of Functioning

ICU- Intensive Care Unit

MDT- Multi-Disciplinary Team

UK- United Kingdom

USA- United States of America

WHO- World Health Organization

TERMINOLOGY

Cannula- part of a tracheostomy tube that holds the tracheostomy open

CHARGE Syndrome- a disorder that affects many areas of the body. CHARGE is an abbreviation for several of the features common in the disorder: coloboma, heart defects, choanal atresia, growth retardation, genital abnormalities, and ear abnormalities.

Decannulation- the process whereby a tracheostomy tube is removed once it is no longer required

Dysphagia- the medical term for the symptom of difficulty in swallowing

Failure to Thrive (FTT) - failure to grow or maintain weight

Granuloma- a mass of granulation tissue, typically produced in response to infection, inflammation, or the presence of a foreign substance

Hemorrhage- an escape of blood form a ruptured blood vessel

Intubation- is the placement of a flexible plastic tube into the trachea (windpipe) to maintain an open airway or to serve as a conduit through which to administer certain drugs.

Laryngomalacia- is a congenital softening of the tissues of the larynx above the vocal cords

Microlaryngoscopy- surgical examination of the larynx under general anesthetic

Nasotracheal- intubation the trachea by way of the nose

Nosocomial- infection acquired in hospital

Oedema- swelling

Obstruction- a blockage

Orotracheal- intubation the trachea by way of the mouth

Phonation- the production or utterance of speech sounds

Pulmonary-relating to the lungs

Stoma- a hole

Subglottic Stenosis- is a narrowing of the airway below the vocal cords and above the trachea

Trachea- called the windpipe, a cartilaginous tube that connects the pharynx and larynx to the lungs, allowing the passage of air

Tracheostomy- an opening in the trachea

Tracheotomy- a surgical procedure performed to make an opening in the trachea

Ventilation- the exchange of air between the lungs and the atmosphere so that oxygen can be exchanged for carbon dioxide in the alveoli (the tiny air sacs in the lungs)

CHAPTER 1: INTRODUCTION

1.1. Problem Statement & Rationale for the Study

This study was aimed at gaining a detailed understanding of the experiences of caregivers following the insertion of a tracheostomy for their child. More specifically, this study was designed to obtain information pertaining to children with a tracheostomy, ranging between the ages of 0-5 years of age, from the perspective of their caregiver. A tracheotomy refers to the procedure of making an opening into the trachea; whereas a tracheostomy refers to the formal stoma that is created (Adoga & Ma'an, 2010). The tracheostomy allows for a passage for effective respiration, therefore, blockage of the tube is life threatening. Although this procedure may be the best option in some cases, this population is vulnerable based on age and the associated risk of complications due to prolonged hospital stays (Jacobs, 2012). In addition to these precautions, international studies have shown that there are challenges transitioning from the hospital to the home environment (Adoga & Ma'an, 2010). Little is known about the experiences of family members in the Gauteng and the Western Cape provinces of South Africa during their transition from hospital to home environments, where family members often become the core responsible care providers (Montagnino & Maurico, 2004).

Care practices vary widely between hospitals, as no standardized protocol exists for the care of paediatrics with tracheostomies between the ages of 0-5 years (Jacobs, 2012). Formal tracheostomy home care programs can allow for a decrease in the duration of hospital stay, and improve patient care both during hospital stay, and post discharge (Vanker, Kling, & Booysen, 2010). Home-based care (HBC) refers to any form of assistance provided to a patient in their home environment. This care is provided by family, friends and members of one's community, taking into consideration the advice and support from trained professionals (WHO, 2018).

HBC has been documented to be beneficial in several ways (Vanker et al., 2010). The benefits of HBC will be addressed in detail in the literature review and the results. In South Africa, there is a lack of information on what happens to the child with a tracheostomy upon hospital discharge. Questions arise as to whether the child with the tracheostomy and caregivers are provided with HBC, follow-up appointments, social work involvement, and referral to community health workers, as has been documented to happen in some international and developed contexts (Vanker et al., 2010). A lack of the above-mentioned information may then have implications for holistic and complete management of the child who has undergone a tracheotomy (WHO, 2018).

Holistic patient management and treatment beyond the immediate hospital context should be advocated (WHO, 2011). The International Classification of Functioning (ICF), a framework of the World Health Organisation (WHO), measures disability at both individual and population levels. The ICF framework emphasizes the importance of considering and analyzing the impact of one's environment and other contextual factors on their functional abilities (WHO, 2011). Therefore, the aim of this study was to explore the experiences of caregivers, caring for their child with a tracheostomy between the age of 0-5-years, once they are discharged from hospital, as these detailed experiences of caregivers remains limited to the speech therapist. This study captures how the caregiver sees the child adjusting to life at home, and socially, through gaining a first-hand account of their report of their support systems, experiences of reintegration back into society, and the role of the caregiver. Hence, the study sought to gain an understanding of this from the perspective of the caregiver of a child in the 0-5-year-old age group, as this remains undocumented information in the South African context.

Qualitative research exploring parental experiences of having a child with a tracheostomy, both internationally and nationally, remains limited. Similar studies have been

conducted in the United States of America (USA) and United Kingdom (UK), mostly quantitative in nature, however, the lack of this data in the South African context, specifically qualitative research designs, advocates the need for this to be investigated further. South Africa appears to be a unique context for the current study, with challenges such as limited resources, poverty, diversity of the population, multilingualism, and access to services such as speech therapy.

If all these areas remain undocumented in the South African context, this highlights a gap in knowledge that may require the attention of the health professionals managing the paediatric patient with a tracheostomy- hence the current study was needed. The expanded views of patient management, and frameworks such as the biopsychosocial model, provide insight into caregiver health and coping mechanisms, and prompted the need for research to expand as well as to consider these dimensions.

CHAPTER 2: LITERATURE REVIEW

This section includes a review of the literature, with presentation of South African and internationally-based studies. The literature reviewed explores the indications, complications, experiences, HBC practices, and quality of life, related to tracheostomies. This will be followed by an explanation of the theoretical frameworks that guided this study.

2.1. Introduction & Definition of a Tracheostomy

The first recorded tracheostomy on a paediatric patient was performed in 1620 by Mabicot, to bypass upper airway diseases and obstructions caused by acute infections (Jacobs, 2012). As noted above, a tracheotomy refers to the procedure of making an opening into the trachea, whilst a tracheostomy refers to the creation of a stoma (refer to Figure 1 and Figure 2 below). The stoma enables communication between the trachea and the overlying skin (Ismail-Koch & Jonas, 2014). The larynx, commonly known as the voice box or glottis, is the passageway for air between the pharynx and the trachea. Normal functioning of the larynx involves the protection of the lower airway, the regulation of air flow, as well as contributing to phonation (O'Connor, 1995). A tracheostomy provides a channel for effective respiration as well as the removal of secretions. In the paediatric population, this procedure is performed as a life saving measure in those with either an airway obstruction or neurological impairment (Carron, Derkay & Strope, 2010). Neurological impairment refers to a dysfunction in any part of the brain, for example, cerebral palsy and neuromuscular diseases (Seddon & Khan, 2003).

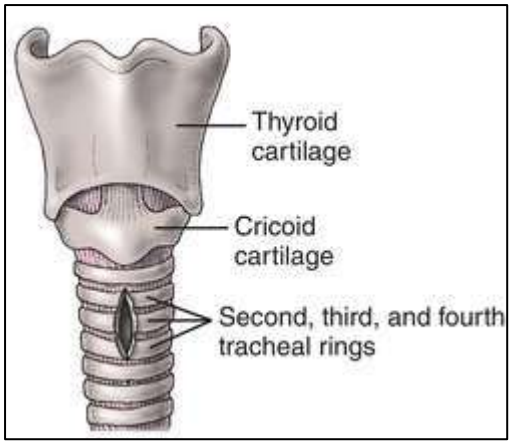


Figure 2.1. Tracheotomy

Retrieved from: https://medical-dictionary.thefreedictionary.com/tracheotomy

21 February 2018

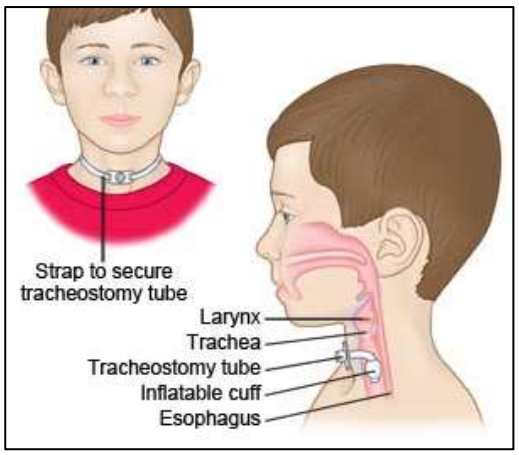


Figure 2.2. Tracheostomy

Retrieved from: https://www.drugs.com/cg/tracheostomy-care-for-children-aftercare-instructions.html

21 February 2018

The anatomy, medical conditions, and prognoses of children undergoing tracheostomies often differ from those in adults (Deutsch, 2010). When used in paediatric patients, a tracheostomy involves greater technical detail with higher mortality rates, than in adults (Dal'Astra, Quirino, Caixêta, & Avelino, 2017). The paediatric airway has several important anatomical differences compared to the adult airway, which places these patients at an increased risk for obstruction (Boss, 2009). Blockage of the tracheostomy tube whether partial or complete is life threatening. In addition, paediatric patients are particularly placed at risk during surgical procedures, due to their limited oxygen reserves (Boss, 2009). Despite the concerns of this procedure in paediatrics, Dal'Astra et al. (2017) confirm that it is a safe procedure that increases the chances of survival in paediatrics who require prolonged mechanical ventilation.

Over and above the listed challenges that may be encountered during hospitalization, equally challenging may be the transition from an in-patient to an out-patient facility and finally

home care (Jacobs, 2012). It is therefore of utmost importance that parents are provided with the relevant information by the respective health professionals and that they demonstrate some level of skills in managing the tracheostomy before they take their child home (Callans, Bleiler, Flanagan, & Carroll, 2016).

2.2. Tracheostomy Indications & Decannulation

Studies show a historical shift in indications for a tracheostomy in children (Schweiger, Manica, Becker, Abreu, Manzini, & Sekine, 2017). Tracheostomies are indicated in the following cases: upper airway obstruction (due to congenital or acquired causes), patients requiring long-term ventilation, and failure to wean from nasotracheal or orotracheal ventilation (Schweiger et al., 2017). An indication for a tracheostomy tube is usually the need to bypass an upper and central airway obstruction (Ismail-Koch & Jonas, 2014). Upper airway obstruction is caused by a spectrum of pathologies, namely, trauma, neoplastic diseases and neurological diseases. In such cases, the tracheostomy tube bypasses the obstruction allowing inhaled air to pass directly from the trachea to the lower airways (Ismail-Koch & Jonas, 2014). In the case of neurological fall out, a patient may be unable to clear airway secretions, therefore the opening created allows for direct access to the lower airways with suction cannulas (Boss, 2009). Obstruction is also caused by a build-up of secretions, which causes a narrowing of the tube which can be prevented by performing humidification and suctioning (Boss, 2009).

The most common indication for paediatric tracheostomies in first-world countries is prolonged intubation following ventilation, while upper airway obstruction remains the most common indication. In South Africa, infectious diseases such as tuberculosis, accounts for 21% of cases of paediatric tracheostomies (Boss, 2009). The Human Papilloma Virus (HPV) a

condition in which wart out-growths develop on the laryngeal mucosa, is the most common indication in other areas of Africa (Adoga & Ma'an, 2010).

The last 20 years has seen a world-wide increase in the paediatric population of with tracheostomies, for differing reasons (Buescher, Whitmire, Brunssen, & Kluttz-Hile, 2006). A major contributor to this are the survival rates of premature children, which have shown a positive increase. In addition, care interventions (long duration of endotracheal intubation and mechanical ventilation), have contributed to and are consequently becoming the most common indications for a tracheostomy (Schweiger et al., 2017). This was supported by a study in Scotland that also found that long-term ventilation was a main indication for a tracheostomy (Douglas, Poole-Cowley, Morrissey, Kubba, Clement, & Wynne, 2015). Some patients are able to cope with intubation without side effects, however, extended periods of intubation often interfere with normal development, and can cause damage to the larynx and trachea (McWhorter, 2003).

Intubation is also a major cause of acquired subglottic stenosis, accounting for 90% of the cases of children requiring tracheostomies (Deutsch, 2010). An increase in the incidence of subglottic stenosis may be attributed to the survival rates of critically ill children undergoing prolonged intubation and ventilation (Jacobs, 2012). The factors contributing to the development of subglottic stenosis are not well understood, however, some theories suggest that subglottic stenosis is caused by orotracheal intubation, repeated intubation, low birth weight, prematurity, and laryngopharyngeal reflux (Deutsch, 2010).

Decannulation refers to the removal of the tracheostomy. This only occurs following effective management of the pathology, or complete resolution of the underlying reason for the tracheostomy. Decannulation is always the objective but is not always possible (Schweiger et

al., 2017). The patient should be well at the time of decannulation, and observed for a period thereafter in hospital for any emergency (Ismail-Koch & Jonas, 2014).

Jacobs (2012) reports that care practices vary widely between institutions and regions, as no standardized protocol exists for the care of patients with a tracheostomy (Jacobs, 2012). Al-Samri, Mitchell, Drummond, and Bjornson's (2010) findings supported this and confirmed that there were no formal guidelines on standards of care and management. In addition, Nassif, Zielinski, Francois, and van den Abbeele (2015) reiterated that tracheotomy must be performed in a specialized center with a multidisciplinary team following predefined protocols guiding the care of such patients. As yet, there are no standardized protocols for the care and management of children with tracheostomies, for the South African context.

2.3. Tracheostomy Complications & Challenges

The placement of a tracheostomy tube in a child results in changes which predispose him/her to lower respiratory tract infections. The placement of a tracheostomy includes bypassing of the protective mechanisms of the upper airway, exposing tracheal mucosa to atmospheric air, the tracheostomy tube acting as a foreign body, as well as trauma to the tracheal mucosa from suction catheters and the tube itself being manipulated (Boss, 2009). In a study by Jacobs (2012) in Johannesburg, Gauteng an overall mortality rate of patients with tracheostomies was found to be 27%, emphasizing the risks involved in tracheostomy insertion and the need for a highly specialized and skilled team. The most common complications were tracheostomy tube obstructions, and the second most common complication was nosocomial pneumonia. Despite these complications, for some children, a tracheostomy is not something to be avoided, but rather the best option (Deutsch, 2010).

Early post-operative complications can involve hemorrhage, pulmonary oedema, swallowing difficulties and local infection. Follow-up care involves regular micro-laryngoscopy to exclude the formation of granuloma and to examine the underlying pathology that resulted in the need to insert the tracheostomy. Late complications can involve tracheal granulomas, tracheomalacia, accidental decannulation or blockage, and delayed speech and language development (Ismail-Koch & Jonas, 2014; Dal'Astra, 2017).

In a retrospective study, Jacobs (2012) explored the management of young patients under the age of 18 with a tracheostomy. This study took place in a resource poor environment over the period of 10 years. Jacobs (2012) aimed at describing the age, indications, complications, and outcome of paediatric patients in the Johannesburg public hospital sector. This study found that in a few government hospitals in Johannesburg, prolonged admissions were observed in younger children, with a mean length of 147 days. This was compared unfavorably with multiple private hospitals, in which patients had much shorter durations of hospital admission. Eight of the patients in the study were admitted for longer than one year for tracheostomy care and training (Jacobs, 2012).

In contrast, a large study of hospitals in North America showed an average duration of hospital admission of 50.2 days (Lewis, Carron, Perkins, Sie, & Feudtner, 2003). Such long hospital stays can negatively impact all aspects of critical development depending on the age of the child (Lewis et al., 2003). Another reported complication of prolonged hospital stay was nosocomial pneumonia. Jacobs (2012) reported that such prolonged admissions result from difficulties in establishing safe home-based tracheostomy care. Collaboration between the members of the multidisciplinary team can potentially decrease the duration of admissions, and enhance the transition from the hospital environment to one's home environment (de Mestral et al., 2011). This will be discussed further under section 2.4. 'The Tracheostomy Multidisciplinary Team'.

Studies show that tracheotomy tubes can be changed by family members with adequate training (Deutsch, 2010). The training would enable family members to assess tracheotomy-related problems, suction, change tubes, as well as resuscitate the child if required (Deutsch, 2010). The importance of cleaning and suctioning of tracheostomy tubes to maintain patency to avoid buildup of secretions that can obstruct the airway, was highlighted in the study by Deutsch (2010).

As reported by Rane, Shankaran, and Natarajan (2013), data on the outcomes of children following tracheostomy in early childhood are scarce. In the study done by Rane et al. (2013), among ten infants who had follow-up assessments, 90% had language deficits, 40% had cognitive deficits, and some had reports of dysphagia, voice and hearing difficulties. Adherence to tracheostomy care can be even more challenging for those living in a resource poor environment (Jacobs, 2012). Tracheostomies within the South African context, specifically in the Gauteng and the Western Cape provinces, will be discussed as part of the current study.

2.4. The Tracheostomy Multidisciplinary Team

Multidisciplinary care is expanding in order to manage the complex needs of tracheostomy patients (Bonvento, Wallace, Lynch, Coe, & McGrath, 2017). de Mestral et al. (2011) conducted a research study in which a multidisciplinary tracheostomy team was created to follow ill patients who had undergone a tracheostomy until their discharge from hospital. This team composed of a surgeon, respiratory therapist, speech-language pathologist and a clinical nurse specialist. The objective of the study was to assess the impact of the MDT related to decannulation and tracheostomy-related complications. de Mestral et al. (2011) showed that the care by a specialized multidisciplinary tracheostomy team was associated with less tracheostomy-related complications and an increase in the use of a speaking valve.

Bonvento et al. (2017) also report that there is increasing evidence of the collective effectiveness of a team approach to tracheostomy care. MDTs have been shown to be effective in patient counselling around insertion of the tracheostomy, within the ICU to reduce weaning time, through to ward-based educational programs in improving safety and reducing complications and readmissions. Keeping in mind the benefit of a MDT as discussed above, the respective roles and scope of practice of the tracheostomy team members will be discussed.

de Mestral et al. (2011) reported that the role of the respiratory therapist is to perform a bedside check of the tracheostomy tube, the oxygen delivery system and the spare emergency tracheostomy tube. Additionally, the respiratory therapist discusses daily tracheostomy care issues with the nursing staff and family. de Mestral et al. (2011) explain that the speech-language pathologist assesses the patient's ability to tolerate a speech valve. The speech-language pathologist also provides recommendations regarding the speech valve and/or augmentative communication strategies.

Bonvento et al. (2017) discuss more members as part of the tracheostomy team members. They describe the role of the medical staff, having a key role in planning, performing and managing patient care throughout their tracheostomy journey. The physiotherapist has a role in assessing and treating the respiratory problems, and the management of those dependent on mechanical ventilation. Secondly, Bonvento et al. (2017) describe the role of the speech-language pathologist in assessing, diagnosing, and managing of the communication and swallowing difficulties in the care of tracheostomy patients. The specialist nursing staff have the role of wound care as well as educating the staff on tracheostomy care. The support of nursing staff has shown to decrease the rates of complications and readmissions to the ICU. Dieticians and occupational therapists have also shown to be beneficial to the tracheostomy care team.

Bonvento et al. (2017) highlight that although there may be overlaps in roles amongst the tracheostomy team members, this is in fact an advantage to the team, enhancing opportunities to learn best practice for the management of these patients, by working together and sharing knowledge. Interestingly, Bonvento et al. (2017) acknowledge that both the speech-language pathologist and the psychologist have a role in addressing some of the psychological consequences of a tracheostomy, although they do point out that research in this area is currently limited.

As part of the multidisciplinary team, support from family and friends is as important as professional care, whereby supportive family members may become primary carers, especially when a child is discharged to their home environment with a tracheostomy (Bonvento et al., 2017). Therefore, it is important that family is include in the journey; including decisions for the patient as well as training.

The multidisciplinary team discussed above seems to be the same in the South African context, whereby Booth (2017) describes the tracheostomy team at Red Cross War Memorial Children's Hospital, comprising of the nurses, doctors, speech therapist, occupation therapist, physiotherapist and the dietician. The one profession which appears to be unique to the South African context and/or was not mentioned in the research papers discussing the Western contexts- is the role of the social worker within the tracheostomy MDT. The social worker offer advice in terms of the benefits and other services, planning for going home and liaising with a patients local social services about support that might be available to the patient when they go home (Booth, 2017).

2.5. Home-Based Care and the South African Context

In South Africa, HBC in children with tracheostomies began in 1989, at Red Cross Children's Hospital in Cape Town (Vanker et al., 2010). HBC refers to any form of assistance provided to a patient in the home environment, by family, friends and members of the community (WHO, 2018). The home-care tracheostomy programme at Tygerberg Children's Hospital in Cape Town, South Africa, was developed to allow children with chronic health illness to be discharged to a home environment. However, Al-Samri et al. (2010) explains that HBC is not always indicated as some paediatric patients may require a tracheostomy for an extended durtion of time, and in some cases even permanently. Such requirements would mean that the patient would have to stay in hospital in order that one receives the correct medical care.

Internationally, HBC was also developed with the goal of decreasing the length of hospital admissions and has been associated with many benefits, as will be discussed in the results section (chapter 4). Vanker et al. (2010) demonstrated that HBC proved to be very effective as it facilitates family unity, improves quality of life, and promotes optimal development. Al-Samri et al. (2010) findings correlate with the above, reporting that HBC arose to address the potential developmental delays that may arise from long hospital admissions, as HBC allows for more normal social development and family involvement for the child (Messineo, 1995). Further benefits of HBC are the reduction in the costs associated with hospital admission, as well as a decrease in the risk of nosocomial infection (Al-Samri et al., 2010).

Despite HBC being successful in many centers in the USA and UK, it is not without risk, and several conditions must be met before a child can be sent home (Al-Samri et al., 2010). Discharge requirements include the provision of home care equipment, assessment of home environments for appropriate facilities, as well as caregiver training. Additional requirements include the assessment of emotional stability and level of social support available to the

caregivers (Al-Samri et al., 2010). At Tygerberg Children's Hospital, discharge criteria involved caregiver competency to manage taking care of the child at home, as well as social worker approval of the home circumstances (Vanker et al., 2010).

Caregivers require training in suctioning, tube changing and recognizing complications such as chest infections, as well as emergency procedures, before being discharged from the hospital (Al-Samri et al., 2010). Abdullah, Mok, Chan, and van Hasselt (2003) report that home-care is challenging and not always possible for differing reasons. Patients that qualify for home-care must be well equipped with oxygen, suction, humidifiers, spare tubes, and other accessories.

Zia, Arschas, Nazir, and Awan (2010) further explain that home environments need to be assessed for electricity and water. This requirement may be a challenge in the South African context, given that significant portions of the Gauteng and Western Cape provinces have little to no access to clean, running water and poor access to electricity supply (Vanker et al., 2010). This may therefore hinder the successful implementation of tracheostomy home care management, according to Zia et al. (2010). Jacobs (2012) also reports that paediatric patients with tracheostomies have very specific needs, with management being challenging particularly in a resource poor environment. All the above factors indicate that HBC involves assessing each child individually, taking all aspects into consideration before sending a patient home.

First world countries allow for the provision of required medical equipment and resources for this vulnerable population (Jacobs, 2012). Unfortunately, the public health care sector in South Africa represents a third-world country, which is under resourced and a poorly educated environment (International Monetary Fund, 2010). Therefore the implementation of HBC may become challenging in the South African context, especially in providing suctioning and humidification for the children with tracheostomies (Jacobs, 2012). In addition, there are

impediments such as language barriers, delayed funding approval for medical equipment, and parental unemployment (International Monetary Fund, 2010). These factors listed are also applicable to the South African public-sector environment, and therefore may create challenges in the implementation of tracheostomy home-care (Jacobs, 2012). The success of HBC is highly dependent on parental training, team support, social services, caregiver motivation, and appropriate technology (Vanker et al., 2010). Therefore a formal tracheostomy home-care program should allow for shorter in-hospital stays, as with these interventions, the care of patients with tracheostomies can improve (Zia et al., 2010). Thus, the current study is relevant in the South African context, as there are no published data in the last 25 years on the overall outcomes of children with tracheostomies, between the ages of 0-5 years, in South Africa (Jacobs, 2012).

South Africa is a context that involved cultural diversity, such as ethnic groups and languages (Orman, 2008). South Africa is a unique context due to not only its rich linguistic and cultural diversity, but also the challenges of poverty and access to services such as tracheostomy care by a professional team of health care providers and allied services. By considering these aspects of the South African context, the current study potentially provides valuable information to and increases awareness amongst medical professionals, speech therapists, speech therapy students as well as speech therapy academics. Lastly, by considering all the above-mentioned studies, we see that the success of reintegration back into family and society post-tracheostomy in the South African context has not yet been researched qualitatively, contributing to the value of this study.

2.6. Family and Caregiver Experiences

There is limited information about the experiences of family members in the South African context during their transition from hospital to home environments, where family members become the core responsible care providers (Montagnino & Maurico, 2004). Despite this being a vulnerable and emotional period, much knowledge and skill needs to be handed over to family members during this time. Life change is instantaneous for family members of a child with a tracheostomy, as the family is required to take care of the child both at the hospital and at home (Montagnino & Maurico, 2004). An international study by Callans, Bleiler, Flanagan, and Carroll (2016) described the experiences of families caring for a child with a tracheostomy during the transition from hospital to home, as well as identified the support systems needed. Callans et al. (2016) reported utterances by caregivers such as: “This is not the life I had planned: coming to accept the new reality,” and “Don’t make the hospital your home; don’t make your home a hospital” (Callans et al., 2016). Amongst the many findings of this study, participants requested continued family group support post-discharge, desire to share their experiences with other families, as well as becoming an advocate for their child (Callans et al., 2016).

Harnick, Bissell, and Parsons (2003) found poor emotional well-being amongst the parents of children with a tracheostomy. Families with children who had tracheostomies reported that they were prone to social isolation (Harnick et al., 2003). This social isolation was linked to a fear of leaving one’s home due to medical reasons, as well as social stigma of having a child with a tracheostomy (Woodgate, Edwards, & Ripat, 2012). As a result of the responsibilities involved in taking care of a child with a tracheostomy, broken marriages resulted. (Hopkins, Whetstone, Foster, Blaner, & Morrisson, 2008). Lastly, parents reported that time is what allowed for them to adapt to their new life, roles and responsibilities (Hopkins et al., 2008).

