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Lived Experiences of Individuals Quality of Life on Prolonged Home Mechanical Ventilation

Munyaradzi Ephie Rwakonda
Walden University

Walden University

College of Health Sciences

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Munyaradzi Rwakonda

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Review Committee
Dr. Leslie Hussey, Committee Chairperson, Nursing Faculty
Dr. Janice Long, Committee Member, Nursing Faculty
Dr. Edna Hull, University Reviewer, Nursing Faculty

Chief Academic Officer
Eric Riedel, Ph.D.

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Abstract

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MA, College of St Elizabeth, 2014

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Dissertation Submitted in Partial Fulfillment
of the Requirements for the Degree of
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Abstract

Improvements in technology have allowed people with tracheostomies to live at home on mechanical ventilation (HMV). Quality of life (QOL) for HMV users has been studied quantitatively; but few qualitative studies have been published. The purpose of this phenomenological study was to explore QOL for individuals with tracheostomies on prolonged HMV focusing on activities of daily living (ADLs) and the role of decision-making. The Roper, Logan, and Tierney activities of living theory were used to categorize activities. Ten participants, 18 years and older, with a tracheostomy and on HMV for at least 6 months were enrolled using purposive sampling. Data were collected through structured, in depth, face-to-face interviews. Themes that emerged were (a) autonomy, (b) significance of ventilator for well-being, (c) feeling tied up, (d) creating meaning, (e) tipping point, (f) reminiscence, (g) building trust and confidence, (h) adjusting to technology, (i) family support and relationships, and (g) meaning of life. The participants were relatively healthy and their QOL was improved when they were on HMV compared to the hospital. The participants felt empowered that they had control in their daily lives at home when they had competent caregivers and family members for continuity of care. Recommendations for future research would include exploring improved methods of collaboration among health care workers and families in providing holistic care and reducing role strain and isolation in young HMV users. The study may promote positive social change through education for family, health care workers, and the public about strategies to promote independence and subsequent improvement in QOL for individuals on HMV.

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Dedication

I dedicate this work to my husband and kids. I truly thank you for your support and holding things together as I pursued my PhD. In addition, I dedicate this dissertation to the men and woman who participated in my study.

Acknowledgments

I want to acknowledge God for his past, present, and future blessings. Moreover, I thank God for allowing me to complete this dissertation. I thank my husband, children, mom, dad, and entire family for their contributions in my life. I want to thank and acknowledge my chair, Dr. Hussey, my committee member Dr. Long, and the University Research Reviewer Dr. Hull. I thank you for agreeing to serve on my committee and giving the best advice for my dissertation. More especially, I want to thank all my participants. I want to thank the representatives of homecare agencies, families and health-care providers for all of your assistance.

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Chapter 1: Introduction to the Study

Improvements in technology have resulted in extended lives for people with chronic diseases (King, 2012). The goal of health care workers is not only to delay death, but also to improve the quality of life (QOL) for individuals, which has become an outcome for this population (King, 2012). Chronic diseases have negative effects on QOL because they influence the individuals' ability to perform activities of daily living (ADL; Barile et al., 2012). Advances in technology have provided those with chronic conditions the ability to live longer. One example of new technology is home mechanical ventilation (HMV) for those with different underlying conditions (Dyrstad, Hansen, & Gundersen, 2013). Mechanical ventilation became popular in the 1950s for patients with poliomyelitis (King, 2012). Improvements in technology in the home have allowed the home setting to become a viable option for individuals on long-term or prolonged mechanical ventilation beyond the intensive care unit (ICU; King, 2012). Although HMV is expensive and is only being used by a limited number of people, it has allowed some individuals with chronic conditions to live at home as opposed to living in an institution.

Improved tracheostomy placement techniques, improved ICU care, decreased mortality, and increased reimbursement for physicians have led to an increase in the number individuals on ventilators (Cheung & Napolitano 2014; King, 2012). Home care is preferred because costs and exposure to hospital infections are reduced, hospital beds are freed for other patients, and integration into the community is facilitated (King, 2012). According to Ballangrud, Bogsti, and Johanasson (2008), having a home ventilator improves QOL as the ventilator builds up strength and helps improve wellbeing. Additionally, HMV users want to be active partners in their care and be involved in activities of their daily life so they can live a normal active life. Most individuals on HMV have tracheostomies. A tracheostomy is a surgical procedure where a stoma or hole is made on the anterior portion of the neck into the trachea to allow air passage for people unable to take spontaneous breaths (Cheung & Napolitano, 2014). A tracheostomy is used for several reasons, such as upper airway obstruction, acute respiratory failure, difficulty weaning off MV, neuromuscular disorders, and trauma (Cheung & Napolitano, 2014).

Tracheostomies can be temporary, but if permanent, the individual may be placed on a ventilator to aid in breathing. Advantages of using tracheostomies include reduced airway resistance, reduced work of breathing, clearance of secretions, reduced sedation, decreased aspiration risk, and increased comfort (Durbin, 2010). Complications include pneumothorax, bleeding, stoma erosion, development of scars, vocal cord damage, development of fistulas, and subglottic stenosis (Durbin, 2010).

According to Mehta et al. (2015), 1,352,432 adults received a tracheostomy between1993 to 2012; tracheostomy use rose from 6.9% in 1993 to 9.8% in 2008. Hospital deaths for patients receiving tracheostomies decreased from 38.1% in 1993 to 17.7% in 2012 (Mehta et al., 2015). As reported by Mehta et al., over time, tracheostomies were performed earlier (median, 11 days in 1998; 10 days in 2012; *P* = 0.0001), hospital length of stay decreased (median, 39 days in 1993; 26 days in 2012*;* *p* = 0.0001), discharges to long-term facilities increased (40.1% vs. 71.9%; *P* = 0.0001). More than 30% of patients who require MV for at least 2 days require prolonged MV, often defined as MV for at least 21 days or continued MV following hospital discharge (Mehta et al., 2015). Therefore, tracheostomy use allows individuals on ventilators to be discharged home. The implication of this study to social change is to bring awareness to the daily challenges of ADL faced by individuals on HMV. It is imperative for clinicians to provide care based on the individual's ability to participate in AL to promote functioning and allow users of HMV to live an active life improving QOL.

Background of the Study

The number of individuals with tracheostomies on HMV following unsuccessful weaning is steadily rising; however, little is known about living conditions and QOL in this population (Huttman, Windisch, & Storre, 2015). QOL is a factor for individuals with chronic, noncurable diseases (Huttman et al., 2014). The home setting is preferable for people on mechanical ventilation because of reduced costs and better QOL, which includes improved social relationships and less risk of acquiring nosocomial infections (King, 2012). However, HMV is not a simple decision to make, because there are barriers and ethical issues that affect QOL (Garber & Guertin, 2010). The AOLs listed in the Roper-Logan-Tierney (1990) model of nursing are maintaining a safe environment, communication, breathing, eating and drinking, elimination, washing and dressing, controlling temperature, mobilization, working, playing, and sleeping. Aspects that are considered key to home discharge include patient stability, a supportive home environment, family preparation, and open communication (Garber & Guertin, 2010*)*.

Quantitative studies have been conducted to evaluate QOL for individuals on HMV, but few qualitative studies have been done to explore the lived experiences of the

HMV users on how they participate in activities of daily living. Huttman et al. (2015) used the Severe Respiratory Insufficiency Scale (SRIC) to measure health-related quality of life (HRQOL) in 32 participants with different underlying conditions and found that HRQOL was different for each person and ranged from good to bad. Neuromuscular patients were younger and had less comorbidities; therefore, they scored high on the SRIS and had higher HRQOL (Huttman et al., 2015). On the other hand, individuals with chronic obstructive pulmonary disease (COPD), or other lung issues, tended to be older and have more comorbidities; therefore, they scored lower on the SRIC and had poor HRQOL (Huttman et al., 2015).

Dybwick, Nielsen, and Brichmann (2011) explored the challenges faced by health care providers when caring for individuals on HMV in the community and found that there are numerous challenges from a financial standpoint, coordination of activities, and ethical issues involving death and dying. Similarly, Dreyer, Steffensen, and Pedersen (2009) explored life experiences on living on HMV and effects on physical impairment for people with Duchene's muscular dystrophy and found that the HMV allowed the people to live an active life in the community.

Dyrstad et al. (2013) described self-care activities while on HMV and claimed that ADLs are effective in reducing dependency and costs in the homecare; therefore, the homecare is a viable option (Whitehead, Worthington, Parry, Walker, & Drummond, 2015). However, a gap in the literature is a lack of studies on the QOL of the HMV users' own experience of living on HMV and how they participate in ADLs. In this study, I addressed this gap by including different underlying conditions, different age groups, and a focus on the individuals' lived experience in their context of how they live on HMV every day, how individuals participate in ADLs, and how participating in ADLs affect QOL. I explored the lived experiences of HMV users as well as how they participate in activities of daily living in their own words. This will allow for the advocacy and provision of resources to enhance QOL for individuals on HMV and facilitate integration into the community.

Problem Statement

Acute respiratory failure requiring mechanical ventilation is common in critical illness (King, 2012). Progressive advancements in the understanding of and use of technologies have resulted in an increase in the number of people who remain dependent on mechanical ventilation for prolonged periods. (King, 2012). However, prolonged dependence on mechanical ventilation after critical illness has emerged as a public health challenge (King, 2012). Approximately 20,377 individuals were discharged to their homes on mechanical ventilation each year over the last 10 years (U.S. Census, 2010). HMV is an improved technology to provide support for patients whose condition would ordinarily require lifelong care in a hospital, skilled nursing facility, or other institution-based program (King, 2012). The home care setting is a viable option for those requiring HMV because costs are minimized and hospital-acquired infections are decreased (King, 2012).

QOL is a broad and multidimensional concept that is defined as an individual's perception of his or her position in life based on his or her culture, values, relationships, goals, expectations, standards, and concerns (Mouser, 2014). QOL is often interchanged with health-related quality of life (HRQOL). HRQOL is the effect of health interventions or the duration of life as modified by impairments, functional states, perceptions, and social opportunities that are influenced by disease, injury, treatment, or policy. Individuals on HMV face many challenges in the home and are dependent on family members and health care personnel (Dyrstad et al., 2013). Mouser (2014) established a relationship between physical functioning and QOL. Difficulty in participating in AOL due to prolonged MV and deconditioning status caused by respiratory insufficiency leads to decreased QOL. Individuals on HMV face physical limitations and decline in functional capacity (Mouser, 2014). Understanding the QOL and their ability to participate in ADLs is crucial to providing a voice to experiences that can be used as a guide by clinicians to provide care and allow users of HMV to live a full, active life, and a life that is meaningful to them.

Purpose of the Study

The purpose of this phenomenological study was to explore the HMV lived experiences and QOL of individuals who live at home on HMV. Care needs of individuals with tracheostomies on a ventilator in the home care setting are complex. There is a need to explore and gain greater understanding about the perception of QOL and participation in ADLs.

Research Questions

1. What is the perceived QOL for individuals with tracheostomies on prolonged mechanical ventilation in the home care setting?

2. To what extent are individuals on HMV involved in decision making and participation in activities of daily living?

Theoretical Foundation

Roper, Logan, and Tierney‘s (2001) theory (RLT) of activities of living (AL) was developed based on the Henderson needs theory that focused on patients interacting with the environment, family, and community after leaving the hospital. The RLT is used to define what living means by categorizing the activities of what people do during the day to maintain their life. Chronic health conditions affect a person’s ability to adapt and cope with daily challenges. Roper et al. stated that acute illness and chronic conditions directs people to adapt to changes necessary for functioning. The RLT is used to assess the patient’s independence and potential dependence based on the life continuum and effect of an illness. Factors that affect AL are biological, sociological, physiological, psychological, and politico economic. Participation in 12 activities of living will ensure that individuals with chronic illness remain functional. Individuals on HMV have chronic respiratory conditions and are limited in participating in ADLs.

The RLT has several assumptions. It is assumed that living or life consists of performing ADLs and how individuals carry them constitutes autonomy. Every person is important, regardless of stage in life (Roper et al., 2001). As individuals progress through the life cycle, they become dependent on ADLs. However, dependence should not erase the dignity of the individual. Factors such as biological, psychological, sociocultural, environment, and politico-economic affect attitude and behavior are associated with ADLs (Roper et al., 2001). ADL performance differs among individuals. ADL can fluctuate depending on the state of the individual (Roper et al., 2001). In a life span, individuals might experience trauma, catastrophic events, or disability that could lead to actual or potential problems with ADLs (Roper et al., 2001).

According to the RLT, the nurse is a teacher responsible for the promotion, maintenance, and prevention of disease (Roper et al., 2001). Whether within or outside of health care settings, nurses work in unison with the individual in decision making to restore health while remaining autonomous (Roper et al., 2001). Nurses and other health care workers work as a team to assist the individual delay, alleviate, manage, or develop alternative ways of dealing with problems associated with ADLs, whether actual or potential (Roper et al., 2001). The theory was aligned to the research questions, as the 12 ADLs were used to formulate open-ended questions. The theory was used because it covers all aspects of ADLs, such as biological, psychological, sociocultural, environment, and politico-economic factors that affect participation in ADLs (Roper et al., 2001).

Nature of the Study

The nature of this study was a qualitative phenomenological study. I explored the QOL of individuals on HMV to gain their perspectives, perceptions, and understanding on the context of their lives (King, 2012). Phenomenologists seek to understand people's experiences in everyday life by asking people about it in order to begin to understand. Karlsson, Bergborn, and Forsberg (2012) conducted interviews of 12 patients on mechanical ventilation 1 week after being discharged from the ICU using phenomenological hermeneutic method. Phenomenology is a philosophy on the lived experiences of human life. Scholars use phenomenology to explore a particular experience in the context of an individual's world (Connelly, 2015). In health care, QOL is used as a clinical outcome to assess the effectiveness of an intervention or study. The phenomenon of QOL has several meanings, such as happiness, well-being, and opportunity for growth and ability to perform activities to fulfill life's functions. Enhancement of QOL is important for people with chronic conditions or for people who use devices or technology for life support.

For purposes of the study, QOL was used to ascertain if placement of tracheostomy and use of mechanical ventilation enhanced or improved QOL. Clemens et al. (2011) noted that QOL is a combination of an individual's feelings towards emotional, social, spiritual, cognitive, physical, and ADL functioning. A tracheostomy is a stoma that is surgically placed in the anterior neck to aid in breathing. Tracheostomies can be temporary or can be used long term. If a tracheostomy is used for long term, it is identified as prolonged mechanical ventilation (PMV). PMV is having a tracheostomy for at least 6 months and use of a mechanical ventilator at least 6 hours or more. A tracheostomy is connected to mechanical ventilation via a trach collar. A mechanical ventilator is a machine that delivers high volume of oxygen and mimics spontaneous breathing (King, 2010). Other terms for tracheostomy are *trach, stoma,* and *tracheotomy.* A mechanical ventilator is a machine that can restrict functioning or impair participation in ADLs. The purpose of this study was to explore QOL for individuals with tracheostomies on prolonged HMV focusing on ADLs and the role of decision making. I also highlighted challenges faced in the home care setting (King 2012).

ADLs are activities that are carried out on a day-to-day basis; such activities include bathing, communication, mobility, sleeping, bowel and bladder elimination, maintaining a safe environment, and working and social roles in the society. ADLs are used interchangeably with activities of living (AL); these are used differently in different parts of the world. People with tracheostomies endure long periods of hospitalization, which result in muscle weakness and affects participation in ADLs. Activity participation varies between the dependence and independent states that are also affected by stage in life.

Data collection involved in-depth, face-to-face interviews, which were conducted in the participant’s home. The interview guide was developed based on the LRT model of AL. The format was made up of open-ended questions with detailed elaboration and clarification probes to dig deeper and clarify statements. Field notes were recorded in a notebook, and interview sessions were recorded on an audio recorder. Field notes and interview sessions were uploaded into NVivo software and transcribed.

Definition of Terms

Activities of living (ADL): Mosby (2009) defined ADLs as the activities normally performed by individuals on a daily basis, such as eating, toileting, dressing, bathing, or brushing the teeth. Activities of living are synonymous with ADL. ADLs are aligned with taking care of a person’s own body and are important to living in society; they facilitate existence and wellbeing (Lakhan, Jones, Wilson, & Gray, 2012). ADLs include bathing, showering, bowel and bladder management, dressing, eating, feeding, functional mobility, personal device care, personal hygiene and grooming, sexual activity, and toilet hygiene (Lakhan et al., 2012).

Health-Related Quality of Life (HRQoL): HRQoL is the impact of health status on the quality of life (Huttmann, Windisch, & Storre, 2015). It measures the physical, mental, emotional, and social well-being of an individual; it is used as an outcome for people with chronic or non-curable conditions.

Home care setting: A home is a place where a person lives permanently as a member of the family or household. A home is an area that provides facilities for sleeping, cooking food, eating, and for grooming.

Home mechanical ventilation (HMV): HMV is the presence of a mechanical ventilation in the home or private setting. HMV represents one of the most advanced and complicated types of medical treatment provided outside a hospital setting (Dybwik et al., 2011).

Mechanical ventilation: MV is a machine that mechanically replaces spontaneous breathing by transporting oxygen into the lungs, removing carbon dioxide from the body, and easing the work of breathing. King (2012) stated that a ventilator consists of positive pressure that simulate spontaneous breathing by supplying pressure/volume to an individual during an inspiratory phase and releasing this pressure/volume during an expiratory phase.

Prolonged mechanical ventilation (PMV): PMV is defined as continuous assistance from a MV for a period of 6h/day for a consecutive 21 days (Lai et al., 2016). Tracheostomies are placed in people who have failed weaning or those who are not able to sustain spontaneous breaths within 7 days after removal of endotracheal tube (Huang & Yu, 2013). For purposes of this study, participants have been on MV for a period of 6 months or greater and use the ventilator for more than 6 hours a day.

Quality of Life (QOL): The concept of QOL is complex and is defined in several ways (Whitford & Olver, 2012). According to the World Health Organization (WHO, 2010), QOL is an individual's view of their position in life in the context of their culture and value systems, where they live in relation to their goals, expectations, standards, and concerns.

Tracheostomy: Tracheostomy (trach) is a procedure performed in critically ill patients for airway support and placement on prolonged mechanical ventilation (Cools-Lartigue, Aboalsaud, Gill, & Ferri, 2013). A tracheostomy is any procedure that opens the trachea to the skin of the neck producing an opening that could be temporary or permanent (Cheung & Napolitano, 2014). Tracheostomies can be surgically inserted in the operating room or through percutaneous dilatation at the bedside (Sonnaike & Ward, 2017).

Virginia Henderson's needs theory: Virginia Henderson's needs theory identified 14 elements of AL of which an individual needs strength and knowledge to carry out to be satisfied with life. Participation in ADL is important to promote health and encourage patient independence so that the patient will continue to progress after being released from the hospital.

Assumptions

Assumptions can be explicit or implied. The following assumptions were implied for patients on HMV. One assumption of this study was that patients desired a certain level of QOL. Participating in care makes life meaningful and worth living, enhancing the QOL for individuals on HMV. Being in the home care setting empowers individuals to participate in activities of living with adequate family support. The ventilator treatment builds up strength overriding the wish to live an active normal life.

Scope and Delimitations

Participants were recruited from two homecare agencies and a pharmacist who managed individuals with tracheostomies on home mechanical ventilators in Northeast Pennsylvania**.** Purposive sampling was used due to the nature of the participants being limited in number. Individuals with different underlying conditions and ability to follow directions and discuss their QOL for an hour were recruited to participate in the interviews.

Inclusion Criteria

- Men or women from 18 years and above
- Tracheostomy for at least 6 months
- Used the ventilator for at least 6 months
- Dependent on mechanical ventilator for at least 6 hours a day
- Live in their own home
- Understand English
- Able to communicate verbally or use of other communication aids

- Ability to follow directions for at least an hour

Exclusion Criteria

- Children and individuals who cannot follow directions for less than an hour.
- Long-term care or institutionalized adults
- People on noninvasive MV

Open-ended questions were used for 40-60 minute interviews that occurred over several meetings if warranted due to an individual’s condition. Use of open ended-questions allowed for the solicitation of more information that would not have been obtained with the use of closed-ended questions.

Limitations

Participants chosen for this study may not be representative of the overall population on HMV due to the convenience sample and small population size. Participants who did not speak English were excluded so the results of this study will not extend to those who do not speak or understand English. Time limitation was a factor because the subjects may not have the stamina or ability to talk for extended periods. I was an ICU nurse and may be biased towards use of HMV as I am aware of the burden of care associated with this population. There was a possibility that interviews had be conducted on more than one session due to subjects’ functional capacity. The study was conducted in the natural setting; thus, findings cannot be generalized.

Significance of the Study

Mechanical ventilation is being integrated into the patient's home as a part of his or her daily living experience. As a result, physicians, families, and other healthcare providers must face the challenges of managing complex conditions beyond the hospital setting. Chronic conditions influence individuals' ability to perform ADL and their self-reported QOL (Barile et al., 2012). Once discharged home, effective communication between all care providers can result in a safe, appropriate success story for long-term HMV that leads to enhanced QOL that can be used as guide in clinical practice, to promote functioning.

Significance to Practice

Health care needs of individuals on HMV are complex. Individuals on HMV are satisfied with their QOL, but face challenges, such as dependence on technology, healthcare personnel, and limitations of freedom (Ballangrud et al., 2009). Health care workers need to understand the needs of HMV so that better care can be provided and more understanding in empowering participation in ADL and its benefits on QOL. Participation in ADLs allows autonomy and control over a person's own life situation improving functioning, satisfaction, and QOL. Users of HMV should be active partners in their own care so that their experience is taken into account. Health care workers need to incorporate information and participation in ADLs while on HMV. Collaboration between health care services, families, and health care entities is paramount in promoting functioning that gives meaning to life (King, 2012).

Significance to Theory

According to Roper et al. (1990), in daily life, individuals are able to perform ADLs independently; but, when disease strikes, it may be difficult or impossible to perform these tasks. Users of HMV have different underlying conditions that limit participation in ADLs. A goal in participating in 12 ADLs for users of HMV is to enable increased autonomy and participation in activities that provide meaning, purpose, and enjoyment in their daily life, thereby improving the QOL. Understanding the lived experiences of individuals on HMV will provide greater understanding on ways to adjust and perform ADLs. Mechanical ventilation boosts energy, resulting in the strength to support participation in ADLs. Early introduction to MV, early education on care, and use of equipment is mandatory for survival (King, 2012).

