

# **PATIENTS EXPERIENCES OF MECHANICAL VENTILATION IN THE INTENSIVE CARE UNIT OF A PUBLIC SECTOR TERTIARY HOSPITAL**

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of  
Master of Science in Nursing

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**DECLARATION**

I, Ooreofe Bolanle Adeyemi, declare that this research report is my own work. It is being submitted for the degree of Master of Science (in Nursing) at the University of the Witwatersrand, Johannesburg. It has not previously been submitted for any degree or examination at this or any other university.

Signature .....

.....day of ..... 2016

Protocol Number (**M150765**)

**DEDICATION**

This research report is wholeheartedly dedicated to God Almighty and my beloved earthly father of blessed memory – Rev. Abayomi Oluremi AJEIGBE. May your soul continue rest in the bosom of your Lord whom you cherished and served all through your sojourn on this side of eternity.

## ACKNOWLEDGEMENTS

My hope is built on nothing less than Jesus blood and righteousness.

The above statement summarises my heartfelt gratitude to God for the wisdom, resilience, strength and courage to pull through this research right from the conception of the project to its successful end against all odds.

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## ABSTRACT

Mechanical ventilation is a life-saving and frequently used treatment modality in a variety of medical diagnosis in the intensive care unit (ICU). Despite that fact, mechanical ventilation can be a distressing experience for the patient, and may result in anxiety and discomfort. In recent years, light or no sedation and the practice of wake-up calls have become common approaches allowing the patient to be more awake during mechanical ventilation. Little is known about how patients experience this particular aspect of ICU treatment in light of changes in sedation practices.

This study explored and described the experiences of patients on mechanical ventilation in the intensive care unit of one public sector hospital in Johannesburg. A qualitative, descriptive and explorative design was used and ten mechanically ventilated patients were recruited from the intensive care units of one public sector hospital in Johannesburg. The data was collected using audio-taped in-depth interviews to keep a record of the actual information presented by the participants. The collected data was transcribed and the information was analysed using Clarke and Braun's (2013) descriptive method.

A general expression from the participants was the fact that being connected to a ventilator induces a physical and emotional discomfort. The data analysis identified three themes which were (i) physical experiences, (ii) emotional experiences and (iii) communication.

The participants described their experiences of breathlessness, mouth dryness, pain and physical discomfort as a result of being placed on the ventilator which caused the physical experiences for the patients.

The experiences of bothering, fear of unknown, anxiety, feeling shocked and frightened at the moment of waking up from anaesthesia culminated into an emotional experience for the patients. The participants described that the extubation process has hard and difficult to endure, also powerlessness, loss of body image and control and near death experiences were findings of the participants.

The lack of information was viewed by the participants in terms of being connected to mechanical ventilation as an important component of the recovery period, the benefit of

purpose of connection during this period and the weaning process although, some of the participants alluded to receiving a measure of information but described it as inadequate to prepare them emotionally for the procedure. The short time for visitation and family presence was also evident in this study as impacting on the emotional state of the participants.

In the midst of these unpleasant experiences, most of the participants appreciated the caring attitude of the ICU nursing staff which gave them a sense of comfort and safety. The findings of this study further showed that administration of sedation to some of the participants affected their memory as they could not recollect things that happen while in the ICU.

Communication was the third theme that emerged from this study as findings revealed that the participants were not happy with the inability to talk as a result of the endotracheal tube. Nevertheless, the use of alternative communication methods such as the use of sign language, writing, scribbling on paper and lip reading gave the participants a bit of a relief.

The findings of this study support the previous findings of the experiences of patients on mechanical ventilation. The findings add to the body of knowledge from the South African context as little is known regarding the patients experiences of mechanical ventilation from the South African context and Africa at large.

As the field of intensive care nursing is growing in the African continent, it becomes imperative for research to be conducted in order to determine the clinical, educational and managerial gaps in ICU focusing more on measures to reduce these unpleasant experiences, increase evidence based practise and nursing perspectives.

It may be appropriate for this study to be replicated in other private and public institution on a larger scale to compliment these findings.

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# **CHAPTER ONE**

## **OVERVIEW OF THE STUDY**

### **1.0 INTRODUCTION**

Mechanical ventilation is a life-saving and frequently used treatment modality in a variety of medical diagnoses in the Intensive Care Unit (ICU). Despite this fact, mechanical ventilation can be a distressing experience for the patient and may result in overwhelming levels of anxiety and discomfort (Samuelson, 2011), which can have consequences in both the short and long-term outcomes for these patients (Adamson *et al.*, 2004). In addition, mechanically ventilated patients are susceptible to various stressors such as fear, agitation, communication problems and loss of control (Hweidi, 2007; Baumgarten and Poulsen, 2015) and as such, these patients are reliant on ICU staff for their care needs.