Taking all the above into consideration, the process of family and patient preparation for discharge should begin on the day of admission. In preparation for discharge, the relationship between family members and nurses is of great importance, as it has the potential of working towards a successful transition (Reeves et al., 2006). In the study by Callans et al. (2016), participants' stories implied that nurse attentiveness to care was paramount to participant ability to ease into the caregiver role. However, due to limited staffing and high caseloads this may not be possible in the South African public healthcare system (Callans et al., 2016).

Callans et al. (2016) explored the experiences of family caring for their child with a tracheostomy, in Boston, Massachusetts, USA. Callans et al. (2016) report that there is a paucity of research exploring family experiences and support during their transition from the hospital to a home environment. They found that when caregivers had other healthy children at home, it intensified their experiences (Callans et al., 2016). The family dynamics shifted along with the home environment and family routines (Callans et al., 2016). In addition to the fear of the child developing an infection, families described fear and anxiety leaving their home and going out in public, because of the fear of stigma. Families reported that they had difficulty finding families with similar experiences (Callans et al., 2016). They further reported that when they had the opportunity to connect with other families with similar experiences, this eased their transition from that of shock to acceptance (Callans et al., 2016). This study demonstrated that support groups had the ability to increase the confidence of family members (Callans et al., 2016).

Flynn, Carter, Bray, and Donne (2013), reviewed published data of parental views and experiences of their child with a tracheostomy. Flynn et al. (2013) described the social experiences that parents had as caregivers of children with a tracheostomy. This review identified a lack of qualitative research on parents' views and experiences of having a child

with a tracheostomy. This indicates that further research is needed in parental tracheostomy management, more specifically, the need to explore the lived experiences of having a child with a tracheostomy, from the perspective of the caregiver (Flynn et al., 2013).

2.7. Paediatrics: 0-5-year-old Age Group

Many children with tracheostomies have significant problems other than their tracheostomy, such as communication difficulties, chronic lung disease, dysphagia, seizures and developmental delays (Jiang & Morrison, 2003). Jiang and Morrison (2003) explain that children without primary neurological deficits who had a tracheostomy placed before the age of one, should eat and communicate normally, however, they are at risk for speech delays. The duration of cannulation would determine the extent of the speech delay (Jiang & Morrison, 2003). A tracheostomy often affects speech and language development, in those with and without neurological impairment (Jiang & Morrison, 2003). Internationally, studies show that the age demographic has also shifted, with most tracheostomies now being performed in children under 1 year of age (Alladi, Rao, Das, Charles, & D'Cruz, 2004). Mrazek (1984) reported that children between 6 months and 5 years are at great risk for short-term and long-term negative consequences of prolonged hospitalization due to the tracheostomy, therefore, the children under the age of 1 year mentioned above, appear to be at risk for long-term hospitalization (Mrazek, 1984).

Early childhood is a period of rapid development in a human life, a stage of development forming a foundation for the child's future learning and well-being (Lewis et al., 2003). The most important years of child development are from conception to the age of three (UNICEF, 2001). Taking this period of child development into consideration, as reported by Lewis et al. (2003), the average hospital admissions were up to 50.2 days and so as a

consequence of this long duration of hospital stay, all aspects of critical development could be impacted negatively. Research shows that much of a child's social behavior, intellectual ability and personality develops before the age of four. In addition, the formation of pre-linguistic skills in this age group is critical for later language competence (UNICEF, 2001). Jiang & Morrison (2003) highlight that early childhood is a period of development in which the child's environment has a direct ability to determine how the brain grows and develops (UNICEF, 2001). Therefore, the current study focused on caregivers of the 0-5-year-old age group, due to it being a critical period of development (UNICEF, 2001).

2.8. Quality of Life

As defined by the World Health Organization (WHO), quality of life refers to an individual's perception of their position in life within their culture and context, and in relation to their goals, expectations, and standards (WHO, 2018). It is a broad concept that is related to one's physical health, psychological state, personal beliefs, social relationships and environmental factors (WHO, 2018).

Hopkins, Whetstone, Foster, Blaney, and Morrison (2009) set out to assess the outcomes of paediatric tracheostomies on both patients and families, in a central London hospital. They made use of the Pediatric Tracheotomy Health Status Instrument, which is a validated quality of life questionnaire. It focuses on the following domains; quality of life of the child and the caregiver, physical symptoms of the child, and financial impact. A core finding was parents' commitment to provide their child with a good quality of life. Parents reported that once they arrived home, their child's quality of life improved (Flynn et al., 2013).

Hopkins et al. (2009) found that there was a wide range of effects on the quality of life of their participants. Their study identified the need for greater family support as well as better

pre-operative preparation (Hopkins et al., 2009). Hopkins et al. (2009) also found far-reaching effects on caregivers, affecting their health, sleep, relationships, and emotional well-being. Flynn et al. (2013) found that fathers' views appeared to be under-represented. A reason as to why their views were under-represented was not given. Interestingly, this study found that caregivers rated the quality of life of their child with a tracheostomy as better than their own (Hopkins et al., 2009). In relation to paediatric tracheostomies, Hartnick, Bissel, and Parsons (2002) discuss that the level of success of management of patients during their hospital stay has a significant impact on their quality of life. Furthermore, they reported a multidisciplinary approach contributed to successful care, in a reduction of death rates, as well as a shorter time to decannulation, which are all factors improving overall quality of life for these individuals (Graf et al., 2008).

2.9. The Grief Process

Soanes (2002) describes grief as a deep sorrow and distress experienced, which are universal and experienced by people from all walks of life. Similarly, according to Alexrod (2006), the grief process most commonly occurs to an individual in response to his or her own, or another individual's terminal illness, or the loss of a close relationship. Elisabeth Kűbler-Ross proposed the five stages of grief, in her 1969 book "On Death and Dying". These five stages of grief are denial, anger, bargaining, depression and lastly, acceptance. Alexrod (2006) provides insight to the above and explains that individuals going through the grief process express each stage in a different manner and that the five stages are not necessarily experienced by individuals in the same order. Alexrod (2006) goes on to say that acceptance refers to the stage of accepting the 'new reality'.

Interestingly, by taking into consideration the research conducted by Bruce, Schultz, & Smyrnois (1996), it appears that caregivers of children with a tracheostomy presented with similar experiences to mothers of children with intellectual disability. For caregivers of

children with intellectual disability, grieving was an ongoing process (Bruce, Schultz, & Smyrnois, 1996). Additionally, it also appears that similar grief experiences were expressed by mothers of children with an intellectual disability who had died (Reilly, Huws, Hastings, & Vaughan, 2008).

The Karg Academy (2019) reported that the U.S. Department of Health and Human Services estimated that by the year of 2004 there were over 9 million children in the United States with physical, developmental, behavioural, or emotional disabilities. They reported that numerous studies examined the most effective strategies to assist the families in the grieving process due to them experiencing the loss of "the perfect child" (The Karg Academy, 2019). Furthermore, these studies showed that the grieving process of families of disabled children lasted just as long as the grieving process for families with children who had died (The Karg Academy, 2019).

2.10. Third-Party Disability

Third-party disability refers to the "disability and functioning of family members…due to the health condition of significant others" (WHO, 2007, p. 264). De Andrade (2015) discusses third-party disability in the context of deafness of children within a rural setting in South Africa. In doing so, De Andrade (2015) reported that although deafness may occur in a medically dominant paradigm, the ICF recognizes the contextual and situational aspects of a disability (WHO, 2002a). De Andrade (2015) also explains that there is now a recognition that disability has an impact on significant others. De Andrade (2015) demonstrated how caregivers of deaf children experienced third-party disability subsequent to their exclusion. This exclusion was related to the sense of alienation from their community because of their children's deafness (De Andrade, 2015).

Resch et al. (2010) also explored the experiences of caregivers of children with disabilities, expressing the barriers related to both financial and family support. By looking at the literature it appears that most studies focus on the child with the disability. In studies whereby the parents are considered (Hall et al., 2012), very little attention is given to the notion of third-party disability, supporting the suggestion that third-party disability needs further investigation. For example, in a study by Hall et al. (2012), the researchers only focused on the experience of stress of caring for a child with a genetic disorder, with no mention of how the caregivers' experiences presented an embodiment of third-party disability.

2.11. Summary

It is evident that current research focuses on the indications for a tracheostomy, associated mortality, the rate of decannulation, and quality of life measures. Such areas of research are important; however, they do not describe the impact of a child's tracheostomy on the caregiver. Furthermore, there is no published data in the last 25 years on the overall outcomes of these patients in South Africa, specifically in the Gauteng and the Western Cape provinces (Jacobs, 2012). Searches on patient and caregiver experiences of tracheostomies revealed that there is very limited research that explores parental experiences of having a child with a tracheostomy tube, both internationally and in South Africa specifically. The search engines that were used were 'Google Scholar', 'Directory of Open Access Journals', 'J-Gate' and 'PubMed', with the use of terms such as 'tracheostomies', 'South Africa', 'caregiver', and 'paediatric'.

The paucity of research implies that health professionals have no literature to guide our understanding and management of such patients. No standards of care for paediatric patient with tracheostomies patients have been established, raising concerns such as: how then do we measure the success of our management, discharge or home-care success? Do we follow-up,

and how? The parents are the ones taking care of the child and therefore we need to get feedback from them as to how we need to improve our services and know what is happening in the home environment. A deeper understanding of caregivers' experience in the South African context, may improve the family and child's transition back into the home environment. This should be the goal of speech therapists in effective management of their patients. Taking into consideration all the above reviewed literature and the role of the speech therapist beyond just in-patient hospital care, the purpose of this study was to explore caregiver experiences of caring for a child with a tracheostomy, after their transition from hospital to home, their role as a caregiver, and to explore the support systems available to the caregivers.

Research Question: What are the experiences of caregivers of the 0-5-year-old paediatric population with a tracheostomy, caring for their child post discharge from the hospital, in the Gauteng and the Western Cape provinces of South Africa?

2.10. Theoretical Framework

By considering the above literature, it is evident that research has mostly focused on the medical aspects of a health condition in terms of the surgical procedures, incidences, indications, and complications related to a tracheostomy. However, by reviewing the literature, the lack of qualitative research into the lived experiences of caregivers of children with tracheostomies was highlighted, whereby the individual as well as their health problem and their social context are considered. The biopsychosocial model of health, the model of disability on which the ICF was based, recognizes that health, illness, and disability result from complex interactions of biological, emotional, social, personal, and environmental factors (WHO, 2018). These theoretical frameworks emphasize the impact of the environment and the context, on functional abilities of a patient and their significant others, thus being useful in this study, in describing caregivers experiences of a tracheostomy (WHO, 2018). By considering and exploring all the above aspects of one's life, holistic patient management is supported.

Figure 3 below illustrates the close relationship between one's health condition, activities, and participation within one's context (WHO, 2007).

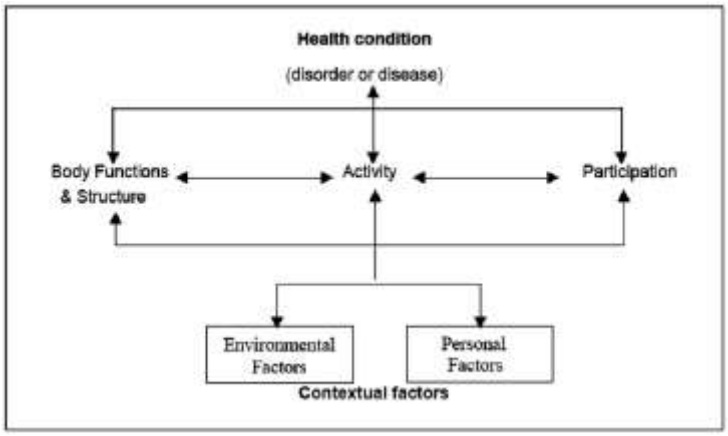


Figure 2.3. The biopsychosocial model of a health condition (WHO, 2007).

The biopsychosocial model also recognizes the role of family members in caring for a person with a health condition, thus advocating for a family-centered approach. Family-centered care refers to the care delivered by family, in which the role of family is specifically to ensure child well-being (Shields et al., 2012). In support of this Smith, Swallow, and Coyne (2015) explain that the family are ultimately the one's taking care of the child, and so in addition to the multidisciplinary team, the family is essential in the management of the child's condition. Furthermore, Smith et al. (2015) explain that family-centered care entails considering parents' experiences, offering parents support, as well as incorporating the expertise of parents into clinical care. Effective involvement of the parents allows for them to express their opinions, building rapport, and mutual care planning (Smith et al., 2015). Considering the above framework and the benefits of family-centered care, through interviewing caregivers of children with tracheostomies, the researcher gave the caregivers a voice, allowing them to share their experience and challenges.

CHAPTER 3: METHODOLOGY

3.1. Aims of the Study

3.1.1. Primary Aim of the Study.

The primary aim of this study was to explore the lived experiences of caregivers of children between the ages of 0-5-years with a tracheostomy, post hospital discharge, in the Gauteng and the Western Cape provinces of South Africa.

3.1.2. Sub-Aims of the Study.

1. To explore the experiences of caregivers of children with tracheostomies between the age of 0-5-years, during their transition back into family, home and society, post hospital discharge.
2. To explore the support systems available to caregivers of children with tracheostomies between the ages of 0-5-years, during their transition from the hospital to home.
3. To gain insight into the role of caregivers in caring for their child post-tracheostomy insertion.

3.2. Research Design

The proposed study employed an exploratory, qualitative research design, as well as an interpretative phenomenological approach. Qualitative research focuses on understanding one's social conext (Smith & Osborn, 2004). This research methodology enables the researcher to pay attention to how the participants interpret and attribute meaning to their experiences and lives. Most importantly, qualitative research has been suggested to be an ideal framework for studying human lived experiences (Tentnowski & Damico, 2001). Interpretative phenomenological analysis was used to explore in detail how participants made sense of their

personal and social world, predominantly accounting for unique experiments and events in the lives of participants (Smith & Osborn, 2004). A phenomenological approach allowed the researcher to examine in detail the caregivers personal experiences, as well as personal perceptions of life events, as opposed to an attempt to produce an objective statement of the object or event itself (Smith & Osborn, 2004).

One must consider the limited research into the unique experiences of caregivers of children with tracheostomies. A qualitative interpretative research methodology enabled the researcher to account for complex human behavior, authentic contexts, and the heterogeneity amongst individuals with tracheostomies (Tetnowski & Damico, 2001).

Furthermore, a qualitative interpretative methodology enabled the researcher to gather rich data of the participants' unique experiences (Fossey, Harvey, McDermott & Davidson, 2002). The researcher was able to capture these experiences, as the caregivers were given the opportunity to tell their 'story' during a face-to-face interview. The reference to 'rich' data refers to the large amount of information that was revealed to the researcher, beyond the questions that were asked. Meaning to say that the caregivers raised and expressed many different 'themes' of their experiences in raising their child with a tracheostomy. Additionally, Merriam (2009) explains that qualitative research focuses on people's experience and therefore is interpretive in nature (Fossey et al., 2002).

3.3. Site Description

The study took place at two government hospitals in South Africa, namely, Chris Hani Baragwanath Academic Hospital (CHBAH) (Gauteng), and The Red Cross War Memorial Children's Hospital (Western Cape). Both hospitals are tertiary level government hospitals that provide specialist services, such as that of tracheostomy management. Government hospitals

had been selected for the purposes of this study as 84% of the population in South Africa access the public services at government hospitals (Pretorius, 2017). Accessing two hospitals, each from a different province, added to the contextual diversity of the participants.

Chris Hani Baragwanath Academic Hospital, housed in the Soweto area of Johannesburg, is the world's third largest hospital in the world, with approximately 3200 beds. The tracheostomy clinic is run by the Ear, Nose & Throat (ENT) specialists, pulmonologists, speech therapists, and physiotherapists, thus providing multidisciplinary care to the patients with tracheostomies. The tracheostomy clinic runs every second week; with children with tracheostomies coming for follow up every 3-4 months. Once the participants were identified for the study, interviews took place in a room in the Paediatric Out-Patient Department.

Red Cross War Memorial Children's Hospital in Cape Town was opened in 1956 and is one of South Africa's dedicated child health institution that offers a comprehensive range of specialist paediatric services to children. Red Cross War Memorial Children's Hospital has 300 beds and services the public domain. The BreathEasy Tracheostomy and Ventilation Homecare Programme is a unique specialist nurse-led initiative at the hospital. Children with a wide range of respiratory problems are taken care of. The programme supports the return to home of children to their families and communities. The tracheostomy clinic is also run by the ENT specialists and pulmonologists and mostly the nurses. The physiotherapists and the speech therapists are not involved in the clinic, but rather play a role in the ward. The tracheostomy clinic runs every week. Once the participants were identified for the study, interviews took place in a private nurse's room in the tracheostomy ward.

3.4. Participants

3.4.1. Participant Description.

The ten caregivers that took place in the individual interviews will hereafter be referred to as P1, P2, P3, P4, P5, P6, P7, P8, P9 and P10. All relevant biographical details of the caregivers are summarized in Table 1 below. The table below illustrates the gender, spoken language and ethnic group of the caregiver participants in the study. Additionally, the ages of their children and the indication for the tracheostomy is presented. It is important to note that all caregivers are South African citizens and have been living in South Africa for more than five years, including participant six who was originally from Somalia.

Table 3.1. Participant and child biographical information

Participant #	**Age and Gender of Child**	**Age and Gender of the Caregiver**	**Languages Spoken**	**Ethnic Group of Caregiver**	**Child Medical Diagnosis**	**Indication for the Tracheostomy**
1	0.11 Female	39 Female	English and Afrikaans	White	GORD SAM FTT	Subglottic stenosis Laryngomalacia
2	2.10 Female	35 Female	English and Afrikaans	Coloured	2q22 Deletion Syndrome	Upper airway obstruction
3	4.5 Male	44 Female	IsiXhosa	African	Paralysis of diaphragm FTT	Acute flaccid paralysis
4	5.0 Male	39 Female	English and Afrikaans	Coloured	Lymphangioma of head and neck	Upper Airway Obstruction
5	1.2 Female	35 Male	Shona and English	African	CHARGE syndrome	Upper airway obstruction
6	1.2 Male	33 Female	Somalian and English	Indian	Laryngomalacia	Laryngomalacia
7	1.9 Male	38 Female	IsiZulu and English	African	Epilepsy	Upper airway obstruction
8	3.1 Female	35 Female	English and IsiZulu	African	Birth Asphyxia	Vocal Cord Palsy
9	1.7 Male	40 Female	English and IsiZulu	African	Epilepsy	Granuloma Tissue Subglottal Stenosis
10	3.2 Female	33 Female	IsiZulu and English	African	Epilepsy	Subglottal Stenosis

The biographical questionnaire also captured information regarding the availability and supply of water and electricity to both the caregivers and children in their respective homes. Such information was captured as it provides the reader with a socio-economic background as well as the living circumstances of the caregivers and their families. The data captured revealed that nine of the participants reported to have running water and electricity supply. The

remaining participant- participant 4 (P4) reported that she did not have running water nor electricity supply at home. They would fill buckets with water from the communal water supply and boil it with fire in order to have hot water.

Additionally, Table 3.2. illustrates the duration of hospital stay of the caregiver and child post-tracheostomy insertion, as well as their location of hospital stay. The information in the table below is relevant for the reader, when reading the results chapter. All the children and caregivers in this study were eventually discharged to their home, post admission in hospital. As shown in the Table 3.2. below, nine of the caregivers received training in hospital, and one caregiver received training in at Lambano (Johannesburg) a step-down facility/hospice for children with life threatening illnesses (Lambano Sanctuary, 2016). By collaborating such information, the average stay in hospital, for both the child and caregiver, was calculated as an average of 3 months overall, with an average of 3 months in the Western Cape, and an average of 2 months in the Gauteng province. The reasons and/or factors contributing to the difference in the duration of stay would have to be investigated further, as it was not the aim of the current study.

Table 3.2. Caregiver and child duration of hospital stay

Participant Number	**Duration of Child's Hospital Stay & Caregiver Training**	**Location of Hospital Stay**
1	3 weeks	Red Cross Children's Hospital
2	6 months	Red Cross Children's Hospital
3	4 months	Red Cross Children's Hospital
4	3 months	Red Cross Children's Hospital
5	5 months	Red Cross Children's Hospital
6	1 month	Red Cross Children's Hospital
7	2 months	CHBAH

8	3 months	CHBAH
9	2 months	CHBAH
10	2 months	Lambano
Total Average Stay	3 months	
Western Cape Average Stay	3 months	
Gauteng Average Stay	2 months	

Table 3.3. Caregiver employment status

Participant Number	Current Occupation	Previous Occupation
1	Hairdresser	
2	Housewife	None
3	Unemployed	Business Manager
4	Chef	
5	Unemployed	Mechanical Engineer
6	Housewife	None
7	Unemployed	Assistant at crèche
8	Unemployed	Saleswoman
9	Unemployed	Marketing Researcher
10	Unemployed	Hairdresser

Additionally, Table 3.3 below illustrates the current employment status of the caregivers, whereby two of the caregivers were employed, two were housewives, and six became unemployed post-insertion of their child's tracheostomy.

3.4.2. Sampling Strategy & Sample Size. Purposive sampling was used to recruit participants for this study. According to Guest and MacQueen (2008), purposive sampling is the most widely recommended method for research that is of a qualitative nature and allows for the most valuable and relevant data collection. In purposive sampling, participants are selected according to whether they fit into the inclusion and exclusion criteria needed for the study

(Daniel, 2011). A sample of ten caregivers of children with tracheostomies were interviewed for this study: six from the Western Cape and four from Gauteng. The researcher used a sample of ten participants as data saturation was reached, with the use of in-depth interviews.

Participants were be recruited for the study in the following manner:

1. The Speech therapist and/or nurse at the hospitals were provided with the selection criteria for the study.
2. The speech therapist and/or nurse then provided the researcher with a list of the appropriate patients from their patient list of those attending the tracheostomy clinic.
3. The potential participant caregivers of the patients were contacted by the speech therapist at the hospital telephonically, to obtain permission to provide the researcher with their contact details, in order to provide them with further information for participating in the study.

The above protocol was compiled based on preliminary discussions with the manager at one of the research sites.

3.4.3. Selection Criteria.

It must be noted that the child as documented in Table 3.3 below was not a participant in the study. However, it is important for there to be inclusion and exclusion criteria for the child that the caregiver is taking care of, for the caregiver to have taken part of the study. These are outlined in Table 3 below**.**

Table 3.3. Participant Inclusion and Exclusion Criteria

Caregiver (Participant)	**Child**
Inclusion Criteria: - Primary caregiver of the child - Caregiver currently living with the child - Caregiver over the age of 18 - Caregiver of any gender - Caregiver with conversational level of any of the 11 official African languages	**Inclusion Criteria:** - Child must be an out-patient, having been discharged from the hospital for at least 1 month - Child currently has a tracheostomy, or has had a tracheostomy for at least 1 month - Child between the ages of 0-5 years - Child of any gender - Child can have any underlying aetiology requiring a tracheostomy - Child currently living with the caregiver being interviewed for the study
Exclusion Criteria: - Caregiver currently not living and taking care of the child	**Exclusion Criteria:** - Child who has had a tracheostomy for less than 1 month - Child currently an in-patient - Child who has been decannulated for over than 2 years

3.4.4. Rationale for the inclusion criteria for the caregivers' participation in the study.

With regard to the inclusion criteria for the caregivers' participation in the interviews, participants were:

- Primary caregivers of the child with the tracheostomy, the persons most responsible for the care of the child with the tracheostomy, and those living with the child. The caregivers could be of any gender and did not have to be the biological relatives of the child. They were included in the study as long as they had been given the role of caring

for the child and living with the child, to be able to give a true reflection of their experience of caregiving for the child with the tracheostomy. In the current study all the caregivers of the children were either the biological mother or father of the child.

- Caregivers had to be over the age of 18, due to the nature of the ethical clearance provided to the researcher: caregivers under the age of 18 are considered ‘minors’ and therefore to ease and comply with ethical regulations, caregivers over 18 years, considered as adults were included in the study.

- South Africa is known for its unique context and rich linguistic and cultural diversity (Orman, 2008). Therefore, to account for this diversity, the researcher included any caregiver who had a conversational level of any of the 11 official African languages, by providing an interpreter where needed.

- Caregivers of children who were outpatients being discharged from hospital for at least 1 month and had the tracheostomy in-situ for at least one month, were included in the study. This duration allowed enough time for parents to truly experience the role of caregiving for a child with a tracheostomy in the home environment.

- The child had to be between the ages of 0-5 years, due to the focus on this specific age group for this study, as explained in the literature review. In addition, children with neurological impairments were not excluded from the study, due to the focus on the caregiver experiences of caring for a child with a tracheostomy, and not on the child’s experience, in which a neurological impairment may hinder their ability to share information with the researcher.

3.5. Research Instrument

Data was collected using semi-structured face-to-face interviews. The interview comprised of two sections. Section one (Appendix A) captured the participant biographical information. Section two (Appendix B) was a pre-formulated format with 12 open-ended questions probing the following areas: feelings and experiences, social perceptions, caregiver roles, and general experiences. This format and selected questions allowed the researcher to obtain rich and deep data of the caregiver's experiences caring for a child with a tracheostomy (Kvale, 2007). The use of semi-structured interviews provided a platform for the participants to express their feelings and experiences. In order to allow the participants an opportunity to use their own words and express themselves, open-ended questions were used (Schensul, Schensul & LeCompte, 1999). The interviewer then probed further in order to elaborate on what the particiants had shared (Schensul, Schensul & LeCompte, 1999). The use of a semi-structured interview appeared to be more effective than the distribution of a questionnaire (Kvale, 2007).

The questions used in the semi-structured interviews were pre-formulated and open-ended. The open-ended questions were formulated with the support of the literature, by identifying the areas that required further research, highlighting the areas which would reveal the unique experiences within a South African context. These questions were formulated to meet the objectives of the study and to sufficiently answer the research main aim and sub aims. A pilot study was completed prior to the main study to confirm validity and reliability of the format and the questions that were used.

3.6. Pilot Study

To maximize the validity of the study, a pilot study was conducted. A pilot study refers to a trial study, which is fundamental as it can greatly improve the proposed design and

methodology of the study (Horn & Monsen, 2008). The pilot study was conducted with the goal of identifying and correcting any problems with the design before the main study was conducted (Hall, 2008). More specifically, the pilot study was aimed at confirming the length of interviews, the type of questions asked, the suitability of sites used to conduct the interviews, as well as to anticipate and prepare adequately for ethical considerations (Collins, 2010).