Significance to Social Change

The purpose of the study was to highlight daily challenges of ADL faced by individuals on HMV. Several ethical challenges, or dilemmas, arise at all levels in the course of treatment. A better and broader understanding of these issues is crucial in order to improve the QOL for both patients and families and to assist health care professionals involved in HMV to make decisions for the good of the individual and his or her family. This study may lead to positive social change by educating family, health care workers, and the public about QOL and prolonged dependence on HMV (King, 2012).

Summary

Users view adjustments to life on HMV as if they are using adaptive equipment, such as wheelchairs or prosthetics. Mechanical ventilation is a technology that supports the health and independence rather than life support. With time, some participants will use various equipment types to suit their conditions. Although some view mechanical ventilation to improve QOL and independence, other aspects of technology are considered self-limiting and acts as barriers to participate in ADLs. The size of ventilators, suctioning, noise levels, inability to talk, altered nutrition, altered elimination, and tracheostomy dressing changes are some disadvantages. Limitations on individual choice of equipment due to funding and insurance benefits are issues to ponder. The size, noise, and weight pose additional challenges to mobility and travel. Inability to be accommodated in someone's house when away from home poses additional challenges. Individuals cannot choose a mechanical ventilator tailor made for them due to different policies between manufactures and policy makers.

The increased need for assistance with ADLs acts as a barrier to enjoy a full and engaged life. Adjustment and acceptance of family members on HMV contributes to a person's ability to accept MV and integrate it into his or her life. Adjustments to HMV is an individualized process that is influenced by many factors, such as time and experience and health benefits, choice and control, social and personal perception, loss of previous lifestyle, equipment limitations, suctioning, dressing changes, nutrition, and elimination. Understanding these experiences is important so that participation in ADLs can be adjusted to maintain functional status and increasing QOL. Chapter 2 will provide an in-depth analysis of QOL, history of tracheostomies, origin of ventilators, AL, and theoretical framework.

Chapter 2: Literature Review

Introduction

Acute respiratory failure requiring mechanical ventilation is common in critical illness (King, 2012). Progressive advancements in the understanding and use of technologies have resulted in an increase in the number of patients who remain dependent on mechanical ventilation for prolonged periods (King, 2012). Mechanical ventilation has evolved due to improvements in technology and use of aggressive surgical procedures to prolong life during the past decade (King, 2012). However, prolonged dependence on mechanical ventilation after critical illness is an emerging public health challenge (King, 2012). Approximately 20,377 individuals are discharged to their homes on mechanical ventilation (U.S. Census, 2010). HMV has emerged as a viable option due to improved technology that allows patients to be at home with conditions that would ordinarily require lifelong care in a hospital, skilled nursing facility, or other institution-based programs (King, 2012). The home care setting is an option for those requiring home mechanical ventilation because costs are minimized and hospital-acquired infections are decreased (King, 2012).

Being on a ventilator at home has created many challenges for individuals who may be dependent on family members and health care personnel for their care (Dyrstad et al., 2013). Difficulty in participating in activities of living due to prolonged MV and underuse of muscles caused by respiratory insufficiency affects the individual’s QOL (Mouser, 2014). QOL is defined as an individual’s perception of his or her position in life based on his or her culture, values, relationships, goals, expectations, standards, and concerns (Mouser, 2014). QOL is interchanged with HRQOL, which is the effect of health interventions or the duration of life as modified by impairments, functional states, perceptions, and social opportunities that are influenced by disease, injury, treatment, or policy (Megari, 2013). Individuals on HMV face physical limitations and a decline in functional capacity (Mouser, 2014). This decline in functional capacity affects HRQOL (Kim, 2016).

There have studies on caregivers, hospitals, and long-term use of tracheostomy and concentration on the ventilators and respiratory equipment and their effect on users; however, there is a lack of research on individual perceptions of how people on MV cope in the home, how they are involved in the decision making of their activities of daily living, and how each decision affects QOL on HMV. The purpose of this phenomenological study was to explore the HMV individuals' lived experience and QOL in the home care setting. Care needs of individuals with tracheostomies on a ventilator in the home care setting are complex; there is need to explore and gain greater understanding about the perception of QOL.

Literature Search Strategy

he following databases were searched for literature (2008 to present) on lived experiences while on prolonged home mechanical ventilation (PHMV) using the Walden and Good Samaritan Hospital library. I used articles from 2000 to 2016. Articles focused on theory were included from the 1990s. Medline, Proquest, Ovid, CINAHL, Google Scholar, Thoreau, and Cochrane databases were used. Search terms used included *mechanical ventilation; PHMV; tracheostomy; tracheotomy; activities of living; ADL;*

phenomenology; Roper, Logan, and Tierney Model; home setting; respiratory chronic conditions; homogenous population; purposive sampling; chronic conditions; ICU; QOL; health-related QOL; chest and thorax; restrictive conditions; spontaneous breaths; weaning; ethical issues; advocacy; and *chronic obstructive disease.* All articles were peer reviewed.

Theoretical Foundation

The Roper, Logan, and Tierney Model

The RLT is a theory of nursing based on ADLs. The model is commonly used in the United Kingdom and is derived from Henderson's need theory (Ahtisham & Jacoline, 2015). Participating in ADL contributes to heath and recovery (Roper et al., 2001) and included are 12 ADLs that help identify actual or potential problems a person might encounter (Li Fang, 2015).

The RLT consists of five main concepts: ADL, developmental stage, the dependence/independence continuum, factors influencing the ADLs and the autonomy in living; the RLT includes the concept of dependent/independent continuum across an individual's life (Li Fang, 2015). The RLT includes five dimensions influencing ADLs that guide the implementation and evaluation of delivery of autonomous individual care and holistic nursing care to support and aid independence in ADLs (Ahtisham & Jacoline, 2015). This model takes the attention away from the disease and allows health care providers to develop a personalized care plan based on the actual and potential needs identified based on 12 ADLs (Li Fang, 2015). The RLT provides a focus on problem prevention and promotion of better health outcomes (Tierney, 1990).

Components of the Model

The RLT (2001) includes a concentration on life progression as measured by age, dependences, circumstances, and environment and the 12 ADLs promoting independence and enhancing the quality of life. Patients on mechanical ventilation require skills across a range of physical, cognitive, psychosocial, and communicative aspects of care. The ADLs are categorized as biological, psychological, sociocultural, environmental, and politico-economic factors (Roper et al., 1990). The biological factor is severity of disease and effect on functioning. Psychological factors are emotion, hope, and spirituality beliefs. Sociocultural factors include expectations by society and politico-economic factors include housing, health care insurance coverage, transport, and other necessary services needed in the home care setting. These categories influence the performance of ADLs, such as maintaining a safe environment, communication, breathing, eating and drinking, elimination, washing and dressing, controlling temperature, mobilization, working and playing, expressing sexuality, sleeping, and death and dying. According to Roper et al. (2001), individuals are able to perform ADLs independently, but are unable to do so due to an illness or disease. Each individual is unique and may alternate between the dependence and independence phases in performing ADLs to enhance the QOL. No modifications were done to this theory. All of the conceptual relationships satisfy the goal to evaluate the QOL for people on PHMV.

For patients on mechanical ventilation, the biological factor is the severity of disease on the anatomy and physiology. Dyspnea and fatigue, a symptom of energy deficiency, is common in patients with chronic respiratory diseases affecting participation in ADLs (Baltzan et al., 2011). Limited participation in ADLs reduces the health-related QOL. The reduction in AOL leads to deconditioning, which further increases dyspnea. Individuals in the home care setting can set up their own routines. Spacing activities and allowing time for rest will increase patients' participation in AL, improving QOL.

According to Roper et al. (2001), psychological factors do not only involve emotion, but also consists of knowing, hoping, feeling, and believing in conjunction with spiritual beliefs. Anxiety is common in patients with chronic pulmonary disease as it is manifested as a fight for control and is associated with panic, helplessness, and fear (Willgoss, Yohannes, Goldbart, & Fatoye, 2012). Anxiety is severe during acute exacerbations and breathlessness. As many as half of all individuals with chronic pulmonary disease have a clinical anxiety disorder. According to Karakurt and Ünsal (2013), anxiety and depression decrease the energy level and affect participation in AOLs. Sociocultural factors are defined as expectations and beliefs as influenced by society. How individuals on mechanical ventilation participate in ADLs can be influenced by personal, spiritual, or cultural beliefs. Society or family members' beliefs and perceptions can influence the degree to which care is rendered to individuals on HMV and their participation in ADLs (Willgoss et al., 2012).

Being in a familiar environment, such as a home, empowers individuals on mechanical ventilation to participate in ADL. Normal sleep cycles of day and night allows for adequate rest periods so the person on MV has enough energy to participate in ADL. Individuals on HMV are physically limited with the ventilator and require services, such as a safe environment and transportation for doctors' visits or grocery shopping.

Strengths and Weaknesses of RLT

Individuality and autonomy are factors central to the RLT. Each individual is unique, so progression through the developmental stages of the dependence/independence continuum changes and as does the ability to perform ADLs. The RLT provides a means for the activities of living to be objectively measured, which makes it easy to apply to a MV user's situation. The disadvantage is that the model is focused on AOLs and does not include the role of spirituality or coping mechanisms (Baker & Kakora-Shiner, 2009).

Similar Studies Using the RLT

To date, the RLT has not been used in studies involving individuals on HMV; however, the RLT has been used in people with different underlying conditions and is most widely used in the United Kingdom (Li Fang, 2015). I chose the RLT because of its flexibility, which allows it to be used in primary and secondary settings (Barnett, 2011). The activity of living model was used by Barnett (2011) in developing a care mode for people with chronic obstructive pulmonary disease (COPD). Difficulty breathing determines the amount of exercise and ability to perform daily tasks. The RLT was used to establish the impact of disability on daily activities. The RLT's 12 ADLs were used as a guide to provide care for people with COPD (Barnett, 2011).

Anemia and RLT Model in Emergency Department

Scholars used the RLT model to formulate a care plan for a patient with anemia and intracranial bleeding. These health care providers applied the RLT model to plan nursing care for an elderly person suffering from iron deficiency anemia and the associated change in mental status (Beh Hui, 2012). Beh Hui (2012) described an elderly man who was admitted to the emergency department after being found confused and drowsy outside a housing complex. The elderly man could not provide a past medical history due to a change in mental status. The 12 ADLs from the RLT model were used to prioritize and provide care during treatment. The use of the RLT model in this case study expedited the identification of actual and potential nursing problems faced by the patients in regards to ADLs (Beh Hui, 2012). Beh Hui found that an advantage of the RLT was that it not only lists the activities, but it also prepares the nurse to examine how biological, psychological, sociocultural, environmental, and politico-economic considerations help with analyzing the impact of ADL on QOL. Beh Hui used the 12 ADLs as a road map to ensure that care planning encompassed mental and physical requirements but cautioned that the fragmentation of ADLs one at a time or examining the ADLs could result in poor outcomes. By using the RLT, comprehensive assessment data and nursing diagnosis related to ADL deficits allows the nurse to focus on the individual so care is efficient and effective (Beh Hui, 2012).

Thalamic Intracranial Hemorrhage and LRT in ICU

Li Fang (2015) used the RLT to provide a treatment involving a middle-aged man who was found unconscious in his home. The patient was admitted to the ICU and found to have suffered a right thalamic bleed. The RLT was chosen because the12 ADLs are interrelated to factors such as physiological, sociocultural, and psychological aspects of the individual that in turn provide a picture between actual and potential issues of ADLs (Li Fang, 2015). The RLT also provided related concepts of the 12 ADLs, developmental stage in life, the dependency/independency continuum, and factors that affect ADL, which allows nurses to prioritize care based on level of dependency at the nurses' discretion or as warranted by the patient. The RLT allows a holistic treatment approach based on actual or potential issues involving ADLs. However, the RLT focuses on nursing issues rather than progress being made by the patient so the model needs further exploration (Li Fang, 2015). The RLT was modified to suit the ICU; as a result, ADLs such as leisure, sexuality, and dying were not included (Li Fang, 2015).

Traumatic Brain Injury Using the LRT Model in the Critical Care Setting

The RLT was used to guide treatment of traumatic brain injury (TBI) patients by health care professionals because it allowed individualization of patients' needs instead of focusing only the patients' medical problems (Barnett, 2011). TBI affects performance and participation in ADL. Each individual is affected differently due to the underlying cause of the TBI. The 12 ADLs of the RTL helps health care providers set guidelines suited for each individual's deficits. The ADL provides a framework to facilitate care, thereby enhancing the QOL for people with TBI. The 12 ADLs provides holistic basis of care (Barnett, 2011). The 12 ADLs were used as guides for assessment, planning, and implementation of care of identified health issues. The RLT was used to provide interventions and prioritize care mostly to guide clinicians because of its flexibility and use in different settings (Barnett, 2011; Beh Hui, 2012; Matter, 2011).

Using Plaster or Cast and LRT in Home Care Setting

Williams (2010) conducted a qualitative study to explore people's experiences while living with a below the knee plaster or cast and how it affects ADLs. A purposive sample of adults, 18 years and above, with a lower limb cast for at least 4 weeks and previously mobile were recruited. Data were explored in relation to the RLT model of ADL and Davis's adaption theory. Themes emerged regarding difficulty completing tasks of daily living (Williams, 2010). The plaster was painful and comprised mobility and other aspects of the ADLs (Williams, 2010). The RLT was chosen because of its five interrelated concepts: AOL, life span, the dependence/independence continuum, factors influencing the ADLs, and individuality in living (Roper et al., 2000). The model provided a clearer picture of information needed to provide care holistically to people with casts (Williams, 2010).

Richardson and Poole (2001) used the RLT to provide care to patients with chronic back pain. The group under study stated that pain affected six activities of daily living such as communication, sleep, sexuality, mobility, safety, and religious needs. The RLT includes activities affected by pain, and it could be used to provide a more comprehensive assessment of coping with chronic pain (Richards & Poole, 2001).

The psychiatry units in Ireland tried to adopt the RLT as a framework to provide care to people with mental illnesses (Murphy et al., 2000). Murphy et al. (2000) explored the nurses' experience in using the RLT model and revealed that the model was too simplistic, there was ambiguity in charting activities of living, and nurses found it redundant at times. The nurses suggested that issues such as counseling and self-esteem needed for this population could not be addressed by the RLT. The nurses felt that the RLT is suitable for the hospital or home care setting and not a psychiatry inpatient facility. A limitation of the model is that it has not been empirically tested (Murphy et al., 2000).

Summary

The RLT was selected to guide the study as evidenced by its flexibility, simplicity, modifiability, and ability to be applied in different settings (Barnett, 2011; Beh Hui, 2012; Li Fang Chan, 2015; Matter, 2011). The interrelatedness of the concept allows comprehensive treatment by allowing and integrating factors such as biological, psychological, sociocultural, and environmental and politico-economic considerations. It has been successfully used to guide treatment plans for people with different underlying conditions, such as anemia, intracranial hemorrhage, TBI, people with casts, chronic back pain, and surgical procedures like hip replacements. It can be applied to different settings, and it can be modified as evidenced by its use in the ICU and home setting. People on prolonged HMV suffer from numerous physical disabilities, such as muscle wasting, weakness, neuro myopathies, and poor nutritional status; these disabilities can compromise functional status and participation in ADLs (Clini et al., 2014). Prolonged bed rest contributes to impaired physical function; the 12 ADL can be used as a guide to assess functioning and QOL post hospitalization.

Physical decline is an unwanted health outcome faced by people with chronic conditions (Pritchard, Brown, Barker, & Haines, 2014). Ability to perform ADLs necessitates increased involvement with the environment, whether household or community appears to be a precondition for independent living in the community (Pritchard et al., 2014). Volition or motivation to engage in an activity depends on self-ability and competency, values, or meaning of activities and level of interest to perform (Pritchard et al., 2014). However, the functional status and outcomes in individuals on

PMV are often limited by poor endurance and pulmonary mechanics, which result from the primary diseases or immobility (Chen et al., 2012). Prolonged bed rest results in muscle weakness, muscle atrophy, and decreased ability to perform ADLs, so it is important to measure QOL using the ADLs (Chen et al., 2012). The 12 ADL, as noted by the RTL, is used to assess functional status after hospitalization (Roper et al., 2001). The 12 activities are maintaining a safe environment, communication, breathing, eating and drinking, elimination, washing and dressing, controlling temperature mobilization, working, playing, sleeping, and death and dying by the RTL model (Roper et al., 2001). These ADLs are used to assess the QOL for patients on MV.

Literature Review of Key Concepts

Several key concepts identified for this study include tracheostomy, definitions, indications, epidemiology and complications associated them. A second concept is MV, definitions, indications, trends and the association with ADLs. A third is ADLs definition, effect of hospitalization on ADLs, tracheostomy placement and use of MV. QOL will also be analyzed and how the placement of tracheostomy and use of MV affect participation in ADLs and its impact on QOL.

Tracheostomy

Due to the increase in the number of people who require MV as a result of various underlying physiologic conditions, there has been an increase in the number of people requiring prolonged MV as well (Kojicic et al, 2011). Advancement and improvement in technology, safe and easy practices at the bedside, have led to increased tracheostomy placement in the ICU internationally and in the United States (Durbin, 2010). Long periods of intubation in the ICU lead to increased risk of acquiring ventilator-acquired pneumonia (VAP) and cause injury to vocal cords, bronchial tree lining and the lungs. Tracheostomy has emerged as a better option compared to endotracheal intubation for long-term use.

Definition of tracheostomy. A tracheostomy is an opening or stoma placed into the trachea through the anterior portion of the neck. Tracheostomies can be temporary and can be closed after the underlying issue has been resolved or can stay permanently to aid in breathing using a MV (Tracheostomy, 2014). Other terms used are trach, stoma, tracheotomy, or tracheostomy, depending on region of the world. In the recent past, tracheostomies were placed surgically in the operating room; now percutaneous dilatation is carried out safely at the bedside reducing costs and facilitating treatment by reducing period of endotracheal intubation. Placement is associated with high reimbursement for the physician as well as the hospitals, an incentive to perform more procedures (Cheung & Napolitano, 2014). Improvements in clinical outcomes compared to prolonged endotracheal tubing have facilitated tracheostomy placement (Cheung & Napolitano, 2014, Liang, Panpan, Feng, & Yu-Guo, 2013). While there is debate about the timeline of tracheostomy placement, there is no agreed timeline because placement depends on the situation, and is individualized (White, 2012). Studies have been conducted to verify whether tracheostomy placement results in better outcomes compared to prolonged endotracheal intubation or if outcomes of early tracheostomy are better than late tracheostomy (Durbin, 2010). A retrospective study of 531 people on MV in mixed/surgical ICU showed that early placement of tracheostomy resulted in shorter ICU and hospital stay and decreased VAP (Cheung & Napolitano, 2014).

History of tracheostomy. Egypt was the birthplace of the first recorded tracheostomy where King Alexander the Great used a sword to open the neck of a soldier who was chocking from a bone in 3600 (King, 2012). Other seminal works include Artaues and Galin in 2nd and 3rd Century AD and Greek physician Asklepiaches in 100BC, in 1956, Antonio Musa Brasavola, another physician, performed a tracheostomy for airway relief and enlarged tonsils (Cheung & Napolitano, 2014).

During the polio era, tracheostomy placement increased for prolonged MV. Tracheostomy placement continues to evolve as the procedure is still being perfected and its use increases in the United States and abroad (Ballangrud et al., 2008, Mehta et al., 2015, Drystad, Hansen & Gundersen, 2013).

Epidemiology. An increase in the use of tracheostomy has been trending in the last decade. Mehta et al., (2015) reported that 1 352 432 adults received tracheostomies from 1993 to 2012. Most of the adults were male, whites with an average age of 61 years, surgical patients and minority and ethnic people on Medicaid. Tracheostomies were performed more in urban teaching hospitals, more in the south than the Midwest and decreased in the Northeast. In North Carolina, between 1993 and 2002, people with tracheostomies requiring PMV increased for all ages from 8.3 to 24.2/100 000 due to decreased mortality, 39% versus 25% and patients had a three times chance to be discharged home (Cheung & Napolitano, 2014). According to the United States Census Bureau (2010), an estimated 20, 377 people use HMV and 76% have tracheostomies.

Indications, benefits, and complications. A tracheostomy is indicated for several reasons. Failure to wean from endotracheal intubation, multiple weaning failures or failure to take spontaneous breathes after 48 hours after extubation are reasons for placement (Tracheostomy, 2014). Emergencies such as trauma, stroke, spinal cord injuries, neurological impairments, respiratory distress, surgery, and infection are indications for placement (Durbin, 2010). A tracheostomy creates a stable airway for people who require long-term use of MV and allows suctioning and removal of secretions. Benefits include improved comfort, less sedation that results in decreased risk for delirium or ICU psychosis and improves functioning and participation in ADLs (Marchese, Coco, & Coco, 2008). The upper respiratory tract is protected resulting in less work of breathing, better oral hygiene, and early ability to speak and eat. Hospital costs are minimized due to shortened length of stay (White, 2012).

Immediate complications of tracheostomy include bleeding or hemorrhage at the incision site, damage to trachea, air embolism, hypoxemia, and death (Durbin, 2010; Wilkison, Freeth, & Martin, 2015). Early complications include hemorrhage, tube dislodgement, subcutaneous emphysema, pneumothorax, accidental removal or improper placement, and dysphagia. Late complications include tracheal stenosis, granulation of tissue, erosion, development of fistulas, aspiration, and dysphagia.

Impact on ADLs and QOL

Individuals with tracheostomies with acute respiratory failure have high mortality rates (Cheung & Napolitano, 2014), but have high morbidity and low mortality compared to non-trach patients. They are labor intensive and are associated with long periods of

ICU, hospital stays, and rehabilitation costs. They need care around the clock whether in the home, institution, or hospital. Home costs include transportation, housing, specialized health-care workers, and supplies. Due to the high rates of morbidity and complex care required, there is a gap in literature, few researchers have focused on the lived experiences of individuals with tracheostomies on MV in the home-care setting (Dyrstad et al., 2013). Due to poor clinical outcomes and challenges faced in the home-care setting, it is important to assess how ADLs and the role in decision making affect QOL in the home-care setting.