However, five years ago, light or no sedation and the practice of wake up calls have become common approaches allowing critically ill patients to be more awake during mechanical ventilation (Mehta *et al.*, 2011). Knowledge of this particular aspect of ICU treatment is, however, limited in the literature internationally and in South Africa. In light of these changes, this study intends to explore patients' experiences during mechanical ventilator treatment in the ICU of one public sector hospital in Johannesburg. .

This chapter presents an overview of the study. The problem statement, purpose of the study, research objectives and significance of the study will be described. The assumptions of the researcher will be discussed and conceptual definitions defined. A brief overview of the study and ethical procedures adhered to will be discussed in greater detail in Chapter Three.

### **1.1 BACKGROUND OF THE STUDY**

Mechanical ventilation is a commonly used mode of respiratory support in the Intensive Care Unit. More than 90% of patients in Intensive Care Units (ICUs) worldwide are mechanically ventilated (Meade *et al.*, 2001). Most patients may require relatively short

periods of respiratory support, whilst one third require long-term mechanical ventilation (Esteban *et al.*, 2000). The number of patients requiring long-term ventilation is likely to increase, particularly amongst those who are elderly or with chronic conditions leading to a likely increase in long-term and prolonged usage (Lone and Walsh, 2011), therefore Intensive Care delivery is complex and likely to be more complicated.

A substantial body of empirical evidence from a patient perspective exists in the area of critical illness in an ICU ( Granja *et al.*, 2005; Karlsson *et al.*, 2012; Engström *et al.*, 2013; Baumgarten and Poulsen, 2015). Johnson (2004), concludes that the findings from studies undertaken prior to 1990 indicate that patients experienced communication difficulties, insufficient explanation of procedures by health personnel, restriction of activities, anxiety and panic, nightmares and hallucinations, feelings of insecurity and helplessness (Hupcey and Zimmerman, 2000; Granberg Axèll, 2001; McKinley *et al.*, 2002; Papathanassoglou and Patiraki, 2003). There was also empirical evidence of discomfort related to equipment and various nursing procedures.

Studies undertaken since 1990 have produced similar results. For example, Stein-Parbury and McKinley (2000), in their review of 26 studies directed at exploring patients experiences, noted that patients had vivid recollections of their stay in ICU. According to these authors, negative experiences included pain, anxiety, sleep problems and impaired cognitive functioning, while positive experiences were promoted primarily by health personnel and associated with a sense of safety and security. Other studies by Grap *et al.* (2003) and Samuelson *et al.* (2003) describe patient experiences in connection with being cared for while mechanically ventilated and show that impaired speech and communication difficulties lead to a sense of vulnerability and powerlessness. These patients also experience pain due to the endotracheal tube, having to maintain an uncomfortable position in bed, a reduction in sensory input, sleep disturbance and feelings of isolation and they that struggle to regain control over their body.

A number of studies have described patients' experiences of critical illness from memories of their time in the ICU. For example, Adamson *et al.* (2004) indicated that at six months after discharge, those patients treated in ICU described a variety of memories but many could not remember anything at all. Similar results were found in studies by Rotondi *et al.*,

(2002), Granja *et al.* (2005) and Samuelson *et al.* (2007). These authors found 189 (93%) patients in their studies described the ICU as calm and friendly (Granja *et al.*, 2005). Amongst those who could recall their time on mechanical ventilation, 59% (n=111) reported discomfort due to being unable to talk, 64% (n=121) were bothered by pain and 81% (n=113) found the tracheal tube uncomfortable (Rotondi *et al.*, 2002; Granja *et al.*, 2005).

In another study by Hofhuis *et al.* (2008), reportedly (n=11) 22% of patients had psychological problems such as insomnia, concentration difficulties, depression and hallucinations after being critically ill in ICU. More recently, in a review of 10 studies aimed at describing the meaning of patient experiences, Fredriksen and Ringsberg (2007) noted that patients express a feeling of disorientation to time and place as a result of unfamiliar medical personnel and the noisy environment of an ICU. According to Johnson *et al.* (2006), mechanically ventilated patients feel a disconnection with their body, which is linked to strange intravenous lines and equipment. These feelings are in addition to suffering with a prolonged illness. However, the limitation in most of these studies is that it is unclear to what extent the patients involved were sedated whilst on mechanical ventilation (Johnson *et al.*, 2006; Fredriksen and Ringsberg, 2007; Hofhuis *et al.*, 2008).

At present there is a trend to support the use of light or no sedation in ICUs, thus allowing patients to be more awake during mechanical ventilation. This is based on extensive empirical evidence that patients who had light sedation or no sedation spent a shorter time in the ICU, a shorter time on mechanical ventilation and a shorter time in the Hospital (Strøm *et al.*, 2010; Shinotsuka, 2013; Shehabi *et al.*, 2013). Studies by Samuelson *et al.* (2003, 2007) indicated that the depth of sedation has an impact on perception of stressful experiences and that light sedation compared with heavy seems to increase the risk of perceiving experiences in the ICU as more bothersome.