The pilot study was conducted with a sample of one caregiver, who then acted as a representative of the sample, and was included in the analysis of the main study. The pilot study was conducted with Participant 1. The semi-structured interview took place in a room in the tracheostomy ward at Red Cross War Memorial Children's Hospital, Western Cape. The participant was asked 13 open-ended questions by the interviewer, with the interview lasting approximately 45 minutes.

The process of data collection was made more efficient by testing the instruments, thus allowing the researcher to make the necessary adjustments. Such changes to the instruments included identifying unanticipated problems, such as eliminating ambiguities in questions as well as difficult or unfamiliar words, and to attain correct and appropriate responses to the questions posed (Collins, 2010; Horn & Monsen, 2008).

The researcher conducted a pilot study in order to practice her interviewing skills, and gain more confidence and competence, by allowing her to identify and modify any practical problems within the interview. The interviewer did not take many notes during the pilot study and rather sat and listened to what the participant had to say, with the intention of giving full attention and eye contact to the participant. The pilot study therefore allowed the researcher to identify the lack of note-taking as an area to adjust, as it was noted that taking notes during the interview could potentially be very beneficial, not only by showing the participant that you as the interviewer are engaged and acknowledging what is being said, but also assisting the

interviewer in the transcription and analyses of the data. Therefore, there was a balance between both listening to the participants, as well as asking the questions and probing.

By conducting a pilot study, the researcher was able to become more familiar with the questionnaire to ensure natural progression of questioning. Additionally, the researcher was able to re-order the questions, eliminate one of the questions from the semi-structured interview questionnaire, as well as construct a few of the questions in a clearer and unambiguous manner. The researcher was able to choose 12 questions that were the most relevant to the study, answered the research questions, and those which provided rich findings. For example, questions such as: “Have your friends asked you anything about the tracheostomy?”, was removed from the questionnaire, as it led to irrelevant information that did not pertain to the research questions exploring the caregiver experiences.

Lastly, the researcher noted during the process of identifying possible participants that most of the patients were between the ages of 3-5 years old. Therefore, to ease the process of identifying participants for the study, the age range was increased to 0-5 years of age, rather than the initial range of 0-3 years of age.

3.7. Data Collection & Procedure

An information sheet, available in English, Afrikaans, and IsiXhosa was given to each potential participant via hard copy before the interview took place. Information sheets in Afrikaans and IsiXhosa were compiled as per the requirements of The University of Cape Town Ethics Committee. Nine of the participants chose to and were able to read the information sheets in English. The other one participant (P3) read the IsiXhosa information sheet, with the assistance of a translator. The translator was a nurse employed in the tracheostomy clinic. She had much

experience with translating for patients, therefore she was able to correctly ask the questions in the interviews.

The information sheets included information of the purpose of the study, methodology, and the assurance of confidentiality. Any questions that were raised regarding the study were answered by the researcher. The participants were then invited to participate in the research study and were informed of what the research would encompass. The participants were made aware that audio-recording would be used in the interview. The participant was required to provide consent for this. The researcher then informed participants that the research would be confidential and that they were able to withdraw from the study at any time should they wish to do so. The caregivers were given time to consider their decision. Thereafter, as participants, they were required to sign a consent form as proof of acknowledgement that they had understood the information sheet and accepted the research procedure. In the case where a participant required consent forms in a differing language, the researcher created one accordingly, with the use of an interpreter.

Once the caregiver agreed to participate, the researcher conducted a face-to-face interview with him/her. The interviews at Chris Hani Baragwanath Academic Hospital took place in a room in the Paediatric Out-Patient Department. The interviews at Red Cross War Memorial Children's Hospital took place in a private nurses room in the tracheostomy ward.

The interviews were conducted in the language preferred by the participant. Nine of the participants chose to have the interviews conducted in English, and one participant chose to have the interview in her home language, IsiXhosa. The interviewer then asked the participants the pre-formulated open-ended questions, and the responses of the participants were audio recorded.

With the participant who required an interview in IsiXhosa (Participant 3), an interpreter was present during the interview. This interpreter was a nurse enrolled at the Red Cross War Memorial Children's Hospital working in the tracheostomy ward. The interpreter had had much experience with interpreting and was especially appropriate for this context due to her experience in tracheostomies, creating a familiarity with the question asked and tersm used. The researcher asked the questions in English to Participant 3, which were then translated to the participant by the interpreter. This interview conducted in IsiXhosa was then transcribed by an IsiXhosa speaking Speech Pathology & Audiology student at the University of the Witwatersrand, in order that it could be used in the process of data analysis.

3.8. Overall Research Procedure

Table 3.4. Outline of the Research Procedure

1. Ethics application was granted by the Human Research Ethics Committees (Medical) at the University of the Witwatersrand and The University of Cape Town
2. Ethics application granted by the ethics committees as Chris Hani Baragwanath Academic Hospital and Red Cross War Memorial Children's Hospital
2. The research sites were contacted and informed consent was obtained from the HOD's of the speech departments
3. Participants were recruited through purposive sampling from the speech department, and contacted telephonically
4. Hard copy information letters and consent forms were distributed to participants and informed consent was attained
5. Pilot Study was conducted

6. Data collection: Semi-structured interviews with participants
7. The data obtained was transcribed verbatim
8. Data was analyzed using thematic analysis
9. Results and discussion presented in the form of a written report

1. Ethical clearance was obtained from the University of the Witwatersrand and University of Cape Town Human Research and Ethics Committee (Medical) as well as the hospital ethics committees: Chris Hani Baragwanath Academic Hospital and Red Cross War Memorial Children's Hospital. Refer to Appendix M, Appendix N, Appendix O and Appendix Q for ethical clearance certificates.

2. Meeting was set up with the HOD of Speech therapy and Audiology departments at the sites. Informed consent was obtained from the sites, allowing the researcher to obtain patient information and contact details. Refer to Appendix P and Appendix D for site consent forms.

3. Participation in the study was open to any caregiver who fitted the inclusion criteria who was willing to discuss their experiences of caregiving for a child with the tracheostomy. Contact was made with two government hospitals, namely Chris Hani Baragwanath Academic Hospital and Red Cross War Memorial Children's Hospital, who then put the researcher in contact with caregivers coming to the tracheostomy clinic. The researcher also attended the tracheostomy clinic at Chris Hani Baragwanath Academic Hospital in order to gain information regarding the logistics of the clinic: starting and ending time of the clinic, nature of how the clinic was run, as well as waiting times. Such information provided the researcher with details as to the process of data collection, and to see whether there would potentially be time in between consultations at the clinic, to interview patients.

4. Information was given to the potential participants, as well as a consent form. The researcher clearly stated that participation in the study was voluntary and that a participant had the right to withdraw from the study at any point, without facing any negative consequences. Participants were assured that no personal or identifying information would be included in the research report, if they prefer anonymity. The participants were also be required to sign a separate consent form indicating their agreement for the interview to be audio-recorded. Refer to Appendix C, Appendix D, and Appendix E for the relevant information letters and consent forms.

5. The pilot study is described in detail below in 3.6.

6. Data was collected through the use of a semi-structured one-on-one interview using pre-formulated open-ended questions (Appendix B).

7. Systematic analysis was completed and entailed converting the conversation from audio-recording to text, which means that the researcher listened to the interview recordings and converted them into text, through typing the exact words that each participant said (Bernard & Ryan, 2010).

8. Data analysis discussed in detail below in 3.9.

9. The results and discussion of the study were presented in the form of a written report.

3.9. Data Analysis

Thematic analysis appears to be a method of analyzing qualitative data, and is therefore widely used (Braun & Clarke, 2006). Through searching the data set for repeated patterns of meaning ,thematic analysis allowed for the researcher to identify, analyse, and report themes within the data collected. Thematic analysis was used to analyse the data that was collected from the

interviews. Inductive thematic analysis was used, which is a "bottom-up" approach. Such a process of analysis ensured that the themes that emerged were data- driven and not derived through the specific questions that were asked in the interviews but rather linked to the actual data provided by the caregivers (Patton, 1990).

Data analysis was performed according to the six phases of thematic analysis outlined by Braun & Clarke (2006). An illustration of this process is provided in Figure 3.1. The process of analysis was performed in the following manner: The audio-recordings were used to transcribe the data from the oral semi-structured interviews. The researcher then transcribed the recordings into written form. The transcripts were checked back against the original audio recordings, to ensure that all data transcribed was accurate.

Through open-coding, the data was then broken down into segments, to identify codes within the data. The process of initial coding allowed for themes to be generated, by identifying links amongst the codes and merging similar ideas together. These themes were then grouped to allow for the communication of participants' view and idea as a common voice (Anderson, 2007). The themes were then reviewed in relation to the coded extracts and the entire data set, generating a thematic 'map' of the analysis (Braun & Clarke, 2006).

Through ongoing analysis of the data, the researcher was then able to refine each theme, generating clear definitions and names for each theme. Lastly, the researcher analysed the selected extracts, referring to the research questions and literature, producing a scholarly report of the analysis. The researcher not only described the data, but also made an argument in relation to the research question.

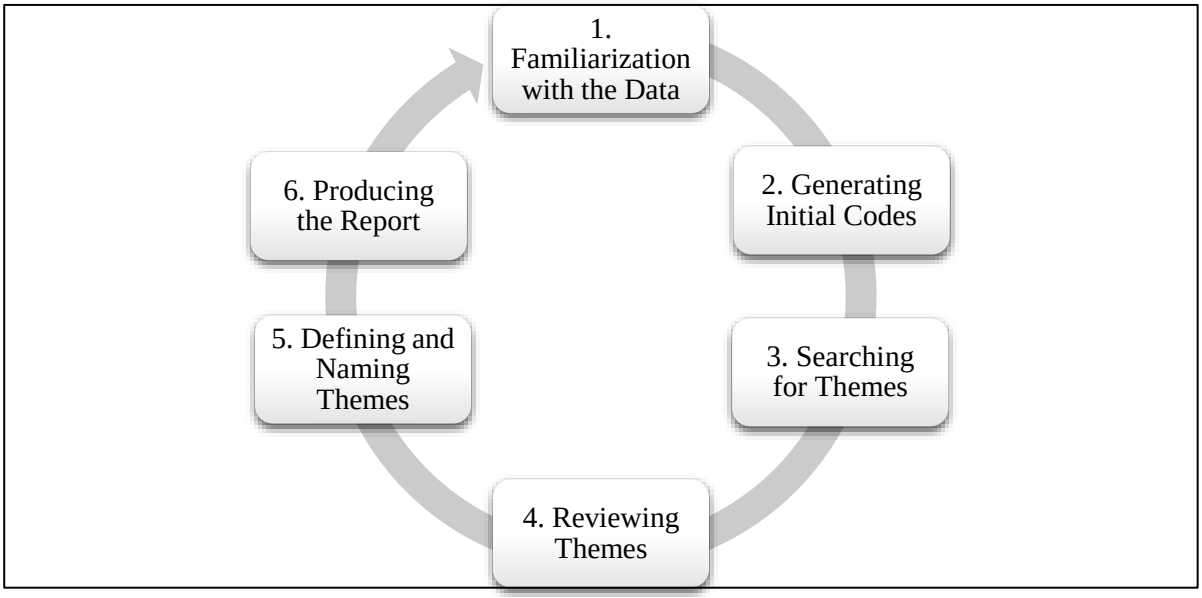


Figure 3.1. Phases of Thematic Analysis- According to Braun & Clarke (2006).

3.10. Triangulation & Trustworthiness

Triangulation was used as a cross-check principle of data collection and analysis to produce more accurate results, thus facilitating validation and credibility (Sarantakos, 2013). Investigator triangulation involved both the researcher and supervisors in the analysis process, by regular consultation with the supervisors. Supervisor involvement increased the trustworthiness of the study as well as helped in eliminating bias (Patton, 2002). When analysing the data according to thematic analysis, inconsistencies in analysis were discussed amongst the researcher, the supervisors, as well as a colleague. This allowed for an in- depth understanding of the findings, eliminating bias (Patton, 2002).

To ensure reliability, the researcher herself conducted all the participant interviews. The researcher asked the same questions to all the participants, ensuring consistency of instrument use to capture data (Leedy & Ormrod, 2005). By ensuring confidentiality of the interviews, participants appeared to feel more comfortable to express themselves, improving the reliability of responses (Leedy & Ormrod, 2005). In addition, the researcher audio-recorded all the

interviews, transcribed them and re-evaluated all the transcripts, to ensure that no mistakes were made in the transcriptions (Creswell, 2009). At the end of each interview, the researcher provided the caregiver with a summary of what transpired during the interview, to confirm that information and responses were captured correctly by the researcher, and to confirm their agreement.

Rigour refers to the trustworthiness in qualitative studies; simply defined as the care by which a researcher conducts a study, from the initial stages of data collection to the analysis and conclusions (Naughton & Hughes, 2008). Rigour is a very important aspect of research quality and so was met in the following ways: the interviews were recorded in order that the researcher could transcribe the verbalizations for further analysis, thereby ensuring that misrepresentation of information should not occur. The researcher asked for the opinion of the supervisor throughout the interpretation process in order to confirm that the interpretation of information gathered was not biased. The researcher also kept a journal log throughout the research process, to prevent biasness.

The following criteria, as adopted from Patton (1990) were used in order to ensure credibility and trustworthiness of the design and analysis procedure: rigorous techniques and methods for the collection, and analysis of data and credibility of the researcher. These criteria are explained in more detail below. Suitable constructs for establishing the trustworthiness of qualitative research are: credibility, transferability, confirmability, and reliability. Traditional constructs such as: internal and external validity, reliability and objectivity are appropriate for qualitative research (Patton, 1990).

3.10.1. Credibility.

Miller & Kirk (1986) point out that it is not possible to control all the variables that may be present in research. Although this is realised the following demonstrates the attempt that was

made to control the following variables: All the informants met the subject selection criteria, therefore the quality and credibility of the data was ensured. Methods and subjects used in this research have been carefully described and contextualized. By doing so, boundaries have been place around the study and the credibility and this the validity of the research is ensured (Patton, 1990).

3.10.2. Transferability/Generalisability.

To enhance generalisability and trustworthiness, literature was used as supplementary validation findings. Corbin & Strauss (1990) state that the literature can be used as a secondary data source, where findings can be confirmed or it can be explained where they differed.

3.10.3. Confirmability.

This construct equated to the construct of reliability (the objectiveness of the researcher) (Marshall & Rossman, 1995). The following strategies were instituted in an attempt to minimize bias of interpretation: during the transcription phase, the interviewer subjectively assessed how she perceived herself during the interviews, and how her feelings were projected to the researcher when handing over transcriptions. A conscious attempt was made to avoid leading questions during the interviews to keep personal responses objective and non-judgmental. All the collected data was kept in a retrievable and organized form so that it could be accessed if needed. Reliability in the context of qualitative research can be attained by thorough and careful documentation of research procedures (Miller & Kirk, 1986).

3.10.4. Reliability.

A number of measures were employed in this study in order to enhance and determine the rigour of the data analysis procedure. These methods were based on the suggestion of Patton (1990). Intra-rater reliability was ensured by the interviewer checking 100% of the transcribed sample that had been prepared for analysis. No significant discrepancies were noted.

3.11. Ethical Considerations

There has been much concerns around the protection of individual participants in research studies (Silka, 2009). Often unanticipated ethical challenges arise in research and are best resolved in an ongoing process rather than only being anticipated, and resolved by the researcher alone prior to conducting research, based on abstract principles (Wertz et al., 2011). In addition to the challenges facing the caregivers of children with tracheostomies, they often experience many psychosocial stresses, including feelings of stigma and shame (Boyle, 2013). Therefore, the researcher had ethical responsibilities towards the caregivers who participated in the study. Prior to the interviews, informed consent was obtained from the participants, ensuring that the aims were clearly explained to the caregiver participants, no false promises were made, any questions were answered, and confidentiality and anonymity were ensured. All identifying information of the participant (Appendix A) were only accessible by the researcher and supervisors. For analysis purposes, each participants' name was replaced with a number, thus removing any form of identification. Address details are included in the biographical information questionnaire (Appendix A), as this provided the researcher with contextual information for analysis purposes, such as the distance between the home of the caregiver and the hospital. Such information was only accessible to the researcher and supervisor.

Informed consent for audio-recording was obtained from the participants, following an explanation that the recordings would be used for data analysis purposes only. The researcher also informed the participants that they have the right to withdraw from the study at any point, and no consequences would follow.

A distress protocol was available had any of the participants experience any discomfort or distress during or after the interviews (Appendix H) (Draucker, Martsolf, & Poole, 2009).

In the case of distress signs during the interview, the interview would be discontinued. All participants would be informed of available services such as the social worker and/or psychologist. Referrals would made for psychological services if indicated (Draucker, Martsolf, & Poole, 2009). In the context of this study, contact was made with the psychological services at the hospital, informing them of the study and that referrals would be made if indicated. Throughout all the interviews, none of the participants showed any signs of distress and/or required the interviews to be discontinued.

3.12. Specific Management Mechanism for Handling Distress

The nature of this research posed psychological risks, as it involved interviewing a vulnerable population: caregivers taking care of their children with a tracheostomy. As indicated by Jorm, Kelly & Morgan (2007), such research may induce or exacerbate emotional distress. As As individuals reveal their experiences, they may show signs of anxiety and stress reactions (Jorm, Kelly, & Morgan, 2007). Therefore, in the case of emotional distress, the researcher had developed strategies to manage it. Such a strategy involved providing information on available psychological services or social services (Griffin, Resnick, Waldrop, & Mechanic, 2003). The aim of this distress protocol was to protect participants and minimize the risk of negative emotional effects (Draucker, Martsolf, & Poole, 2009).

- At the beginning of the interview the researcher verbally informed the caregiver that she is aware of the possibility of emotional distress and/or reactions. Should this occur the caregiver was encouraged to communicate this with the researcher, and the interview would be discontinued. There would be no consequences for the caregiver should this case arise.

- The researcher looked out for the following possible signs of emotional distress: being tearful, outburst of anger, experiencing high levels of anxiety, sustained low mood, withdrawing verbally and/or displaying agitation (Draucker, Martsolf, & Poole, 2009).
- Should the researcher have seen any distress cues during the interview, she would discontinue the interview, followed by asking the caregiver if he/she feels that they need the interview to be discontinued.
- Researcher would then provide caregiver with contact details of psychological or social services.
- Referral would be made to psychological and social services by the speech therapist/HOD of the speech department at the given site.
- Researcher would follow-up on the referral.

As there were no evident signs of emotional distress throughout the interviews, the researcher asked the caregivers at the end of the interview if they were feeling any level of emotional distress. If the caregiver replied yes, the above procedure would be followed out. However, all the caregivers reported that they were feeling good and did not require are further help and/or referrals to another professional. The participants at Red Cross War Memorial Children's Hospital expressed that they had a very close relationship with the head nurse, and therefore would discuss all their concerns and feelings with her.

CHAPTER 4: RESULTS & DISCUSSION

This section presents the results from the participant interviews, in answering the main aim of the current study: the lived experiences of caregivers of children between the ages of 0-5 years with a tracheostomy, post discharge, in the Gauteng and the Western Cape provinces of South Africa. The main aim and sub-aims were answered through the presentation of themes that emerged from the data captured in the interviews. The themes will be presented in the following manner:

- Each sub-theme was presented through providing the responses of various participants, and by discussing pertinent literature in relation to the responses.
- Figures and tables were used to represent the descriptions, as well as assist the reader in understanding the relationship between differing characteristics of each theme.
- Lastly, the researcher critically discussed the results, and highlighted the implications of the data in the South African context.

Despite the use of common themes, the researcher ensured that the individual voice of each participant was heard. Prior to reading the results, the reader is encouraged to refer to Appendix I, which provides a brief description of each of the ten participants that were used in the data analysis of the study.

Through the process of thematic analysis (Figure 3.1), the following main themes emerged from the study and represent the experiences of caregivers of children with a tracheostomy: emotional experiences, support systems, caregiver roles, and medical experiences. Table 5 represents all the themes that emerged in answering the aims of the current study.

Table 4.1. Outline of themes that emerged in relation to the aims of study

Aims of the Study	**Themes of the Study**
4.1. Sub-Aim One The experiences of caregivers of children with tracheostomies between the ages of 0-5 years, during their transition back into family, home and society, post hospital discharge.	4.1.1. Caregiver Feelings towards the Tracheostomy
	4.1.2. The Grief process
	4.1.3. Third-Party Disability
4.2. Sub-Aim Two To explore the support systems available to caregivers of children with tracheostomies between the ages of 0-5 years, during their transition from hospital to home.	4.2.1. Faith
	4.2.2. Family Support
	4.2.3. In-Hospital Tracheostomy Training
4.3. Sub-Aim Three To gain insight into the role of caregivers in caring for their child post-tracheostomy insertion.	4.3.1.Tracheostomy Training and Care
	4.3.2. Providing Financial Stability
	4.3.3. Home-Based Care

4.1 Sub-Aim One

Sub-aim one of the study explored the experiences of the caregivers during their transition back into their family, home, and society. Analysis of the findings revealed that this experience was an emotional one that encompassed their feelings towards their child's tracheostomy, their experiences of the grief process, as well as their embodiment of third-party disability. Caregivers reported both positive and negative feelings towards the tracheostomy. They also reported that once they reached a level of acceptance within the grieving process, they were able to cope better with this transition from the hospital back into their home environment.

4.1.1. Caregiver Feelings towards the Tracheostomy.

With very limited research on caregiver feelings towards a tracheostomy, the current study explored the day-to-day lived experiences of caregivers of children with tracheostomies. The

caregivers were asked how they felt towards their child's tracheostomy. This question revealed both positive and negative feelings towards their child's tracheostomy. Seven of the caregivers reported positive feelings towards the tracheostomy, whereby they described that the tracheostomy saved their child's life, hence they were very grateful towards the tracheostomy. The other three caregivers reported some negative feelings towards the tracheostomy and a desire for the tracheostomy to be removed. Such a feeling may suggest a lack of acceptance among the caregivers towards their child's tracheostomy.

The caregivers personified the tracheostomy in describing it as a 'life-saviour'. Despite the challenges that they expressed (as will be discussed further), seven of the caregivers reported that overall they had positive feelings towards their child's tracheostomy. Participant 1 described the following: "*Well I would say if it wasn't for it, I wouldn't have a child. I would say if it saves lives you know, you feel positive about it"* (P1, 68-69). Participant 7 and 9 shared similar feelings: *"Um, I think trachy its fine because of if it wasn't maybe for this trachy, my son would be maybe gone long time ago. It saves my son's life. So I think um, it saves my son's life"* (P9, 51-52). "*I'm feeling okay because it helped me a lot. I thought he's gonna die that day."* (P7, 43-47). Participants 5 also spoke positively of the tracheostomy, describing that the insertion of the tracheostomy facilitated other medical factors such as growth and weight gain: *"The trachy is good. It's a good thing. It helps a lot. As I was saying, that she wasn't like this, she was very tiny"* (P5, 73-74).

The remaining three caregivers shared feelings that revealed negative associations towards the tracheostomy. Participant 6 expressed concern: "*I was worried about it. If it would be for a long time or something like that"* (P6, 16-17). The other caregivers expressed that they didn't like the way the tracheostomy looked, as it felt foreign to them and therefore they also expressed a desire for the removal of the tracheostomy: "*Uh I just wish they can take it out soon*" (P2, 33). Participant 5 similarly expressed desire for removal of the tracheostomy.

> *"Uh well what will make me happy is later on in the future if the tube is gone, if the doctors remove the tube. And if she's breathing well through the nose, well later on maybe they will remove the trachy. My prayer is later on that these things will be removed and she will be okay like any other babies"* (P5, 139-143).

In describing their emotional experiences, caregivers also described their negative feelings and stress resulting from the communicative and health changes presented in their child, following their medical changes and insertion of the tracheostomy. These changes were the most evident when they arrived home, as this was a time when the caregivers compared their child's previous functional abilities (prior to the event that led to the need for a tracheostomy to be inserted), to their abilities when they arrived home from the hospital. These changes pertained to the differences in their child's speech abilities and their child's ability to walk.

Participant 1 expressed this longing for her child's vocal function in the following words: *"It's difficult you know cos you always love to hear a baby cry. There's little things like um when she coughs, we make the sound with her and we laugh about it"* (P1, 189-190). She went on to say: "*We just waiting for one of these days to take it out so that we can hear her voice. To have a cry or..."* (P1, 205-206).

Caregivers in the current study provided varying reasons for the absence of vocal function in their children, which included but were not limited to: not being able to tolerate a speech valve, as well as vocal cord paralysis. Caregivers described that their child's inability to vocalise limited and adversely impacted their communicative abilities with their child.

Four of the caregiver's revealed further emotional burden and expressed their deep desire for their child to walk again: "*Before he was like this, he was speaking. He was walking. He was playing. Like any other kids. Until his seizures"* (P9, 84-89). The symbolic significance

of walking mostly remains unexplored (Gibson, Teachman, Wright, Fehlings, Young, & McKeever, 2012). The symbolic significance of walking appeared to have been explored within the context of children with cerebral palsy, but remains unexplored amongst children with tracheostomies.

There appeared to be very limited research describing caregiver's feelings and expected challenges due to lack of verbal speech as a form of communication with their child, as a result of the tracheostomy. Most studies focused on describing the deprivation of speech for extended periods while the tracheostomy was in, from a medical perspective (Simon, Fowler, & Handler, 1984). Additionally, studies mostly reported on the long-term consequences of the lack of speech prior to decannulation, such as language delay and phonological impairment, with less focus on caregiver experiences of communicating with a child with no verbal speech.

Taking into consideration the above-discussed feelings of the caregivers towards the tracheostomy and the challenges revolved around the motor and speech abilities of the child, the researcher critically analysed the potential consequences of such feelings. According to Mastandrea (2015), one's experiences shape their feelings and perceptions. This was clearly noted in the current study, where caregiver's experiences with the tracheostomy seemed to shape their feelings towards it. Therefore, caregivers with more positive, happy experiences, appeared to have more positive feelings towards it, recognizing the tracheostomy as a source of life, or life-sustaining. In contrast, caregivers who seemed to experience negative interactions with their friends and family as a result of their child having a tracheostomy displayed negative perceptions. For example, it appeared that for the caregiver who had a negative association with the tracheostomy, firstly it would be difficult to explain the nature of the tracheostomy to family and/or friends, as well as withstand any negative remarks.