Tracheostomy affects ADLs such as speech, eating, sleeping, working, and home environment. The presence of a tracheostomy can also lead to dysphonia, which is altered speech and spasms associated with the anatomical position of the tracheostomy tube. The presence of a tracheostomy can lead to mental and emotional morbidity, whereas, disfigurement of the neck is associated with reduced body image perception and may lead to anxiety and depression (Hashmi, Ransom, Nardon, & Redding, 2010). This might lead to decreased participation in ADLs, poor interpersonal relationships, and a diminished sense of well-being; therefore, it is important to understand the impact of tracheostomies on QOL.

Communication difficulty during mechanical ventilation is associated with feelings of panic, stress, anger, sleeplessness, and frustration (Cruice, 2008). Tracheostomies affect speech volume and vocal quality, in return, inability to be understood by others can lead to a negative impact on QOL. Effect of voice and quality, affects the listener, how they accurately interpret the message being conveyed by the speaker. Communication allows participation in life situations such as ADLs where knowledge, information feelings are exchanged. Communication allows one's voice to be heard and allows involvement in decision-making. A study of 19 participants of whom 17 had tracheostomies, was carried out to assess communication issues associated with HMV (Laakso, Markström, & Hartelius, 2009). Findings revealed that speech intelligibility was decreased and communication difficulties led to dysfunction (Laakso et al., 2009). The opening of the neck for placement of a tracheostomy presents problems. The stoma acts as a port for bacteria entry and bypassing the upper nasal passages alters the oral flora. Speech and eating ADLs are also affected.

Mechanical Ventilation

Ventilator manufacturers have made continued efforts to improve home ventilators thereby increasing use. As in Europe, there is no registry for individuals on HMV in the United States, as a result, the exact number of HMV users is unknown (King, 2012). There are challenges associated with HMV such as caregiver training, adequacy of supplies for respiratory care and reimbursement (King, 2012).

Definition of mechanical ventilator (MV). A ventilator or respirator is equipment utilized to mechanically assist breathing by pushing air into the lungs. These large and complex machines are common in the ICU and hospitals settings. Ventilators in the home are small, lightweight, portable, and can be mounted on a wheel chair, cart, or bedside-stand. They use batteries or electricity and backup is necessary in case of power outages. Other names used are ventilator, vent, or breathing machine. The MV simulates the work of breathing (King, 2012).

In normal circumstances, the diaphragm and intercostal muscles are used for inspiration. Other muscles such as chest, neck and shoulders are involved. Due to different underlying physiologic conditions, muscles become weak, or paralyzed, making it hard to breathe (Vasconcelos et al., 2014). A ventilator takes over breathing, assisting the weak respiratory muscles. Abdominal muscles aid in breathing out an effective cough. Expiratory muscles that are weak result in impaired cough and difficulty clearing secretions in addition increases risk for infections. Underlying neuromuscular disorders impair swallowing, speech and coughing. Mechanical devices clear secretions through breath stacking and lung-volume recruitment. Breath stacking is adding one breath to another without exhaling (Guest, 2015).

A MV or ventilator is a machine that aids in breathing by simulating spontaneous or the natural process of breathing. Spontaneous breathing occurs when air enters through the nostrils into nasal passages and into the lungs where gas exchange occurs. A MV provides oxygen via a tracheostomy collar into the lungs by applying volume during inspiration and releasing pressure during expiration. A MV provides high volume of oxygen to a tracheostomy collar, a tube that is connected to the ventilator and attached to the stoma via a collar. Important features are rate, inspiratory time setting, expiratory pressure (PEEP), tidal volume, and oxygen or Fio2 (Guest, 2015).

History of MV. MV was used in the 1950s for people with polio in the home-care setting for prolonged mechanical ventilation (Vockley, 2014). Use of positive pressure allowed people with tracheostomies to be discharged home on MV. In 1977, a portable ventilator, LP3, was approved by the Food Drug and Administration (FDA) outside of the hospital for pediatric patients. The ventilator was then introduced in Pennsylvania to initiate the first home ventilator program (Goldberg, 2010). The first ventilator in the homecare setting was used for an infant who had contracted encephalitis and her parents wanted her home but could not qualify for reimbursement from Medicaid. Since then a law was passed to allow reimbursement and funding for HMV increasing the number of users as well. To date, funding is available for use of various equipment and expertise outside the hospitals and long-term facilities. HMV is long-term use of ventilator support for people who are no longer in acute respiratory distress and do not require ICU or hospital care. An LP10 was designed for adult use in the home setting for people who are obese and have severe chest-wall deformities requiring high inflation pressure (King, 2012).

Indications for HMV/ discharge criteria. Discharge planning and implementation should be initiated early to ensure a smooth transition into the home. Collaboration with other health care providers, coordination of resources and patient teaching on self-care are warranted. To qualify for HMV, factors such as inability to control sections, impaired swallowing and increased risk for aspiration are considered (Sole et al., 2014). Individuals who need at least 6 hours or more on a ventilator are considered. Discharge criteria involve medical stability free of cardiac issues, infection adequate nutrition, and stable medication regimen. The tracheostomy should be mature, free of bleeding, and airway stable. Arterial blood gas results should be within acceptable range on oxygen of less than 40%. Contraindications for discharge home include unstable medical condition, immature tracheostomy, and refusal of HMV and safety hazards in the home where utilities such as electricity are inadequate.

Trends in MV use. According to Mehta et al. (2015), 8 309 344 nonsurgical patients received invasive MV (IMV) from 1993 to 2009. Utilization of IMV increased from 178.8 cases per 10,0000 US adults in 1993 to 310.9 per 10,0000 in 2009). During the study period, chronic obstructive pulmonary disease, heart failure, and pneumonia accounted for 33.5% of all nonsurgical IMV cases (Mehta et al., 2015). Use of IMV for pneumonia had the most growth from1993 and 2009, doubling from 30.5 to 62.1 cases per 10,0000 US adults (Mehta et al., 2015).

Advantages of PHMV

There are several advantages of PHMV compared to the hospital, long-term institutions, or other care facilities. The home-care setting is preferred because costs are reduced, quality of life improved and simulation into society facilitated (Marchese, Loco & Locco, 2008). Familiar surroundings allow for day and night routines that promote an uninterrupted sleep and an environment that allows healing. Being at home promotes spending quality time with loved ones, reduces nosocomial infections, and frees hospital beds for other patients. Freedom to choose when and how to perform activities allows adequate periods of rest and promote normal sleep cycles. A hospital setting is noisy, cramped, limited visitation, limited communication, high reliance on technology, and less nurturing time. Sleep time is often interrupted for blood draws, baths, and diagnostic tests. The home setting allows unlimited visitation of friends and family, increases mobility and time for speech development. There is close supervision by family members and independence is promoted (King, 2012).

Ventilator Design and Complications

The FDA developed a code system to identify and track ventilators so that in the event of a recall, the device can be retrieved from the user's home (King, 2012). Most common ventilators used in the home are the NOU and ONZ. The NOU is a continuous HMV commonly referred to as full or life support to manage people who cannot take spontaneous breathes and are dependent on the ventilator (King, 2012). The ONZ is for people who can take spontaneous breathes but need support during ambulation or activities. Other features on the ventilator are rate, tidal volume, oxygen that is measured as a percentage (FiO2) and PEEP that is positive expiratory pressure. Ventilator modes can be volume or pressure cycled depending on the needs of the HMV user. Ventilators have built in alarms and other safety features built in for safety; however, malfunctions still occur causing injury and death.

Ventilator malfunctions or failures can lead to death; thus, protocols and support lines should be established. There are limited data on HMV failure in the United States. According to the U.S. Department of Health and Human Service (U.S. DHHS), FDA Manufacturer and User Facility Device Experience (MAUDE; 2010), 150 malfunctions were recorded. In 1998, there were 189-recorded incidences for ventilator failure concerning users, age 2-77 years old over a 1-year period (King, 2012). Another study was conducted in the United Kingdom by reviewing the support hotline of ventilator users, out of 1,211 adult and pediatric users, 12 had a tracheostomy, 188 emergency visits for ventilator failure were made (U.S. DHHS, FDA, 2010). Eleven deaths related to HMV were reported, five of the 11 deaths was due to failure of the ventilator to alarm and 50 people had MV failure that required backup (U.S. DHHS, FDA, 2010). Causes of ventilator malfunction include alarm failure, accidental disconnection of tubing, and tracheostomy tube dislodgement. Causes of death include progression of underlying condition, cardiac and acute respiratory failure, sepsis, brain death, multiple organ failure and tracheal bleeding, obstruction, or dislodgement (Vockley, 2014).

Impact on QOL

Along with the underlying etiology leading to HMV, people in this group face complex tasks such as the dependence on external device for daily life, the numerous hours spent on ventilation, limited opportunities to work/pursue daily activities, as well as sudden changes in disease progression. These factors are true manifestations of a chronic and impairing condition such as HMV. An in-depth understanding of such issues is important to improve quality of life in this population and optimize clinical outcomes. MV affects participation in ADLs (Chlan, Tracy, Guttormson, & Savik, 2015).

Activities of Living (ADL)

Besides the different underlying conditions resulting in PHMV, individuals in this group face many challenges such as the external use of MV for long hours, limited capabilities to work and participation in ADLs. Domains of QOL for individuals on PHMV include competent mental functioning, the ability to perform ADLs and to participate in meaningful use of time, social behavior, and maintain a balance between positive and negative emotions. Individuals with limited or impaired ADLs avoid outdoors, are unsatisfied with their lives, and have low self-esteem (Andersson, Marcusson, & Wressle, 2014). Researchers have identified a significant relationship between ADLs and QOL (Soh, Morris, & McGinley, 2011). The RLT Model uses the 12 ADL to define what living means. Living means ability to perform ADL as required by each individual in his or her own way before, after hospitalization, or due to a chronic or acute condition. By using the 12 ADLs as noted in the RLT model, the analysis will help assess QOL.

Definition of ADLs. ADLs are activities carried out on a daily basis such as self-care; home maintenance and communication (Tornquis & Sonn, 2014). These are performed daily or less depending on personal habits, social and cultural roles. The degree to which a person performs a task is closely linked to the environment. An activity is a goal oriented or purposeful interaction of a person with an activity or object. The activity or task dictates and influences how an individual performs a given activity. To perform or to do an activity means a person has the ability to perform to meet demands. He/she has the know-how and is able to perform the activity he/she wants when it is necessary or needed or must do. An activity is complex and requires proper functioning of body organs and systems. Limitations in organs or different systems can result in decline or disability to participate or perform an activity. ADLs change over time due to hospitalization (Tornquist & Sonn, 2014). ADLs and activities of living (AL) are used interchangeably. ADL are going to be used as variables for this study, due to its effect on QOL. It is used to demonstrate how each activity is vital and essential in living on a daily basis.

Effects of hospitalization on ADLs. Hospitalized older adults frequently experience declines in physical functioning during and after hospitalization and several studies have demonstrated persistence of dysfunction as long as 12 months after discharge (Ehlenbach, Larson, Randall, Curtis, & Hough, 2015). Some longitudinal studies have included prehospitalization data, strengthening the evidence that illnesses and injuries leading to hospitalization can cause disability in older adults and decreased participation in ADLs (Ehlenbach et al., 2015).

Profound muscle weakness. Profound muscle weakness during and after critical illness is termed intensive care unit-acquired weakness (ICUAW; Fan et al., 2014). The ICUAMW is a neuromuscular disorder presenting with profound muscle weakness and diminished or absent deep tendon reflexes which are associated with increased duration of mechanical ventilation, weaning period suggesting a possible relation between the limb and respiratory neuromuscular involvement (Abu-Khaber, Abouelela, & Abdelkarim, 2013). Severe sepsis, difficult ventilator liberation, and prolonged mechanical ventilation are associated with ICUAW (Fan et al., 2014). Skeletal muscle wasting and weakness are significant complications of critical illness, associated with degree of illness severity and periods of reduced mobility during mechanical ventilation and contribute to the profound physical and functional deficits observed in survivors (Connolly, 2015). These impairments may persist for many years following discharge from the intensive care unit (ICU) and can markedly influence health-related quality of life (Connolly, 2015).

Hermans et al. (2014) carried out a randomized control trial of surgical patients one year post discharge from ICU who had ICUAW during hospitalization and upon discharge. The purpose of the study was to assess the degree of recovery from ICUAW 1 year after hospitalization for patients who had different underlying conditions. Data revealed that patients who acquired weakness in the ICU did have higher 1-year mortality than matched patients without weakness. Researchers noted that both peripheral and respiratory muscle weakness were related to severity of illness (Demoule et al. 2013; de Jonghe, Lacherade, Sharshar, & Outin, 2009) and respiratory muscle weakness were associated with peripheral muscle weakness (Hermans et al. 2014). A clear relationship between respiratory muscle weakness measured using magnetic stimulation, a method not requiring patient cooperation, and worse outcome has been demonstrated (Demoule et al., 2013). Results showed that ADL reduction was related to imbalance between oxygen delivery and consumption (Miranda, Malaguti, & Corso, 2011). Impaired limb muscle function is a common occurrence in patients with underlying respiratory conditions, and it negatively influences exercise tolerance, participation in ADLs and QOL (Demoule et al., 2013).

Barnato et al., (2011) carried out a longitudinal study to assess the impact of disability of people hospitalized with MV compared to the people without MV. Functional status was assessed pre and post hospitalization focusing on ADLs and functional status over a period of 7 years using data from Medicare beneficiaries. A modified Roscow-Bresley Functional Health Assessment Scale was used to calculate mobility difficulty among three items, difficulty walking three blocks, lifting 10 pounds and bending. The Katz ADL was used to calculate disability focusing on difficulty and received assistance in personal hygiene, getting in and out of bed or chair, eating, ambulating, and elimination. Results showed that the marginal increase in disability among survivors of MV compared to survivors without MV was larger than would be predicted from prior functional status (Barnato et al., 2011). However, Barnato et al. (2011) used data from Medicare beneficiaries and concluded that although there was a decrease in functional status among survivors with MV, these patients post discharge, had better functioning status than people hospitalized without MV.

The researchers concluded that large decrements in ADL disability and mobility difficulty scores is likely due to acute illness, intensive therapies and the ICU environment. According to Cox et al. (2009) outcomes for people on prolonged mechanical ventilation (PMV) are viewed negatively as by physicians and significant others.

Ali et al. (2008) measured handgrips and hand-dynamometry to determine if handgrip dynamometry is a concise measure of global strength of extremities and independently associated with mortality in ICU patients. A prospective multicenter cohort study was conducted in the ICU of five academic medical centers (Ali et al., 2008). Adults requiring at least 5 days of mechanical ventilation without evidence of preexisting neuromuscular disease were followed until awakening and were then examined for strength of upper and lower extremities (Ali et al., 2008). Results revealed that ICUAW is independently associated with increased hospital mortality. Handgrip strength is also independently associated with poor hospital outcome and may serve as a simple test to identify ICUAW (Ali et al., 2008).

Effects of prolonged mechanical ventilation. MV is a necessary treatment for patients with respiratory failure and other underlying conditions (Chen et al., 2012). However, complications may occur. Patients on PMV have weak muscle strength due to the impact of underlying diseases, side effects from medications, and prolonged time bedridden (Chen et al., 2012). After prolonged bed rest, PMV patients may suffer from respiratory muscle weakness, limb muscle atrophy, and decreased ability to perform ADLs (Chen et al., 2012). The complications of PMV, such as barotrauma and/or ventilator-induced diaphragm dysfunction can also further impair pulmonary mechanics (Chen et al., 2012). Hayes and Llewellyn (2008) described the model as an aid in assisting and measuring the patient's ability to achieve independence at each stage of care. All 12 activities include, maintaining a safe environment, communication, breathing, eating and drinking, eliminating, personal cleansing and dressing, controlling body temperature, mobility, working and playing, expressing sexuality, sleeping and dying. All activities according to Holland et al. (2008), are used as a framework for the assessment, planning, implementing and evaluating process in the provision of care.

Maintaining A Safe Environment

Maintaining a safe environment is one example of how the activities can relate to patient care. Diamond (2011) uses the home care setting as an example how a person’s human rights can become easily compromised. Clinical outcomes of neuromuscular patients using long-term MV go beyond medical factors to include equipment and the quality of the home support (Lofaso et al., 2014). Selecting the best MV equipment and the optimal settings for each patient is crucial for the success of long-term MV (Lofaso et al., 2014). Patient comfort is affected by many factors, including patient-ventilator synchrony, ventilator inability to cope with the patient's respiratory demand, skin lesions caused by the interface, inappropriate humidification, and difficulty speaking during MV (Lofaso et al., 2014). Patients receiving long-term MV at home are expected to have an expert opinion on MV because they have been using MV for years in various daily life conditions. As a result, patients are more reluctant, compared to prescribers, to adopt new technologies, which might be explained by lack of information regarding MV updates (Lofaso et al., 2014).

Before a patient comes home on MV, the home should be assessed for proper space, electrical outlets, phone service, and other criteria necessary to ensure a safe environment (Marr, Klages, & Capolongo, 2016). A key part of any home care program should be education of patients, families, and caregivers to help them use the equipment confidently and safely and to have a sensible plan of action once a problem arises (Garber & Guertin, 2012). Good communication and a structured discharge plan adapted to the individual are required. The patient and/or caregivers should complete competency training on how to operate the equipment, identify simple problems, and when to seek advice. Educational materials are now widely available (Marr et al., 2016). Arrangements are necessarily more complex in patients who are dependent on tracheostomy ventilation. There are additional risks associated with the tracheostomy, which include blockage and displacement, which are dangerous because those receiving ventilation via a tracheostomy often have little or no spontaneous breathing capacity (Marr et al., 2016). Tracheostomy care and safe suctioning, as well as ventilator operation, need to be taught before discharge. Safety considerations need to evolve with the course of the underlying disease (Marr et al., 2016). Maintaining a safe environment facilitates participation in ADL by promoting mobility. Any barriers to safety such as throw rugs, tubing and equipment should be properly arranged to increase mobility. An environment free of clutter prevents falls and accidents and gives confidence to users of HMV to increase mobility and improve QOL. Limited mobility affects performance of ADLs and results in poor outcomes and decreased QOL. Safety in handling equipment and supplies provides knowledge and skills necessary to engage safely in AL.

Communication

The presence of a tracheostomy decreases the ability to communicate (Hess & Altobelli, 2014). After placement of a tracheostomy, air does not pass through the mouth, nose, and vocal cords to produce sound (Ahmad, Dargaud, Morin & Cotton, 2009). According to Morris (2015), diseases that affect the pharynx, larynx, and vocal cords can interfere with the ability to produce speech (Kunduk et al., 2010). The tracheostomy tube itself blocks the trachea resulting in poor airflow, increased airway resistance and labored breathing resulting in difficulty producing speech (Morris, 2015). In order to produce speech while having a tracheostomy, an adequate supply of air should reach the vocal cords with minimal resistance, which depends on the diameter, length, and type of tube. Restoring speech for people on MV can be a daunting task, which depends on whether a person can tolerate cuff deflation or not (MacBean et al., 2009).

Communicating effectively for users of HMV is essential so that various basic physiological and psychological needs can be conveyed and decisions, wishes, and desires about the plan of care and end-of-life decision making can be expressed (Grossbach, Stranberg, & Chlan, 2011). Effective communication is necessary as it facilitates participation in ADLs. Loss of communication can lead to social isolation, disengagement and noncompliance to treatment regimens (Hess & Altobelli, 2012, Morris, 2015). Communication difficulties create great stress and result in psych emotional distress, depression, anxiety, fear and anger, frustration, panic, sleeping disorders, decreased self-esteem, and loss of control, and pain (Grossbach et al., 2011). Additional stressful experiences or discomfort associated with MV such as tube fastenings, suctioning can interfere with sleep, feeling choked, insufficient air, breathing difficulty (Khalaila et al., 2011). Effective communication using different strategies ensures that patients' specific needs are communicated and quality care provided. Reduction in stress levels, anger, discomfort, and pain allow participation in ADLs, which improve QOL.

Numerous strategies are available for effective communication, and range from simple to complex (Grossbach et al., 2011). For successful communication, specific factors are crucial and these include, establishing a communication friendly environment, assess functional skills that affect communication, facilitate lip-reading, and use of alternative devices. Picture boards, lip-reading, writing, hand signals, eye blinking, nodding answers to yes-no questions are some communication alternatives that can be used (Morris, Bedon, McIntosh, & Whitmer, 2015). It is important to assess if the individual needs glasses, hearing aids and has adequate muscle strength needed for writing. For individuals who can tolerate cuff deflation, leak speech can be used, and for those who cannot protect the airway, they require an approach that maintains cuff inflation such as talking tracheostomy tubes, cuffed fenestrated and Blom tracheostomies (MacBean et al., 2009).

Leak speech. Suitable conditions for Leak speech are individuals who can tolerate cuff deflation or have a cuff-less tube. The cuff is deflated and the ventilator settings are modified to house the air leak that results. Tidal volume settings are increased to make-up for the loss of volume during inspiration through the upper part of the airway. In normal circumstances, people speak on exhalation, but in contrary, leak speech transpires on inhalation (McBean et al., 2009). The leak during the inspiratory phase allows speech to occur, so the patient must be coached to speak on inspiration, as the breath is being given (McBean et al, 2009). Leak speech generally produces short phrases followed by long pauses, thus it is recommended to increase the inspiratory time on the ventilator to accommodate more syllables per minute. Thorough suctioning before and after cuff deflation to avoid aspiration, coughing and difficulty breathing are important (McBean et al., 2009).

Speaking valve. A speaking vale or the Passy-Muir can be built in the ventilator system and suitable for people who need uninterrupted cuff manipulation (Egbers, Bultsma, Middelkamp, & Boerma, 2014). When placed at the hub of the tracheostomy or in the ventilator circuit, the Pussy-Muir redirects air into the nose, mouth and vocal cords, producing speech (Grossbach et al., 2011). Disadvantages with this method include buildup of secretions above the cuff, which can block the air supply line that can result in absent airflow necessary for speech. Uncomfortable and bothersome, dry mucous membranes can result due to high airflows (MacBean et al., 2009). The air used for speech is different from the air used for breathing, thus as a result no ventilator settings are needed. Accumulation of secretions above the cuff can clog the air supply line, resulting in no airflow needed for speech (McBean et al., 2009). Discomfort and drying of mucous membranes can occur with high airflows so humidification is needed (Egbers et al., 2014).

Cuffed fenestrated trach tube. A fenestrated trach tube allows air to travel through the opening above the cuff, allowing ease flow of air in the trachea to produce speech, as a result, ventilator volume may need to be adjusted (Grossbach et al., 2011). The fenestrated tube is not tolerated in patients with increased respiratory rate, high levels of anxiety or respiratory distress during attempted speech (McBean et al., 2009). A fenestrated trach tube requires proper fitting to prevent granulation of tissue in the fenestrations, suctioning can be done by replacing the tube with a non-fenestrated one to prevent the suction catheter to be lodged in the fenestrations (McBean et al., 2009)

Blom trach tube. The Blom tube has an opening above the cuff to reduce the risk of granulation tissue. A speech valve is used and is made up of two valves. One flap valve opens during inhalation, allowing air through the tube. During exhalation, the second flap valve closes; letting air out through the opening to a bubble valve, as a result, alarms need to be adjusted for the low exhaled volume (Leder et al., 2013). This system can be used for people are cognitively impaired but might want to communicate. Proper suctioning is required before the speech cannula is inserted to prevent respiratory distress, Blom is not recommended for people with thick copious secretions (McBean et al., 2009). People on PMV need a way to communicate their feelings as well as their physical and emotional needs, which will improve QOL for this population (Freeman-Sanderson, Togher, Phipps, & Elkins, 2011).

Breathing

Breathing is essential for survival and experiencing breathing difficulties is terrifying and can be due to trauma, chronic conditions or difficulty weaning off the ventilator. Gasping for air or air hunger causes anxiety and is an uncomfortable situation. People with tracheostomies need suctioning frequently due to inability to clear secretions. Weakness and disease process coupled with frequency of suctioning can be a daunting and exhausting activity. Management of the ventilator and presence of oxygen can be hazardous if safety is not observed (Guest, 2015).

Loerzel, Crosby, Reising, and Sole (2014) noted that tracheostomy management at home requires the caregiver to be familiar with complex medical equipment and skill to complete complex medical tasks. Caring for a tracheostomy patient can often lead to anxiety if the caregiver did not receive adequate training prior to discharge nor has minimal hands on skills. Lack of training leads to risk for complications such as pneumonia, skin breakdown around the stoma, airway obstruction, stenosis, and accidental dislodgment of the tracheostomy tube. As a result, different techniques to clear secretions such as chest vibration, postural drainage, and Trendelenburg positioning are useful to adopt and use. Humidification should be used as it thins out secretions and reduces drying of secretion membranes (Baker & Kakora-Shiner, 2009). King (2012) recommended respiratory companies that provide ventilators to follow-up regularly and be responsible for equipment maintenance, cleaning and servicing. Having a tracheostomy requires proper management and vigilance in the home for effective breathing.

Dyspnea is difficulty breathing during exercise or difficulty breathing while performing ADLs (O'Donnell et al., 2013). It is the most frequent complaint experienced while performing ADL for people on MV, as a result, to compensate; participation in ADLs is reduced, leading to a reduction in QOL (Barusso et al., 2015, Nishimura, Yasui, Nishimura, & Oga n.d,; Pan et al., 2012). It can be inferred that dyspnea and depressive symptoms affect participation in ADLs and lead to poorer clinical outcomes resulting in poor QOL for people on HMV.

Eating and Drinking

The presence and location of a tracheostomy disrupts airflow in what is normally a closed system (Seckel & Schulenburg, 2011). A tracheostomy is placed below the vocal cords; as a result, airflow bypasses the larynx during inhalation and exhalation. This in-turn disrupts normal movement of the vocal cords, closing of the laryngeal vestibule, and proper closing of the epiglottis during swallowing. As a result, swallowing difficulties or dysphagia is common in 50% of people with a tracheostomy on a mechanical ventilator, with the elderly population at increased risk (Baumgartner, Bewyer, & Bruner, 2008). In addition, the presence of an inflated cuff, results in food and liquid buildup above the cuff resulting in ventilator-associated pneumonia (Batty, 2009, Dikeman, Kazandjian, &

Lerner, 2008). Other obstacles include difficulty coordinating eating and breathing, muscle atrophy and laryngeal damage (Seckel & Schulenburg, 2011). Speech language pathologists perform a swallow evaluation to determine the kind of diet warranted by the individual. Different swallow evaluation tests are performed and diets ordered based on the clinical assessment. Food maybe be chopped, pureed and fluids maybe normal, honey, or nectar thick to allow extra time for airway protection (Edmiaston, Connor, Loehr, & Nassief, 2010).

According to Hussain et al. (2016), the most common method of nutritional support for people who cannot swallow is a peg-tube, which is a surgically inserted plastic tube in the abdominal wall into the stomach. It is used as a port to infuse medications, water and commercially prepared liquid nutrition. Complications include infection, clogging, dislodging, and leaking. Different feeding solutions are based on the patient's clinical status; feedings are available for renal, diabetic, low, or high calorie needs. Feedings can be by bolus, intermittent or continuous on a pump. Individuals with tracheostomies who cannot swallow can have a peg tube inserted and this provides nutrition essential for everyday functioning. Depending on the route of nutritional intake, it is important to take precautions to prevent infection, aspiration while fulfilling nutritional aspects to promote healing. It is necessary for swallow evaluations to be performed frequently or due to change in status.

Nutrition is an important factor in maintaining health and healing especially during PMV. Lack of nutrition results in muscle wasting and fat loss, which leads to decreased physical function and reduction in participation of ADLs resulting in poor

QOL (Barusso et al., 2015). Nutritional deficit is associated with increased risk of infection, poor wound healing and less energy requirements needed to carry out ADLs. People on PMV have high caloric needs, interruptions in feeding for care interventions result in decreased energy sources resulting in decreased energy levels, and participation in ADLs.

Elimination

Dignity and respect are crucial when it comes to bowel or bladder elimination**.** Continence habits depend upon underlying medical conditions. Chronic respiratory failure, effects of medications and other comorbidities can cause decreased muscle strength and ability to independently manage bowel and bladder control. It is important to assess hydration, monitor eating habits, provide stool softeners to avoid straining and to provide bedside commode for use. In case of neurogenic bladder, a Foley catheter might be present and meticulous care is warranted to prevent infection. A Foley catheter is a tube that is inserted into the bladder to drain urine and meticulous care is practiced to prevent infection (Macy & Saint 2010).

Loss of control in bowel and bladder can result in embarrassment, shame**,** fear, isolation and avoidance of sexual activities for people on PHMV (Cotterill, 2011). Both have been reported to cause the most interruptions in life, including participation in physical activities such as ADLs (Seshan & Muliira, 2014). Lack of control in elimination affect individuals physically, psychologically, mentally, and socially. People might be afraid to travel for fear of accidents leading to isolation, or some might perceive a Foley bag as unattractive and burdensome to carry around. Psychologically, people might perceive themselves as less attractive and avoid significant others, lack of self-confidence might lead to alienation and result in poor QOL.

Personal Hygiene, Washing, and Dressing

Hygiene tasks include regular washing of body, hair, brushing or flossing teeth, and cleaning feet to maintain health and fight disease. Hygiene is essential for personal, professional, and all spheres of living. Improper or neglect hygiene can be viewed as disgusting, disrespectful causing an individual to be isolated. Keeping up high levels of hygiene, boosts self-esteem and confidence. Hygiene is used to judge people on at face value so meticulous care in body, hair, oral, and feet care is important for survival and fight against disease (Mol, 2010).

The oral cavity is made up of different bacterial species and some have an inclination to colonize the mouth's surface and lack of oral hygiene causes some to migrate into the lungs causing ventilator associated pneumonia (VAP), common in people who use a mechanical ventilator (Fields, 2008). Oral hygiene strategies such frequent mouth-care, hand-washing, semi fowlers position to facilitate draining of secretions and sub-glottal suctioning reduce colonization and prevent VAP. In the home-care setting, a toothbrush with soft bristles and toothpaste can be used to brush teeth and remove plaque; a soft suctioning tube can be used to drain water after rinsing. Toothbrushes should be kept in a dry play place and should be replaced frequently. Other oral assessments include monitoring for inflammation, bleeding, thrush, calculus, and caries. Aseptic technique is important during suctioning, use of gloves is encouraged and all the equipment should be cleaned after use. Hand washing with soap and water after completion of tasks is most effective way of getting rid of bacteria (Macy & Saint 2010).

In the home care setting unlike the ICU or long-term care setting, people on MV can choose best time for washing and bathing according to personal preference. Some people prefer morning rather than evening baths, choices should be given in how to perform the task and to avoid fatigue. Bathing increases oxygen consumption, timing and grouping activities is encouraged. Participation in self-care such as using a washcloth to wash face and choosing appropriate clothing is encouraged. Clothing should be monitored to promote body temperature. Oral health and personal hygiene influences how people enjoy life, look, speak and socialize. For individuals on PMV, the position of the tracheostomy disrupts quality of life through disfigurement, constant secretions, chronic infections, pain and sleep disruptions (Tracheostomy, 2014).

Controlling Body Temperature

Thermoregulation or maintenance of stable temperature is important for survival. External changes such as air vapor decrease or increase in temperature can affect the skin's temperature. When body temperature is below or above average, it is an indication of a disease that can lead to destruction of body organs. The presence of fever varies and depends on underlying conditions. For mechanically ventilated individuals, fever could have a negative effect on gas exchange, compromises cardiac output and oxygen usage causing hypoxemia (Schortgen et al., 2012). On the other hand, increased carbon dioxide production may deteriorate minute ventilation requirements. Fever also results in worsened lung tissue injury by mobilizing neutrophils and causing oxygen toxicity.

People on MV are not able to maintain or regulate body temperature; regular observations are required to prevent complications. Environmental monitoring is necessary and important to maintain homeostasis and comfort thereby promoting QOL. Proper clothing is required if it is too hot or cold.

Mobility

Mobilization refers to activities that allow or produce movement. Activities include getting in and out of bed, sitting up in a chair, positioning such as prone, side-to-side, continuous lateral rotation therapy beds, electrical stimulation, and range of motion and tilting on a table. The main purpose of mobilization is to prevent complications associated with immobility (Umei et al., 2016). Mobilization promotes comfort, protects skin integrity, and prevents formation of pressure ulcers. Passive or active range of motion promotes pulmonary drainage, oxygenation, and ventilation decreases the risk of acquiring pneumonia.

Standing or using a tilt table improves ventilation. Unused muscle atrophy, active, or passive range of motion and electrical stimulation can be used to maintain muscle strength (Timmermann, 2008). Resistive muscle training and structured exercises can restore muscle strength and joint flexibility (Wilson, 2012). Ambulation and active exercises are used to promote cardiopulmonary fitness (Chen et al., 2012). Energy is utilized during movement and the extent to which energy is released depends on the situation (Umei et al., 2016). Movement of any kind is encouraged to prevent muscle atrophy and decline in muscle strength associated with immobility.

For individuals on HMV, exercises such as passive range of motion and positioning utilize minimal energy. Higher energy activities such as ambulation use more energy, calories, increase cardiovascular and respiratory fitness, and these needs to be individualized. Safety is of concern for people on HMV and mobilization. Cardiovascular concerns might be hypotension, increased oxygen consumption, and the inability to meet oxygen demand. Other concerns are dislodgement of tubes and equipment, falls, injuries, and anxiety. Due to these safety concerns, the home environment has to be assessed and planning required before mobilization. Mobilization is a combination of physical and psychological system, every body system is affected as systems interact with each other (Timmerman, 2008). Psychological factors are improved mood, active and social cognitive feelings about self and functional ability. Immobilization has been found to produce strange thoughts, exaggerated emotions, impaired intellect, and time distortion (Amidei, 2012). Mobilization is beneficial in preventing psychological phenomena and enhances QOL.

Working and Playing

Individuals on HMV are likely are likely prone to social isolation and may feel excluded from social functions around them (Baker & Kakora-Shiner, 2009). Long periods of watching television can lead to boredom therefore, it is important to make recreation meaningful and fun. Relatives and friends are encouraged to take an active involvement through talking short walks and other leisure activities suitable and preferable. Too many activities in one day may be strenuous leading to fatigue. The physical environment can be improved by installing pictures, meaningful furnishings, and creating privacy keeping in mind infection control, health, safety, and risk management. Recreational activities and hobbies are important in maintaining QOL, a life worth living. Activities should be provided according to the person's interest, should be enjoyable and useful. Activities should provide a sense of belonging, improving QOL (Edvardsson, Petersson, Sjogren, Lindkvist, & Sandman, 2014).

Expressing Sexuality

Sexuality includes choices of clothes, hairstyles, make-up, and self-expression. Intimacy is encouraged with significant others and private and undisturbed time should be allowed. Private discussions are encouraged and this could be rewarding (Baker & Kakora-Shiner, 2009). For individuals on PMV, clothing can be adjusted for comfort and ease when putting on or taking off, it is not a one size fit all as the hospital gown. It is my experience as a nurse that patients want to feel as normal as possible by wearing clothing of their choice. Women are conscious about hair, make-up, and men conscious about beard whether to shave or not. Mouth care is essential and should be offered as early as the individual can tolerate. Individuals need to express who they are and remain autonomous just like life prior to placement of the tracheostomy. QOL is enhanced if individuals on HMV are happy with the image they see in the mirror. Self-expression separates each individual and allows him or her to have an identity. Self-identification and acceptance enhances QOL (Mol, 2010).

Sleeping

Sleeping rejuvenates and facilitates healing, yet sleeping disturbances in individuals on mechanical ventilation are common (Blissitt, 2016). Sleep deprivation results in negative outcomes such as decreased immunity, delayed wound healing, and increased risk for infection, cardiovascular problems, and many other physiological factors. Sleep is interrupted due to several factors such as pain, disease state, and noisy equipment, interventions such as suctioning, repositioning, and sleeping aids. Ventilator modes and inappropriate settings can cause sleep to be fragmented choosing correct ventilator modes and titrating settings can result in quality sleep. Sleep is important for maintaining QOL. Sleep plays an important role in quality of life, and it preserves health, activity, and energy essential for living.

Death

Individuals on HMV should be allowed to express their wishes and verbalize concerns on issues of death and dying when appropriate. Advanced directives are in place and used as a guide once an individual becomes incapacitated to make decisions for them. However, there are barriers in the home-care setting as it depends on the physician's comfort level to introduce the topic. Discussion of this topic is often viewed with anxiety or taking away of hope and lack of information based on the diagnosis (Hajizadeh, Crothers, & Braithwaite, 2010). Appropriate psychiatric counseling may also need to be made available in the event of any distress caused by the discussion of end of life scenarios. Age, religion, living circumstances actual patient preference elicitation, will better inform ADL shared decision-making and is one-step towards increasing preference-congruent care at the end of life (Hajizadeh et al., 2010). However, the concept will not be used to evaluate quality of life due to concerns from Institutional Review Board (IRB) to provide resources in case participants are distressed during the interview, however, the subject can be discussed if the participant brings the topic up on a voluntary basis.

Quality of Life

QOL is a complex concept that has many meanings to different groups of people. Meanings are abundant and diverse as influenced by feelings, culture, education, and religious beliefs. In nursing and healthcare, QOL measures are used as outcome variables to evaluate if an intervention is being effective. Health care interventions should improve quantity and QOL. Psychosocial evaluation such as assessment on QOL and health related behavior should be used in all clinical evaluations. I explored the perceived impact of ADLs and role in decision making on QOL.

Participation in ADLs and role in decision-making promotes simulation into society, reduces hospital costs, and reduces risk of nosocomial infections. The purpose of the study is to bring awareness to the public, families, healthcare providers about challenges faced in the home-care setting. Having a tracheostomy and connected to a ventilator results in limited participation in ADLs and modifications have to be made. The home-care setting is converted into a hospital room to accommodate equipment and supplies necessary for use. Gaps noted in the literature are studies that explore QOL of PMV users in their own words. The following discussion will highlight history of the concept, the aims or purposes of analysis, identify all the uses of the concept possible, attributes will identify model case, borderline, antecedents, consequences and empirical referents and why the concept was chosen for use in the study.

History of the concept of QOL. According to Meeberg (2008), the concept of QOL concept became popular after the Second World War, and since then, the definition has evolved. QOL is frequently studied by sociologists, who look at the housing conditions and general welfare on QOL, which is referred to as well-being. Home mechanical ventilation (HMV) has increased during the past decade (King, 2012). Underlying physiological conditions for people on HMV are slowly progressive and complicated by hospitalizations and exacerbations of symptoms. Due to the complicated nature of PMV, management of diseases includes health promotion; management of symptoms, reducing episodes of exacerbations that can lead to improved QOL, as a result, QOL is an important outcome for individuals on PHMV (Barnett, 2011). Despite the popularity of the concept, it remains ambiguous and interpreted differently by different disciplines. The meaning also varies according to associated health conditions. The purpose of this analysis is to examine the concept of the QOL for individuals on PHMV in the nursing context.

During the 1970s, the concept was used as an outcome for health care and benchmarks for social change. The concept is very broad and abstract and it relates to all aspects of humans. The concept is utilized in three branches, which are economics, social sciences, and medicine (Dignani, Toccaceli, Guarinoni, Petrucci, & Lancia, 2015). In nursing, the concept has emerged as a key concept to for assessing quality and outcomes of healthcare. Patient outcomes are end-points of care where significant changes in health-condition are caused by a medical intervention (Ying et al., 2014). QOL is an outcome for individuals on HMV because of interventions such as tracheostomy and use of mechanical ventilation. QOL is an umbrella term that covers concepts such as functioning, health status, life conditions, behavior, happiness, life-style, and symptoms (Dignani et al., 2015). The Rodgers Evolutionary Concept Analysis waw used to analyze the concept of QOL, in nursing, concepts are necessary to provide meaningful research and bring clarity (Tofthagen & Fagerstrøm, 2010).

Surrogate terms. QOL concept is very broad and multidimensional and depends on the discipline it originates from, which could be sociology, psychology, or medicine. There is no agreed upon definition thus it can be used in the context of the subject being studied. According to the Oxford English dictionary (quality of life, 2010), QOL is the general well-being of a person or society, defined in terms of health and happiness, rather than wealth. The World Health Organization (WHO, 2010) defined QOL as individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns.

There are different levels in the QOL, the general, the global, and disease. The global QOL is the total satisfaction or happiness in life. QOL is used interchangeably with health-related quality of life (HRQOL; Dignani et al., 2015). HRQOL is quality of life as determined by a person’s state of health. The disease or condition specific HRQOL is described as experience of special symptoms and difficulties related to the diseases, which reflect the patient’s symptoms, functional status, and general health views (Al-Jabi et al., 2015). Disease specific and disease specific health-related QOL refer to QOL in the context of people on PHMV.

Antecedents. Antecedents are factors leading to a concept or events that occur prior to the concept (Tofthagen, & Fagerstrøm, 2010). QOL is the individual's subjective definition of well-being in relation to the impact of the burden of disease on their physical, social and psychological health (Finkelstein, Wuerth, & Finkelstein, 2009; Porter et al., 2012). There must be life and mental capacity to evaluate one's life. Individuals on home mechanical ventilation experience dyspnea, fatigue, anxiety, depression and social isolation affecting activities of daily living. Other antecedents of QOL include tools to measure QOL, professional figures and individual's personal ability, disease characteristics, and conditions that negatively affect QOL (Dignani et al., 2015).

Questionnaires are used to explore quality of life (Hogg et al., 2009); quantitative measures include Short Form 36, which is disease- specific, and the Saint Georges' Respiratory Questionnaire, which is divided into QOL domains (Weldam, Schuurmans, Liu, & Lammers, 2013). Professional uses by case-managers and other health-care professionals allow individualization of care, development of quality of life issues and allow a trusting relationship with families and people on PHMV thereby improving QOL. Clinical care management of disease for individuals on PHMV includes symptom management and prevention of exacerbations and hospital readmissions to improve QOL. Pulmonary rehabilitation is important because it restores people to their highest level of functioning. Conditions that negatively affect QOL are interrupted sleep, impaired communication, and recurrent hospitalizations (Blumenthal et al. 2009). Emotional instability or difficulty coping can affect QOL (Kil, Oh, Koo, & Suk, 2010).

Other antecedents noted are self-care practices such as physical and mental wellbeing, exercise capacity and self-advocacy because self-care plays a major role in QOL and prevents readmissions in the hospital, and minimize physician's visits (Warwick, Gallagher, Chenoweth, & Stein-Parbury, 2010). Disease components such symptom progression negatively affect QOL. Functional status and QOL decrease with disease severity (Ade-Oshifogun, 2012).

Defining attributes. Attributes of a concept are characteristic that help identify situations that can be grouped together under the concept (Tofthagen, & Fagerstrøm, 2010). The attributes for QOL are adequate mental capacity, acceptable state of physical social, emotional health, and ability to evaluate life as satisfactory. For individuals on mechanical ventilation, QOL is defined by the ability to perform ADL and ability to engage in family, social and occupational roles, ability to communicate, minimize depression, and mental capacity to evaluate their life. Full mental capacity is defined as being alert, oriented to person, time, place and situation, ability to engage in a meaningful conversation, and evaluation by other people as competent. For this study, full mental capacity is required, as mentioned; a participant has to engage fully in the interview, and is evaluated by others such as family members or health-care providers as competent (Meeberg, 2008).

Other attributes identified for the study involve the individual on HMV and the meaning of life in their context or environment. Blumenthal et al. (2009) pointed out that

QOL covers domains such as physical, emotional, social functioning, views on health, well-being, and disease symptoms, it can be deduced from this statement that QOL is a multidimensional concept that covers physical, psychological and social domains of life. Bele, Bodhare, Mudgalkar, Saraf, and Valsangkar (2012) defined QOL as an individual's view of self, how they function on a daily basis taking into account elements such as physical and mental being, education, recreation, leisure time and social belonging. QOL is aligned to the meaning of health and happiness in one's life.