The feelings expressed by the caregivers appear to have commonalities with the feelings expressed by caregivers of children with disabilities, whereby they described feelings of stress in caring for their young disabled children (Singer & Farkas, 1989). However, it appeared that the feelings of caregivers of children with a tracheostomy in specific, needs to be pursued in further research. Despite the researchers' attempts on various search engines, such as Google Scholar, the researcher was unable to find much information discussing caregivers' feelings specifically towards their child's tracheostomy. Therefore, this theme needs to be explored further.

4.1.2. The Grief Process.

When describing their experiences, the caregivers revealed that the grief process was very much part of their emotional experience. The caregivers discussed how the stage of 'acceptance' of the grief process contributed to their experience when transitioning back into family, home and society, during their hospital stay and post-hospital discharge. Initially the caregivers expressed feelings of emotional burden of accepting the altered body image of the child with the tracheostomy. Thereafter, when the level of acceptance was reached caregivers reported that they had positive feelings towards the tracheostomy as was discussed in the above-mentioned theme whereby seven of the participants had positive feelings towards the tracheostomy.

Grief refers to a deep sorrow and distress experienced, which are universal and experienced by people from all walks of life (Soanes, 2002). According to Alexrod (2006), the grief process most commonly occurs in response to an individual's terminal illness, or the loss of a close relationship. In the context of the current study, caregivers mostly described their

experience of reaching a level of acceptance within the grief process, in response to their child's illness and insertion of the tracheostomy.

Elisabeth Kűbler-Ross proposed the five stages of grief, in her 1969 book "On Death and Dying", as illustrated below in Figure 6. Alexrod (2006) explains that individuals going through the grief process express each stage in a different manner and that the five stages are not necessarily experienced by individuals in the same order. In this context, it appeared that the grief process occurred in the life of the caregivers in response to the diagnosis as well as fitting of their child's tracheostomy. Therefore, the grief process was used to understand the experiences of caring for a child with a tracheostomy. Five of the caregivers mentioned that the grief process was relevant in their experience of caring for their child, and that reaching the stage of acceptance had a positive effect on their overall experience.

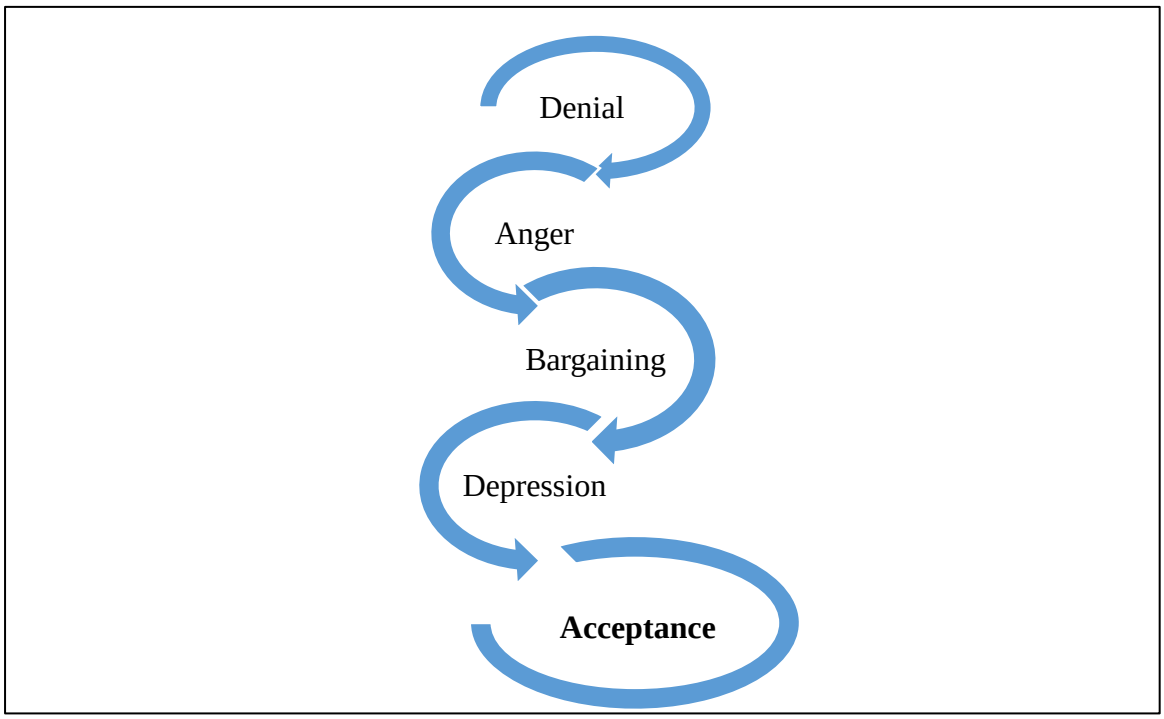


Figure 4.1. The stages of the grief process.

In this context, acceptance refers to the stage of accepting the 'new reality'. Acceptance facilitated the caregivers' ability to reach out to their child and become more involved in their

lives (Kűbler-Ross & Kessler, 2005). This correlates with the words of Participant 5, in which the caregiver expressed improved coping abilities once he had accepted his child's condition:

> *"Well, what I can say is at first it had been tough. To accept the fact that eish she's got a trachy and so many things was happening to her so.. You know when you are ah, you haven't had a baby like this, in your life, it's difficult to accept it first time. Now, I accept the fact that it's my baby and that's how she is, so I can say, ya, we are getting there day by day. Now we are coping well. We are getting there day by day*" (P5, 2-8).

Although the grieving process is typically discussed around the death of a loved one, it appeared to be appropriate in this context, as it was evident that the caregivers mourned the loss of their 'old' child, their child prior to the insertion of the tracheostomy. Scase (2004) confirms this by reporting that the initial reactions of parents are profound, and they may experience an emotional response to the loss of their 'normal' child, which manifests in a grief-like reaction. Participant 4 described her experience of grieving her 'old' child and accepting her 'new' child: *"I had to learn my child. I actually had to learn my child. Because you frightened. You didn't know what's coming"* (P4, 43-46). She went on to say: *"The quicker you accept it, the better it gets. Because if you don't accept it you are going to struggle"* (P4, 50-52).

Participant 9 described the stage of denial and explained that once she experienced the stage of denial, she was ready to move to the next stage of acceptance. In this stage of acceptance, she was able to feel happier and at ease: *"I have to be strong for my son. Because you know, when you keep on crying and be in denial, it's not helping. Because he also needs my strength. You have to accept. Even though it's not easy"* (P9, 41-43). It appeared that reaching a level of acceptance facilitated Participant 9, as was evident in her words in the previous theme, describing her positive feelings towards the tracheostomy, and mentioning that

she believed that the tracheostomy saved her son's life. From analysis it emerged that caregiver feelings towards the tracheostomy may have contributed to the grief process, and likewise, the grief process may have affected the way in which the caregivers viewed the tracheostomy, emphasizing the relationship between the emotional experiences of feelings towards the tracheostomy and the experience of the grief process.

Interestingly, by taking into consideration the research conducted by Bruce, Schultz, & Smyrnois (1996), it appears that caregivers of children with a tracheostomy presented with similar experiences to mothers of children with intellectual disability. For caregivers of children with intellectual disability, grieving was an ongoing process (Bruce, Schultz, & Smyrnois, 1996). So to the caregivers in the current study, who seemed to be experiencing the different stages of the grief process at different periods of time.

Additionally, it also appears that similar grief experiences were expressed by mothers of children with an intellectual disability who had died (Reilly, Huws, Hastings, & Vaughan, 2008). Therefore, this similar grief experience demonstrates the large degree of grief that parents experience post insertion of their child's tracheostomy, being partly similar to that of caregivers who had lost a child. Additionally, caregivers in the study by Reilly, Huws, Hastings, and Vaughan (2008) reported fear related to the death of one's child and parents outliving their child. Similarly, a few caregivers in the current study mentioned how the tracheostomy 'saved' their child's life (presented in the theme of Caregiver Feelings towards the Tracheostomy) , which reveals to us that death was a possible reality that the caregivers thought they could face, even though that was not something explicitly mentioned to the researcher by the caregivers.

The Karg Academy (2019) reported that the U.S. Department of Health and Human Services estimated that by the year of 2004 there were over 9 million children in the United

States with physical, developmental, behavioural, or emotional disabilities. They reported that numerous studies examined the most effective strategies to assist the families in the grieving process due to their experiences of the loss of "the perfect child" (The Karg Academy, 2019). Furthermore, these studies showed that the grieving process of families of disabled children lasted just as long as the grieving process for families with children who had died (The Karg Academy, 2019).

The three other stages of the grief process (anger, bargaining and depression), were not reported by any of the caregivers. While this is not confirmed, it is likely that because caregivers had already reached the stage of acceptance, these stages did not surface during the interviews. However, not mentioned by the caregivers, this does not imply that these stages of the grief process (anger, bargaining and depression) were not experienced by the caregivers. It is of significance to note that the duration since the fitting of the tracheostomy ranged from at least 5 months, to 4 years at most. On average, at the time of the interviews, it had been 1 year and 9 months since the fitting of their child's tracheostomy. Therefore, it appeared that time is what allowed for the stage of acceptance to develop. Such a finding appears to correlate with Hopkins et al. (2008), whereby they acknowledge that time is also what allowed caregivers to accept and adapt to their new life and roles. This is evident in the words of Participant 3, expressing that time allowed for her to reach a level of acceptance of the tracheostomy: "*Time healed me. The tracheostomy no longer stresses me out, I've gotten used to it"* (P3, 311-312).

Taking into consideration all the above-mentioned emotional experiences and reaching a level of acceptance, it is important that the healthcare team address the grieving process before discharging both the caregiver and the child with the tracheostomy from the hospital. The healthcare team should introduce caregivers to other tracheostomy users, providing them with a platform to share their personal experiences and to create a social network (Scase, 2004). This correlates with the findings of Bonvento et al. (2017), in describing the role of the medical

staff having a key role in planning, performing and managing patient care throughout their tracheostomy journey. Through extrapolation, the presence of the grief process suggests the role of the medical staff in addressing this process amongst families and the patient. Furthermore, Bonvento et al. (2017) acknowledge that the speech-language pathologist and the psychologist have a role in addressing some of the psychological consequences of the tracheostomy. However, it is important to take into account that Bonvento et al. (2017) do mention that there is limited research discussing the role of team members in relation to psychological processes-such as the grief process.

4.1.3. Third-Party Disability.

In the context of the current study, it can be argued that the experience of the insertion of the tracheostomy did not only occur in the child, but also became embodied in their caregivers. Third-party disability refers to the "disability and functioning of family members…due to the health condition of significant others" (WHO, 2007, p. 264). This theme describes how a lack of knowledge amongst the public of tracheostomies, as well as negative reactions towards the tracheostomy, had an impact on the caregiver experiences, ultimately contributing to the caregiver's embodiment of the 'disability'- third-party disability.

De Andrade (2015) discusses third-party disability in the context of deafness of children within a rural setting in South Africa. In doing so, De Andrade (2015) reported that although deafness may occur in a medically dominant paradigm, the ICF recognizes the contextual and situational aspects of a disability (WHO, 2002a). Very pertinent to the current study, De Andrade (2015) also explains that there is now a recognition that disability has an impact on significant others. This was clearly evident in the current study.

As discussed in the literature review, families with children who had tracheostomies reported that they were prone to social isolation (Harnick et al., 2003). Similarly, caregivers in this study were prone to limitations in social participation. Such barriers to participation were created by public lack of knowledge and negative reactions.

These social challenges were linked to a fear of leaving one's home due to negative reactions from the public, as well as fear associated with changing of the tracheostomy, resulting in less support from family members and friends when it came to the need for physical support of changing the tracheostomy (Woodgate, Edwards, & Ripat, 2012). This demonstrated how public lack of knowledge and negative reactions contributed to the overall experience of the caregivers, and 'disabled' them in their ability to for example, to receive assistance from family as well as participate in either family and/or social gatherings. As described by the participants during the interviews, the current study suggested a few potential barriers to participation of the caregivers and their child within their family, home and social environments. In some instances, the reactions of the public became barriers to participation for the caregivers, as illustrated in the excerpts below.

Table 4.2. Public reactions towards the child with the tracheostomy

Public Reactions	**Excerpts from the participants' interviews.**
Fear	"*They (friends) were very afraid. Some they just come for one day and they say no, we won't come back. Sometimes they cry*" (P10, 34-36). "*Even now they (family) scared. Especially when I'm taking out the trachy, they rather go out the house"* (P8, 50-51). *"You know, we are not so used to this, to the trachy. Black people we not so used to this. They say: 'Ih, I don't want, I'm very scared, I'm very scared". So I can't force them if they don't want to. So they say "Ah, so this tube*

	there's a pipe inside its going where? Uy! What if I put the pipe wrong, I don't want to!' They don't understand" (P8, 69-73).
Negative Reactions	"*They were undermining and would say that he doesn't have a future*" (P3, 346-347). *"It's traumatic hey. Because everybody, when he coughs, everybody they just turn around and look at you"* (P9, 28-29).
Lack of knowledge	"*Well you know, the environment we are living in, it's not like everyone knows about these things. And every person is just watching- what's going on with this kid. Why does she have this? What's this? People they asking a lot of questions"* (P5, 54-56). "*No, they were all amazed at it. Still until today. In Atlantis, there's now two (children with a tracheostomy). But people is still very curious" (*P4, 163-165).

The above excerpts from the participant interviews demonstrated the fear, negative reactions, and lack of knowledge amongst friends and family members of the caregivers. As a result of the insertion of the tracheostomy, as well as the medical condition, caregivers reported that their family members as well as friends became fearful of the child and visiting the family of the caregiver. Additionally, this fear led to a father refusing to change his child's tracheostomy, as reported by Participant 8. Other family members would leave the house when the mother would change her child's tracheostomy, and/or react negatively when they heard the child cough or when the child was being suctioned. These reactions then often resulted in the mother having had to be the main responsible member for taking care of the child.

By extrapolation, it appeared that lack of knowledge and negative reactions from both family members and friends contributed to and possibly had a negative impact on tracheostomy care, social reintegration, caregiver feelings and family structure. This is closely related to third-party disability, as it demonstrates how the caregiver, as a significant other of the child with the tracheostomy, in addition to becoming the main individual responsible for the child,

has to live with the burden and the consequences of public lack of knowledge and negative reactions. Due to the close relationship between the child and the caregiver, the caregiver him/herself appears to embody the 'disability' as well.

A lack of knowledge about tracheostomies was expressed by Participant 1: "*It's just that some people don't know about it."* (P1, 87), illustrating that a lack of knowledge amongst the public became a barrier for the caregiver and the child. Participant 3 in particular described that the children in the community would try pull out her son's tracheostomy. As a result, he felt much physical pain, and feared going outside to play with other children. This led the researcher to conclude that a lack of knowledge could unintentionally cause harm, if not death. Caregiver 3 described this challenge in the following words:

> *At home we have small children, they would tend to pull the tracheostomy, they didn't like and that didn't sit well with me*. (P3, 152-153*). It would become painful for him and he would have difficulties breathing* (P3, 174-175). *He was scared of playing, I would have to take care of him 24/7 as he was scared that the other children would pull the tracheostomy.* (P3, 224-225).

Due to negative reactions such as fear of changing the tracheostomy, family members were unwilling to take care of the child, and therefore in some instances the caregivers were forced to leave their jobs and stay home to take care of their child, as there was no other individual whom would be able to perform the responsibilities that came with caring for a child with a tracheostomy. When one is unable to and/or is limited in partaking in an activity, the World Health Organization recognizes this as a form of 'disability', depicting third-party disability. Participant 8 explained that: "*I was working... I had to leave. There's no choice now*" (P8, 9-10). As well as Participant 7: "*Now I'm not working as I need to look after him. I was working at a crèche. But now..I closed it now because I want to see the baby*" (P7, 8-9).

A lack of knowledge and negative reactions from both family members and friends resulted in the caregivers being limited in certain activities as well as their ability to participate in family gathering and/or their ability to be employed- demonstrating caregiver third-party disability.

In contrast to the views expressed by the majority of participants that prevented them from going to certain places or seeing certain people, the remaining 3 caregivers reported that they did not face any barriers to participation. They confirmed that they took their children with them wherever they went, such as to the shops and/or to church. Participant 4 reported as follows: "*We always together. There's a lot we can do together*" (P4, 178). Participant 3 reported: "*I go with him everywhere."* (P3, 535). This raised questions as to why such contrasting experiences were expressed by the caregivers of children with a tracheostomy. The researcher questioned whether this had to do with post-tracheostomy information relayed to parents (and if this differed from one parent to the next), or whether it was related to the aspects of faith and support, or a psychological component that had to do with how the medical condition was understood by the caregiver and their outlook on the implications of having a child with a tracheostomy.

The quotes above provided evidence for the theme of third-party disability and these aligned with the sentiments expressed by De Andrade (2015). De Andrade (2015) demonstrated how caregivers of deaf children experienced third-party disability subsequent to their exclusion. This exclusion was related to the sense of alienation from their community because of their children's deafness (De Andrade, 2015). The results of the current study also showed how negative reactions from the public resulted in caregivers feeling the need not to interact with these people and contexts, thus having excluded themselves from the environment and people around them.

Resch et al. (2010) also explored the experiences of caregivers of children with disabilities. Similar to the challenges expressed by caregivers in the current study, they expressed the barriers related to both financial and family support. Therefore, it appears that the notion of third-party disability experienced by caregiver's of children with tracheostomies, is also experienced by other caregivers of children with disabilities (without a tracheostomy). However, by considering the finding of the study, the caregivers of children with tracheostomies seem to embody even more of a third-party disability, as a result of the nature of care needed by their child and the scarcity of awareness and knowledge of tracheostomies amongst the public (Montagnino & Maurico, 2004).

By looking at the literature it appears that most studies focus on the child with the disability. In studies whereby the parents are considered (Hall et al., 2012), very little attention is given to the notion of third-party disability, supporting the suggestion that third-party disability needs further investigation. For example, in a study by Hall et al. (2012), the researchers only focused on the experience of stress of caring for a child with a genetic disorder, with no mention of how the caregivers' experiences presented an embodiment of third-party disability.

4.2. Sub-Aim Two

4.2.1. Faith.

In exploring the support systems available to caregivers, it was evident that faith was a major form of support -during the time of their child's hospitalization, as well as when they came home from the hospital. Faith refers to the complete trust and strong belief in a religion and worship of a God (Soanes, 2002). In the context of this study, the caregivers mentioned faith, whereby their belief in a God helped them cope during the difficult period of their child's

illness. As evident in the words expressed by the caregivers, their belief in God comprised of both a faith in, as well as the act of praying to God. Faith was used by the caregivers for emotional support and provided a coping mechanism during hard times.

A support system refers to a network that provides an individual with practical and/or emotional support, with the goal of decreasing stress (Merriam-Webster, 2018). The caregivers described the role of faith practices as a coping mechanism and a form of emotional support during this 'stressful' journey in which their child was diagnosed and fitted with a tracheostomy. Taking into consideration that faith was mentioned by eight of the caregivers, it is of importance to discuss faith as a theme of this study, as it evidently had a positive impact on the caregivers' experience of caring for their child with a tracheostomy. The caregivers expressed a connection of faith and its connection to health:

> *"You know, to tell you the honest truth, with it or without it (tracheostomy), it doesn't make a difference. Because at the end of the day, I have people coming to pray for me. I started building my faith. I thought to myself, I have to be strong…God be with me, guide me, you know" (*P4, 133-138).

Participant 4 went on to say: *"Um I approached my husband. I said 'You know, the Lord doesn't give you something you cannot handle, because it's a test'*" (P4, 63-64). In response to the researcher asking who her support was, Participant 10 also identified family and God as her support: *"My mother. My mother and my aunt. I was praying a lot"* (P10, 56). Similarly, Participant 8 expressed the following:

> *"The first time I was like really scared. You know cos I've never seen a child with a trachea before and it was my first time. But as they told me about the trachy story, I got used to it. Now it's good cos I believe that God is helping me out"* (P8, 19-21)

Research on social and cultural factors in mental health has expanded (Dressler, 1985). It has gone beyond the study of status characteristics in relation to mental health, to encompass more specific hypothesis relating to the effects of the life events, coping styles and social support in the stress process (Dressler, 1985). In light of this, Koenig (2001) recognized the power of faith. As a physician working with patients of all ages, Koening (2001) noted that patients who endured much physical and emotional illness, had a strong connection between health and faith (Koenig, 2001). The findings of his study confirmed the theme of faith that emerged in the current study as caregivers coped with and navigated their experiences of child illness through explicit reference to their religious beliefs and values. This was supported by Curlin, Roach, Gorawara-Bhat, Lantos & Chin (2005). Faith helped with acceptance, as well as effective care and management of the tracheostomy, demonstrating a correlation between the theme of the grief process and the current theme of faith.

Masuku and Khoza-Shangase (2018) explored spirituality as a coping mechanism for family and caregivers of persons with aphasia. Through purposive sampling, they investigated 14 family caregivers of persons with aphasia from a historically disadvantaged South African community. Their findings suggest spirituality to be important to carers of people with aphasia. Additionally, carers derived hope and strength from spiritual activities such as prayer.

Masuku and Khoza-Shangase (2018) also acknowledge that there is a paucity of research evidence on the role of spirituality and/or religiosity among caregivers of people with communication disorders. This can be applied to the current study whereby the caregivers expressed the powerful role of faith and religious practice during this time in their lives when their child was fitted with a tracheostomy. Masuku and Khoza-Shangase (2018) went on to say that participants believed in a higher being guiding them in their role of caregiving as well as reported to have derived hope and strength from spiritual activities such as prayer. They described and understood prayer as a way of communicating with God and/or ancestors, and

was deemed a source of healing (Masuku & Khoza-Shangase, 2018). As acknowledged by Pierce and Steiner (2013), similarly, the caregivers in the current study expressed that prayer was a source of strength and healing for both themselves and their families.

Faith communities such as one's church also often support a person and their families during times of ill health (Gunderson & Pray, 2006). This finding correlated with the current study whereby caregivers reported their church as one of a few of their support systems. This was evident in the following: *"Time healed me, as well as going to church did have an impact as I would pray and things got better"* (P3, 303-304). Faith appeared to help with accepting the tracheostomy and as well as coping on a daily basis. In contrast to the insertion of the tracheostomy limiting caregivers from going out and socializing with friends (as reported in the previous theme), this did not appear to be the case when it came to going to church. The insertion and presence of the tracheostomy did not appear to withhold one being able to go to church and continue with their faith practices. This is evident in the following: *"We normally go to church on Sundays, we go with her. We take our manual or electrical suction, its portable. It has got a battery so we can go anywhere we want. So I appreciate it"* (P5, 126-127).

In light of the above, it is also important to explore the impact of faith in medical settings. Literature often discusses and presents the negative impact that religious practice can have on the medical decision making process- from the perspective of the medical practitioner (Curlin et al., 2005). For instance, when exploring how physicians responded to conflict between medical advice and patients' religious beliefs, Curlin et al. (2005) found that despite religion and medicine being intertwined, there were times that patients' religious beliefs conflicted with physicians' recommendations.

The results from the current study demonstrated how faith and religious practice can in fact be used as a tool to strengthen relationships between patients, families and medical

practitioners. While some studies advocated the need for physicians to remain neutral about religion (Scheurich, 2003), others expressed the need for religious beliefs to be supported and respected in line with professional adherence to the ethical parameter of beneficence (Post, Puchalski & Larson, 2000). In this study, faith didn't appear to conflict with medical care, rather it appeared to facilitate care. In addition to the benefits of faith as a tool to strengthen relationships, in a group-based intervention of mindfulness-based stress reduction , Robins, Keng, Ekblad and Brantley (2012) found that religious practice, such as prayer, also proved to decrease stress levels, fear of emotions, as well as difficulties regulating emotions.

> *"Then it's up to God, God normally is the one that knows everything. What I know is, the doctor helped us with the trachy so that she can breathe well. All the nurses, they helping a lot. We thank God for that. Everything is well"* (P5, 60-63).

Faith appeared to alleviate some expected emotional strain (as discussed in the first sub-aim), for the caregivers who did mention faith as a religious practice. This was deduced from the researcher analyzing the data from caregiver interviews and finding that the 8 caregivers who mentioned faith practices reported that they have accepted their child's tracheostomy, whereas the other 2 caregivers, did not mention faith, and described that they were currently feeling stressed and expressed no feelings of acceptance of their experience and current situation. This was evident in asking Participant 1 how the experience had been caring for her child, to which she responded the following: "*Stress. A lot of stress*" (P1, 31). Participant 6 and 10 went on to say how they were also stressed, however, prayer helped them cope: *"If I am not strong she also won't recover. Eish I wasn't myself. I wasn't myself. I was just praying"* (P10, 80-81).

The above findings demonstrated how knowledge of the role of faith in the lives of the caregivers and their families, can be used by speech therapists and nurses before discharge. In

discussing and identifying the support systems available to the caregivers, the patient and their families, the healthcare team can provide support during discharge from the hospital to home. Considering the positive outcomes of faith practices, it means that we as Speech therapists need to accommodate this, allowing for caregivers to perform their practices, to pray, to go to church etc. In doing so, we need to then prepare parents for the following: parents being able to take their child out, addressing the reactions of people towards the tracheostomy, as well as support and reinforce confidence of the caregivers in changing the tracheostomy in a case of an emergency when they are out. Such considerations and practices will allow for participation and activity, according to the ICF framework. As health-care practitioners, we have the responsibility to adhere to the ICF principles when treating patients and/or managing cases (WHO, 2011).

As discussed in the literature review, the ICF framework emphasizes the importance of considering and analyzing the impact of one's environment and other contextual factors on functional abilities (WHO, 2011). The ICF framework can be used to guide and improve the services offered by the health-care team, such as their delivery and quality of care. For the purposes of this discussion, the focus is not on the full classification system, but rather on the participation and activity components, which include environmental and personal factors. Such considerations range from social interactions, family systems, community, and caregiver employment (Glader, Plews-Ogan, & Agrawal, 2016). These aspects will be discussed in detail in the next couple of themes.

In addition to faith as a form of a support system, caregivers described their families as a large form of support during their difficult times when their child was diagnosed with a medical condition and fitted with a tracheostomy. Therefore, the next theme that will be discussed is 'Family Support'- demonstrating the role of the family in supporting the caregivers of a child with a tracheostomy.

4.2.2. Family Support.

It is well known that children live and thrive within a family system, and that caring for a child with chronic illness can cause significant stress, especially for parents who are the primary caretakers (Glader, Plews-Ogan, & Agrawal, 2016). Therefore, it is crucial to attend to the specific need for a family system, as it is essential to the child's well-being. Holistic child care requires one to see this aspect of care as a unique entity that needs to be concretely addressed, and allows providers to delineate specific goals that underpin the success of care (Glader, Plews-Ogan, & Agrawal, 2016).