Consequences

Consequences are an outcome, results of actions of decisions made (Tofthagen & Fagerstrøm, 2010). Outcomes for people on PHMV are related to care, caregivers, and health-care providers. Outcome measures for people on HMV include functional status such as ability to participate in ADLs, role in decision making, health perceptions, and living at home. QOL is an outcome for people living at home on PMV. In regards to caregivers, QOL is decreased with severity of disease (Caress, Luker, Chalmers, & Salmon, 2009). The goal for QOL is not to cure the disease, rather, to alleviate the symptoms, maintain functional status through ADLs, decrease readmissions and enhance QOL. For users of PMV, QOL is affected by both intrinsic factors related to the disease such as symptom management and exacerbations, and extrinsic, such as poor suction techniques. Individuals on PHMV with moderate to severe disease have frequent exacerbations and when combined with disease progression leads to decreased QOL (Hutchinson et al., 2010).

Limitations of the Concept

The concept of QOL is very broad and multidimensional, thus researchers must remain objective and let the meaning of the concept emerge from literature to reduce bias. Inconsistency of the definition of QOL result in different views of defining attributes. QOL and HRQoL are sometimes used interchangeably thus confusing at times. As technology advances and is easier to use for patients of all ages, the concept of QOL is also evolving, what was true 10 years ago could be irrelevant today.

Survival rates for people with tracheostomies on PMV have increased; yet, there are limited data on QOL and the relationship between QOL and participation in ADLs and role in decision-making. Practitioner beliefs and practices, education about mechanical ventilation, psychological trauma, and loss of previous activities need to be included in research on ADLs. Evaluation of QOL has become important in research and health care practice to evaluate the human and financial costs and benefits of modern medical techniques. Accordingly, outcome researches on people who live on HMV have changed from survival-analysis to complex investigations that include evaluating QOL.

Similar Studies

A systematic review of literature evaluating QOL for people on mechanical ventilation using validated tools to measure occurrences of hospitalizations, caregiver burden and utilization of services was conducted. Included in the review were neuromuscular disorders, restrictive thoracic diseases, and obesity. Findings revealed that QOL was found to be favorable. Mental compared to physical states were ranked higher

(MacIntyre, Asadi, Mckim, & Bagshaw, 2016). Hospitalization occurrences and length of stay decreased with the implementation of HMV and caregiver burden was high.

A qualitative study of nine participants of patients with Duchenne muscular dystrophy on HMV was conducted to capture life experiences of living with a chronic illness and respiratory failure. Themes that emerged were roles in decision-making that included difficulty in making the decision to have a tracheostomy placed electively, which led to the delay in treatment (Dreyer & Penderson, 2009). Another theme was relief from fear of dying from breathlessness because MV provided relief and gave new meaning to life.

Summary and Conclusion

Placement of tracheostomy in what is usually a closed system affects speech, eating and grooming. Tracheostomies impact body image and perceptions, it affects speech, swallowing and is a source of bacterial invasion. Use of MV affects breathing, mobility, sleeping, safety environment, bowel and bladder elimination, work and play and expressing sexuality. The MV is self-limiting, the size and equipment associated with use limits participation in ADLs. Complex underlying pathological conditions cause fatigue and dyspnea. Long periods in the ICU can lead to muscle weakness, which may take years to recover. The present study fills the gap by exploring the individuals' perception of life on PHMV and how the 12 ADL impact QOL and role in decision-making. Previous studies focused on perceptions of individual user satisfaction based on caregiver support and training on healthcare providers. Few studies have been carried out on functional status of MV users in the ICU; no researcher has addressed the impact of tracheostomy and limitations noted in ADLs. It is my hope to go beyond equipment and procedures, and dig deep and investigate life as perceived by HMV participation in ADLs, and role in decisions making. Chapter 3 will cover phenomenon of the study, the theoretical framework and methodology used.

Chapter 3: Research Method

Introduction

Qualitative studies on QOL for individuals on PMV focusing on ADLs are scarce. Scholars have examined caregivers, families, and the mechanical ventilator itself. Due to the increase in the number of people obtaining tracheostomies and being discharged into the home care setting on PMV, it is important to address how this population participates in ADLs. The purpose of this study was to explore QOL for individuals with tracheostomies on prolonged HMV focusing on ADLs and the role of decision-making. I also highlighted the challenges faced in the home care setting (King, 2012). The phenomenological approach was used to encapsulate the experience of individuals with tracheostomies who live on HMV. A better understanding of QOL for those on HMV is paramount to protect and promote the dignity, health, safety, rights, and QOL for individuals on HMV. It is important to educate families, health care providers, and the public to bring a new understanding and awareness to QOL and prolonged dependence on HMV in the home care setting (King, 2012).

This chapter includes the methodology used and why the phenomenological approach was suitable to answer the research questions. This approach was used to gain an in-depth understanding on QOL for individuals on HMV in the context of their environment. A phenomenological approach is made up of the lived descriptions of meanings of multiple participant experiences (Creswell, 2013). Moura et al. (2016) posited that phenomenology includes the view that human experience is projected with social meaning through understanding of the world through a person’s experience.

Pringle et al. (2011) stated that researchers use phenomenology to use evolving data, while standing firm in the analysis of participant's words.

Research Questions

The following questions were used to guide the study:

1. What is the perceived QOL for individuals with tracheostomies on prolonged mechanical ventilation in the home care setting?
2. To what extent are individuals on HMV involved in decision-making and participation in ADLs?

Research Design and Rationale

The phenomenological approach was chosen because it produces data on how participants live their life rather than explain it (Meide, Olthuis, & Leget, 2015). The phenomenological approach includes open-ended questions, which allows collection of more information compared to quantitative, closed ended-questions (Flood, 2010). Creswell (2013) suggested that the best way to use phenomenology is when the research problem requires an in-depth understanding of human experience common to a group of people. The group should be made up of six to10 participants who should be able to verbalize their lived experiences (Creswell, 2013). If participants are diverse, it is hard for the researcher to find and extract themes. The role of the researcher is to build or construct meaning of the topic or phenomenon being studied (Creswell, 2013). Grounded theory was not chosen because the purpose of this study was not to construct a theory. Ethnography was not used because the purpose of this research was not to study a cultural phenomenon. A case study research design was not used due to the limited number of people on mechanical ventilation in the community.

Individuals with tracheostomies who live on a mechanical ventilator are viewed by society as a vulnerable population. I used a phenomenological study to explore the QOL as viewed by this population, their perspectives, perceptions, and understanding in the context of their lives (Thorpe & Holt, 2008). The issues within QOL consist of what it is like to perform AOL or living in general while on a ventilator and how the individual goes shopping, eats, communicates, dresses, or interacts with friends and their social environment. The issues are part of the QOL for all the individuals on a mechanical ventilator at home. Central concepts of the study, such as tracheostomy, mechanical ventilation, PMV, and QOL were explored.

Central Concepts in the Study

Tracheostomy

Percutaneous dilatational tracheostomy (PDT) is a routine surgical procedure for critically ill patients who require prolonged ventilator support. Tracheostomies help prevent the development of complications associated with long-term intubation (Parchani et al., 2013). Critically ill patients often require tracheostomy for continued airway support. The procedure can be performed either via open surgery in the operating room or via the percutaneous method at the bedside. The number of tracheostomies being performed internationally in ICUs is increasing (Paul, 2010) and 100, 000 are performed annually in the United States (Yu, 2010). Tracheostomies are placed due to underlying neuromuscular or respiratory conditions, trauma, or difficulty weaning from endotracheal intubation. The purpose of this study was to explore QOL for individuals with tracheostomies for at least 6 months, in the homecare setting and how participation in ADLs improve QOL.

Mechanical Ventilation

Individuals with tracheostomies are placed on PMV to aid in breathing. Mechanical ventilation is the preferred treatment for individuals in respiratory distress. Advances in technology have led to an increase in the number of individuals who remain dependent on mechanical ventilation beyond the acute and long-term setting into the community. Indications for tracheostomy include acute respiratory failure, inability to wean from mechanical ventilation, upper airway obstruction, and copious secretions. Prolonged intubation results in ventilator-acquired pneumonia, contamination of the bronchial tree lining, and lung and sinusitis. Placement of a tracheostomy has become an alternative to prolonged endotracheal intubation. Mechanical ventilation leads to improved patient comfort, reduced amount of sedation, lowered airway resistance, and allows for easier airway care. There is no agreed definition on PMV. Some stated that PMV is endotracheal intubation greater than 96 hours. For purposes of this study, PMV is having a tracheostomy for at least 6 months and use of a ventilator for at a minimum of 6 hours a day (Department of Health and Human Services, 2014).

Activities of Daily Living

ADL are activities essential for every human being to perform and live on a day-to-day basis. These activities include eating, drinking, dressing, elimination of stool and urine, communication, sleeping, and ambulating to mention a few. Difficulty in performing ADLs can lead to psychological distress and social isolation. Presence of acute or chronic health conditions affect participation in ADLs requiring people to relearn how to do these activities. In some instances, ADLs have to be adjusted to accommodate the new health status. Individuals with tracheostomies on HMV have different underlying physiological diseases or conditions that prevent them from participating in some or all ADLs. The purpose of this study was to explore QOL as an outcome based on participation in ADLs and role in decision-making (Vest, Murphy, Araujo, & Pisani, 2011).

The RLT was used as a framework to guide the interview protocol (Appendix B). The 12 ADLs identified are maintaining a safe environment, communication, breathing, eating and drinking, eliminating, personal cleansing and dressing, controlling body temperature, mobility, working and playing, expressing sexuality, sleeping, and dying. The RLT is based on Henderson's theory that when people are hospitalized, participation in ADLs is compromised; therefore, Henderson developed an ADL theoretical framework to guide clinicians in nursing people to their pre-hospitalized function or to adjust to suit health condition. The purpose of using the 12 ADLs as an outcome to measure for QOL is to assess the person's ability to function after placement of tracheostomy and use of the mechanical ventilator for long-term use in the home care setting. Each individual has a unique way to adapt and adjust to participation in ADLs and may alternate between the dependence and independence phases in performing ADLs to enhance the QOL. The purpose of the study was to assess how 12 ADLs can improve

QOL and how care can be tailor made to suit patient needs because of the themes extracted from the interviews (Vest et al., 2011).

Quality of Life Concept

QOL includes physical health, psychological state, independence, social engagement, and environment. QOL can be interpreted according to the context of which it is being used (Boudreau & Dubé, 2014; Mouser, 2014). The construct that was explored in this study was QOL and how it was viewed by people on HMV. QOL outcomes are used to create clinical decisions to guide health care providers when rendering care to people with chronic conditions (Boudreau & Dubé, 2014). QOL is a person's view of his or her life in respect to societal and personal goals in life; however, when illness or sicknesses affect QOL, QOL involves a person's personal experience of life and health (Boudreau & Dubé, 2014). People on MV face challenges when participating in ADLs due to underlying health conditions and physical limitations of the mechanical ventilator; it is important to assess QOL as an outcome based on ADLs. People on MV are viewed by society as a vulnerable population and burden to society; yet the users view a MV as an aid to life just like a wheelchair or other equipment is used to sustain life. As a result, QOL is used as an outcome to assess if participation in ADLs improves or enhances QOL (Beh Hui, 2012; Kruse et al., 2013).

Role of the Researcher

My role in this study was that of interviewer and observer. As an ICU nurse who has worked with patients with tracheostomies on MV, I am aware of how to take care of individuals on MV and tracheostomies. It was important to bracket my feelings and ensure that they did not interfere with the study results. According to Chan, Fung, and Chen (2013), bracketing requires the researcher to set aside what he or she already knows about the phenomenon. Bracketing ensures validity of data collection and analysis when researchers put aside their notions, beliefs, values, and experiences to rule out bias (Chan et al., 2013). Interviews were guided by the Roper et al.'s (1990) theoretical framework of AL to evaluate QOL, participation in ADLs, and role in decision making. Interviews were audio taped for participants who could speak.

Methodology and Participant Selection Logic

The populations for the study were males and a female who lived in Northeast Pennsylvania, and were serviced by home care agencies that manage people on prolonged HMV. A purposive sampling technique was used to recruit 10 participants with tracheostomies on prolonged HMV. Inclusion criteria included males or females; 18 years and above; have a tracheostomy; have been on HMV for at least 6 months; use MV for at 6 hours or more; had the ability to complete a 1-hour interview; could follow directions and use different communication aids, such as Passy-Muir valve, iPad, Tobii eye gaze, or used eyes to respond to the alphabet; and understood English. Exclusion criteria included subjects under the age of 18; noninvasive MV; non-English speaking participants; and people with tracheostomies on MV in the hospital, skilled facility, or group home.

Sample Size

The participants had different underlying conditions that necessitated the use of MV, had tracheostomies, and were on prolonged HMV. Following Walden IRB approval, letters of cooperation were obtained. Flyers with contact information and details of the study were distributed to individuals on HMV. For nonverbal users of HMV, spouses, family members, and nurses called on behalf of the family member to participate in the study. For verbal volunteers, calls were made through the phone and others via e-mail. I made a call to obtain demographic information, and the selection criterion was reviewed. If met, another call was made to set an interview date. According to Creswel (2010), a phenomenology sample size should be between six to10 participants to reach saturation. Dyrstad et al. (2012), Ballangrud et al. (2009), and Briscoe and Woodgate (2010) used six to 11 subjects to reach data saturation.

Instrumentation

Face-to-face interviews were conducted in the participant's home using an interview guide (Appendix C) based on AOL. The interviews lasted between 1 to 1 ½ hours. The interviews started with demographic data, such as age, disease, and marital status. Field notes were recorded in a notebook. Open-ended questions were used to allow participants to expand more on their thoughts. Participants were given an opportunity to discuss questions that could emerge through the conversations.

Procedures for Recruitment, Participation, and Data Collection

Clinical managers, supervisors of the home care agencies, and pharmacists received an explanation of the purpose and nature of the study. Letters of cooperation were obtained after IRB approval (Appendix B). Some flyers were distributed by home care agency and representative, and I distributed some after gaining access to individuals who use HMV (Appendix A). On the date of the interview, consents were given to participants (Appendix F).

An interview protocol that I design that was based on the RLT using open-ended questions was used to guide the interview (Appendix C). Audio tapes were destroyed after data transcription, and transcribed data will be discarded after 5 years as required by Walden policy. Field notes will be locked in a filing cabinet and used exclusively by me.

Data Analysis Plan

NVivo was used for coding the data. NVivo has the ability to organize and analyze interviews, field notes, and audio files. NVivo allows a project to be created that consists of all of the uploaded files in one folder. Once this is completed, notes/themes are created and analyzed. NVivo allows creation of projects that contain different documents needed for analysis. Data were analyzed from recurring themes and findings summarized (QRS International, 2010).

Issues of Trustworthiness

Qualitative research is subjective, interpretive, and contextual in nature (Thomas, 2011). Rigor applied in quantitative research is not possible in qualitative research; as a result, validity in qualitative studies have developed numerous categories to fulfill this dilemma (Patton, 2015). The dependability of research is guarded by the practices of the researcher through consistency of findings and application over time. This study was written using best practices in research as advised by the university and the IRB. Participants were provided confidentiality statements. On the day of the interview, I described my role as the researcher. In order to maintain my level of bias, I explained that

I was an ICU nurse who has taken care of individuals on prolonged MV in the hospital and home setting, I am familiar with the intensity of care and monitoring required for this population. I stated that my goal was to listen to their story, and they could stop the process if they chose.

The interviews were carried out in the comfort of the participants' homes with close proximity to supplies such as suctioning, nebulizer treatments and toileting. Data was collected, transcribed and analyzed directly from the words provided by the participants in telling their lived experiences. Copies of the transcripts were sent back to participants for review and accuracy. Participants were able to review the transcript of the interview and made changes to if they felt information was represented incorrectly. Data are stored at home in a filing cabinet and computer with password security. According to Creswell (2013), a researcher should employ a minimum of two strategies to develop quality of their research. This study included rich descriptions, ability of participant to withdraw from the study, field notes for observations and researcher's thoughts, ability to read and review their transcript and member checks by committee members. For purposes of this study, validity was established through credibility, transferability, dependability, and conformability.

Credibility

According to Thomas (2011), credibility refers to accuracy of the data. To ensure credibility triangulation was used. Triangulation is using multiple sources of data to strengthen the research stud such as interviews, observations, member checks. According to Patton (2015), triangulation strengthens the study by combining methods; as a result, field notes as well as interviews were used to collect data. Interviewing participants allowed me to ask questions and listen to the experiences of the individual. Participants reviewed the transcripts (Member checks). The interview was part of the rich data focusing on the lived experiences and perceptions on prolonged HMV. There were some similarities and differences in responses but each participant is an individual with autonomy. Credibility was also maintained by extensive interaction with the participants, spouses, caregivers and nurses during the interview; this allowed the researcher to build an in-depth understanding of lived experiences and role in decision-making of the participants. Saturation can be reached between six and 10 participants (Creswell (2013) and 10 participants allowed the researcher to reach saturation. Reflexivity was used to set biases and preconceived notions aside.

Transferability

Transferability is the ability to apply the results or findings to another setting (Thomas, 2011). In qualitative studies, targeted sampling techniques are used to elicit data from a specific group of participants that can provide sufficient expertise so that comprehension of phenomena and development of theory directly related to phenomenon are achieved (Thomas, 2011). To ensure transferability in this study, a purposive sampling was used to reveal in depth descriptions of participants' experiences, their perception on QOL, participation in ADLs and role in decision-making while on HMV which will allow transfer of information to another setting.

Dependability

Dependability is the stability of data over time, or its consistency of findings (Patton, 2015). The methods used for selection of participants, sessions to observe, interview were clearly presented. An independent auditor who reviews interviews as recorded by an audit trail ensures credibility and transferability. Triangulation was used to strengthen the study with the use of field notes, interview, member checks, and supervision of data collecting procedures by chair. Member checks were used; participants reviewed findings and data interpretation for accuracy.

Confirmability

Confirmability or interpretive validity involves how the researcher reports the participants meaning of events, objects or behaviors, noting that interpretations are based on researcher's perspective but that of participant (Thomas, 2011). To ensure truth, accuracy and true representation of participants' action, transcripts were sent to participants for accuracy and corrections. I was careful not to influence my participants' opinions and allowed data to reveal findings. The study was reviewed by committee members who are experts in qualitative studies.

Ethical Procedures

IRB approved the study as sought from Walden University. The home care agencies reviewed my plan to ensure federal regulations that protect research participants' privacy. Participants identified through purposive sampling were given an informed consent form that explained that the purpose of the study was to fulfill a doctoral degree requirement. A consent form must be given if working with human participants (Creswell, 2013). Participants were informed that they could withdraw from the study at any stage of the interview if they felt uncomfortable with the questions. To ensure confidentiality, the letter P followed by numbers 1 to 10 such as P1, P2 to P10 were used for identification and to track the interview. No identifying information was used to report the data. Participants were treated with dignity and respect and ample time allowed as the subject's tolerance for interviewing allowed. A laptop computer that is password protected was used to store recordings. Ethical standards involving data collections were carefully observed during the research process.

Participants were advised to stop the interview at any point and could withdraw if they became uncomfortable with the questions or other reasons. A contingent plan for respiratory or medical distress was in place, and the interview would have been stopped, however, all interviews were completed in one sitting without any distress. Research compromises tenets such as sincerity and respect of individual rights (Patton, 2015), therefore, it was ensured by me that the findings in this study are based on findings and results and literature from previous studies.

Summary

This chapter was a description of the qualitative phenomenology. Phenomenology was the best approach to address the research questions and form of data collection for this study. This study relied on participants' experiences on prolonged HMV. The purpose of this qualitative study using a phenomenological approach was to explore the lived experiences of people on HMV. Phenomenology provides rich in-depth lived exploration of lived experiences of people on prolonged HMV. Purposive sampling was used to recruit 10 participants since it allowed access to individuals on prolonged HMV. The interviews were conducted in the home care setting in a face-to-face interview that lasted between an hour to an hour and a half. Data were collected through a structured interview that included open-ended questions with the aim of soliciting responses from participants.

Ethical considerations were observed in all phases of the study, consent forms that discussed the study were given before data collection and NVivo software was used for data analysis. All data obtained through interviews will be destroyed after 5 years. This section included the research design, data collection method, sampling procedure, data analysis plan, sample population, treatment of participants and the procedure that identified ethical procedures. Results of the study will contribute to greater understanding of lived experiences that can be used for further studies.

Chapter 4 represents the results and findings of this study. It begins with a detailed description of the data collection and analysis process carried out during the study and moves to discussion of results. Chapter 4 frames the responses provided by participants during the interview and their lived experiences in relationship to the research questions.

Chapter 4: Results

Introduction

The purpose of this study was to explore QOL for individuals with tracheostomies on prolonged HMV focusing on ADLs and the role of decision-making. In the study findings, I highlighted challenges faced in participating in ADLs in the home care setting (King 2012). A phenomenological approach was used to capture the experience of individuals with tracheostomies who live on HMVs. A better understanding of QOL for those on HMV is paramount to protect and promote the dignity, health, safety, rights, and QOL for individuals on HMV. It is important to educate families, health care providers, and the public on QOL and prolonged dependence on HMV.

The phenomenological approach was suitable because it produced data on how participants lived their life rather than explained it (Meide et al. 2015). The use of open-ended questions provided insights and depth of understanding to a greater extent than quantitative closed ended-questions could have provided (Flood, 2010). Creswell (2013) suggested that the best way to use phenomenology is when the research problem requires an in-depth understanding of human experience common to a group of people.

The purpose of this study was to awareness to the daily challenges faced in performing ADL by individuals on HMV. A better understanding of these issues is crucial in order to improve the QOL for both patient and family and to assist health care professionals involved in HMV to make informed decisions for the benefit of the individual and his or her family. I found that several challenges restrict participation in ADLs; therefore, there is a need for understanding the challenges.

In this chapter, I will present the research setting, participant demographics relevant to the study sample, data collection, and analysis procedures. I will discuss issues of trustworthiness, results, themes, theoretical framework, and summary of findings.