Despite the family being fearful in both observing and assisting in changing of the tracheostomy as reported earlier, the family of the children in the current study did however show support in other ways, such as through offering words of encouragement and support. As presented in the Figure 6 below, it appeared that physical and emotional support was provided to the caregivers by their respective family (which included spouses, parents, children and siblings), community (which included the church and friends), and medical team.

The goal of the findings presented below is to highlight the evident impact that a medical diagnosis and the fitting of a tracheostomy has on the family, as well as the role and benefit of support from one's family, community and medical team. Such support was expressed by nine of the caregivers as they narrated their experiences of caregiving for their child with a tracheostomy. It is important to note that family support was mentioned by nine of the participants, and communal and medical support was mentioned by only two of the participants, highlighting the significance of family support.

In the literature review, the roles of the multidisciplinary team were discussed. It appeared that literature has a large emphasis on the role of the healthcare team, and although the role of family is acknowledged, it appears to be unrepresented (Bonvento et al., 2017). From the current study, it appears that the caregivers strongly relied on and valued family support.

Additionally, this study also suggests that the community such as friends and the church (see Figure 4.2. below) also have a role in supporting caregivers of children with tracheostomies. Hence, a clinical implication would therefore be to reconsider the members making up the MDT, i.e. the members that play a major role in supporting caregivers of children with tracheostomies.

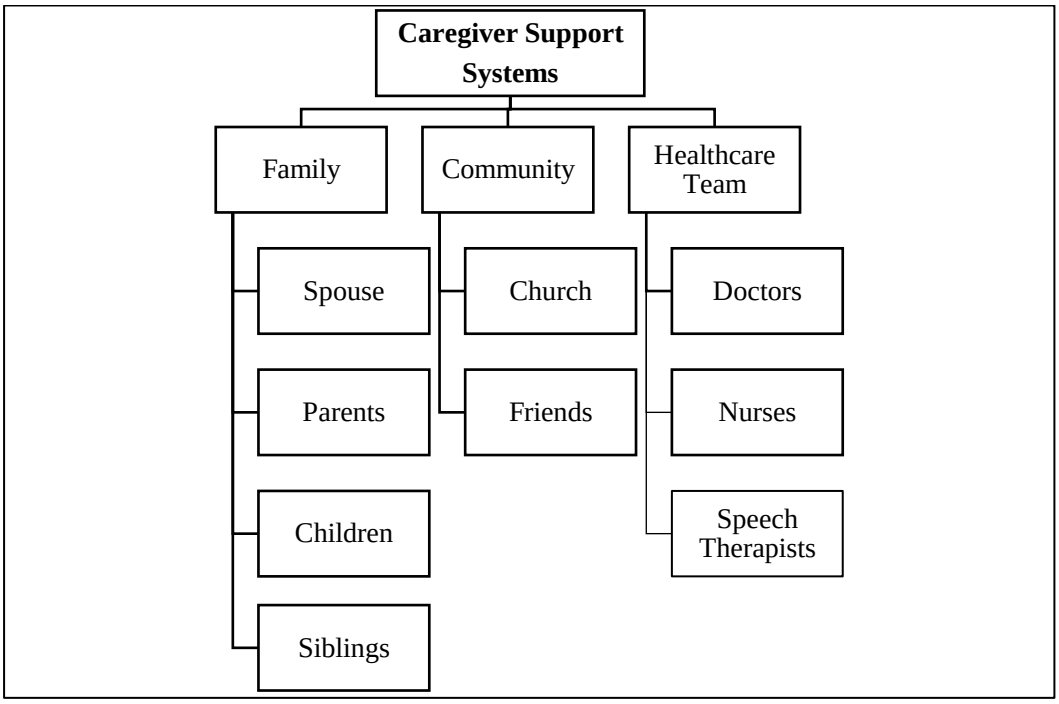


Figure 4.2. Caregiver support systems.

Participant 1 reported that she was living with her husband and 11-month old daughter. During the day, the caregivers' parents took care of her daughter, while she and her husband were both at work. Spousal support was similarly reported by participant 4: *"My husband, I must say. I can still up until today, I can still depend on him. He is at home with the baby"* (P4, 145-146), as well as Participant 8 responding the following when asked who her support was: *"The father. He has to"* (P8, 97). Participant 1 and 4 further described the support they received from their spouse. *"My husband. He's actually raising my kids for me. And he's doing an excellent job. And he's supporting me with washing the washing, doing the chores. So I can*

really depend on him" (P4, 4-7). Participant 1 also described support from her spouse with changing of the tracheostomy:

> *"Dad, he helps a lot as well. Obviously he can't do the trachy much cos his fingers are too big, so he does everything, but can't tie cos his fingers are too big. So every now and then he tries but.. So he can do it and he helps a lot"* (P1, 111-113).

From the excerpts above, several key factors were highlighted that gave weight to the importance of support that is necessary when caring for a child with a tracheostomy. Tracheostomy care involves a lot of work on part of the caregiver such as cleaning, washing, suctioning and performing humidification. (Al-Samri et al., 2010). This can be very strenuous for the caregiver to perform on her own, and therefore family support is essential.

Several studies report on the unintentional negative consequences that can culminate from having a child with a tracheostomy in a family. For instance, due to the added responsibilities that come with caring for a child with a tracheostomy, strained and broken marriages may result (Hopkins et al., 2008). This did not emerge in the current study; instead, spouses in the current study were able to offer support to each other during these difficult times. It is also possible that the belief in prayer and faith that the majority of caregivers spoke of in the current study either reduced the weight of challenges that the families faced, or in fact prevented tasks from becoming challenges altogether. This was supported by McNally & Mannan (2013), noting that faith can be used as a form of support and hope, which helps caregivers during stressful times.

Analysis of the data also confirmed that support during this process and transition from the hospital to home eased the caregivers' emotional experiences. Family members also appeared to acknowledge the strength and role of acceptance within the process of grievance.

> *"My family told me: 'You know what sis, you supposed to be together now. Anything can happen. You must accept. You must accept. God give you this child. But the breathing is for God, not for you. So you must be strong'. And I'm strong. I'm strong now. After crying, my mind wake up. Life goes on*" (P7, 58-64).

Firstly, from the excerpt above it seems that the caregiver felt that she had to accept the situation, with the use of the word "must", referring to her role in accepting the tracheostomy. These words suggest that perhaps the caregiver felt that as a way of coping and accepting the situation, she had to be open to the insertion of the tracheostomy.

Additionally, it appeared that support was not only limited to parental or spousal support on behalf of the caregiver, as some participants noted that their children (i.e. siblings of the child with the tracheostomy), also assisted with what the caregivers perceived as a form of support. Participant 3 expressed that: *"I share my burdens with my children as I do not have parents"* (P3, 275). We see that Participant 3 faced many challenges, as she described the pain of seeing other children hurt her son, having to take her son with her everywhere as there was no one else to take care of him, as well as her having to share her burdens with her children, as she had no spouse nor parents to share with. In contrast, Participant 10 had minimal to no support *"If I have someone to talk to me like this, I feel much better"* (P10, 81-82). It was clear that she viewed the researcher as someone who could offer support and lend an ear.

As mentioned previously, life change is instantaneous for family members of a child with a tracheostomy, as the family is required to care responsibly for the child both at the hospital and at home (Montagnino & Maurico, 2004). While there is limited research describing the role and value of family support for caregivers of a child with a tracheostomy, results from the current study emphasized the importance of both family support, but most importantly, allowing for family support- by involving them in the process. The results suggest

that when treating a patient, it should not be done in isolation, but rather by considering the patient and his/her family as an entity (WHO, 2018). Such consideration involves collaboration, family care, sharing of information, and mutual respect (Kuo, Houtrow, Arango, Kuhlthau, Simmons, & Neff, 2012). Kuhlthau et al. (2011) found positive associations of care that included families, with improvements in health status, access to care, communication and family functioning.

4.2.3. In-Hospital Tracheostomy Training.

The in-hospital tracheostomy training provided to caregivers appeared to form part of these support systems, by preparing the caregivers for tracheostomy care at home, and also by allowing for them a platform to receive education and information about their role as a caregiver of a child with a tracheostomy. With advancements in medical care, individuals with long-term respiratory health care needs, such as a tracheostomy, are becoming increasingly common (Scase, 2004). Al Samri et al. (2010) reported that discharge requirements include not only the provision of home-care equipment and assessment of home environments, but most importantly, caregiver training.

In the respective sites of the current study, Chris Hani Baragwanath Academic Hospital and Red Cross War Memorial Children's Hospital, the caregivers took part in training, which included receiving both education and information about the tracheostomy. This training was provided by the nurses as well as some training by the speech therapist in the ward. The training was given to the caregiver, and in some cases, also to family members.

The current study provided insight into the success of the training programmes at both hospital sites, as well as the caregivers' feelings and attitudes towards the training which they received. When asked about the training and home-care preparation, all 10 of the caregivers

reported that they were satisfied with the training they received, felt supported and confident post-training, as well as felt well-prepared to take care of their child at home. In light of this, the caregivers expressed their experiences, whereby Participant 9 described that: "*Yes, I was well-prepared. It was scary at first. But it was fine."* (P9, 70-71). Participant 6 similarly expressed that: *"The first one it's very hard. You scared also how to change it. But they give me training 2 weeks. After that I'm confident"* (P6, 4-5). Callans et al. (2016) reported that training and care by the nursing staff is not always available in the South African public healthcare system. However, findings of this study proved that the caregivers were satisfied with the care and training that they received- indicating the success of the health-care team in providing services to the caregivers, at both hospital sites. It appears that the health-care teams in both hospitals were very well aware of the specialized training and care that they need to offer to caregivers of children with tracheostomies.

Below are excerpts from the participants in relation to the training they received in preparation for home-care:

Table 4.3. Excerpts from participant interviews in relation to the tracheostomy training

In-Hospital Tracheostomy Training	**Excerpts from the participants' interviews**

Feedback on the Training	*"I didn't know what was the trachea about, and how am I going to you know cope with this thing. With what I learned here (Red Cross War Memorial Children's Hospital), from the doctors, the nurses, everyone else, now we are coping well. We are getting there day by day"* (P5, 6-8). *"They here to deliver a service and they do it very good. They doing enough as they are. You know, we are so blessed to have this. We are so blessed. I live in Atlantis but you can ask Sister Booth, I've never missed an appointment once. In my life"* (P4, 193-196). *"Ah the nurses they prepare me yes. Also the doctors. They say it is the trachy round and I am supposed to change. The first time was the doctor and me, the second time the doctor, third time, it's me. The first time I was very shaking. The doctors say: 'No, don't be stress, it will be okay' Simple. Ah I'm fine now"* (P7, 72-76).

Taking into consideration the importance and significance of training for the caregivers, it is evident that the training in and of itself formed part of the support given to parents. Therefore, when exploring the support systems that are available to the caregivers, in addition to the identified support systems of family and faith, training also appeared to be a support system for the caregivers.

4.3. Sub-Aim Three

4.3.1. Tracheostomy Training and Care.

The third aim of the current study was to gain insight into the roles of caregivers in caring for their child post-tracheostomy insertion as part of HBC. In the current study, tracheostomy care became the role of the caregivers who were the mother or father of the child with the

tracheostomy. The results of the current study suggested that the caregivers believed that they had a role in tracheostomy care as well as training other individuals, such as family members.

In addition to the training in hospital by the healthcare professionals (as discussed in the sub-aim two), some of the caregivers reported that once they were in their home environment, they themselves then had a role in becoming 'trainers', having trained some other family members and/or friends who were willing to receive tracheostomy care training. *"My mom and aunty had to come (to the hospital). They had to see what to do and how to do it. If I go to work then they can do it. When my mom's busy then she (aunt) takes over"* (P1, 97-98).

Furthermore, including the family in the training appeared to not only ensure safety for the child in case of an emergency in which the tracheostomy needed to be changed, but also empowered the family members as they felt part of the process. It is evident that with two participants, the whole family became involved in the tracheostomy care, as reported by Participant 2: *"Friends and family they used to it. They know what to do. And the brother also, he knows what to do. He looked what I do then he knows"* (P2, 36-38). The mother of Participant 1 (grandmother of the 11 month old) also reported family assistance in tracheostomy care:

> *"I'm getting training from her (the child's mother). We still on the programme that we are starting now to do the trachy around the neck, the vent size and the suctioning…Me and my husband now are training to do the trachy. Every day we learn something new. And grandpa is also learning now"* (P1, 171-187).

However, it is important to consider that this willingness of family members to assist was not available to all caregivers, as was evident in the words of Participant 8:*"I'm the only one that is taking care of her. There's gonna be issues maybe when I get sick, or something like that. There's no one to care for her*" (P8, 60-62).

In addition to the consideration of the accessibility of the training to all family members, one must also consider the quality of the training given. Participant 4 provided an explanation as to the nature of training required for caregivers of children with tracheostomies, as presented below.

> *For other people to do it, you watch them, it's fine. But to do it yourself, it takes a lot. It really takes a lot. Because you dono, are you hurting him? You dono what you doing, is it right? You see things like, you know the doctors come and they show you in and out, that's the way they do it. It's not, we must learn how to do it. You must get used to changing it like you do it in your everyday life"* (P4, 45-51).

By considering the nature of training needed by the caregivers (as presented above by Participant 4), it provides health care professionals with insight into parents' experience of the training, and the need for the training to be very specific and appropriate for the individual. (Gilbert, Counsell, & Ross, 1997). Participant 4 explained that watching the nurses and doctors change the tracheostomy was not enough for the caregiver to know how to do it, but rather the caregivers needed hands-on training and experience in order that they should gain the skill as well as confidence to be able to perform tracheostomy care at home. Therefore, the caregivers had to be actively involved in training.

The information above suggested that the level and success of training in the hospital setting, has a direct effect on the training that the caregivers provided to others, as well as the tracheostomy care that was administered in the home environment. The caregivers received training in hospital, which then allowed them to share their knowledge and train other individuals. Therefore, successful in-hospital training eased the role of the caregiver in training others. This highlights that the training is continuous, and not limited to the hospital setting.

The training received appeared to have an impact on the caregivers' experiences within their family, home, and social settings.

The caregivers went on to describe their roles related to tracheostomy care, which were as follows, as presented in the Figure 4.3. below:

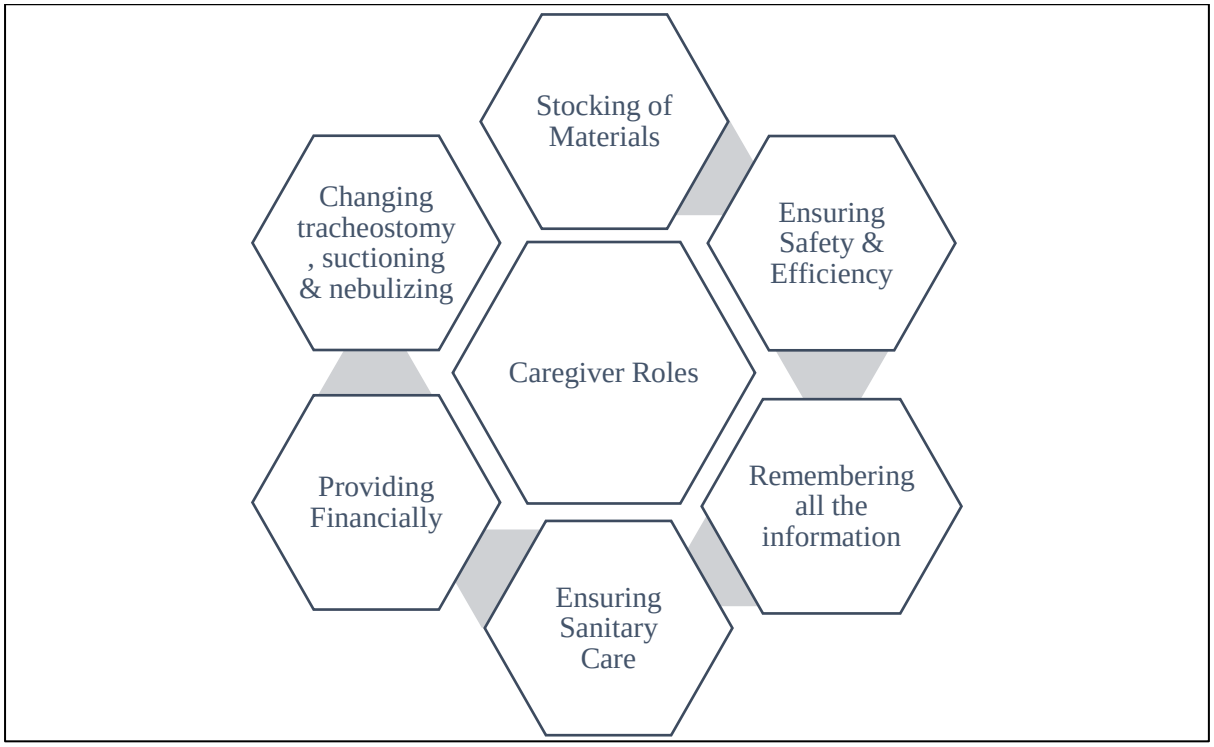


Figure 4.3. Caregiver roles in taking care of their child with a tracheostomy.

Caregivers emphasized the importance of their role as they had to constantly watch their child to ensure that the secretions did not block the tracheostomy, and that germs did not accumulate in the tracheostomy tube. The caregivers described that this role was very time-consuming and was stressful. In addition to the secretions as a potential cause of blocking the airway, Participant 3 described another safety hazard; in that young children in the community would bully her son and try pull out his tracheostomy, as they didn't like the way it looked. She reported: *"He was scared of playing, I would have to take care of him 24/7 as he was scared that the other children would pull the tracheostomy"* (P3, 224-225).

Furthermore, caregivers described their role in ensuring that they had all the materials stocked at all times; such as vents, tubes, gel and catheters. These materials needed to be easily accessible, and the caregivers had make space for these materials on a surface that was easily accessible in the home. The caregivers described their experience in having to remember all the information that was given to them during training. They explained that it was stressful for them to have to remember all the information, as they felt that there would be consequences if they hadn't remembered the correct procedures for tracheostomy care.

> *"Cos there's so much to remember and to do. If you forget anything, it's like life-changing you know. You have to have everything ready all the time. And just in case something happens. It was very traumatic at the time as well"* (P1, 58-60).

> *"It's easy to say "put in, do this, do that", it doesn't work that way. There's a certain technique that has to be done. You must be prepared. All your stuff must be ready. On your towel. For me I thought it was so simple, but it wasn't at all"* (P3, 43-48).

Additionally, the caregivers expressed the need for changing the tracheostomy very quickly, to maintain a patent airway (White, Kher, & O'Connor, 2010), and therefore this required them being very organized, efficient, and confident with the process of changing the tracheostomy. Lastly, the caregivers described the actions they took to ensure good sanitation of the tracheostomy as well as the environment around their child. For example, Participant 1 reported that that her mother-in-law needed to wash her hands and change her shirt before touching her granddaughter, as she was a smoker: *"And obviously people that smoke they need to put another top on, wash their hands, sanitize their hands. Especially my mother in law. My mother in law doesn't see her much because number 1 she smokes, a lot!"* (P1, 130-132)

Studies found that families felt pressurized by staff to take responsibility for the patients discharge home and viewed their role as being automatically expected of them, thereby

deducting from their sense of autonomy (Adam, 2000). However, in the current study, caregiver burden of care was evident as it appeared that the caregivers did not have freedom of choice in deciding whether or not to accept the responsibility of taking care of the child. It appeared that the South African context differed, whereby parents are very rarely given the privilege of choosing other options of care for their child.

Universally, caregivers had more options of care for their child, such as care facilities as well as private nurses in their home environment. However, in the South African context of the current study, caregivers faced many challenges finding care facilities for their child. The caregivers described a scarcity of crèches and/or care facilities available for their child following the insertion of the tracheostomy. Caregivers reported that they had also been unsuccessful in finding a suitable crèche or a nanny/baby sitter even for a few hours during the day. The caregivers suggested some reasons for this, explaining that the crèche assistants or care takers felt that they did not have the required skills to take care of a child with a tracheostomy. Additionally the crèche staff explained to the caregivers that it was too much of a responsibility for them to take care of a child with such needs. This demonstrated how the lack of knowledge about tracheostomy care resulted in one having made assumptions about the commitment and time required for a caring for a child with a tracheostomy. Caregivers 8 and 9 described the following:

> *"Even I told them I will teach them (crèche staff). They say they watching too many kids so 'I can't guarantee that all the time I will be looking. Maybe I need to leave for a couple of minutes and the kids will take out the trachy and I'll be in trouble'. Cos when they told me that if they take out the trachy, the child is struggling to breathe, I have to be in like 5 minutes and the hospital. So now when I'm at work it's going to be difficult to take the taxi, go home, back again. And you dono about the traffic and all that. So I said okay, I have to wait"* (P8, 1-7).

> *"I can't take him to crèche because of uh, even a nanny, when I find a nanny, I have to train my nanny to clean the trachy, change it, everything about the trachy. It's a lot of work. So I can't take him to a crèche."* (P9, 67-69).

In addition to the limited access that the caregivers had to care facilities for their children, they also expressed challenges accessing transport as well as employment. These appear to be common challenges faced in the South African context (Adato, Carter, & May, 2006) and seem to be causing barriers for caregivers of children with tracheostomies. On the other hand, it is important to take into account that caregivers had access to tracheostomy training at both hospitals as well as tracheostomy materials. Despite the challenges mentioned, access to tracheostomy training and materials highlights the success of the MDT and hospital systems in providing these services to the caregivers. These are examples of the outcome of the success of MDT collaboration.

In summary regarding tracheostomy training and care as part of HBC, the current study suggested that the tracheostomy training (both receiving as well as training others) is as important as the acute phase of the child's management. Caregivers had a role in the day-to-day assessment, care and problem-solving related to their child's tracheostomy. The goal for the health care team is to facilitate as normal a life as possible for the child and family- within their existing family structure (Scase, 2004). Taking the above into consideration, as healthcare providers we have a role within the MDT to prepare caregivers for reintegration back into their family, home and society.

4.3.2. Providing Financial Stability.

The caregivers also described their responsibility as adding to the income of the family, which changed post-insertion of the tracheostomy. This was due to them being required to leave their

jobs in order for them to take care of their child with a tracheostomy. It has now become more accepted that children with tracheostomies should be able to live in their home environment (Adam, 2000). Although HBC has proven to be cost-effective, the financial impact upon the family should not be dismissed (Scase, 2004). Table 3.3 (Chapter 4) illustrated the current employment status of the caregivers as well as their previous occupations- prior to their child's tracheostomy insertion. Table 3.3 illustrates that two of the caregivers were employed prior to and after the insertion of their child's tracheostomy (as a hairdresser and a chef). Eight of the caregivers were unemployed, of which two were housewives prior to the tracheostomy insertion, and the other six were previously employed but had lost their jobs post-tracheostomy insertion of their child.

Participant 3 described her financial difficulties; as she was previously running a business but then needed to stop, in order to take care of her child. She explained that: *"My son (eldest son) provides me with support as he has started working, when it's difficult he would assist where he can"* (P3, 258-259). She went on to say: "*When I used to work, I used to have money to buy stock for my business but now I am dependent on grant money so it is difficult to re-open my business*" (P3, 432-434). *"I only need money*" (P3, 427).

> "*As I am saying, that ever since he got this trachy, it hasn't been peaceful, I had to be also unemployed because he would've often be sick, every month he had to be admitted at hospital. I don't work, even if I work get employed I wouldn't be able to work as he gets sick all the time"* (P3, 239-242)".

Similarly, four other participants also described that they had to leave their jobs. Participant 8 explained that: "*I was working... I had to leave. There's no choice now*" (P8, 9-10). As well as Participant 7: "*Now I'm not working as I need to look after him. I was working at a crèche. But now.. because I closed it now because I want to see the baby*" (P7, 8-9).

Often one parent stays home to look after their child, resulting in a situation in which a parent was forced to give up paid employment, substantially decreasing the family income (Scase, 2004). This is evident in the current study, in which Participant 4's husband left his job at a factory, so that he could take care of the children at home, while his wife (Participant 4) worked as a chef. She reported: *"My husband, I must say. I can still up until today, I can still depend on him. He is at home with the baby*" (P4, 145-146). Similarly, this strain of care was also reported by Masuku, Mophosho, & Tshabalala (2018), explaining that caregivers of people with Aphasia (a language disorder) also experienced much strain in caring for their family member who was not independent. Financial implications were more evident when the child was cared for by a single parent (Scase, 2004). This was apparent with two of the caregivers, who were both taking care of their children single handedly without family support.

Two of the caregivers expressed that their roles and lifestyles had changed drastically, leaving them feeling unfulfilled. When asked about her role at home, Participant 9 responded "Nothing!" (P9, 63). Participant 10 expressed similar feelings:

> *"I just like playing with them. Cooking. Washing. Most of the time I like playing with them. But it's hard for me. Just staying home, nothing I'm doing. Just looking after them. You see, when you are not working it's hard. I want to work but I can't. Nobody is going to look after her. They are afraid of her. They say this one is not okay"* (P10, 28-31).

Thus, it appeared that the caregivers faced challenges and feelings of resentment, lack of purpose, independence, as well as sense of self (Pierce & Gardner, 2004). It is evident that there was a sense of burden when having to take care of a child with a tracheostomy. This emphasized the importance of family support, as well as support from the MDT, both before and after discharge from the hospital. The availability of family support allowed caregivers the

opportunity to still work, take some time off for themselves, and to engage socially. Additionally, by making reference to the roles described in the literature review, the one profession which appears to be unique to the South African context and/or was not mentioned in the research papers discussing the Western contexts- is the role of the social worker within the tracheostomy MDT. The social worker offer advice in terms of the benefits and other services, planning for going home and liaising with a patients local social services about support that might be available to the patient when they go home (Booth, 2017). Therefore, by extrapolation, it seems that the social worker would have a role in assisting caregivers with the correct solutions for employment opportunities.

In summary, caring for a child with a tracheostomy appeared to be a complex experience for caregivers resulting in an embodied third-party disability, especially pertinent in rural contexts in which the caregivers faced challenges of poverty, limited resources, and limited access (De Andrade, 2018). The current study demonstrated that because of the time and extra input required for caring for their child with a tracheostomy, they were excluded from employment. In summary, the current study suggests that tracheotomies in children may become embodied as a third-disability amongst the caregivers of children with tracheostomies.