Research Questions

1. What is the perceived QOL for individuals with tracheostomies on PMV in the home care setting?
2. To what extent are individuals on HMV involved in decision-making and participation in ADL?

Research Setting

I contacted a pharmacist and two home care agencies that worked with individuals with tracheostomies on HMV in Northwestern Pennsylvania to recruit participants. The clinical manager, supervisor, and a representative were provided with verbal and written information about the study and were requested to hand flyers to individuals who used HMV. Of the 14 individuals who volunteered to participate, one did not meet the selection criteria; he had a tracheostomy, but did not use a ventilator. Two did not complete the study due to scheduling conflicts, and two did not respond after the initial call to set up an appointment. All participants were Caucasian, spoke or understood English, and were on PMV for more than a year. Every participant was given a consent form and confidentiality agreement, as required by Walden University's IRB. After completing the consent form, participants responded to several open-ended questions in a semi structured interview. In the questions, I sought to capture the phenomenon of living at home on a ventilator and their role in decision-making.

Demographics

The study sample included one female and nine males who ranged in age from 27 to 81 years; their experiences with HMV ranged from 2 to 27 years. Ten participants completed face-to-face interviews for this study. Participants represented a range of diagnoses and levels of functioning; some were dependent on the ventilator around the clock, while others used it only during the night when asleep. Underlying conditions or events leading to tracheostomy placement included muscular dystrophy (MD), trauma such as motor vehicle accident (MVA), cancer, stroke, aspiration pneumonia, and amyotrophic lateral sclerosis (ALS). Disease progression varied with ALS diagnosis from 5 to 19 years. During the interviews, participants communicated by means of aids such as iPad, Tobii Dyavox, speech valves, or blinking eye movements when spelling out the alphabet. Interview times ranged from 1 to 1 1/2 hours in length. Interviews were completed independently by the participant, or with help of nurses and families. Living conditions varied; one participant lived alone, was independent, ambulates and still droves. Two participants lived alone with nursing care around the clock, four lived with their parents, two lived with their spouses and children; one had nursing care during the day only and the other no nursing care in the home. The 10 th participant lived with a spouse and with nursing care 24 hours per day. One participant's father relocated to come and live with him, but has nursing care 24 hours per day. Participants did not discuss cost of provisions various services or end-of-life issues, as this was not a part of the study. Participant will not be described individually to protect their identity.

Data Collection

Recruitment of the participants for the study took about 2 weeks after approval from the Walden University IRB (05-18-17-059243). Data collection began on June 4, 2017 and concluded on June 19, 2017. I had originally planned to collect data from one home care agency; but, due to lack of participants, I obtained letters of cooperation from an additional agency and a pharmacist who manages and supplies medications for individuals on home mechanical ventilation.

Purposive sampling was used to recruit volunteer participants. The 10 participants included one female and nine males'. Upon receiving flyers, participants, family members, parents, spouses, and caregivers contacted me using the phone, text, or e-mail. I accepted participants who met the inclusion criteria. I sent possible dates for interviews via e-mail or phone and made appointment times convenient for participants. Two participants decided not to participate because of conflicting schedules; one did not meet the inclusion criteria because he did not use the ventilator. Two never responded after initial calls were placed.

Interviews were conducted in the participants' home and ranged from 1 to 1 1/2 hours to accommodate the participants, as some were interrupted for suctioning as well as to allow rest periods. I obtained consent with the help of family members, power of attorney, or nurses, as some participants could not sign due to the disease condition. Most interviews were carried out in the house where some participants sat in wheelchairs in the living room, and others at the bedside for bed-bound participants. Participants were geographically separated as far as 300 miles apart in Northeast Pennsylvania.

Interviews were completed successfully in one appointment with each participant. Three participants, who could speak using a Passy-Muir valve, gave permission for their interviews to be audio taped. One participant did not have a speaking valve; instead, he placed a finger on his stoma to produce speech. His interview was slightly longer as he could not breathe and talk at the same time; therefore, the interview was interrupted when he needed to be suctioned or needed rest periods. An elderly participant used the iPad with the help of family and nursing to guide his hand.

Responses were recorded in my field notebook. Two participants used their eyes for communication by spelling letters of the alphabet; from A to N, they would blink upwards, and from N to Z blink downwards. Family members helped the participant spell the response, which was exhausting. In this particular case, some of the responses were yes, no, or just one-word answers. During the call to schedule the interview, some family members verbalized a need to have the interview guide ahead of time to allow ample time for participants to complete the interview questions. The interviews in those cases were slightly longer than the average interview and exhausted the participant. As a result, questions were sent via e-mail directly to the participant. The participant used the Tobii eye gaze or Dynavox. On the day of the scheduled interview, I conducted the interview, question by question, and reviewed the responses that allowed me to see facial reactions and body language so I could properly interpret areas of emphasis within the reply. The last participant used the Tobii eye gaze; he received questions via e-mail and answered all the questions, which I transferred into a word document. I jotted responses read to me from the iPad into my field notebook and later transcribed them into a word document.

There were several unusual circumstances during data collection. One of the agencies went with me to distribute the flyers to potential participants. On one occasion, after distributing the flyers, a participant wanted to be enrolled in the study and be interviewed immediately. After reviewing my inclusion criteria, the interview was conducted successfully in one sitting. Due to the disease process of the participants, family members, caregivers, or nurses had to stay during the data collection to either help with the communication, such as assisting with the iPad, frequent repositioning, suctioning, medication administration, or toileting.

There were several interruptions during the interview by family to remind the participant of some events or relevant information they had forgotten. Some audio tapes had poor sound quality due to various noises in the background; as result, I had to listen several times to each transcription. In some residences, cats came to sit and snuggle with the participant; distracting them for a while; but, I did not try to stop them. In one household, the children were sent into a separate room to allow privacy; as a result, they came into the room occasionally for curiosity.

Data Analysis

For quest of in-depth experiences and tradition with phenomenology, I sought lived experiences on quality of life and role of decision-making for individuals on PHMV. After data collection and transcription of the recorded interviews and field notes, I began data analysis. I relied solely on the interpretation of the participants' perception of their lived experience of life on how they live on prolonged HMV. From this perspective, I was able to gain insight of the phenomenon and document direct responses as they occurred. Phenomenology provided an opportunity to understand how individuals on prolonged HMV live, carry out activities of daily living and clarify their role in decision-making and how these factors contribute to the QOL.

By applying knowledge of the Roper, Logan and Tierney Model (2001) AL was developed based on the Henderson's needs theory that focuses on patients interacting with the environment, family, and community after leaving the hospital. Roper et al. (2001) defined what living means by categorizing the activities of what people do during the day to maintain their life. Chronic health conditions affect a person's ability to participate in ADLs and cope with daily challenges. Roper et al. stated that acute illness and chronic diseases direct people to adapt to changes necessary for functioning.

The activity of living theory assesses the patient's independence and potential dependence based on the life continuum, and effect of an illness. Factors that affect ADL are biological, sociological, physiological, psychological, and politico economic. Participation in activities of daily living will ensure that individuals with chronic illness remain functional. Individuals on prolonged HMV have chronic underlying conditions and are very limited in participating in ADLs, and this model is being used as a guide. Applying knowledge of the theory of ADLs, the perception on quality of life from males and female participants made responses easier to understand. The theory provided a platform for data analysis.

Upon review of participants’ responses and data, I exported the data into NVivo software, which assisted in coding, organizing, and analysis of data. Uploading of data was less time consuming as it eliminated the copy and paste function. Once I uploaded data, identifying information was removed and a P followed by a randomly assigned number was used to maintain anonymity. Due to geographical location and time needed to travel, I started transcription after I completed all the interviews. Transcripts were read four times for accuracy and uploaded into NVivo software. Nodes were formed based on the word frequency queries, word tree visualizations and cluster analysis and themes identified on performance of ADLs, role of decision making, environment safety, family and relationships.

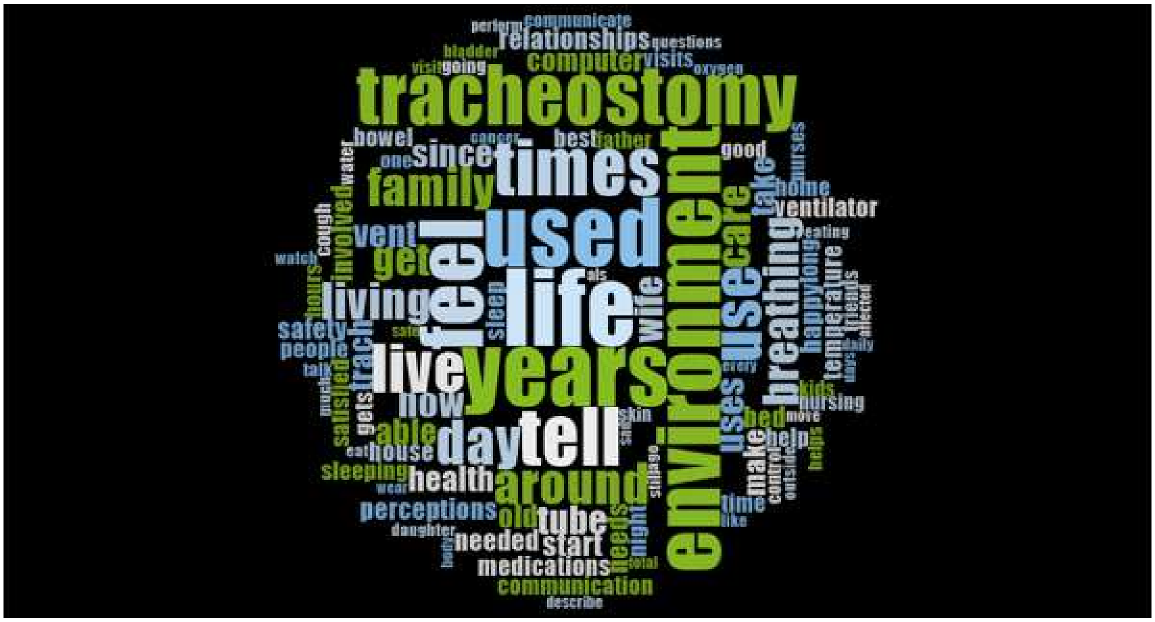

Figure1. Word frequency cloud.

Evidence of Trustworthiness

Qualitative research is subjective, interpretive and contextual in nature (Thomas, 2011). Rigor applied in quantitative research is not possible in qualitative research, as a result, validity in qualitative studies have developed numerous categories to fulfill this dilemma (Patton, 2015). The dependability of research is guarded by the practices of the researcher through consistency of findings and application over time. This study was written utilizing best practices in research as advised by the university and the IRB. Participants were provided confidentiality statements. On the day of the interview, I described my role as the researcher. In order to maintain my level of bias, I explained that I was an ICU nurse who has taken care of individuals on prolonged MV in the hospital and home setting and are familiar with the intensity of care and monitoring required for this population but maintained that my goal was to listen to their story and could stop the process if they choose.

The interviews were carried out in the comfort of the participants' homes with close proximity to supplies such as suctioning, nebulizer treatments and toileting. Data were collected, transcribed, and analyzed directly from the words provided by the participants in telling their lived experiences. Copies of the transcripts were sent back to participants for review and accuracy. Participants were able to review the transcript of the interview and made changes to if they felt information was represented incorrectly. All transcripts are stored at home in a filing cabinet and computer with password security. According to Creswell (2013), a researcher should employ a minimum of two strategies to develop quality of their research. This study included rich descriptions, ability of participant to withdraw from the study, field notes for observations and researchers thoughts, ability to read and review their transcript and member checks by committee members. For purposes of this study, validity will be established through credibility, transferability, dependability and conformability.

Credibility

According to Thomas (2011), credibility refers to accuracy of the data. To ensure credibility triangulation was be used. Triangulation is using multiple sources of data to strengthen the research study such as interviews, observations, and member checks. According to Patton (2015), triangulation strengthens the study by combining methods; as a result, field notes as well as interviews were used to collect data. Interviewing participants allowed me to ask questions and listen to the experiences of the individual. Participants reviewed the transcripts (member checks). The interview was part of the rich data focusing on the lived experiences and perceptions on prolonged HMV. There were some similarities and differences in responses but each participant is an individual with autonomy. Credibility was also maintained by extensive interaction with the participants, spouses, caregivers and nurses during the interview; this allowed me to build an in-depth understanding of lived experiences and role in decision-making of the participants. Saturation can be reached between six and10 participants (Creswell (2013); 10 participants allowed me to reach saturation. Reflexivity was used to set biases and preconceived notions aside.

Transferability

Transferability is the ability to apply the results or findings to another setting, in qualitative studies, targeted sampling techniques are used to elicit data from a specific group of participants that can provide sufficient expertise so that comprehension of phenomena and development of theory directly related to phenomenon are achieved (Thomas, 2011). To ensure transferability in this study, a purposive sampling was used to reveal in depth descriptions of participants' experiences, their perception on QOL, participation in ADLs and role in decision-making while on HMV which will allow transfer of information to another setting.

Dependability

Dependability is the stability of data over time, or its consistency of findings (Patton, 2015). The methods used for selection of participants, sessions to observe, interview were clearly presented. An independent auditor who reviews interviews as recorded by an audit trail ensures credibility and transferability. Triangulation was used to strengthen the study with the use of field notes, interview, member checks, and supervision of data collecting procedures by chair. Member checks were used and participants reviewed findings and data interpretation for accuracy.

Confirmability

Confirmability or interpretive validity involves how the researcher reports the participants meaning of events, objects or behaviors, noting that interpretations are based on researcher's perspective but that of participant (Thomas, 2011). To ensure truth, accuracy, and true representation of participants' action, transcripts were sent to participants for accuracy and corrections. I was careful not to influence my participants' opinions and allowed data to reveal findings. The study was reviewed by committee members who are experts in qualitative studies.

Ethical Procedures

IRB approved the study as sought from Walden University. The home care agencies reviewed my plan to ensure federal regulations that protect research participants' privacy. Participants identified through purposive sampling were given an informed consent form that explained that the purpose of the study was to fulfill a doctoral degree requirement. A consent form must be given by the researcher if working with human participants (Creswell, 2013). Participants were informed that they could withdraw from the study at any stage of the interview if they felt uncomfortable with the questions. To ensure confidentiality, the letter P followed by numbers 1 to 10 such as P1, P2, and P10 were used for identification, and to track the interview. No identifying information was used to report the data. Participants were treated with dignity and respect and ample time allowed as the subject's tolerance for interviewing allowed. A laptop computer that is password protected was used to store recordings. Ethical standards involving data collections were carefully observed during the research process.

Participants were advised to stop the interview at any point and could withdraw if they became uncomfortable with the questions or other reasons. A contingent plan for respiratory or medical distress was in place, and the interview would have been stopped, however, all interviews were completed in one sitting without any distress. Research compromises tenets such as sincerity and respect of individual rights (Patton, 2015), therefore, it was ensured by this researcher that the findings in this study are based on findings and results and literature from previous studies.

Themes and Findings

The following themes were identified in the data:

- Autonomy
- Feeling tied up
- Role in decision-making
- Significance of ventilator to well-being
- Creating meaning
- Reminiscence
- Tipping point
- Adjusting to technology
- Meaning of life
- Building trust and confidence
- Family support and relationships

Themes were identified and were used to answer research questions:

1. What is the perceived quality of life for individuals with tracheostomies on prolonged mechanical ventilation (HMV) in the home care setting?
2. To what extent are individuals on HMV involved in decision-making and participation in activities of daily living?

The study consisted of interviews with nine males and one female on HMV. I entered transcripts from the interview questions and responses into NVivo. As a functionality of NVivo software, I assigned the initial themes as multiple nodes, which organized and identified patterns in the interview data. NVivo software, through the utilizations of word the cloud (Figure 1) are noted from all the nodes. Themes are categorized by interview questions to make sure I capture all data (Table 1). The interview questions and responses correspond to the themes. This process allowed me to explore the research question in depth: This section includes answers to the questions posed to individuals on HMV and questions coincide with themes. Research question one was answered from themes derived from General Questions 1, 2, 3, 4 and 5, questions on perception of health and impact of tracheostomy 1, 2, 3, question on ADLs i through x, family relationships 7 and 8, life quality 1, 2 ,and 3. Research Question 2, role in decision-making was answered from themes extracted from questions under environment and safety 4, 5, and b. Several questions were utilized to extract themes; this method allows solicitation of information using different lenses, QOL is a multidimensional concept, it is requires more than a cut and dry response, as a result; several questions allowed in-depth collection of data.

Study Results

According to Creswell (2013), the next step is to identify statements. These statements were organized into themes. The results section of this research reports the interview questions as categorized under the themes and analyzed based on the interview responses.

Research Question 1 was answered from themes derived from General Questions 1, 2, 3, 4, and 5, questions on perception of health and impact of tracheostomy 1, 2, and

3, question on ADLs i through x, family relationships 7 and 8, Life quality 1, 2, and 3. Research Question 2, role in decision-making was answered from themes extracted from questions under environment and safety 4, 5, and b. Participants were asked a series of questions, and their responses illuminated the shared lived experiences on quality of life on prolonged HMV and role in decision-making. The themes that evolved from the interview question and statements from participants include, autonomy, significance of ventilator for well-being, feeling tied up, creating meaning, tipping point, reminiscence, building trust and confidence, adjusting to technology, family support, and relationships and meaning of life.

Autonomy

Autonomy is personal victory as it involves accomplishments in a lifetime and differs due to age, culture, and environment. Participants in this study portrayed that each individual is unique and has a different story to tell. Individuals are accomplished in different ways and then one day their lives changed. They were diagnosed with a variety of health conditions such as MD, cancer, stroke, ALS, or lived on a ventilator secondary to spinal cord injury following trauma from a MVA, or secondary to aspiration pneumonia. In each case, the events experienced changed their lives. Circumstances and complications arose which warranted the needed for a tracheostomy to prolong their life or to stay alive.

Autonomy, the ability to care for oneself independently was a theme identified in all of the participants indicating they valued their ability to care for themselves or wanted to discuss their loss of their own independence. One participant, who had aspiration pneumonia after undergoing surgery for a bowel obstruction, described his loss of independence as he experienced complications of aspiration pneumonia. After rehab, he was able to return home to live (P6).

> I am a 68 years old, male. I went to the hospital for possible bowel obstruction. A CT-Scan confirmed this; I had this problem before. They lowered my bed, and I had aspiration pneumonia. I went home but came back in two weeks because of difficulty breathing due to a mucus plug. I coded three times, and while trying to rush me to ICU, I could not make it; they placed the tracheostomy emergently in the ER. I was transferred to ICU and later transferred to a rehab. (P6)

Another participant who lives with advanced ALS since 2007 expressed his memories of working and traveling and the gradual inability to care for himself since 2013 when he was placed permanently on the vent (P9). A 27-year female spoke of her love for doing crafts and playing games on the computer (P1).

> I am a 27-year female; and I am a January baby. I went to college for four years and have a bachelor’s degree. I have one sister, a brother-in-law, and many, many cousins, my grandparents passed and are in heaven, and then my mom and dad. I love to do crafts, play games on the computer. (P1)

One patient spoke of a car accident in which his neck was broken and left him as a quadriplegic. He described his resulting dependence upon a tracheostomy and ventilator as just something that he had no choice about as it is a necessity for life (P2).

> I am a 32-year-old male. One day when I was 20, I was driving home from a party, I was not far from the corner, there was another car coming because I saw

> the lights, it hit me head-on, and all I remember is hitting my head on the air bag. My friend who was following me hit me from behind, the air bag opened, and I broke my neck resulting in spinal cord injury and now a person with quadriplegia. During my hospitalization: I woke up intubated. Later, I had a tracheostomy: I had no choice, it was necessary for life (P2).

Another participant described his career as a teacher and his influence on young people and his love for participating in different sports as well as his accomplishments (P10).

> I am 49 years old with ALS since the age of 37. I taught high-school mathematics for 15 years and coached both baseball and football. I also began a Bench Press Team and hosted a competition each year for various schools. I was involved in the sport of powerlifting for more than 20 years, becoming a teenage state champion in two states. I also played on teams for football, basketball, and baseball. (P10)

Significance of Ventilator for Well-Being

Participants' length of time living with a tracheostomy and a ventilator ranged from a minimum of two years to a maximum of 26 years for one. Participants all required a ventilator to live. For people who are unable to breathe on their own, a ventilator prolongs life (King, 2010). With improvements in technology and with ongoing research people on mechanical ventilation can now live longer (Lindahl, 2010). One participant described difficulty breathing and failure to thrive as a child, after tracheostomy placement and using ventilator she was able to go to school and was able to participate in different activities (P1).

> The first insertion was when I was nine months old. At two, I had two revisions to the stoma and had not touched it since then. Before that, I had difficulty breathing and was not growing and gaining weight. I have muscular dystrophy (MD), which affects my breathing muscles, at 13; the MD exacerbated, and I was placed on a ventilator at night. I went to a traditional elementary school, but other kids were afraid of the trach. At 13, I stayed at home and teachers came to my house to teach, the school district was involved. The elementary and middle school was not handicapped friendly; environment was not welcoming. I was last in school in 6th grade. There were rumors in school about the trach; other kids did not know what it was. Students were afraid to approach me. I was lonely. My sister's friends were older and more compassionate; they protected me and felt they were my friends. A friend, who later became and stayed my best friend up to now, settled the myth about the trach, she told them the truth that she needs it for breathing. (P1)

Feeling Tied up

Although the technology could be adjusted to perform ADLs, the daily routine is associated with feelings of being tied up. These feelings are due to time-consuming nature of medications and treatments that require a strict schedule. Participants described how their day is controlled by medication administration and other activities associated with tracheostomy and ventilator care. It is important to plan and have a scheduled time for medications and activities on hand. Many feel tied up with such a schedule that it is imperative to follow in order to avoid any medical or respiratory distress. One participant described how everything is hooked up, vent, oxygen, humidifier, and tube feeds (P1).

> Everything is hooked up, vent, oxygen, lighted humidifier and tube feeds. Stuffed animals that I have sewn are placed for positioning and comfort. If I do not sleep immediately; sometimes, I watch TV, a movie or read a book till I get tired or play on my laptop with a touch screen that is full of my favorite games. (P1)

Another participant described how medications and treatment regiments dictate activities of the day (P8).

> I wake up in the morning and make breakfast, sausage, and eggs. At 6 am, I give myself a breathing treatment using, mucomyst. I also take cough medicine and hydrocodone for pain on stoma induced by coughing. I wait a ½ hour then take thyroid medicine on an empty stomach. I wait another ½ hour and take singulair and blood pressure medicine. Wait ½ hour to take pills for rheumatoid arthritis twice a day. It gets depressing at times; my life is guided by medications. I always have been active all my years. (P8)

Creating Meaning

Creating meaning is the ability to choose activities or hobbies of interest. Several participants watch movies, sports and read papers. Some participants are able to go for short trips and then travel back home. Activities chosen by participants are low impact and utilize the sense of sight and hearing. Several participants read newspapers to keep up to date with current events, watch movies whether bed-bound or in a wheelchair. These are activities of their choice and are available to them as needed. Televisions and computers use eye-gaze method or voice recognition. Participants sit in their wheelchair and sit in the sun for short periods as tolerated. One participant reported that in the early stages of ALS he could use the computer, now in advanced stage watch movies (P9). Another participant described that watching television allows his young children and pets to snuggle with him and spending quality time (P3). “Early stages of ALS I could still type on computer walk a few blocks, with advanced ALS too many movies, easier to do, reading, listening to music” (P9). P3 said, “I like to watch sports such as baseball, watches movies with kids, kids sleep around the bed and play with me, cats sleep near me while watching TV.” P1 responded, “I love arts and crafts. I sew with a machine and make stuffed animals. I also like coloring, paper crafts, selling Avon products. Playing on the computer, games, banking and using Facebook.” According to P10, “I like to read, write a monthly newsletter, shop on the Internet, and watch a lot of sports on TV.”

Tipping Point

Having a tracheostomy was a matter of life or death for some participants; as a result, they mentioned that they have to learn to live with it. It was a tipping point or point of no return to have a tracheostomy. Tracheostomy allows them to live, but at the same time affect body image, eating and drinking. Having a tracheostomy and ventilator brings challenges such as the inability to participate or perform physical exercises. For some participants, they hope they serve as a model to kick habits such as smoking that can increase the risk of respiratory problems. One participant reported that he has difficulty drinking water and that the tracheostomy affects his body image (P8). Another participant verbalized that not being physically active is causing some health issues (P6).

> Tracheostomy is necessary as it helps me breathe. I cannot drink water. It affects me psychologically and emotionally when I am walking with a pipe sticking out of my throat; I feel embarrassed at times as I receive stares from people, as some are afraid to talk about cancer when you have it, it seems as if it is contagious. I have no qualms and can talk about it. Friends are afraid to say the word, people are afraid, that is not right. They treat you as if cancer does not exist. A friend of mine wanted to talk, he wrote on a pad and passed it to me, and I returned it to him and told him that my voice is the problem and not my hearing (P8).

P6 said, "Well, not that much except for the skin issue. I do the same things I used to do. Now, I am on a diet; I need to lose some weight, I have just learned that I have sugar problems because of the carbs."

Reminiscence

Reminiscence involves sharing of ideas and personal experiences helping bridge the gap between people. It transcends differences in age, culture, geography, professional alliance, but above most, unforgettable experiences. In sharing their stories, participants allowed rediscovery of understanding, fresh perspectives, and courage to face the future. Responses to this question showed a different range of life experiences across ages, serving the notion that reminiscence is a source of great satisfaction, it enriches, informs, entertain and reveal present limitations to heal and improve the well-being and QOL. Below are participants' stories of their life. One participant described his professional journey as a physician and working in different hospitals (P6). Another participant described how he was going to college and spent time with friends (P2).

> I was married. I used to work as tech in the hospital while doing my masters. I went to medical school and graduated. After graduation, I traveled to Europe by myself. Later. I worked delivering babies and assisted with C-sections. I worked at a big teaching hospital for trauma. (P6)

> I was 20 and very active; I used to party all the time. I was going to a community college and studying hotel and restaurant management and had declared it in my third year; I did not like it, so I do not know if I had stayed with it. I had two part time jobs. (P2)

Building Trust and Confidence

A safe environment allows building of trust and confidence and allows individuals to be engaged in their environments. Most participants reported a safe environment and some have lived in the same house for several years. Participants stayed on the ground floor in apartment buildings for ease of movement of which many took advantage where they sit outside for short periods. Participants have built or lived in their neighborhoods for many years, and trust their surroundings.

> I love it. It is nice and quiet. I moved from another state because it was expensive to live. I had a big house, a mother daughter type. My mother used to live in the front; when she passed, I decided to move. I found out about this area through a friend who had a family here. Winters can be rough if you get around a wheelchair. I am satisfied; I have plenty of privacy here. (P6)

"I have been living in the same house since I was 4 years old. I live in the woods and mountains, and it is beautiful. There is fresh air, and it is closer to the city where I can visit and come back. It is very safe" (P2).

> I have lived in this house since I was 7 years old. The landlord allows us to make changes to suit my needs. I am able to get around the house. We had a wear and tear carpet installed because the wheelchair can destroy carpet; plank floors are not good for the wheelchair. I have gliding stairs to my bedroom for the last ten years. I live near the playground and used to go when I was young. My neighborhood is very quiet; everyone watches for each other. There is no violence. We live near a high school, so we have to be cautious about traffic. In 2012, we went away on vacation, and my neighbor fed the cats and watered the flowers. I move up and down the street with supervision. (P1)

Role in Decision-Making

Decision-making is the ability to make decisions in life. Participants reported being involved in the decision-making process. Many family members as well as the health-care providers came together without imposing on the HMV user. Complex and numerous decisions are made about symptom management and quality of life while living on prolonged home mechanical ventilation, it is necessary to include everyone and keep them informed. Most participants described the collaboration of family, health care provider's and participants' roles in the decision-making process. The following are quotes from different participants:

- “My wife makes most of the decisions. I make all the ones I can control from my computer” (P7).
- “My two sons help me make all decisions” (P5).
- “My father, the nursing staff and I decide” (P4).
- “My family and I make decisions as a unit” (P1).
- “I discuss with my wife what is best for my family and me” (P3).
- “My mom, nursing and I decide on what is best for me” (P2).

Adjusting to Technology

After placement of tracheostomy, several adjustments are made in terms of communication, breathing, eating, drinking, and mobilizing. When it came to communication, participants reported use of several communication devices to make needs known. Some participants used speaking valves while others used computer-guided systems such as Tobii eye gaze. For participants with advanced disease, they used eye communication, participants reported difficulties encountered during communication and several ways adopted to facilitate communication. Participants have managed to adopt ways of communication depending on the disease stage. Participants have shown ways of making needs known at different stages of the disease process. As the condition changes or progress, participants adjust their communication to make needs known and live a meaningful life. One participant did some research and discovered a valve that would be suitable for eating and drinking if turned on the left or right, so he requested to have the shikani valve inserted (P6). Another participant described how he had to make adjustments as the ALS progressed (P9).

> I did some research 1 ½ years ago about a Passy-Muir valve called shikani. Shikani makes it easier to breathe and talk. It is not color-coded making it less pronounced, but I do not care anymore. I also use the Amazon echo that can turn the radio, answer the phone and turn the lights on or off or increase or decrease temperature using voice commands. (P6)

> During the early stages of ALS, I used a Passy- Muir valve and Progressed to Tobii Gaze and cannot use for several years. Now I use eye blinks, "yes"; or "no" and mainly by writing with one finger on an iPad App, Penultimate, wife or nursing guide hand to write, but with much difficulty. (P9)

For effective breathing participants used cough assist devises to loosen and remove secretions. Several participants described the cough assist and nebulizer treatments necessary to mobilize and clear secretions P1, P5, and P3.

> It is not easy; sometimes I feel shortness of breath. I try not to suction frequently as I bleed from my lungs. I use a cough assist two times a day so that mucus does not solidify. I have no cough reflex. I am on the ventilator around the clock but can be off for at least 2 hours, sometimes in the morning and sometimes in the evening. At night, the ventilator has to be plugged in, I need it for sleep, and I have sleep apnea. The ventilator is not only for comfort. It is essential and good for me. (P1)

"I use ventilator 24/7, Suctioned by nursing staff as needed, Use a cough assist when needed. Get nebulizer treatments around the clock; I have not been hospitalized for pneumonia" (P5).

When it came to eating and drinking, most participants reported use of peg-tubes for nutrition and medications and some complications such as leaking. One participant reported precautions taken to prevent aspiration (P7) and another described complications such as leaking (P8).” I cannot eat any food by mouth due to the risk of aspiration; I use a G-tube placed seven years ago for feedings. I get continuous feedings for 24 hours, and flushed with water, feedings are stopped for medications. I get 2cal at 50 ml/hour, and flush with 60ml every 3 hours” (P7).

> I eat regular food but cannot drink liquids. Button-tube for 12 years for fluids, medications, and hydration, took 4 to 5 years and then 3 years ago was reinserted and has been changed three times. The tube broke and reinserted without a clamp. I asked how I could stop it, had problems when I slept at night and leaked. My daughter a nurse, found a clamp, so I can close it off. A button-tube less pronounced. (P8)

Participants reported challenges faced with mobilization. A couple of participants have not been out of bed for several years. Several participants reported using devices such as Hoyer lifts to get out of bed (P7). Participants who are bed bound reported repositioning pillows or special mattresses to prevent skin breakdown (P3).

> I have not been out of bed for 2 years. I used to get up by using a ceiling lift with a sling. Loops attach are placed behind the back, crisscrossed, and placed in electric chair with had hand controls, can tilt forward and back but unable to use now. (P7)

> I have not been out of bed for 2 years, the primary physician makes house calls, Skin intact except ear that was irritated by the bell switch, and I use sheepskin and repositioning pillows for support on bony prominences. I used to get out of bed and out of the house, ramp outside the house used during transfer. (P3)
>
> I am not able to move without assistance. I have been bedridden since my tracheostomy in January 2009. My nurse and parents use a Hoyer lift to transfer me to a recliner twice a week. I am out of bed for about 4 hours each time and watch movies or TV shows. During the summer, they transfer me to my wheelchair every few weeks so that I can go outside on the porch. It does not sound like much, but it is a nice change of scenery after being in the house for about 9 months a year. (P10)

Activities such as suctioning, toileting, medication administration, less physical activity and noisy equipment can result in difficulty sleeping. Participants reported that sleeping is often interrupted causing difficulty sleeping (P1 and P2).

> I have trouble sleeping when I have trouble breathing, so I set my watch for four and half hours for a breathing treatment. I cough a lot when I start coughing; I take hydrocodone I and do not feel to be dependent. Sometimes, when the weather is good, I skip doses. Sometimes I wake up with a tickle in my throat and start coughing. I have been taking Hydrocodone for four years. I do not take sleep aids. I sleep in bed with one pillow. (P8)

> I sleep poorly only for 2 hours but do not take sleeping aids. I have good and bad days. Sometimes I wake up then go back to sleep again. I wake up at 11:30 am and stay up to 1 am. I am used to sleeping late. (P2)

Limited physical activity, medication schedules for pain or sleep aids can affect bowel and bladder function. Several participants reported use of different ways to regulate bowel function ways to improve hygiene to prevent skin breakdown. One participant described the use of pain medication affected his bowel movements (P8). Another participant stated how she manages her elimination and her susceptibility to infection (P1).

> I get constipated, but I think it is from Hydrocodone; so I take prune juice. I am regular, go every day, I do not void 10 times anymore, but enough. I take sulfasazine and methotrexate, so I have to use a lot of water to protect my kidneys; my urine turns yellow if I am not using a lot of water. (P8)
>
> I use depends pull-ups during the day and wear a diaper at night. I do not know when I am going to wet myself. I am prone to UTIs; I have a family history, so I stay on ABTs for long periods. I have bugs in my lungs that make me bleed. (P1)
>
> I get a suppository once a night and sit on the toilet for defecation before going to bed. I also use other stool softeners. I have no control of bowels but sit on the toilet before going to bed. I use a Foley catheter for urine with infrequent urinary tract infections. (P1)

Family Support and Relationships

Support can be emotional or help in making decisions and perform tasks. Participants reported receiving support from family members and health-care providers. Emotional support is crucial for it involves acceptance for adjusting work and social activities for the participants' technology and capacity, no less important, someone to talk with. Valued support from minor children involved showed empathy being helpful and careful not to touch or play with equipment. Participants living with their parents, wives, children, nurses, or significant others received the support needed in organizing and managing ADL. One participant who does not receive nursing care described how his family helps (P7).

> My wife is the primary caregiver; there are no nurses at the house. My mother lives 15 minutes away, visits regularly, and helps. My son who is 30 years old visits and is managing the company but leaving to pursue teaching. My daughter is now 23; she was 10 when I was diagnosed with ALS. She helps mom and has been inspired to pursue a career in Physical Therapy (PT) after accompanying father to PT sessions and observed how they worked and uplifted her father. PT was the highlight of my days. Taking care of her father has inspired her to help people in need my older brother, lives nearby, he will be taking over the business. A friend I met through church comes to visit, we watch Penguins together, and he plays the guitar. An old neighbor still visits as well. (P7)

P2 said, "I live with my mom and nurses. A friend from out of state visits occasionally. A niece also visits occasionally. Friends from before the injury come to visit."

Meaning of Life

People perceive their life as meaningful when they find purpose in life. The meaning of life is tied to making sense of life events; individuals with tracheostomies have experienced some traumatic events that threated their lives. Placement of tracheostomy and use of ventilator have given them a new lease on life. Despite having tracheostomies and living on a ventilator, participants reported being satisfied with their lives. One participant reported that a positive attitude has given him a purpose to live (P6). Another participant reported that he is happy to beat cancer several times and now spent time with his grandson (P8). Another participant noted that placement of tracheostomy has allowed him to live and he has to plan accordingly to accommodate needs as needed (P7).

> I enjoy life. I am never bored; I keep myself entertained, I love music and watch TV at times. Everyone has problems. I have a positive attitude that is why I am still here. I feel happy when I am going out to the coffee house or group wine drinking. I do not take pain medications or any sleep aids. I take valium, and just kept it going on. Most of my medications are for my bowels. (P6)
>
> I do not feel the negative feelings you describe. Jesus teaches not be anxious. Happy times are when I get visitors. Having a trach and vent was a choice I had to make. With ALS, everyone has a different progression of muscle decline. In my case, the respiratory muscles were very weak, which was making it hard to breath. I was faced with a life or death decision, and I chose the trach and vent. All of us have a fear of the unknown and living on a vent there are a lot of questions. How

> will I eat? Will I be able to talk? What other limitations will I have to deal with? Well, I was able to speak and eat. After some time I had problems with aspirating food, which leads to an infection in my lungs and I could no longer eat orally. My speech was good until the ALS captured my vocal muscles. Good planning was having a feeding tube installed at the same time as the trach. (P7)

> Every morning, I feel happy. When you have beaten cancer twice, stroke and have a beautiful daughter and grandson. I used to be a navy seal. I used to live in the water; once you take me out of the water, you hurt me. That is what I miss the most. (P8)

Summary

This chapter covered the data collection, data analysis, and result process for this research. The process sought to provide insight of the lived experience of individuals with tracheostomies on HMV. In addition, the process aimed to answer the research questions. After the data collection, the data analysis process yielded themes for this research, which simplified achieving the results. When triangulated, the results of the themes provided the answer to the Research Questions 1 and 2. Chapter 5 is a discussion and interpretation of findings, and implications for social change. It includes my reflections and the limitations of the study. In addition, the chapter offers recommendations for action and future research while providing a conclusion for this study.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

This chapter provides a summary and interpretation of the findings of this phenomenological study, which was designed, via interviews, to explore the QOL for individuals with tracheostomies on prolonged HMV focusing on ADLs and the role in decision -making. I found that there was QOL for individuals with tracheostomies on prolonged HMV. Several challenges restricted the performance of ADLs; however, participants were involved in decision-making based on their cognitive status and the stage of the disease. A better understanding of these issues is crucial in order to improve the QOL for HMV users and family and to assist health care professionals involved in HMV to make decisions for the benefit of the individual and his or her family.

The study findings are presented in the following sections: the review of the purpose of the study, interpretation of the findings in the context of phenomenology compared to those reviewed in Chapter 2, summary and interpretations of the findings, and the limitations of the study. Finally, recommendations for further research and implications for nursing practice and positive social change for individuals with tracheostomies on prolonged HMV are made. This study may lead to positive social change by educating family, health care workers, and the public on QOL and prolonged dependence on HMV (King, 2012).

Summary of Findings

I found that the QOL of individuals on HMV is improved when they have control in their daily lives and have competent caregivers and family members for continuity of care. Participants' own assessment of their state of health indicated that they were relatively healthy. King (2012) suggested that people with serious chronic conditions who felt dependent on advanced technical support are characterized as having poor treatment outcomes. A number of the participants expressed that they were happy to be alive. The perceptions of health are based upon the individual; health is not the equivalent of the absence of disease (Lindahl, 2010). There is more to the sense of being healthy, that is related to independence. To be able to stay in a person's home and feel in charge of his or her everyday life in spite of a ventilator and various other aid measures is a valued benefit, with autonomy and control.

A safe and therapeutic environment is essential for wellbeing; it allows participants to be involved in the decision-making process, from treatment modalities to hobbies chosen in their spare time. Participants in this study were involved in the decision-making process, and they had the ability to choose when to go to bed, what to wear, what to watch, when to have visitors, and how to spend the day. Having the ability to make these choices contributed to their sense of wellbeing. Family and emotional support was identified as important for participants when organizing and managing ADLs. Chronic health conditions affect a person's ability to adapt and cope with daily challenges. Roper et al. (2001) stated that acute illness and chronic conditions directs people to adapt to changes necessary for functioning. The patient's independence and potential dependence based on the life continuum and effect of an illness.

Interpretation of Findings

The purpose of the study was to explore the QOL for individuals with tracheostomies on prolonged HMV focusing on ADLs and the role in decision-making. In addition, nine males and one female participants' perceptions were aligned with the RLT (2001) activities of living (AL), which focused on modifications needed on ADLs after leaving the hospital or when affected by a chronic illness. The RLT is used to define what living means by categorizing the activities of what people do during the day to maintain their life.

The results for this study were consistent with the literature. The theory of ADL is changed by the effects of sickness or chronic disease at different stages of life. Ideally, the participants validated their lived experiences and the QOL and role in decision-making. It is imperative to be consistent for reliability and transferability of the research findings (Creswell, 2013). The study was based on the interviews of 10 individuals.

Discussion of Research Questions on Perceived QOL

1. What is the perceived QOL for individuals with tracheostomies on OMV in the home care setting?
2. To what extent are individuals on HMV involved in decision making and participation in ADL?

The questions were broad and examined the perceived QOL for individuals with tracheostomies on prolonged HMV and participation in ADLs. Research Question 1 was answered from themes derived from General Questions 1, 2, 3, 4 and 5; questions on perception of health and impact of tracheostomy 1, 2, 3; question on ADLs i through x;

family relationships 7 and 8; and life quality 1, 2 and 3. Below are interpretations of the findings based on participants' responses, which that confirm or disconfirm the peer-reviewed literature in Chapter 2.

Having a home ventilator enhances the QOL- a life worth living for individuals on ventilators. The home setting is preferable for people on mechanical ventilation because of better QOL, which includes improved social relationships and less risk of acquiring nosocomial infections (King, 2012). However, HMV is not a simple decision to make, because there are barriers and ethical issues that affect QOL (Garber & Guertin, 2010). This is consistent to Ballangrud et al. (2009) who noted that having a home ventilator improves QOL as the ventilator builds up strength, and helps improve wellbeing.

I found perceived QOL for individuals with tracheostomies on HMV. Each individual is unique; as a result, they have different care, they require sufficient knowledge of treatment modalities, and the available options to choose from in order to make informed decisions free from coercion and manipulation. Participants described that living on HMV has allowed them to choose how to live and make decisions based on their choices. Participants described ability to choose when to sleep and get up, what to eat and wear, and what to watch. Participants choose treatment modalities that suit their needs and they are comfortable using, such as cough assists, suction devices, and equipment for providing nutrition. If autonomy is to play a significant analytical and practical role in the home care setting where people are in need of help from others, then it must be acknowledged as the essential social nature of human development and incorporate dependence as a non-accidental feature of the human condition (Dyrstad et al., 2013).

Autonomy for people with chronic conditions and using the ventilator is actual autonomy (Ballangrud et al., 2009). Actual autonomy means that autonomy depends on a person's current development and environment. An individual can only realize his or her autonomy in relation to his or her social and physical context. This is true for prolonged HMV, where an individual is highly dependent on others. Autonomy for individuals on prolonged HMV is validated by similar studies. Bele, Bodhare, Mudgalkar, Saraf, and Valsangkar (2012) and Noble (2008) described QOL as an individual's perception of self and how he or she functions in everyday life, taking into consideration elements such as physical and mental well-being, education, recreation, leisure, and social belonging. Therefore, QOL is an objective and subjective state that includes the individual's behavioral, cognitive, emotional well-being, and motivation to perform domestic, vocational, and social roles.

Another significant finding from the study is that the ventilator is necessary as it provides strength for individuals who cannot breathe on their own. Some participants described initial experience on ventilator as frightening. They associated the ventilator with the terminal phase of life; however, after the adaption phase, and improved breathing, the ventilator became a natural part of everyday life not associated with serious illness. Most of the participants felt healthy and happy about their state of health. According to P8, “For being 68 years old, I am in better health than most people are. I beat cancer, stroke, and came back strong. I have a positive attitude that helps me get through.” P3 said, “Healthy as far as not being sick with pneumonia or other short-term illnesses.” P10 said, “Other than not being able to move or breathe on my own, I would say that I am relatively healthy.”

The ventilator improves the QOL for individuals on HMV. As noted from the literature, emergencies such as trauma, stroke, spinal cord injuries, neurological impairments and respiratory distress, surgery, infection are indications for placement (Durbin, 2010, Tracheostomy, 2014). A tracheostomy creates a stable airway for people who require long-term use of MV and allows suctioning and removal of secretions. Benefits include improved comfort, less sedation that results in decreased risk for delirium and improves functioning and participation in ADLs (Marchese, Coco, & Coco, 2008).