4.3.3. Home-Based Care.

The researcher set out to critically analyse the role of the caregivers in providing training and care in their home environment (HBC). As stated in the literature review, HBC refers to any form of assistance provided to a patient directly in their home environment, by family, friends, and or member of the local community, following the advice and support from trained professionals (WHO, 2018). As discussed throughout the themes, it was evident that the transition from the hospital to home was challenging for most caregivers as they needed to

adapt very quickly to the new lifestyle and proceed on their own at home, implying that the transition to home is a significant experience for the caregivers. Nevertheless, some benefits of HBC were reported by some of the caregivers.

For instance, some of the caregivers explained that a home environment was able to provide them with comfort, which the hospital was unable to. Participant 6 expressed the following: *"Home is always better than the hospital. You sit all the time. You feel tired. It's better to go home. Home is best. At home you relaxing, because you feel free in your home"* (P6, 37-38). Participant 2 also expressed that it felt better to be home: *"The sleeping on this bed, and the sitting and doing nothing. At home it's different. I can clean, or cook, or do whatever. Not much time for myself, but at least a little bit of time for myself"* (P2, 24-27). The above excerpts suggested that caregivers felt more relaxed when they were home and the caregivers had more time for themselves to perform activities that made them feel fulfilled.

Caregivers explained that although they received adequate training in preparation for HBC, the transition into their home environment was a big shift, and involved a lot of feelings of stress and nervousness. Much of the stress encountered by the caregivers was related to the extent and unique nature of care needed by a child with a tracheostomy. In cases whereby the children were unable to walk, it appeared to have physical strain on the caregivers, resulting in a caregiver having had to carry her child on her back. Five of the participants carried their child on their back when going out, two had a pram to push their child in, and the other 3 of caregivers' children were able to walk. The extent of physical strain was expressed by Participant 10, in which she reported weight loss and back pain due to the physical strain of carrying her child on her back wherever she went.

In addition to the practical challenges of taking care of a child with a tracheostomy, Participant 7 also revealed emotional reactions, such as the responses and reactions of family

members when they saw the condition of her child, whom was previously able to walk and talk, but then on arrival back at home, was not able to do so any longer. Furthermore, the challenge of negative family reactions towards the child with the tracheostomy, could then impact on the caregiver well-being as well as her ability to feel comfortable in the home environment.

The literature reported benefits of HBC, such as of reduction in the costs of hospital admission and the decrease in nosocomial infection in the children (Al-Samri et al., 2010). However, the current study demonstrated that despite caregiver reported benefits of HBC of feelings of comfort when in their home environment, these benefits were outweighed by challenges faced of being at home. It appeared that the context of South Africa, specifically the Gauteng and Western Cape provinces, differed to developed contexts and therefore contextual variables make HBC challenging in this context. The results of the current study led to the researcher reconsidering whether HBC is really as beneficial as reported in the literature.

As discussed in the literature review, Vanker et al. (2010) explained that the success of HBC is highly dependent on parental training, team support, and social services. In the context of this study, the findings also correlated with the above, describing the importance of training as well as support. However, the caregivers did not mention any form of social work involvement and/or having been referred to the community health workers, as has been documented to happen in some international and developed contexts (Vanker et al., 2010). For these reasons, the implementation of HBC for children with tracheostomies is queried, given the reality of the South African context. It appears that HBC still requires work. Despite there being areas of excellence that provide training, monitoring and support of caregivers of children with a tracheostomy, the noticeable lack of involvement of social services, home visits by health professionals and inability of the government to provide support services for caregivers with special needs

Based on the input from the caregivers, it appeared that CHBAH and Red Cross War Memorial Children's hospital had a couple of similarities as well as differences. In terms of similarities, both the hospitals had dedicated wards for the children with tracheostomies, the healthcare professionals worked within a MDT, and both hospitals supported HBC. The caregivers from Red Cross War Memorial Children's hospital seemed more satisfied than the caregivers from CHBAH, as it appeared that they received more family support, more family involvement in the training, as well as a shorter duration of hospital stay than the caregivers from CHBAH. Lastly, the caregivers at Red Cross War Memorial Children's Hospital described the close relationships that they had with the nurses. However, at CHBAH the caregivers seemed to have more contact with the allied healthcare team during their follow-up appointments (e.g. Speech therapists and dieticians).

4.4. Latent Theme: Caregiver Hospital Experiences.

Braun & Clarke (2006) describe two levels of themes: semantic and latent. As opposed to the semantic themes that focus on the explicit meanings of the data, the latent themes identify underlying idea of the data. In the context of the current study, 'medical experiences' appeared as a latent theme. Despite not fitting into any of the targeted aims, medical experiences emerged from the caregiver responses. It appeared that the medical aspect of the process was something that remained with the caregivers, highlighting the trauma they felt for their child undergoing the tracheostomy procedure. The period of hospitalization, the interactions with the doctors and healthcare team, and the procedures the child went through, were the forefront of caregivers' memories. These memories were regardless of the memories that came post the medical aspects pertaining to the tracheostomy. It seems unlikely that this experience will ever leave the caregivers, as not only was it life-altering for the child, but even more so for the adult who understood the ramifications and consequences for the child growing up. Giving up a once

'normal' child, required significant strength, and while this emerged for some of the participants, it was apparent that not all the caregivers felt this way.

As a researcher I suggest the reasons as to why the medical experience was the most prominent of the experiences expressed by the caregivers. The caregivers described what had happened to their child in terms of the medical event that took place. In most cases, it appeared that this was a vulnerable period for the caregivers as what had happened was both unexpected and a big shock for the caregivers. For example, the caregivers described the incidents leading up to their child's diagnosis. The caregivers described feelings of uncertainty and apprehension in understanding what was wrong with their child. These experiences were then followed by those of medical procedures that had to take place, as well as staying in the hospital Intensive Care Unit (ICU).

> *"He was diagnosed with epilepsy in January.. he fell sick with seizures, uncontrollable seizures and then he ended up in ICU. So ya. They intubated him for 21 days. And then apparently his airway was damaged, so they had to put him a trachy because he was not breathing. They had to put the trachy so that he could breathe. Eish, it was not easy. I don't even want to lie to you. It was not easy*" (P9, 5-12).

The hospital experience appeared to be the first point of contact with the 'problem' (ie. The incident that led to the need for a tracheostomy); a time period filled with much emotional experiences that most parents often referred back to, in an attempt to understand what had happened to their child. For example, Participant 7 described the medical history of her child and the events that led to the indication for a tracheostomy. Furthermore, she describes that she didn't know the cause of the problem, and that till this day she is still trying to understand.

> *"Because when we was at home, he was very hot. He was very very very hot. So that's why I came. I go to the clinic neh, in Orange Farm. .So when I came here, the doctor*

they asked me the question, did you give the baby poison? No. I dono what happened to my baby" (P7, 20-24).

This illustrated that the medical experience is what stays with the caregivers, as supported by Al-Abri and Al-Balushi (2014), who mentioned that caregivers remember the hospital experience the most, due to the feelings of trauma of the experience and the uncertainty of the outcome of their child. Despite the current study's goal of exploring the caregiver experiences post hospital discharge, the findings of the current study suggested that the experiences that caregivers had in the hospital were very significant and were the at the forefront of the experiences described of the caregivers experiences post hospital discharge. This has implications for the role of the MDT, emphasizing the significant role that each member plays in creating an overall positive experience for the caregivers.

CHAPTER 5: CONCLUSIONS & IMPLICATIONS

5.1. Conclusions

The results of this study have led to a couple of important conclusions that will be discussed below. Most importantly, we learn that the experiences of caregivers of children with a tracheostomy, within the South African context, are very individually-based and complex. All the themes presented and discussed above, reflected the experience of ten caregivers in taking care of their child with a tracheostomy; presenting some of the common experiences. It is evident that the lived experiences incorporated a lot more than the tracheostomy itself, as it included other significant factors that created and contributed to this experience, namely, emotional experiences, support systems, caregiver roles, and medical experiences.

The insertion of a tracheostomy extended way beyond its physical nature, and had social, emotional, and financial impacts on the caregivers of children with a tracheostomy (Scase, 2004). It was evident that feelings and perceptions towards the tracheostomy were inseparable from the health condition itself, and thus the insertion of a tracheostomy was not merely a medical experience, but rather a combination of concomitant emotional feelings and unique experiences. The results of this study correlated with the theoretical framework of the study; the biopsychosocial model of a health condition, illustrating the close connection between one's health, activities, and participation within one's context (WHO, 2007). For example, the current study demonstrated how the insertion of a tracheostomy in a child contributed to caregiver unemployment, and a limited ability to partake in family and communal gatherings, which they had previously taken part of prior to the insertion of their child's tracheostomy.

The results of the study emphasized the strength of faith and/or religious practice during difficult times, such as at the time of diagnosis and fitting of the tracheostomy. For those caregivers who identified faith as a coping strategy, they believed that it alleviated expected emotional strain that came along with the tracheostomy. The results of this study also demonstrated how faith and/or religious practice were used as tools to strengthen relationships between caregivers and their families. While some studies advocated the need for physicians to remain neutral about religion and not incorporate it in the management of a patient (Scheurich, 2003), others expressed the need for religious beliefs to be supported and respected, in line with professional adherence to the ethical parameter of beneficence (Post, Puchalski & Larson, 2000). In this study, faith didn't appear to conflict with medical care, rather, it appeared to facilitate care and a positive experience for the caregivers.

In addition to the above, the caregivers described many experiences around the grieving process. In this context, it appeared that the grief process occurred in the life of the caregivers, in response to the diagnosis, as well as fitting of the tracheostomy of their child. Therefore, the grief process can be used to understand the experiences of caring for a child with a tracheostomy. This study showed that family members may also experience difficulty accepting the altered body image of the individual, in this context, the child with the tracheostomy. This related to the ICF framework, whereby the health condition was accompanied by other emotional experiences that contributed to one's ability to participate in activities, for example, the case of a caregiver not having yet 'accepted' the tracheostomy, thus avoiding going to family gatherings, as a form of avoidance behaviour. It was evident that there is very limited research correlating the grief process in the experience of tracheostomies.

The notion of third-party disability was applied to the current study, when considering the disabling effects of unemployment and financial burden. Not only do parents face exclusion from or limited social participation (De Andrade, 2015), results of the current study showed

that caregivers also faced exclusion from job opportunities and/or employment, because of the nature of care that is required of a caregiver taking care of a child with a tracheostomy. The researcher was aware that all caregivers may be facing financial challenges, however, as a researcher I noted that this experience is particularly a burden for caregivers of children with tracheostomies, as they are limited with opportunities of where to send their child for day-care. For example, the caregiver's in the study expressed that most of their financial strain was due to the fact that no crèche was willing to accept their child.

Previous research placed much focus on the experiences of the patient themselves, in this case the child with the tracheostomy. However, this study advocated for the caregivers of children with tracheostomies, and in doing so provided evidence that led to the finding that the caregivers themselves embodied 'third-party disability' as a result of the nature of care needed in caring for a child with a tracheostomy. In addition to the care needed, the results of the study also presented other factors that contributed to the third-party disability, whereby caregivers described how they had to leave their jobs, resulting in much financial strain on the family. Additionally, due to lack of public knowledge and negative reactions from the public and family, this jeopardized family support, leaving the caregivers once again with the burden of being the core care-takers of their child.

Although the caregivers reported that they had family support, when the researcher analyzed the data it appeared that in fact the family support was very limited when it came to the physical aspects of support such as tracheostomy care of suctioning and changing the tracheostomy. Possible reasons for this lack of support was attributed to both fear and a lack of knowledge amongst the family and/or friends, describing that they felt their skills and knowledge in this regard was inadequate. This emphasizes the consequences of a lack of knowledge- to the caregiver and ultimately the child and the family. This finding provided the

researcher with clarity as to why the caregivers were experiencing social isolation, negative feelings towards the tracheostomy, as well as feelings of stress.

Additionally, Scase (2004) explained that HBC has become more common in recent years for multiple reasons. The current study demonstrated that despite some benefits of HBC reported by the caregivers, such as feelings of comfort, HBC appeared to not be ideal for caregivers in the South African context. The challenges of HBC appeared to outweigh the benefits, as was evident by considering these factors discussed that posed challenges to the caregiver's experience of HBC:

1. Family reactions to their child's the tracheostomy
2. Changes in the role of the caregiver
3. The nature of tracheostomy care
4. Financial and employment implications
5. Physical strain of carrying child around
6. Social isolation due to people's reactions and environmental factors

Additionally, as mentioned in the literature review, Al-Samri et al. (2010) explained that an assessment of emotional stability and level of social support available to caregivers needs to be included before HBC can take place. In the South African context, these seemed to be missing. In the case where emotional and social support are provided to parents in the South African context, then the potential benefits of HBC could be seen.

As health professionals, it is important to understand that the tracheostomy is not the only aspect of the caregiver experience, but that often there is also an underlying medical condition and/or diagnosis (as illustrated in Table 1), that required the insertion of a tracheostomy. Therefore, the child has to be viewed with a holistic approach, as it has a direct influence on the caregiver experience. Additionally, it emphasizes that despite some external

commonalities between the children (the tracheostomy) and their caregivers' experience, each child's condition manifests in a unique manner and so the experience is individualized.

It is appeared that for the caregivers, there was a continuity of hospital-related experiences to post-hospital experiences at home. As apparent in the findings of the study, it appeared that the diagnosis of the medical condition of the child as well as the insertion of a tracheostomy elicited certain reactions from the public, when the caregiver and child arrived home from the hospital. Secondly, the training received by the caregivers while in hospital with their child, would determine the level of home based care that the caregiver would be able to perform. Thirdly, due to the insertion of the tracheostomy, hospital duration of stay and the level of care that accompanied this insertion, caregivers lost their jobs, thus contributing to their experience of unemployment. Lastly, the experience of the caregivers at the hospital as a whole, starting from admission and then the diagnosis of their child's medical condition and insertion of the tracheostomy, contributed to the extent and manner in which the caregivers were able to grieve, and accept the 'new reality', contributing to the grief process.

By considering all the above findings, it is evident that the medical aspects of a health condition (body function and structure), in this case- tracheostomies, are accompanied by lived experiences of caregivers of the children with tracheostomies. In the current study, there appeared to be a link between the health condition to activity and participation, whereby the diagnosis and insertion of a tracheostomy, contributed to multiple experiences and changes in the lives of the caregivers, specifically in their home, social and family environments. The theoretical framework of this study- the biopsychosocial model, recognizes that health status results from a complex interaction between biological, emotional, social, personal, and environmental factors. Throughout the results and discussion, it is evident that as per the biopsychosocial model of a health condition, there is a close relationship between one's health condition, activities and participation within one's context (WHO, 2007).

Taking into consideration all the findings of the study, the researcher suggests a model of care that includes the following factors, in order to improve HBC for the caregiver and patient:

1. In-hospital caregiver tracheostomy training
2. Training specifically addressing caregivers' feelings and attitudes
3. In-hospital family and/or friend training by the nurses and the caregivers
4. Caregiver referral to social work services as well as community health-workers
5. Caregivers to train individuals in the community and/or the crèche assistants
6. Communal family support groups, at least once a month

5.2. Implications of the study

Caregivers of children with tracheostomies appear to have very complex experiences in multiple domains related to medical, emotional and social influences. The results obtained from this study provide valuable information to and increase awareness amongst nurses, medical practitioners, speech therapists, speech therapy training students, as well as amongst caregivers themselves of children with medical conditions, specifically, those with a tracheostomy.

5.2.1. Clinical and Theoretical Implications.

The results of this study are clinically valuable for clinicians assessing, treating, and counselling families of children with tracheostomies. Results suggest that speech therapists have a very important role in advocating success of reintegration back into their family, home, and society, post discharge from the hospital. This could be achieved through informing, training, counselling, supporting families, and making appropriate referrals to other professionals when indicated.

The results of this study demonstrated how faith and religious practice can be used as a tool to strengthen relationships between patients, families and medical practitioners. The data demonstrated faith and prayer as coping mechanisms and ultimately emotional support systems for caregivers experiencing emotional stress and trauma. This has implications for healthcare professionals working with these individuals, as it was clear in the current study that caregivers were in need of such a coping mechanism to help them through the stress of caring for a child with a tracheostomy. Furthermore, the above findings demonstrated how the knowledge of the role of faith in the lives of the caregivers and their families, can be used by speech therapists and nurses before discharge. In discussing and identifying the support systems available to the caregivers, the patient and their families, the healthcare time can provide support during discharge from the hospital to home. Therefore, amongst the caregivers who value faith and/or religious practice, clinicians should encourage this as a tool and/or as a practice. Rather than discourage, clinicians should encourage these practices, with the goal of facilitating and enhancing caregiver experiences of caring for their child with a medical condition, more specifically in this study- children with a tracheostomy.

The current study suggested that the grief process be used to understand the experiences of caring for a child with a tracheostomy. Taking into consideration all the experiences of reaching a level of acceptance and the emotional aspects involved, it is important that the clinicians both understand and are informed of the grief process. Once this has been achieved, clinicians will then be able to support caregivers and address the grieving process before considering home-care education. Scase (2004) explains that a criteria before discharge can take place, is to introduce the caregiver to other tracheostomy users, to share their personal experiences and to provide a support network.

Additionally, Alexrod (2006) explains that the stage of acceptance is the ultimate stage, however is not necessarily reached by all individuals experiencing grief. As therapists, we need

to brainstorm ways in which to facilitate and support the grieving process, more specifically, the stage of acceptance for parents. Although the grieving process is experienced differently by each caregiver, it can be used as a guide. By identifying the stage in which parents appear to be in, one can then gain more of an understanding, assist, support and counsel caregivers in moving to the next stage if the grieving process. In addition to counselling, clinicians should know when to refer to other health professionals within the multi-disciplinary team.

The grieving process can also be facilitated through caregiver support groups, in which the grievance experiences can be shared amongst the caregivers. Callans et al. (2016) reported that families expressed that they had difficulty finding families with similar experiences. The findings of this study further correlate with the findings by Callans et al. (2016), as he reported that caregivers went on to say that when they had the opportunity to connect with other families with similar experiences, this eased their transition from that shock, to acceptance. Overall, the study by Callans et al. (2016) found that family support groups enhanced the confidence of family members.

Correlating with the findings of Callans et al. (2016), the current study also found that the caregiver's expressed a desire for support groups and a sense of belonging to a community. They went on to day that they wanted to be listened to, share their experiences and form relationships with caregivers that were going through the same journey. Caregivers expressed that if they were part of a support group, they would have felt 'a lot better'. This has an implication for speech therapists, informing our role in creating support groups for caregivers, during their hospital stay with their child, as well as when their child is discharged from the hospital, to ensure continuity of care. Such support groups could potentially empower caregivers, thus facilitating the success of HBC for children with tracheostomies.

The above-mentioned implications highlight the nature of skill and services needed for therapists working with such caregivers, emphasizing the need for speech therapists to have more of a role in counselling of caregivers. Such counselling training needs to begin at a university level, in which students in the field of speech therapy are trained to counsel specific populations, such as those caring for children with tracheostomies. Currently, ASHA (2019) does include counselling as a service delivery domain of a speech therapist, however, as mentioned previously, research regarding the role a speech therapist has in counselling is limited and required further research.

The current study demonstrated that because of the time and extra input required for caring for their child, caregivers were excluded from employment. Such findings have an implication for the clinical work of the speech therapist emphasizing the need to consider socio-economic status and employment status, as a results of their child's medical condition. The speech therapist should consider the impact that the health condition has on the caregiver and family, as well as the effects of possible unemployment for the family. Referrals to other professionals such as social work may be indicated.

The results of the current study suggested that both the caregivers and the families of the children with a tracheostomy had a very important role in both tracheostomy training as well as tracheostomy care. As part of planning and ensuring a safe environment for tracheostomy care, training and support needed to take place (Scase, 2004). Implications of this study highlight the role of healthcare professionals in supporting, informing and preparing the caregivers in preparation for taking care of their child. The current study suggested that the tracheostomy training, as part of the discharge process in preparation for home, is as important as the acute phase of the child's management and has a role in determining the quality of life of the caregiver. Taking into consideration the evident benefits of HBC, as healthcare providers, we have a role within the multi-disciplinary team to prepare caregivers for

reintegration back into their family, home and society. Training needs to be provided to individuals by the healthcare team, allowing for successful reintegration post hospital discharge. Caregivers need to be encouraged to train other members in their community, as such a sharing of knowledge, could benefit many caregivers and have positive outcomes.

5.2.2. Policy Implications

It appears that there need to be policies developed at a national level in order to address and stipulate specific guidelines and minimum criteria related to HBC. Should such policies be developed, they may improve the caregiver experiences, for example, finding a crèche that is suitable for the needs of their child. Caregivers reported that they had been unsuccessful in finding a suitable crèche, explaining that the crèche assistants or care-takers felt that they did not have enough skills to take care of a child with a tracheostomy, and that it was too much of a responsibility for them to accept. Such a finding highlights the need for policies to be created that advocate for inclusive education. Furthermore, policy makers should pay attention to the needs of parents related to environmental support, with the goal of creating interventions and policies that are more family-centered.

5.2.3. Implications for Further Research

As health professionals, we have an ethical responsibility towards the advancement of knowledge, such as in the form of further research (WHO, 2002). South Africa is a unique and complex social context (Orman, 2008), with challenges such as limited resources, poverty, access to services such as speech therapy, as well as diversity and multilingualism. It is recommended that further research expand on this present research, as well as in the form of longitudinal research measures, by exploring the lived experiences of caregivers of children

with a tracheostomy in additional hospitals in South Africa, in a variety of cultures, and contextual backgrounds. Qualitative research exploring parental experiences of having a child with a tracheostomy, both internationally and nationally, remains limited. Similar studies have been conducted in the United States of America (USA) and United Kingdom (UK), mostly quantitative in nature, however, the lack of this data in the South African context, specifically qualitative research designs, advocates the need for this to be investigated further.

Taking into consideration the very limited research on faith practices and medical experiences as well as the value held by the participants of faith and/or religious practice, it is recommended that further research explore the role of faith in the context of medical experiences, and well as more specifically the relationship between faith and religious practice to medical conditions requiring tracheostomies.

In addition, a few other topics arose in the interviews which were not explored extensively. Amongst these were themes of unemployment and consequently third-party disability related to caregivers of tracheostomies, the impact on the caregivers related to the absence of voice in their child, the communication difficulties faced by caregivers of children with tracheostomies, as well as the caregiver decision-making process in accepting responsibility and caring for their child (such as their autonomy, ability to refuse responsibility, and the role played by the medical team in this regard).

It was evident amongst the sites of the study that the duration of hospital stay of the children between Western Cape versus Gauteng differed. The average duration of stay in the Western Cape (Red Cross War Memorial Children's Hospital) appeared to be 3 months, whereas the average duration of stay in Gauteng (Chris Hani Baragwanath Academic Hospital) was 2 months. Further research could be conducted to explore the reasons for these differences.

In relation to the frequency of changing of the tracheostomy, the caregivers from the Western Cape reported that they changed their tracheostomy every day, and the caregivers from Gauteng reported that sometimes they change it every day, or otherwise every second day. Research can be conducted in this domain, exploring both the positive and negative outcomes of the differences in frequency of changing the child's tracheostomy.

There appeared to be very limited research discussing third-party disability, and of the very few studies discussing third-party disability, they were all related to the experiences of significant others related to deafness and aphasia There appeared to be no literature discussing third-party disability in relation to tracheostomies. This correlates with the findings of De Andrade (2015), reporting that the WHO concedes the need for further study in the area of third-party disability, as it appears to be under-investigated.

Lastly, this study led to many questions around the notion of HBC, whereby research advocates for and emphasizes the benefits for HBC, however, the results of the current study led to the researcher questioning whether HBC is ideal for caregivers within the South African context. Therefore, HBC in the South African context, is an area that would need further investigation.

5.3. Limitations of this Study

There were a few of limitations that were acknowledged and considered throughout the study. Firstly, the sample size of this study was small, consisting of only 10 participants. Although the sample size was adequate to provide a descriptive investigation, the participation of more caregivers could contribute additional significant unique experiences of caring for a child with a tracheostomy. In addition, because the study was only conducted in 2 hospitals in South Africa, the researcher needs to be careful in generalizing such findings to a larger population.

The participants in this study consisted of 9 females and 1 male individual. Therefore, the participants were predominantly female which may reflect a gendered description of the caregivers' experience. However, according to de Villiers & Giese (2008), the South African context seems to reflect a demographic profile of majority of the participants being female.

Secondly, the participants in this study were the caregivers of the children with the tracheostomies, and not the children themselves. Although the age group of children in this study were of the ages 0-5-years old, and so obtaining qualitative data would be limited, nevertheless, this is a limitation as it excludes the experience of the patient; in this study- the child. Additionally, this study did not explore the experiences of health professionals as well as those of significant others, such as the siblings of the child with the tracheostomy.

Thirdly, the caregiver interviews for the purposes of this study, took place in a room at the hospital sites of this study (Chris Hani Baragwanath Academic Hospital, and Red Cross War Memorial Children's Hospital). This was a limitation as more information could have potentially been obtained would the researcher conduct interviews and observations in the participants' home environment. However, due to factors such as time constraints and ethical considerations, the interviews were conducted in the hospital environment.

Although considered in the different aspects of this study which are detailed in the methodology of this study, it is nevertheless important to consider and account for the cultural, racial, linguistic, geographical and economic difference between the principal researcher and the participants. This is a limitation as it potentially creates a power differential, which could have led to results that were less indicative of the caregiver true lived experiences of caring for their child with a tracheostomy.

The methodology of this study was cross-sectional in nature. This could be seen as a limitation, as longitudinal research methods could provide more information on the experience

over time, even though that was not the focus of the study. Yet, the inclusion of longitudinal aspects could have yielded more information about the argued benefit of participation in the interviews and in the group interviews.

Notwithstanding the identified limitations at different stages of the project, this study has highlighted the experience of caregivers of children with tracheostomies and has offered some insight into that experience.

REFERENCES

Abdullah, V. J., Mok, J. S., Chan, H. B., & van Hasselt, C. A. (2003). Paediatric Tracheostomy. *Hong Kong Journal of Paediatrics, 8,* 283-289.

Adato, M., Carter, M. R., & May, J. (2006). Exploring poverty traps and social exclusion in South Africa using qualitative and quantitative data. *The Journal of Development Studies,* 42(2), 226-247.

Adam, J. (2000). Discharge planning of terminally ill patient's home from an acute hospital. *International Journal Palliative Nursing,* 6(7): 338–345.