A significant finding from the study is that the home environment allows choice of activities that are enjoyable for the participant and his or her family, thereby improving the QOL. Nine out of 10 participants discussed hobbies that utilized the sense of sight and hearing such as watching television, using the computer and reading various materials. This is consistent with findings by Baker and Kakora-Shiner (2009) who stated that individuals on HMV are likely prone to isolation and may feel excluded from social functions around them. Long periods of watching television can lead to boredom therefore, it is important to make recreation meaningful and fun. Additionally, activities should provide a sense of belonging, which improves QOL (Edvardsson, Petersson, Sjogren, Lindkvist, & Sandman, 2014).

Participants are constantly making adjustments as the disease progresses in areas such as communication, eating, dressing, bowel and bladder elimination, controlling temperature in order to improve QOL. This aligns with the literature on communicating effectively for users of HMV is essential so that various basic physiological and psychological needs can be conveyed and decisions, wishes, and desires about the plan of care and end-of-life decision making can be expressed (Grossbach et al., 2011). Participants reported the absence of pneumonia or need for hospitalizations. Loerzel et al. (2014) noted that tracheostomy management at home requires the caregiver to be familiar with complex medical equipment and possess skills to complete complex medical tasks. King (2012) recommended respiratory companies that provide ventilators to follow-up regularly and be responsible for equipment maintenance, cleaning and servicing. Participants described sleeping interruptions for suctioning, medication administration or for toileting. This aligns with research that showed that sleep disturbances are not a result of the mechanical ventilator itself, but a result of severity of illness, daily routine care and effects of medication (Rittayamai et al., 2016).

The importance of family relationships in providing care and help in decision-making facilitated by a safe environment was a significant finding to QOL. Participants highlighted the importance of making their own decisions and being taken seriously. Successful collaboration was perceived when the HMV user was given the opportunity to participate in decision-making about treatment and care, where to live and how to organize daily activities. Most participants stated that family members and significant others are involved in care and help make complex decisions in their care. Family members and competent health-care providers are important in continuity of care.

Positive social support whether family or friends plays an important role in individuals on HMV to make informed decisions. Social support means being able to access people to rely upon if needed. Having such support system is beneficial in helping HMV users to follow and adhere to medical regimens, provide rides for various errands such as doctors' visits or supermarket. Participants mentioned involvement of spouses, parents and children in providing care and transport to physicians or other health-care facilities. Maintaining a social life with family is an important goal for many people irrespective of their life conditions (Fex, Ek, & Söderhamn, 2009). These findings are supported by previous researchers who found that HMV users valued emotional support given by family and significant others to perform various activities and making decisions (Baker & Kakora-Shiner, 2009, Ballangrud et al., 2009; Lindahl, 2010).

A safe environment was found to be paramount to improve QOL. Home environment for individuals on HMV were remodeled to increase safety, reduce anxiety and promote functioning. Participants described use ramps to the ground floor bedrooms for easy entry and exit and allowed mobility of equipment. One participant described living in the same house for many years and use of gliding chair to go back and forth to her bedroom. Adequate lighting and heating system allowed her to stay warm in the winter months. Participants described use of cell phones and room monitors for communication with family and health care providers. HMV treatment generated a strong need to experience safety and security. Access to telephone support and the health care specialists were mentioned, as important options. Noted in the field were bedrooms free of clutter and placement of oxygen away from heating devices. The 10 participants described the environment as suitable and meeting their needs. One participant built his own home and has lived in it for 26 years. He described how his bedroom is on the ground floor and has a large window where he sat during the day. Two participants have lived in their home since the age of 4 and 7, respectively.

Participants stated that it is important to feel safe when one's health and strength are impaired. This is consistent with the LRT Model (2001) which stated that nurses and other health-care workers work as a team to assist the individual delay, alleviate, manage or develop alternative ways of dealing with problems associated with ADLs, whether actual or potential. The model also concludes that factors that affect ADLs are biological, sociological, physiological, and psychological and politico economic as validated by the findings.

Limitations of the Study

The study was limited to English speaking participants so findings may not reflect QOL in non-English speakers. Study participants lived Northeast Pennsylvania; perhaps a nationwide study over a longer researching period with more participants might have yielded different results. The participant pool consisted of more males with similar underlying conditions, one female, and lack of diversity could have affected the outcome.

Interruptions during the interview for suctioning and nebulizer treatments could have disrupted the momentum of the interview preventing in-depth responses. The study excluded pediatrics or individuals under 18 years of age, which could have provided different experiences. My study required participants who could sit and successfully complete an interview thus the possibility that the experiences of more seriously ill clients omitted. For bracketing, as an ICU nurse familiar with working with individuals with tracheostomies on prolonged HMV, I maintained my language simple and as close to the participants' language by avoiding theoretical influence or expressions. The findings can be considered to have transferability to individuals with tracheostomies on prolonged HMV in addition to other people with chronic illnesses.

Recommendations

Recommendations for ensuring that the QOL for individuals with tracheostomies using HMV remain favorable and provision of necessary services facilitated.

- Build multi professional teams involving home-care, community care services, and allow families to be involved in providing care.
- Awareness that placement of a tracheostomy and starting HMV is a life-changing event with a unique life story and situation that requires different care needs.
- Promote communication that allows HMV users the opportunity to make autonomous decisions concerning treatment.
- Allow accessibility and building of frameworks for HMV users and their next of kin.
- Promote and expand education for individuals, families and health professionals working within HMV in users' homes.

- Implement planned home visits with a holistic approach from health-care providers with competence in HMV treatment. Continuity of care by competent healthcare personnel is essential for living a good and active life with home mechanical ventilation.
- Facilitate dialogue and contact between HMV users and manufacturers of HMV equipment to facilitate development of user-friendly technology.
- Encourage manufacturers to participate in research and quality control programs from a user/HMV user's perspective.
- Reducing caregiver role strain by providing respite care.
- Allow younger participants to form support groups of their peers to allow access to new friendships and to reduce isolation.

Recommendation for Future Research

I explored the QOL for individuals on HMV and role in decision-making. More qualitative studies that include non-English participants carried over a wide area with a balance of female participants and varied underlying conditions should be included to provide more knowledge on QOL. Longitudinal studies on pediatric HMV users into adulthood would explore participation of ADL at different developmental stages in life and bring about a more understanding into QOL.

The findings of this study can act as a foundation for future researchers that wish to carry out research on a similar topic. The literature review enriches the literature on the QOL theory as applied to individuals on HMV and this study contributes to the body of information about the challenges faced in the home setting in performing ADLs. It also provides information about adjustments and care needed to families and individuals who have just started life on prolonged HMV. Listening to other's stories might provide insight and guide new HMV users as they start. The findings of the study can be utilized by health-care workers to provide more personalized care and enable understanding of what it is to live on HMV (Lindahl, 2010).

Implications to Nursing Practice

Health care needs of individuals on HMV are complex. Individuals on home mechanical ventilation are satisfied with their quality of life but face challenges such as dependence on technology, healthcare personnel and limitations in participating in ADL (Ballangrud et al., 2009). Health care workers have to identify the needs of individuals on HMV so that better care can be provided and more understanding in participation in ADL and its benefits on QOL. Participation in ADLs allows autonomy and control over one's own life situation improving functioning, satisfaction and QOL. Users of HMV should be active partners in their own care so that their experience is taken into account. It is important to feel in control of their situation and have an overriding wish to live a normal and active life. Health-care workers need to be more knowledgeable by incorporating information and participation in ADLs while on HMV. Collaboration between health-care services, families and health-care entities is paramount in promoting functioning that gives meaning to life (King, 2012).

Significance to Social Change

The significance of the study is to highlight and bring awareness to daily challenges faced in participation in ADLs by individuals on HMV. Findings showed that several challenges restrict participation in ADLs. A better and broader understanding of these issues is crucial in order to improve the quality of life for HMV user and family as well as assisting healthcare professionals to make informed decisions. The significance of this study to positive social change is to educate family members, healthcare workers and the public and to bring about a new understanding and awareness to QOL to those who have prolonged dependence on HMV (King, 2012).

Researcher Reflection

As an intensive care nurse, I was always curious and wondered how QOL for individuals on tracheostomies on prolonged HMV was compared to the hospital setting. Having been involved in taking care of such a population and aware of the demanding care needs, it was a quest of mine to pursue this study. I wanted to hear what participants had to say regarding perceived QOL in their own words. Through this research, I succeeded in finding the perceived experiences and role in decision-making. Representatives of the home-care agencies, wives, fathers, mothers, adult and minor children, nurses and the clients welcomed me into their homes. For that, I shall ever be indebted to them. To me, this was more than a dissertation. The responses of the participants and the warm reception I received will forever remain with me as a researcher.

Conclusion

Findings revealed that HMV users perceive that they have a good QOL and are in control of their daily lives. This has implications for health care providers, the public and families who are seeking to improve the quality of care for people living with HMV.

HMV treatment has positive outcomes for both the individual's physical function and experiences of health and wellbeing. The development of evidence-based guidelines and research can contribute to more thoughtful and sensitive practice for these individuals. The starting point should be the individual's perspective, as it is they, who have the lived experience and knowledge of what the treatment really means. My research offers some insight into the HMV users' daily life experience but further research with this in focus is needed. Studies that offer insight into the experience of people living close to the HMV users would also be required.

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Appendix A: Flyer

TRACHEOSTOMY AND USE OF MECHANICAL VENTILATION AT HOME: RESEARCH PARTICIPANTS NEEDED

If you have a tracheostomy and use a ventilator at home, you are invited to participate in a study to discuss how you live at home and manage your daily life.

PURPOSE: To evaluate Quality of life for people with tracheostomies on Mechanical ventilation in the home.

ELIGIBILITY:

- Tracheostomy for 6 months and use mechanical ventilation at home
- for at 6 hours or more per day.
- Male or females, ages 18 to 75 years old
- Able to communicate orally or with other communication aids
- Speak English
- Ability to answer questions in the interview for about one hour

BENEFITS: Your voice needs to be heard. This study is about issues that affect how people with tracheostomy manage to live at home and how they participate in activities of daily living to improve their quality of life. I am interested in learning about your experiences in terms of how satisfied you are with taking part in activities of living in your life.

REASON FOR STUDY Degree requirement for Walden student to complete PhD. Program.

COMPENSATION: No compensation is given.

CONTACT: xxxxxxxxxxxxxxxx

Appendix B: Letter of Cooperation

Address of Agency

Dear Walden Student,

Based on my review of your research proposal, I give permission for you to conduct the study entitled Perceived Quality of Life for People on Prolonged Mechanical ventilation within the xxxxxxxx agency. As part of this study, I authorize you to conduct interviews using an interview protocol in the participant's home. Data collection, member checking, and results dissemination activities will be carried out and managed by the researcher. Individuals' participation will be voluntary and at their own discretion.

We understand that our organization's responsibilities include acting as a resource center when a participant goes into distress. We reserve the right to withdraw from the study at any time if our circumstances change.

The student will be responsible for complying with our site's research policies and requirements, including completing forms for confidentiality of PHI, consents.

I confirm that I am authorized to approve research in this setting and that this plan complies with the organization's policies.

I understand that the data collected will remain entirely confidential, and may not be provided to anyone outside of the student's supervising faculty/staff without permission from the Walden University IRB.

Sincerely,
xxxxxxxxxxxxxx

Appendix C: Interview Guide

Interview Guide

This study is about issues concerning people with tracheostomies using mechanical ventilation to explore how satisfied they are with their life through participation in activities of daily life (ADLs). I am interested in hearing all your experiences in terms of how satisfied you are with different aspects of your life.

General Information and Perceptions

1. Tell me a little bit about yourself.
2. How long have you been living on a ventilator?
3. How do you start your day?
4. How do you perform activities of daily living?
5. What are your hobbies?

Perceptions of Health/ Impact of tracheostomy on life

1. How would you best describe your health?
2. In what ways has the tracheostomy affected your life?
3. Tell me how life was for you before you had a tracheostomy

Environment and Safety

The next questions are about the area or environment around you where you live, in your home or outside.

4. Tell me about the environment where you live.
5. What is your role in deciding about what happens in your environment?

a. What about safety?
b. How satisfied are you with your environment?

Communication

Do you feel that you are able to communicate your needs? What are some difficulties you encounter in performing the following?

i. Communication
ii. Breathing
iii. Eating and drinking
iv. Bowel and Bladder control
v. Personal cleansing and Dressing
vi. Controlling body temperature
vii. Mobilizing
viii. Working and playing
ix. Expressing sexuality

x. Sleeping

Family and Relationships

6. What are your most valuable relationships?
7. How is your family involved?

Life Quality

1. How do you feel about your life?
2. Tell me about the times you feel:

a. sad
b. discouraged
c. alone.

3. Tell me about the times you feel happy.

Appendix D: Confidentiality Agreement

Name of Signer:

During the course of my activity in collecting data for this research: "Perceived quality of life for people on prolonged mechanical ventilation" will have access to information, which is confidential, and should not be disclosed. I acknowledge that the information must remain confidential, and that improper disclosure of confidential information can be damaging to the participant.

By signing this Confidentiality Agreement, I acknowledge and agree that*:*

1. I will not disclose or discuss any confidential information with others, including friends or family.
2. I will not in any way divulge copy, release, sell, and loan, alter or destroy any confidential information except as properly authorized.
3. I will not discuss confidential information where others can overhear the conversation. I understand that it is not acceptable to discuss confidential information even if the participant's name is not used.
4. I will not make any unauthorized transmissions, inquiries, modification or purging of confidential information.
5. I agree that my obligations under this agreement will continue after termination of the job that I will perform.
6. I understand that violation of this agreement will have legal implications.
7. I will only access or use systems or devices I am officially authorized to access and I will not demonstrate the operation or function of systems or devices to unauthorized individuals.

Signing this document, I acknowledge that I have read the agreement and I agree to comply with all the terms and conditions stated above.

Signature: **Date:**

Appendix E: Consent Form

You are invited to take part in a research study on how you live your life on a mechanical ventilator and how you complete daily tasks such as washing, eating and communication to improve your quality of life. The researcher is inviting people with tracheostomies to discuss how they live day to day by performing activities of living and how it helps or improve quality of life. People to be considered in the study:

- Have Tracheostomy for 6 months and use mechanical ventilation at home for at least 6hrs or more
- Male or females, ages 18 to years and above.
- Able to communicate orally or with other communication aids
- Speak English
- Ability to follow verbal directions and answer questions appropriately.

If the above requirements are not met, then individuals will not be included in the study.

This form is part of a process called "informed consent" to allow you to understand this study before deciding whether to take part. This study is being conducted by a researcher named xxxxxxxx, who is a doctoral student at Walden University. This study is a requirement to complete the doctoral study.

Background Information:

The purpose of this study is to determine how people with tracheostomies and use a mechanical ventilator participate in activities of daily living and how it helps improve quality of life in their own words. The purpose of the study is to bring awareness to healthcare providers, families and the public about the challenges faced by people on mechanical ventilation and help provide resources as needed by each individual.

Procedures:

If you agree to be in this study, you will be asked to:

- Participate in an Interview that takes one hour
- Choose between your home or a private place of your choice as a meeting place appropriate to you.
- Stop the interview at any time if you wish to do so. If unable to finish within one hour, the interview can be completed at another time convenient for you.

- Allow the interview to be audio recorded and upload data into the computer for analysis.

Reporting of abuse/ neglect or criminal activity:

> **The Older Adults Protective Services Act (OAPSA), which was amended by Act 13 of 1997, mandates reporting requirements on suspected abuse or criminal activity, and as such, I am mandated to report to Statewide Elder Abuse Hotline : 1-800-490-8505 if such instances are observed or verbalized during the interview.**

Here are some sample questions

General Information and Perceptions

1. Tell me a little bit about yourself.
2. How long have you been living on a ventilator?
3. How do you start your day?
4. How do you perform activities of daily living?
5. What are your hobbies?

Perceptions of Health/ Impact of tracheostomy on life

1. How would you best describe your health?
2. In what ways has the tracheostomy affected your life
3. Tell me how life was for you before you had a tracheostomy?

Environment and Safety
The next questions are about the area or environment around you where you live, in your home or outside.

4. Tell me about the environment where you live.
5. What is your role in deciding about what happens in your environment?
a. What about safety?
b. How satisfied are you with your environment?

Voluntary Nature of the Study:

This study is voluntary. You are free to accept or turn down the invitation. No one at xxxxxxxxx will treat you differently if you decide not to be in the study. If you decide to be in the study now, you can still change your mind later. You may stop at any time. The researcher will conduct the interviews. The researcher will follow up with you if you volunteer to take part in the study and let you know if you were selected for the study.

Risks and Benefits of Being in the Study:

Being in this type of study involves some risk of the minor discomforts that can be encountered in daily life, such as fatigue, stress or becoming upset. Being in this study would not pose risk to your safety or wellbeing. In case you are unable to complete the full interview, another session can be arranged at a convenient time to you. In instances of respiratory distress, please call 911 for help.
For **Psychological distress** please call Prevention Lifeline (800-273-8255)
For further assistance beyond this study, please call Patient Advocate Foundation
Phone: (717) 787-4410. Fax: (717) 787-0420 or
Statewide Elder Abuse Hotline: 1-800-490-8505

The study's benefits to the larger community is to bring awareness and information as to how people on mechanical ventilation survive in the community and discuss any limitations that are faced and how to provide suitable resources as needed.

Payment:

No gifts, money or compensation will be given in return for participating in this study. xxxxxxxx is not sponsoring this study. This study is being conducted as part of the degree requirement of the PhD program for Walden University.

Privacy:

Reports coming out of this study will not share the identities of individual participants. Details that might identify participants, such as the location of the study, also will not be shared. The researcher will not use your personal information for any purpose outside of this research project. Data will be kept secure by using a computer only used by the researcher with protected passwords, encryption, and use of codes in storing names and will be kept separate from data. Data will be kept for a period of at least 5 years, as required by the university.

Contacts and Questions:
You may ask any questions you have now or if you have questions later, you may contact the researcher via email at xxxxxxx@waldenu.edu or cell phone no xxx-xxx-xxxx
If you want to talk privately about your rights as a participant, you can call the Research Participant Advocate at my university at 612-312-121. Walden University's approval number for this study is **05-18-17-0529243** and it expires **on May 17, 2018**.

The researcher will give you a copy of this form to keep.

Obtaining Your Consent

If you feel you understand the study well enough to make a decision about it, please indicate your consent by signing below

Printed Name of Participant ________________________________

Date of consent ________________________________

Participant's Signature ________________________________

Researcher's Signature ________________________________

Appendix F: Oral Consent Script

Lived Experiences of Individuals Quality of Life on Prolonged Home Mechanical Ventilation

Name of Researcher

Introduction:

Hello. I'm xxxxxxxxxxxx. I am conducting interviews about Lived Experiences of Individuals Quality of Life on Prolonged Home Mechanical Ventilation. I'm conducting this as part of research for PhD studies for Dr. of Phillosophy at Walden University's online college based in Minnesota. I'm working under the direction Dr. xxxxx of Walden Department of Health Sciences and Nursing Education.

You located/found my name through the flier that was posted in several home-care agency offices searching for individuals with tracheostomies on home mechanical ventilation interested in participating in a study of Lived Experiences of Individuals Quality of Life on Prolonged Home Mechanical Ventilation. By having you call me, and inform me of your interest to participate, and after reviewing the inclusion criteria, I am glad to inform you that I accept you as a participant.

Study procedures: **What will happen during the study?**

I'm inviting you to do a face –to-face interview that will take about 60 minutes. I will ask you questions about your life on HMV such as 1. how do you start your day? 2. How do you perform activities of daily living and how best would you describe your health? "I will take handwritten notes to record your answers as well as use an audio recorder to make sure I don't miss what you say". We can set up a time and place that works for us both.

Risks: **Are there any risks to doing this study?**

The risks involved in participating in this study are minimal and these are encountered in daily life such as fatigue, difficulty breathing, stress or becoming upset. …. **Or** It is not likely that there will be any serious harms or discomforts associated with the interview. However, you may feel a little tired ...You may feel uncomfortable with (anxious, uneasy when discussing your life prior to tracheostomy …. You may find it stressful to talk about your daily struggles on home mechanical ventilation…. You may worry about how others will react to what you say

or you might find some questions uncomfortable to answer. (Such as bowel and bladder control).

You do not need to answer questions that you do not want to answer or that make you feel uncomfortable…. And you can withdraw (stop taking part) at any time. I describe below the steps I am taking to protect your privacy.

Benefits:

It is unlikely that there will be direct benefits to you; however, by better understanding Lived Experiences of Individuals Quality of Life on Prolonged Home Mechanical Ventilation, researchers and others may be able to use the information to provide individualized care for individual's on HMV.

I will keep the information you tell me during the interview confidential. Information I put in my report that could identify you will not be published or shared beyond the research team unless we have your permission. Any data from this research will be not be shared or published individually but will be combined data of all participants. That means it will be reported for the whole group not for individual persons.

Voluntary participation:

- Your participation in this study is voluntary.
- You can decide to stop at any time, even partway through the interview for whatever reason. We can reschedule to complete the interview at a time convenient to you if you wish.
- If you decide to stop participating, there will be no consequences to you.
- If you decide to stop, we will ask you how you would like us to handle the data collected up to that point.
- This could include returning it to you, destroying it or using the data collected up to that point.
- If you do not want to answer some of the questions you do not have to, but you can still be in the study.
- If you have any questions about this study or would like more information you can email **xxxxxxxx** or call at **xxx-xxx-xxxx**

This study has been reviewed and cleared by the Walden Institute Review Board. If you have concerns or questions about your rights as a participant or about the way the study is conducted, you may contact:

Walden University Institutional Review Board (IRB)
100 Washington Avenue South, Suite 900
Minneapolis, Minnesota 55401
E-mail: IRB@waldenu.edu

I would be pleased to send you a short summary of the study results when I finish going over our results. Please let me know if you would like a summary, and what would be the best way to get this to you.

Consent questions:

- Do you have any questions, would like any additional details? *[Answer questions.]*

- Do you agree to participate in this study knowing that you can withdraw at any point with no consequences to you?

[If yes, choose date and time for the interview.]
[If no, thank the participant for his/her time.]