Adoga, A., Ma'an, N. (2010). Indications and outcome of pediatric tracheostomy: results from a Nigerian tertiary hospital. *BMC Surgery* 10(2). Available: http://www.biomedcentral.com/content/pdf/1471-2482-10-2.pdf [Accessed 18.01.2018].

Al-Abri, R., & Al-Balushi, A. (2014). Patient satisfaction survey as a tool towards quality improvement. *Oman medical journal, 29*(1), 3.

Alladi, A., Rao, S., Das, K., Charles, A.R., D'Cruz, A.J. (2004). Pediatric tracheostomy: a 13-year experience. *Pediatric Surgery International,* 20: 695–698.

Alexrod, J. (2006). The 5 stages of loss and grief. *Psych Central.*

Al-Samri, M., Mitchell, I., Drummond, D.S., Bjornson, C. (2010). Tracheostomy in Children: A Population-Based Experience Over 17 Years. *Pediatric Pulmonology,* 45:487–493.

Anderson, R. (2007). *Thematic Content Analysis: Descriptive presentation of qualitative data*. Retrieved from:

http://www.wellknowingconsulting.org/publications/pdfs/ThematicContentAnalysis.p df

American Speech-Language- Hearing Association (ASHA) (2019). Scope of Practice in Speech-Language Pathology. Retrieved from: https://www.asha.org/policy/SP2016-00343

Beddar S, Aikin J. Continuity of care: A challenge for ambulatory oncology nursing. *Seminar Oncol Nurs* 1994; 10(4): 254–263.

Bernard, H.R., & Ryan, G.W. (2010). *Analyzing qualitative data: Systematic Approaches*. USA: SAGE Publications.

Boss, E. (2009). Pediatric tracheostomy. *Operative Techniques in Otolaryngology*, 20:212-217.

Boyle, M. P. (2013). Assessment of stigma associated with stuttering. Development and evaluation of the Self-Stigma of Stuttering Scale. *Journal of Speech, Language, and Hearing Research*, 56, 1517-1529.

Bonvento, B., Wallace, S., Lynch, J., Coe, B., & McGrath, B. A. (2017). Role of the multidisciplinary team in the care of the tracheostomy patient. *Journal of multidisciplinary healthcare*, *10*, 391.

Booth, J. (2017). *The BreathEasy Training Manual. How to look after your child with a tracheostomy.* Retrieved from: http://breatheasyprogramme.org/uploads/6ba5c67c361fb06ba9c67c3f/1442588335920/Home-Care-Book-final-email.pdf

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101.

Bruce, E. J., Schultz, C. L., & Smyrnois, K. X. (1996). A longitudinal study of the grief of mothers and fathers of children with intellectual disability. *British Journal of Medical Psychology*, 69(1), 33-45.

Buescher, P. A., Whitmire, J. T., Brunssen, S., & Kluttz-Hile, C. E. (2006). Children who are medically fragile in North Carolina: Using Medicaid data to estimate prevalence and medical care costs in 2004. *Maternal Child Health Journal, 10*(5), 461-466.

Callans, K. M., Bleiler, C., Flanagan, J., & Carroll, D. L. (2016). The Transitional Experience of Family Caring for their Child with a Tracheostomy, *Journal of Pediatric Nursing, 31 (4), 397-403.*

Carron, J. D., Derkay, C. S., & Strope, G. L. (2010). Paediatric tracheotomies: changing indications and outcomes, *Laryngoscope,* 110 (7) 1099–1104.

Collins, H. (2010). *Creative research: The theory and practice of research for the creative industries.* Switzerland: AVA Publishing.

Corbin, J., & Strauss, A. (1990). Basics of Qualitative Research. California, USA: Sage Publications.

Curlin, F. A., Roach, C. J., Gorawara-Bhat, R., Lantos, J. D., & Chin, M. H. (2005). When Patients Choose Faith Over Medicine: Physician Perspectives on Religiously Related Conflict in the Medical Encounter, *Archives of Internal Medicine, 165*(1), 88-91.

Dal'Astra, A. P., Quirino, A. V., Caixêta, J.A., & Avelino, M. A. (2017). Tracheostomy in childhood: review of the literature on complications and mortality over the last three decades. *Brazilian Journal of Otorhinolaryngology, 83,* 207-214.

Daniel, J. (2011). *Sampling Essentials: Practical guidelines for making sampling choices*. USA: SAGE Publications.

De Andrade, V. M. (2015). *"We do not understand each other": the experience of caregivers of deaf children in a rural South African setting* (Doctoral dissertation).

Deutsch, E. S. (2010). Tracheostomy: Pediatric Considerations. *Respiratory Care, 55*(8), 1082- 1090.

de Mestral, C., Iqbal, S., Fong, N., LeBlanc, J., Fata, P., Razek, T., & Khwaja, K. (2011). Impact of a specialized multidisciplinary tracheostomy team on tracheostomy care in critically ill patients. *Canadian Journal of Surgery*, *54*(3), 167.

Douglas, C. M., Poole-Cowley, J., Morrissey, S., Kubba, H., Clement, W.A., & Wynne, D. (2015). Paediatric tracheostomy: a 11-year experience at a Scottish paediatric tertiary referral centre. *International Journal of Pediatric Otorhinolaryngology, 79*, 1673-1675.

Draucker, C. B., Martsolf, D. S., & Poole, C. (2009). Developing Distress Protocols for research on Sensitive Topics. *Archives of Psychiatric Nursing, 23* (5), 343-350.

Dressler, W. W. (1985). Extended family relationships, social support, and mental health in a southern black community. *Journal of health and social behavior*, 39-48.

Flynn, A. P., Carter, B., Bray, L., & Donne, A. J. (2013). Parents' experiences and views of caring for a child with a tracheostomy: A literature review. International Journal of Pediatric Otorhinolaryngology, 77, (10) 1630-1634.

Fossey, E., Harvey, C., McDermott, F., & Davidson, L. (2002). Understanding and evaluating qualitative research. *Australia and New Zealand Journal of Psychiatry, 36(1),* 717-732.

Gadamer, H. G. (1985). *Truth and method*. New York: Crossroad Publishing. (Original work published 1960).

Gibson, B. E., & Teachman, G. (2012). Critical approaches in physical therapy research: investigating the symbolic value of walking. *Physiotherapy Theory and Practice*, *28*(6), 474-484.

Gibson, B. E., Teachman, G., Wright, V., Fehlings, D., Young, N. L., & McKeever, P. (2012). Children's and parents' beliefs regarding the value of walking: rehabilitation implications for children with cerebral palsy. *Child: care, health and development*, *38*(1), 61-69.

Gilbert M, Counsell C, Ross L. (1997). *Evolution of a Role to Enhance Care Co-ordination*. Lippincott-Raven Publishers, 2(1): 19–22.

Glader, L., Plews-Ogan, J., & Agrawal, R. (2016). Children with medical complexity: creating a framework for care based on the International Classification of Functioning, Disability and Health. *Developmental Medicine & Child Neurology*, *58*(11), 1116-1123.

Graf, J. M., Montagnino, B. A., Hueckel, R., & McPherson, M. L. (2008). Children with new tracheostomies: Planning for family education and common impediments to discharge. *Pediatric Pulmonology*, 43, 788–794. http://dx.doi.org/10.1002/ppul.20867

Graham, L., Moodley, J., & Selipsky, L. (2013). The disability–poverty nexus and the case for a capabilities approach: evidence from Johannesburg, South Africa. *Disability & Society, 28*(3), 324-337. doi: 10.1080/09687599.2012.710011

Griffin, M. G., Resick, P. A., Waldrop, A. E.8 & Mechanic, M. B. (2003). Participation in trauma research: Is there evidence of harm? *Journal of Traumatic Stress*, 16(3), 221–227.

Guest, G., & MacQueen, K. M. (2008). *Reevaluating guidelines in qualitative research*. In G. Guest & K. MacQueen (Eds.), Handbook for team-based qualitative research (pp. 205-226). Plymouth: Altamira Press.

Gunderson, G. R., & Pray, L. (2006). *Leading causes of life*. Memphis, United States of America: Methodist LeBonheur Healthcare Centre of Excellence in Faith and Health.

Haddad A. Ethics in action. *Regist Nurs* 2001; 64(7): 21–22.

Hall, R. (2008). *Applied Social Research: Planning, Designing and Conducting Real-World Research.* Macmillan Education, AU.

Hall, H. R., Neely-Barnes, S. L., Graff, J. C., Krcek, T. E., Roberts, R. J., & Hankins, J. S. (2012). Parental stress in families of children with a genetic disorder/disability and the resiliency model of family stress, adjustment, and adaptation. *Issues in comprehensive pediatric nursing*, *35*(1), 24-44.

Hartnick, C., Bissel, C., & Parsons, S. (2002). The impact of pediatric tracheotomy on parental caregiver burden and health status. *Archives of Otolaryngology, Head, Neck Surgery*, 126, 228–233.

Harnick, C. J., Bissell, C., Parsons, S. (2003). The impact of pediatric tracheotomy on parental caregiver burden and health status. *Otolaryngology Head and Neck Surgery*, 129, 1065- 1069.

Hatun, O., Yavuz-Birben, F., Ince, Z., & Kalkan-Yeni, G. (2016). The ticket to Heaven: A spiritual resource for coping with disability. *Spiritual Psychology and Counceling*, *1*(2), 209-235. doi: 10.12738/spc.2016.2.0013

Hochstadt, N. J., & Yost, D. M. (Eds.). (1991). *The medically complex child: the transition to home care*. Taylor & Francis US.

Hopkins, C., Whetstone, S., Foster, T., Blaney, G., & Morrison, G. (2008). Impact of paediatric tracheostomy on both the patient and the parent. *International Journal of Pediatric Otorhinolaryngology*, 73, 15-20.

Hopkins, C., Whetstone, S., Foster, T., Blaney, S., & Morrison, G. (2009). The impact of paediatric tracheostomy on both patient and parent. I*nternational Journal of Pediatric Otorhinolaryngology*, *73*, *1*, *15-20*.

International Monetary Fund; World Economic and Financial Surveys; World Economic Outlook Database - WEO Groups and Aggregates Information (2010). Washington (D.C). Available from: http://www.imf.org/external/pubs/ft/weo/2010/01/weodata/groups.htm [Accessed 15.07.2019].

Ismail-Koch, H., & Jonas, N. (2014). Paediatric Tracheostomy. *Open access atlas of otolaryngology, head & neck operative surgery.* Retrieved from http://www.entdev.uct.ac.za

Jacobs, C. R. (2012). *Paediatric Tracheostomies in Johannesburg: a ten year review* (Master's thesis). Retrieved from http://wiredspace.wits.ac.za

Jiang, D., & Morrison, G. A. (2003). The influence of long-term tracheostomy on speech and language development in children, *International Journal of Paediatric Otorhinolaryngology*, 67, 217-220.

Jolley, J., & Shields, L. (2009). The evolution of family-centred care. *Journal of pediatric nursing*, 24(2), 164-170.

Jorm, A. F., Kelly, C. M.8 & Morgan, A. J. (2007). Participant distress in psychiatric research: A systematic review. *Psychological Medicine*, 37, 917–926.

Klompas, M., & Ross, E. (2004). Life experiences of people who stutter, and the perceived impact of stuttering on quality of life: Personal accounts of South African individuals. *Journal of Fluency Disorders*, 29, 275–305.

Koenig, H. (2001). The Healing Power of Faith. In H. Koenig & M. McConnell, *The healing power of faith: How belief and prayer can help you triumph over disease* (pp. 13-20). Simon and Schuster.

Kűbler-Ross, E., & Kessler, D. (2005). *On grief and grieving: Finding the meaning of grief through the five stages of loss.* Simon and Schuster.

Kuhlthau, K. A., Bloom, S., Van Cleave, J., Knapp, A. A., Romm, D., Klatka, K., Homer, C. J., Newacheck, P.W. & Perrin, J. M. (2011). Evidence for family-centered care for children with special health care needs: a systematic review. *Academic pediatrics*, *11*(2), 136-143.

Kvale, S. (2007). *Doing Interviews. The Sage Qualitative Research Kit.* Thousand Oaks, CA: Sage.

Lambano Sanctuary (2016). Retrieved January 13, 2019, from http://www.lambano.org.za/

Leedy, P. D., & Ormrod, J. E. (2005). *Practical Research: Planning and Design*. Upper Saddler River, New York: Pearson Education.

Lewis, C. W., Carron, J. D., Perkins, J. O., Sie, K. C. Y., Feudtner, C. (2003). Tracheostomy in pediatric patients: a national perspective. *Archives of Otolaryngology Head Neck Surgery*, 129, 523-529.

Marshall, C., & Rossman, G. B. (1995). Designing qualitative research (2nd ed.) California, USA: Sage Publications.

Mason, J., Murty, G., Foster, H., et al. (1992). Tracheostomy self-care: The Nottingham system. *Journal Laryngology Otology,* 106: 723–724.

Mastandrea, S. (2015). How emotions shape aesthetic experiences. *Motivation and Emotion,* 37(2), 245- 260.

Masuku, K. P., & Khoza-Shangase, K. (2018). Spirituality as a coping mechanism for family caregivers of persons with aphasia. *Journal of Psychology in Africa,* 28(3), 245-248.

Masuku, K. P., Mophosho, M., & Tshabalala, M. D. (2018). 'I felt pain. Deep pain…': Experiences of primary caregivers of stroke survivors with aphasia in a South African township. *African Journal of Disability (Online*), 7, 1-7.

McNally, A., & Mannan, H. (2013). Perceptions of caring for children with disabilities: Experiences from Moshi Tanzania. *African Journal of Disability*, *2*(1), 12–22. https://doi.org/10.4102/ajod.v2i1.21

McWhorter, A. J. (2003). Tracheotomy timing and techniques. *Current Opinion in Otolaryngology & Head and Neck*, *11*(6), 473-479.

Merriam-Webster (2018). Definition of faith. Retrieved December 4, 2018, from https://www.merriam-webster.com/dictionary/faith

Messineo, A., Giusti, F., Narne, S., Mognato, G., Antoniello, L., Guglielmi, M. (1995). The Safety of Home Tracheostomy Care for Children. *Journal of Pediatric Surgery, 30,* 1246- 1248.

Michael Davis, G. (2006). Tracheostomy in children. *Paediatric Respiratory Reviews, 7,* 206-209.

Miller, Y. S., & Kirk, E. A. (1986). *Naturalistic Enquiry*. Beverly Hills, California: Sage.

Montagnino, B. A., & Maurico, R. V. (2004). The child with a tracheostomy and gastrostomy: Parental stress and coping in the home. *Pediatric Nursing*, 30, 373–401.

Mrazek, D. A. (1984). Effects of Hospitalization on Early Child Development. In: Emde: R. N., Harmon, R. J. (eds) Continuities and Discontinuities in Development. Topics in Developmental Psychobiology. Springer: Boston, MA.

Nassif, C., Zielinski, M., Francois, M., & van den Abbeele, T. (2015). Tracheotomy in Children: A series of 57 consecutive cases. *European Annals of Otorhinolaryngology, Head and Neck diseases*, 132, 321–325.

Naughton, G. M., & Hughes, P. (2008). *Doing action research in early childhood studies: A step-by-step guide.* England: McGraw-Hill International.

O'Connor, D. M. (1995) Physiology of the airway. In: Myer, C. M., Cotton, R. T., & Shott, S. R., (Eds), *The pediatric airway: an interdisciplinary approach (*pp 15-23). Philadelphia: JB Lippincott.

Orman, J. (2008). *Language Policy and Nation-Building in Post-Apartheid South Africa.* New York: Springer Publishing.

Patton, M. Q. (1990). *Qualitative Evaluation & Research Methods* (2nd ed.). Newbury Park, CA: Sage.

Patton, M. Q. (2002). *Qualitative research and evaluative methods.* (3rd Ed.). California: Sage.

Pierce, J. L., & Gardner, D. G. (2004). Self-esteem within the work and organizational context: A review of the organization based self-esteem literature. *Journal of management*, 30(5), 591-622.

Pierce, L., & Steiner, V. (2013). Usage and design evaluation by family caregivers of a stroke intervention website. *The Journal of Neuroscience Nursing, 45*(5), 254–261. https://doi.org/10.1097/JNN.0b013e31829dba61

Post, S. G., Puchalski, C.M., Larson, D.B. (2000). Physicians and patient spirituality: professional boundaries, competency, and ethics. *Annals of Internal Medicine*, 132, 578-583.

Pretorius, L. (2017, August 8). Does SA's private healthcare sector only serve 16% of the population? Retrieved from: https://africacheck.org/reports/does-sas-private-healthcare-sector-only-provide-care-for-16-of-the-population/

Price B. (1992). Living with altered body image. *British Journal of Nursing*, 1(3): 641–645.

Rane, S., Shankaran, S., & Natarajan, G. (2013). Parental Perception of Functional Status Following Tracheostomy in Infancy: A single Center Study. The Journal of Pediatrics, 163, 3.

Reeves, E., Timmons, S., & Dampier, S. (2006). Parents' experience of negotiating care for their technology-dependent child. *Journal of Child Health Care*, 10, 228–239.

Reilly, D. E., Huws, J. C., Hastings, R. P., & Vaughan, F. L. (2008). 'When your child dies you don't belong in that world any more'–Experiences of mothers whose child with an intellectual disability has died. *Journal of Applied Research in Intellectual Disabilities*, *21*(6), 546-560.

Resch, J. A., Mireles, G., Benz, M. R., Grenwelge, C., Peterson, R., & Zhang, D. (2010). Giving parents a voice: A qualitative study of the challenges experienced by parents of children with disabilities. *Rehabilitation psychology*, *55*(2), 139.

Ritchie, J., & Lewis, J. (Eds.), *Qualitative research practice: A guide for social science students and researchers.* Great Britain: SAGE.

Robins, C. J., Keng, S. L., Ekblad, A. G., & Brantley, J. G. (2012). Effects of mindfulness-based stress reduction on emotional experience and expression: A randomized controlled trial. *Journal of clinical psychology*, *68*(1), 117-131.

Sarantakos, S. (2013). *Social research.* (4th Ed.). Basingstoke: Palgrave Macmillan.

Scase, C. (2004). Long-Term Tracheostomy and Continuing Care. In T. Johnson & L. Andrews (Eds.), Nursing Care of the Child with a Tracheostomy. *A Multiprofessional Handbook*, 288-302. New York: Cambridge University Press.

Scarinci, N., Worrall, L., & Hickson, L. (2012). Factors associated with third-party disability in spouses of older people with hearing impairment. *Ear & Hearing, 33*, 698-708.

Schensul, S. L., Schensul, J. J., & LeCompte, M. D. (1999). *Essential Ethnographic Methods: Observations, Views, and Questionnaires.* USA: AltaMira Press.

Scheurich, N. (2003). Reconsidering spirituality and medicine. *Academic Medicine*, 78, 356-360.

Schweiger, C., Manica, D., Becker, C. F., Abreu, L. S., Manzini, M., & Sekine, L. (2017). Tracheostomy in children: a ten-year experience from a tertiary center in southern Brazil. *Brazilian Journal of Otorhinolaryngology*, 83, 627-632.

Seddon, P. C. & Khan, Y. (2003). Respiratory Problems in Children with Neurological Impairment. *Archives of Disease in Childhood, 88,* 75-78.

Shields, L., Zhou, H., Pratt, J., Taylor, M., Hunter, J., & Pascoe, E. (2012). Family-centered care for hospitalised children aged 0–12 years. *Cochrane Database Systematic Reviews.*

Silka, L. (2009). Partnership ethics. In D. M. Mertens & P. E. Ginsberg (Eds.), *The handbook of social research ethics* (pp. 337-352). Thousand Oaks, CA: Sage.

Simon, B. M., Fowler, S. M., & Handler, S. D. (1984). Communication development in young children with long-term tracheostomies: preliminary report. *International Journal of Pediatric Otorhinolaryngology*, *6*, 37-50.

Singer, L., & Farkas, K. J. (1989). The impact of infant disability on maternal perception of stress. *Family Relations*, 444-449.

Smith, J. A., & Osborn, M. (2004). Interpretative phenomenological analysis. *Doing Social Psychology Research*, 229-254.

Smith, J., Swallow, V., & Coyne, I. (2015). Involving Parents in Managing Child's Long-Term Condition- A Concept Synthesis of Family-Centered Care and Partnership-in-Care. *Journal of Pediatric Nursing*, 30, 143-159.

Soanes, C. (Ed.). (2002). *South African Pocket Oxford Dictionary* (3rd ed.). South Africa: Oxford University Press.

Tetnowski, J., & Damico, J. (2001). A demonstration of the advantages of qualitative methodologies in stuttering research. *Journal of Fluency Disorders*, 26, 17–42.

The Karg Academy (2019). *What you need to know to fight for what your child needs.* Retrieved from: www.kargacademy.com

Tsai, P. A. (2003). Middle-Range Theory of Caregiver Stress. *Nursing Science Quarterly*, 16, 137.

UNICEF (2001). *Early Childhood Development: The key to a full and productive life*. Accessed from: https://www.unicef.org/dprk/ecd.pdf

Vanker, A., Kling, S., Booysen, J.R., Rhode, D., Goussard, P., Heyna, L., & Gie, R. P. (2010). Tracheostomy home care: in a resource-limited setting. *Archives of Disease in Childhood.* Available: http://adc.bmj.com/content/early/2010/09/23/adc.2010.187153.full.html [Accessed 22.01.2018].

Tsai, P. A. (2003). Middle-Range Theory of Caregiver Stress. *Nursing Science Quarterly*, 16, 137.

Ward, R. F. (1997). Current trends in paediatric tracheotomy. *Paediatric Pulmonology Supplements, 16,* 290-310.

Watkins, M., & Schulman, H. (2008). *Toward psychologies of liberation*. New York: Palgrave Macmillan.

Wertz, F. J., Charmaz, K., McMullen, L. M., Josselsohn, R., Anderson, R. & McSpadden,E. (2011). *Five Ways of Doing Qualitative Analysis: Phenomenological Psychology, Grounded Theory, Discourse Analysis, Narrative Research, and Intuitive Inquiry.* New York: The Guilford Press.

White, A. C., Kher, S., & O'Connor, H. H. (2010). When to change a tracheostomy tube. *Respiratory Care*, 55(8), 1069-1075

WHO. (2002a). Towards a common language for functioning, disability and health: ICF - the international classification of functioning, disability and health Geneva: World Health Organisation.

WHO. (2007). International classification of functioning, disability and health: children & youth version: ICF-CY. Geneva, Switzerland: World Health Organization.

Williams, C. (2014). The Importance of Developing a Support System. Retrieved December 5, 2018, from https://www.bjceap.com/Blog/ArtMID/448/ArticleID/139/The-Importance-of-Developing-a-Support-System

World Health Organization (2007). *International Classification of Functioning, Disability and Health: Children & Youth Version.* WHO Press: Switzerland.

World Health Organization & World Bank (2011). *World report on disability*. Geneva: World Health Organization.

World Health Organisation (2018). Community Home-Based Care Training. Retrieved from http://www.searo.who.int/myanmar/areas/hivaidschbctraining/en/

Woodgate, R. L., Edwards, M., & Ripat, J. (2012). How families of children with complex care needs participate in everyday life. *Social Science Medicine*, 75, 1912-1920.

Zia, S., Arshad, M., Nazir, Z., Awan, S. (2010). Pediatric tracheostomy: complications and role of home care in a developing country. *Paediatric Surgery International*, 26, 269-273.

APPENDICES

Appendix A: Biographical Information

Please provide the following information:

Child Information	**Caregiver Information**
Age of Child/ DOB:	Age of Caregiver/ DOB:
Gender:	Gender:
Address:	Occupation:
Home & additional languages:	Home & additional languages:
Ethnic Group: Asian / African / Coloured / White	Ethnic Group: Asian / African / Coloured / White
Medical Diagnosis:	Number of Children at Home:
Date & Age of child at time of tracheostomy insertion:	Do you have running water and electricity?
Indication for tracheostomy:	
In-patient hospital complications:	
Decannulation date (if applicable):	
Duration of hospital admission	

Participant number (to be given by researcher): __

Appendix B: Semi-Structured Interview Open-Ended Questions

Caregiver Questions

- Feelings and Experiences
    1. What have been your experiences of caring for your child?
    2. What was it like to arrive home with your son/daughter?
    3. What has changed since your child came back home from the hospital?
    4. What are your thoughts towards the tracheostomy?
    5. Who has been your support during this time?
- Social Perceptions
    1. Do you think your neighbors and friends know about a tracheostomy?
    2. What were their reactions when they encountered the tracheostomy, if any?
- Caregiver Roles
    1. What are your roles at home?
    2. How has your role changed as a caregiver of a child with a tracheostomy?
- General
    1. Please tell me about some of the ways your family likes to spend time together?
    2. Has any of this changed since your child got his/her tracheostomy?
    3. Is there anything the Doctors and/or Speech Therapists could have done to make your and your child's experience easier
        - When in hospital? And when you were discharged to home?

Appendix C- Participant Information Sheet

SPEECH PATHOLOGY & AUDIOLOGY
THE SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT (SHCD)

Private Bag 3, Wits, 2050 • Tel: 011 717 4577 • Fax: 011 717 4572 • E-mail: sppa.SHCD@wits.ac.za

Dear Potential Participant,

RE: Information on Proposed Study

Hello. My name is Aderet Segev. I am a Master's student in Speech Pathology at the University of the Witwatersrand. As part of the requirement for my master's degree, I am required to conduct a research study. I want to know more about the experiences of caregivers in caring for their child with a tracheostomy, in South Africa. I am interested in what you have to say and would like to know more about your experiences being a caregiver to a child with a tracheostomy. Please consider participating in my research study.

I will give you time to think about it. If you are interested and would like to take part, you will need to sign a consent form, to show that you agree to participate in the study. You do not have to decide immediately regarding whether or not you would like to participate in this research. If there is anything which you do not understand, please feel free to contact me or anyone you feel comfortable to discuss you concerns with. You may also ask questions during the research process. If you agree to participate in this study, I will give you a form to sign which shows your consent to participate. You will be given a copy of this form to keep.

Why is this study being done?

This research study is being done as I would like to understand the experiences of taking care of a child with a tracheostomy, and to hear about things that went well and things that did not go so well. I would like to know more about how you feel about the tracheostomy and if it has affected your role as a caregiver.

This study can provide speech therapists with an understanding of your experiences, which can help us in caring for you and your child.

Why am I asking you to participate?

You were asked to participate in this study as you are a caregiver of a child with a tracheostomy or has had a tracheostomy.

What am I asking you to do?

If you agree to take part, I will sit with you for about 45 minutes and I will ask you some questions. You can give me as much information as you'd like, and if you don't want to answer a question, that is also okay. If you want me to stop at any time, that is also okay. I will record our conversation on a recorder. If you are happy for me to record the information, I will ask you to sign a piece of paper to show that you allow me to record.

What happens to the information being gathered?

At the end of the study, I will write up the results in a research report. You will be given the results of the study if you would like to know them. The data gathered will be kept in a locked cupboard at the University of the Witwatersrand and it will be destroyed 4 years after the study.

What are the benefits of participating in this study?

There are no direct benefits in participating in the study. Your involvement within the study may provide me with more information of the experiences of caregiving of paediatric patients with a tracheostomy, as well as provide you with an opportunity to share your experiences. This can further add to the knowledge of our profession and it can benefit other parents that are going through a similar journey as you.

What are the risks of participating in this study?

There are no direct risks involved in the participation of my study. However, the researcher is aware of her ethical responsibilities towards you, the caregiver, who may be participating in this study. During the interview, you may feel emotional or distressed. Should you experience any discomfort or distress during the interview, you will not have to continue answering questions, and the interview will be discontinued. The researcher will inform you of available services such as the social worker and/or psychologist at the hospital. Referrals will be made for psychological services should you show any signs of distress, or request psychological help.

What will the study cost you?

The study will not cost you anything. You will not be paid for participating in this study.

In the case that you will have to make extra arrangements to get to the hospital for the interview (ie. If you can't attend the interview on the same day as your tracheostomy clinic appointment), arrangements will be made to cover the costs of your transport.

What are your rights as a participant?

Your participation in this study is completely voluntary, therefore

1. You have the right to remove yourself from the study at any time, without penalty/consequences

2. You have the right to contact me at any time during the study with any questions.

3. You have a right to be informed of the results of the study.

4. If you are unhappy with anything that I am doing, you have the right to contact the chairperson and/or secretariat of the Wits Medical Ethics Committee:

- Prof C Penny: Tel 011 717 2301, email: Clement.Penny@wits.ac.za
- Ms Z Ndlovu, Ms Mapula Maila and Mr Rhulani Mkhansi Administrative Officers: Tel 011 717 1234/1252/2656/2700, emails: Zanele.ndlovu@wits.ac.za; Rhulani.mkansi@wits.ac.za; mapula.ramaila@wits.ac.za

Confidentiality

Your identity throughout the study and within the written-up report will be kept confidential. Your name will not appear on any documentation and will be replaced with a code. Only I, Aderet Segev and my research supervisor, will be able to access the information.

If you have any questions please contact myself or my supervisor, our contact details are below.

Aderet Segev

Speech Pathology Masters Student

aderetsegev@gmail.com

Dr. Jaishika Seedat

Head of Department: Speech Pathology & Audiology

Jaishika.Seedat@wits.ac.z

Appendix D- Participant Consent Form

I,_____ have read and understood this document and information sheet and agree to participate in Aderet Segev's research study. In giving consent, I understand the following:

- This research is for a Master's degree requirement at the University of the Witwatersrand.
- I will need to give up approximately 45 minutes of my day in order to answer interview questions.
- I voluntarily agree to participate in the study by taking part in an interview and am aware of my right to withdraw from the study at any time without any risk to myself.
- My identity will be kept confidential and will be replaced by a code on all documentation.
- The information gathered from this research will be used to document the caregiver and/or patient experiences of tracheostomies
- I can contact Aderet (the researcher) if I have any questions regarding the study.
- I recognize that Aderet is the researcher of this project and I agree to participate in her study.

Participant Name (Print): _____Participant Signature:_____

Date and Place: _____

Witness Name (Print): _____Witness Signature:_____

Date and Place: _____

Appendix E- Audio-Recording Consent Form

I, _____ hereby consent to audio-recording of the interview. I understand that my confidentiality will be maintained at all times and that audio-recordings will be kept in a locked cupboard at the University of the Witwatersrand.

Please sign on this form if you are willing to participate and you agree with what is included above.

Participant Name (Print): _____Participant Signature:_____

Date and Place:

_____

Witness Name (Print): _____Witness Signature:_____

Date and Place:

_____

Appendix F- Research Site HOD Request for Permission

SPEECH PATHOLOGY & AUDIOLOGY
THE SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT (SHCD)

Private Bag 3, Wits, 2050 • Tel: 011 717 4577 • Fax: 011 717 4572 • E-mail: sppa.SHCD@wits.ac.za

Dear Head of Department,

RE: Permission to conduct research on caregiver experiences of caregiving for a child with a tracheostomy, ages 0-5-years-old, post hospital discharge, at Chris Hani Baragwanath Academic Hospital/ Red Cross War Memorial Children's Hospital

I am a qualified speech-language therapist and audiologist, currently registered for a Master's degree (Speech) at the University of the Witwatersrand. I am conducting a research study as part of completing the degree requirements. I am interested in researching the lived experiences of caregivers of the 0-3-year-old paediatric population with a tracheostomy, post hospital discharge. My objectives are 1) to describe the experiences of caregivers of children with tracheostomies between the age of 0-3-years during their transition back into family, home and society, post hospital discharge 2) to explore the emotional support systems available to the caregiver of children between the age of 0-3-years, during their transition from the hospital to home and 3) to gain insight into the role of caregivers in caring for their child post-tracheostomy insertion.

I therefore request your permission to conduct my research at *Chris Hani Baragwanath Academic Hospital* (pending ethical clearance). A minimum of 8 caregivers will be interviewed face-to-face, for approximately 45 minutes. During the semi-structured interview, they will be asked 12 open-ended questions relating to feelings and experiences, social perceptions, and roles related to caregiving for a child with a tracheostomy. The study will include caregivers for children of any gender, between the ages of 0-3 years, who have had a tracheostomy for at least one month, and who have been discharged from the hospital for at least one month. The

caregiver being interviewed for the study must currently be living with the child, as well as have a conversational language ability in English.

The researcher is aware of her ethical responsibilities towards the caregivers who will be participating in the study. Prior to the interviews, informed consent will be obtained from the participants, ensuring that the aims are clearly explained to the caregiver participants, no false promises are being made and any questions to be answered. A distress protocol will be followed should any participants experience any discomfort or distress during or after the interviews. In the case of distress signs during the interview, the interview will be discontinued. All participants will be informed of available services such as the social worker and/or psychologist. Referrals will made for psychological services if indicated.

Results from this study will provide detailed descriptions of caregiver experiences of home-based care, reintegration back into home, family and society, as well as the role of the caregiver in caregiving for a child with a tracheostomy. Such in-depth data may increase awareness of caregiver experiences among caregivers themselves, speech therapists, medical staff, and university staff. Such data could also guide the creation of resources specific to this population.

If permission is granted, the researcher will obtain caregiver contact details from the speech therapist in the speech department (following caregiver permission). The caregivers will be invited to participate in the study and be informed about the study and the process thereof. Their participation in this study is voluntary, and they are free to withdraw at any point, with no negative consequences. Caregivers who agree to participate will be required to complete a consent form as well as an audio-recording consent form. Confidentiality and anonymity will be maintained, and details of the participants will only be known to the researcher and supervisor.

For further clarification please do not hesitate to contact me via email, aderetsegev@gmail.com or my supervisor Dr. Jaishika Seedat via email, Jaishika.Seedat@wits.ac.za

Sincerely,

Aderet Segev
(Speech-Language Therapist & Audiologist)

Appendix G- Research Site CEO Request for Permission

SPEECH PATHOLOGY & AUDIOLOGY
THE SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT (SHCD)

Private Bag 3, Wits, 2050 • Tel: 011 717 4577 • Fax: 011 717 4572 • E-mail: sppa.SHCD@wits.ac.za

Dear Chief Executive Officer,

RE: Permission to conduct research on caregiver experiences of caregiving for a child with a tracheostomy, ages 0-5-years-old, post hospital discharge, at Chris Hani Baragwanath Academic Hospital/ Red Cross War Memorial Children's Hospital

I am a qualified speech-language therapist and audiologist, currently registered for a Master's degree (Speech) at the University of the Witwatersrand. I am conducting a research study as part of completing the degree requirements. I am interested in researching the lived experiences of caregivers of the 0-3-year-old paediatric population with a tracheostomy, post hospital discharge. My objectives are 1) to describe the experiences of caregivers of children with tracheostomies between the age of 0-3-years during their transition back into family, home and society, post hospital discharge 2) to explore the emotional support systems available to the caregiver of children between the age of 0-3-years, during their transition from the hospital to home and 3) to gain insight into the role of caregivers in caring for their child post-tracheostomy insertion. I therefore request your permission to conduct my research at *Chris Hani Baragwanath Academic Hospital* (pending ethical clearance). A minimum of 8 caregivers will be interviewed face-to-face, for approximately 45 minutes. During the semi-structured interview, they will be asked 12 open-ended questions relating to feelings and experiences, social perceptions, and roles related to caregiving for a child with a tracheostomy. The study will include caregivers for children of any gender, between the ages of 0-3 years, who have had a tracheostomy for at least one month, and who have been discharged from the hospital for at least one month. The caregiver being interviewed for the study must currently be living with the child, as well as have a conversational language ability in English.

The researcher is aware of her ethical responsibilities towards the caregivers who will be participating in the study. Prior to the interviews, informed consent will be obtained from the participants, ensuring that the aims are clearly explained to the caregiver participants, no false promises are being made and any questions to be answered. A distress protocol will be followed should any participants experience any discomfort or distress during or after the interviews. In the case of distress signs during the interview, the interview will be discontinued. All participants will be informed of available services such as the social worker and/or psychologist. Referrals will made for psychological services if indicated.

Results from this study will provide detailed descriptions of caregiver experiences of home-based care, reintegration back into home, family and society, as well as the role of the caregiver in caregiving for a child with a tracheostomy. Such in-depth data may increase awareness of caregiver experiences among caregivers themselves, speech therapists, medical staff, and university staff. Such data could also guide the creation of resources specific to this population.

If permission is granted, the caregivers will be invited to participate in the study and be informed about the study and the process thereof. Their participation in this study is voluntary, and they are free to withdraw at any point, with no negative consequences. Caregivers who agree to participate will be required to complete a consent form as well as an audio-recording consent form. Confidentiality and anonymity will be maintained, and details of the participants will only be known to the researcher and supervisor.

For further clarification please do not hesitate to contact me via email, aderetsegev@gmail.com or my supervisor Dr. Jaishika Seedat via email, Jaishika.Seedat@wits.ac.za

Sincerely,

Aderet Segev
(Speech-Language Therapist & Audiologist)

Appendix H: Distress Protocol

- At the beginning of the interview the researcher verbally informed the caregiver that she is aware of the possibility of emotional distress and/or reactions. Should this occur the caregiver would encouraged to communicate this with the researcher, and the interview would be discontinued. There would be no consequences for the caregiver should this case arise.
- The researcher looked out for the following possible signs of emotional distress: being tearful, outburst of anger, experiencing high levels of anxiety, sustained low mood, withdrawing verbally and/or displaying agitation (Draucker, Martsolf, & Poole, 2009).
- Should the researcher see distress cues during the interview, she would discontinue the interview, followed by asking the caregiver if he/she feels that they need the interview to be discontinued.
- Researcher would then provide caregiver with contact details of psychological or social services.
- Referral would be made to psychological and social services by the speech therapist/HOD of the speech department at the given site.
- Researcher would follow-up on the referral

Appendix I: Participant Descriptions

Participant one was a 39 year old white female caregiver, working as a hairdresser, and living in the Southern suburb of Cape Town, Western Cape, with her husband and 11 month old daughter. This caregiver reported that she herself has a hearing loss, and therefore needed some repetition of questions during the interview. Her daughters' tracheostomy was inserted at the age of 2 months, due to subglottic stenosis and laryngomalacia. She described her experience of caregiving for her child, as stressful. Her challenges involved cleaning and changing the tracheostomy, as well as limitations to going out to spend time with family and friends.

Participant two was a 35 year old coloured female caregiver, living in the Southern suburb of Cape Town, Western Cape, with her husband and two young children. She reported that she was unemployed. Her daughter of 2.10 years was fitted with a tracheostomy at 3 months of age, due to upper airway obstruction. She expressed that in her eyes, her child is a "normal child". Her biggest challenge was related to the reactions of people when they see her daughters' tracheostomy.

Participant three was a 44 year old African female caregiver, living in the Southern suburb of Cape Town, Western Cape, caring for four young children at home. The interview was conducted in IsiXhosa, with the use of a translator. She reported that she was unemployed and was facing financial difficulties. This caregiver also reported that she had a hearing loss, and therefore needed some repetition of questions during the interview. Her 4.5 year old son was fitted with a tracheostomy at the age of 3 years, due to an acute flaccid paralysis of vocal cords post an infection. She expressed much heartache related to seeing her son being bullied by other children in the neighborhood. She also expressed much financial difficulties since the insertion of the tracheostomy, as she was consequently unemployed.

Participant four was a 39 year old coloured female caregiver, living in the Southern suburb of Cape Town, working full time as a chef, supporting her husband and 3 young children. She reported that they don't have running water and electricity at home. Her 5 year old son was fitted with a tracheostomy at 1.5 years, due to a lymphangioma of his head and neck. She emphasized that the quicker she could accept her son's medical diagnosis and the insertion of a tracheostomy, the easier the experience was for her. She also expressed that faith was what supported her through the journey of caring for her son.

Participant five was a 35 year old African male caregiver, a medical engineer currently unemployed, as he was caring for his 1.2 year old daughter on his own. They live in the Northern suburbs of Cape Town, Western Cape. His daughter was born with CHARGE syndrome. He expressed difficulty accepting that his daughter was fitted with a tracheostomy, as well as feelings of shame around people's reactions to the tracheostomy. However, he mostly felt that *"The tracheostomy is good. It's a good thing. It helps a lot."* (P5, 73).

Participant six was a 33 year old female caregiver, living with her husband and 1.2 year old son. She reported that she had always been a housewife. Her son was fitted with a tracheostomy as 3 months of age, due to a laryngomalacia. She expressed that initially she was very shocked as well as scared to change the tracheostomy, but with training from the nurses, she became confident in doing so. She also emphasized the benefits of home-based care.

Participant seven was a 38 year old African female caregiver, living in Soweto, Johannesburg. She was previously an assistant at a crèche, but had left her job to take care of her 1.9 year old son, who was fitted with a tracheostomy at 1.5 years. She expressed that she

felt very positive feelings towards the tracheostomy, as it had saved her child's life. Her dream was that her son will walk again.

Participant eight was a 35 year old African female caregiver, residing in Soweto, Johannesburg with her husband and 3 year old daughter. She reported that she was unemployed. Her daughter was fitted with a tracheostomy at 3 years of age, due to vocal cord palsy. She described her difficulties of having has to leave her job, so that she could take care of her daughter, as well as difficulty finding a crèche that would take care of her daughter. She also emphasized that "*When you at home you more relaxed. You know in the hospital, it's okay, I'm not saying it's bad, but it's not like home."* (P8, 41-42).

Participant nine was a 40 year old African female, living in Soweto, Johannesburg, with her 1.7 year old son. She reported that she was previously employed, but currently unemployed. Her sons' tracheostomy was fitted when he was 5 months old, due to subglottic stenosis. She described her experience as traumatic: "*It's traumatic hey. Because everybody, when he coughs, everybody they just turn around and look at you."* (P9, 41-42). She also emphasized the importance of acceptance, as well as the tracheostomy saved her son's life.

Participant ten was a 33 year old African female, living in Soweto, Johannesburg with her 1.7 year old son. She also reported that she was unemployed. Her son was fitted with a tracheostomy since 5 months old, due to a subglottic stenosis. She used to be a hairdresser, but had to leave her job to take care of her son. She described feelings of feeling alone, as well as inferior to the nurses and doctors, thus being left out of medical decision-making process. She also expressed that: *"If I have someone to talk to me like this, I feel much better."* (P10, 82).

Appendix J: Biographical Participant Data

Participant #	Age of Child with the Tracheostomy in years and months	Gender of Child with the Tracheostomy	Age of the Caregiver	Gender of the Caregiver	Languages Spoken	Occupation of the Caregiver	Ethnic Group of Caregiver	Medical Diagnosis of the Child with the Tracheostomy	Indication for the Tracheostomy	Age at Insertion of the Tracheostomy	Duration of Hospital Stay	Water and Electricity Availability at Home	No. of children at home	Decannulation
1	0.11	Female	39	Female	English and Afrikaans	Hairdresser	White	Subglottic Stenosis with laryngeal web, GORD, Laryngomalacia, FTT, SAM	Subglottic Stenosis with laryngeal web, Laryngomalacia	2 months	3 weeks	Yes	1	No
2	2.10	Female	35	Female	English and Afrikaans	Unemployed	Coloured	22q11 Deletion Syndrome	Upper airway obstruction with choanal stenosis	3 months	6 months	Yes	2	No
3	4.5	Male	44	Female	IsiXhosa	Unemployed	African	Acute flaccid paralysis post an infection Paralyzed diaphragm Failure to thrive	Acute flaccid paralysis	3 years	4 months	Yes	4	No
4	5.0	Male	39	Female	English and Afrikaans	Chef	Coloured	Lymphangioma of head and neck	Upper Airway Obstruction	1.5 years	3 months	No electricity or water in home	3	No
5	1.2	Female	35	Male	Shona and English	Unemployed (Mechanical Engineer)	African	CHARGE Syndrome	Upper airway obstruction Anterior glottis web Choanal Atresia	1 months	5 months	Yes	1	No
6	1.2	Male	33	Female	Somalian and English	Housewife	Indian	Laryngomalacia Microlarynx	Laryngomalacia	3 months	1 month	Yes	1	Yes
7	1.9	Male	38	Female	IsiZulu and English	Unemployed Previously creche	African	Epilepsy	Upper airway obstruction	1.5 months	2 months	Yes	3	No
8	3.1	Female	35	Female	English and IsiZulu	Unemployed	African	Birth Asphyxia and Vocal Cord Palsy	Vocal Cord Palsy	1 month	3 months	Yes	1	No
9	1.7	Male	40	Female	English and IsiZulu	Unemployed (marketing manager)	African	Epilepsy	Granuloma Tissue Subglottal Stenosis (post prolonged intubation)	5 months	2 months	Yes	3	No
10	3.2	Female	33	Female	IsiZulu	Unemployed	African	Epilepsy	Subglottal Stenosis	2.7 years	2 months	Yes	1	Yes
Summary	Average age= 2.4	5 female 5 male	37 years	9 female 1 male	Most common language: English	8 unemployed 2 employed	6 African 1 Indian 2 Coloured 1 white				Average Stay: 3 months	90% had 10% no water and electricity	Average children: 2	8 Yes 2 No

Appendix K: Themes of the Study

Aims of the Study	**Themes of the Study**
Sub-Aim One Caregiver experiences	Caregiver Feelings towards the Tracheostomy
	The Grief process
	Third-Party Disability
Sub-Aim Two Support Systems	Faith
	Family Support
	In-Hospital Tracheostomy Training
Sub-Aim Three Caregiver Roles	Tracheostomy Training and Care
	Providing Financial Stability
	Home-Based Care

Appendix L: Approval of Title Change

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

18 January 2019

Miss Aderet Segev
Speech Pathology and Audiology

Sent by email to: aderetsegev@gmail.com

Dear Miss Aderet Segev

Re: **Protocol Ref no: M180472**
Protocol Title: Caring for a Child with a Tracheostomy in South Africa: Caregiver Lived Experiences
Principal Investigator: Miss Aderet Segev
Request for title change: Change title to; Caring for a Child with a Tracheostomy in the Gauteng and the Western Cape Provinces of South Africa: Caregiver Lived Experiences

This letter serves to confirm that the Chairman of the Human Research Ethics Committee (Medical) has approved the request for a title change for the abovementioned protocol, as detailed in your letter, dated 03 December 2018.

The following documents were received:

- Summary Letter
- Clearance certificate

UNIVERSITY OF THE WITWATERSRAND OFFICE OF THE DEPUTY VICE CHANCELLOR RESEARCH 18 JAN 2019 RESEARCH OFFICE HREC (Medical) JOHANNESBURG

Thank you for keeping us informed and updated.

Yours Sincerely,

Miss Charmaine Khumalo
Administrative Officer
Human Research Ethics Committee (Medical)

Research Office Secretariat: Faculty of Health Sciences, Phillip Tobias Building, 3rd Floor, Office 304, Corner York Road and 29 Princess of Wales Terrace, Parktown, 2193 Private Bag 3, Wits 2050 | T +27 (0)11-717-1234/2656/2700/1252 E: Charmaine.Khumalo@wits.ac.za | Office E: HREC-Medical.ResearchOffice@wits.ac.za | Website: www.wits.ac.za/research/about-our-research/ethics-and-research-integrity/

Appendix M: University of the Witwatersrand HREC Medical Clearance Certificate

UNIVERSITY OF THE WITWATERSRAND JOHANNESBURG

R14/49 Miss Aderet Segev

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M180472

NAME: (Principal Investigator)	Miss Aderet Segev
DEPARTMENT:	Speech Pathology and Audiology Chris Hani Baragwanath Academic Hospital Red Cross War Memorial Children's Hospital, Cape Town
PROJECT TITLE:	Caring for a Child with a Tracheostomy in South Africa: Caregiver Lived Experiences
DATE CONSIDERED:	04/05/2018
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Dr Jaishika Seedat
APPROVED BY:	Professor CB Penny, Chairperson, HREC (Medical)
DATE OF APPROVAL:	30/07/2018

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office Secretary on the Third Floor, Faculty of Health Sciences, Phillip Tobias Building, 29 Princess of Wales Terrace, Parktown, 2193, University of the Witwatersrand. I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report**. The date for annual re-certification will be one year after the date of convened meeting where the study was initially reviewed. In this case, the study was initially reviewed in **April** and will therefore be due in the month of **April** each year. Unreported changes to the application may invalidate the clearance given by the HREC (Medical).

Appendix N: University of Cape Town HREC Medical Ethics Clearance

UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee

Room E53-46 Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone [021] 406 6626
Email: shuretta.thomas@uct.ac.za
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

01 August 2018

HREC REF: 445/2018

Dr J Seedat
Speech pathology & Audiology
University of Witwatersrand

Dear Dr Seedat

PROJECT TITLE: CARING FOR A CHILD WITH A TRACHEOSTOMY IN SOUTH AFRICA: CAREGIVER LIVED EXPERIENCES: (Master's candidate-Miss A Segev)

Thank you for submitting your response to the Faculty of Health Sciences Human Research Ethics Committee 26 July 2018.

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned.

Approval is granted for one year until the 30 August 2019.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.
(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

Please quote the HREC REF in all your correspondence.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please note that for all studies approved by the HREC, the principal investigator **must** obtain appropriate institutional approval, where necessary, before the research may occur.

The HREC acknowledge that the student, Aderet Segev will also be involved in this study.

Yours sincerely

PROFESSOR M BLOCKMAN
CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE
Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938
This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical

Appendix O: Red Cross War Memorial Children's Hospital Clearance Letter



Western Cape Government
Health

DR AN PARBHOO
Manager: Medical Services
Red Cross War Memorial Children's Hospital
Email: Anita.Parbhoo@westerncape.gov.za
Tel: +27 21 658 5430 Fax: +27 21 658 5006/5166

13 September 2018

Ms A Segev
Speech Pathology and Audiology

Dear Ms Segev,

RESEARCH: RXH: RCC 125

PROJECT TITLE: Caring for a Child with a Tracheostomy in South Africa: Caregiver Lived Experiences

It is a pleasure to inform you that approval is hereby granted to conduct above-mentioned study at Red Cross War Memorial Children's Hospital.

Yours sincerely,

DR AN PARBHOO
MANAGER: MEDICAL SERVICES

Appendix P: Chris Hani Baragwanath Academic Hospital Clearance Letter

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

MEDICAL ADVISORY COMMITTEE

CHRIS HANI BARAGWANATH ACADEMIC HOSPITAL

PERMISSION TO CONDUCT RESEARCH

Date: 18th April 2018

TITLE OF PROJECT:

Caring for a Child with a Tracheostomy in South Africa: Caregiver Lived Experiences

UNIVERSITY: Witwatersrand

Principal Investigator: Aderet Segev

Department: Speech Pathology and Audiology

Supervisor : J Seedat

Permission Head Department (where research conducted): Yes

The Medical Advisory Committee recommends that the said research be conducted at Chris Hani Baragwanath Academic Hospital. The CEO / management of Chris Hani Baragwanath Academic Hospital is accordingly informed and the study is subject to:-

- Permission having been granted by the Committee for Research on Human Subjects of the University of the Witwatersrand.
- The Hospital will not incur extra costs as a result of the research being conducted on its patients within the hospital
- The MAC will be informed of any serious adverse events as soon as they occur
- Permission is granted for the duration of the Ethics Committee Approval.

Recommended
(On behalf of the MAC)
Date: 18/4/2018

Approved/Not Approved
Hospital Management
Date: 23/04/18

Appendix Q: Chris Hani Baragwanath Academic Hospital Speech Department HOD Clearance Letter

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

Chris Hani Baragwanath Academic Hospital

Department of Speech Therapy/Audiology

PO Bertsham

2013

6/04/2018

To whom it may concern

Re: Research application

Permission is granted for Miss A. Segev to conduct her research titled **Caregiver experiences of caregiving for a child with a tracheostomy, ages 0-3-years-old, post hospital discharge, at Chris Hani Baragwanath Academic Hospital.** The permission entails providing the researcher with contact details of patients (with the patient's permission). The researcher will not have any access to patient records. The researcher will make logistical arrangements with patients and cover any costs incurred for them to attend the interview. I am unable to commit to providing space in the department for the interviews as we have a shortage of available rooms. The researcher is welcome to contact Ms Annika Vallabhjee to request a room when her dates are confirmed. This permission is subject to permission from the hospital's research committee.

It is the expectation that results of this study is shared with the department on completion.

Yours Sincerely

Dr Sadna Balton(Head of Department)

Appendix R: Turnitin Report



turnitin

Digital Receipt

This receipt acknowledges that Turnitin received your paper. Below you will find the receipt information regarding your submission.

The first page of your submissions is displayed below.

Submission author:	Aderet Segev
Assignment title:	Dissertations
Submission title:	aderetsegev@gmail.com:Aderet_Se..
File name:	c-9501-65961f3932ef_Aderet_Seg...
File size:	328.35K
Page count:	96
Word count:	27,449
Character count:	148,420
Submission date:	13-Mar-2019 08:20AM (UTC+0200)
Submission ID:	1092513849