Nursing health personnel working in the South African ICUs are expected to provide optimal nursing care in this complex environment. Optimal care, which ideally should be based on the best available evidence, includes not only the technical skills and expert knowledge required to manage critically ill patients competently, but also knowledge of the psychosocial aspects of critical care illness (Elliott *et al.*, 2011). It is important for

Intensive Care nursing (health) personnel to have an awareness and understanding of patients' experiences and ICU treatments, as these provide evidence on which to base the delivery of patient care. In light of changes in sedation practices, this study therefore intends to explore patients' experiences on mechanical ventilation in the ICU of one public sector hospital in Johannesburg in light of changes in sedation practices.

## **1.2 PROBLEM STATEMENT**

Little is known about how South African critically ill patients experience mechanical ventilation in light of sedation practice changes. This is because only two studies have been found which explored this aspect of Intensive Care treatment in South Africa (Turner *et al.*, 1990; Jordan *et al.*, 2002). The current practices indicate lighter sedation or no sedation is far more beneficial to mechanically ventilated patient outcomes in the Intensive Care Unit (Strom *et al.*, 2010). Many studies conducted overseas have found that the depth of sedation has an impact on perception of stressful experiences and that lighter sedation seems to increase the risk of perceiving experiences in ICU as more bothersome (Kress *et al.*, 2000; Schweickert *et al.*, 2004; Strøm *et al.*, 2010; Mehta, 2012). Also, this seems to suggest mechanically ventilated patients may be expected to endure anxiety and discomfort, in addition to their illness situation. As these patients are reliant on Intensive Care health personnel for all their care needs, this study will attempt to address the following research question:

- What are the patients experiences of mechanical ventilation in the Intensive Care Unit of one public sector hospital in Johannesburg?

## **1.3 AIM OF THE STUDY**

The aim of this study is to explore and describe the experiences of patients on short and long-term mechanical ventilation in the Intensive Care Unit of one public sector hospital in Johannesburg. This study is an attempt to provide evidence in order to offer recommendations for the intensive care nurses to better understand and care for patients who receive mechanical ventilation. .



## **1.4 OBJECTIVES**

The objectives of the study were:

- To identify and describe the experiences of patients on mechanical ventilation in the Intensive Care Unit.
- To explore the physical and psychosocial experiences of patients on mechanical ventilation in the Intensive Care Unit

## **1.5 SIGNIFICANCE OF THE STUDY**

In today's health care setting, treatment and care interventions are expected to be evidence-based. Patients contribute to evidence because their perspectives are a valuable resource when it comes to knowledge about what opportunities and obstacles there are when we want to implement a particular form of treatment. The researcher believes this study would not only create self-dependence and self-reliance for patients, but also better equip the Intensive Care nurse to care for patients on a mechanical ventilator with greater insight and understanding, especially as these patients require the highest level of care needs in the Intensive Care Unit.

## **1.6 PARADIGMATIC PERSPECTIVES**

A paradigm, is a general perspective on the complexities of the world, or the world view of a phenomenon (Polit and Beck, 2012). It is a philosophical stance which guides qualitative research as it informs the question to be asked, observation made and how the data is interpreted. A paradigm helps in guiding the researcher's enquiry. In this study, the researcher's enquiry is based on meta-theoretical, theoretical and methodological assumptions.

### **1.6.1 Meta-theoretical Assumptions**

Assumptions are basic principles accepted to be true without proof which are based on logic, custom, theories and nursing research (Polit and Beck, 2012). Assumptions in all

research, according to Burns and Grove (2009), help to provide ground for the conduct of the research, they are embedded in the study design and interpretations of the findings. The four common concepts that influence the practice of nursing and nursing theories are (i) Person, (ii) Environment, (iii) Health and (iv) Nursing.

- **The person**

A person is the most important concept in nursing practice as he/she forms the focus of nursing. A person in this context is therefore the critically ill patient admitted to the Intensive Care Unit and being cared for by the multidisciplinary team.

The nursing conceptual framework, University of North Carolina (2013), defines a person as a unique individual, an holistic being with unique culture, beliefs and values, whose physical, biological, psychosocial and spiritual aspects influences their development. As such, all these aspects need to be taken into consideration by the nurse.

In this study, a critically ill patient admitted into an Intensive Care Unit requires a highly sophisticated care and monitoring in order to meet their needs.

Critical illness is a life threatening condition which occurs unexpectedly, altering not only the physiological function of the body but also the psychosocial and spiritual function. It does not only affect the individual but also the family and as such, impacts on the internal equilibrium of the family (Morton and Fontaine, 2013).

- **The Environment**

The environment encompasses the internal, external phenomena and processes the individual interacts with which impact on the individual at a given time. The environment from a conceptual framework by Georgia Southern University, (2010), includes the physical, social, psychological and spiritual elements which affect or are affected by the people. In this study, the internal environment are the stressors related to receiving care in an ICU, while the external environment is the Intensive Care environment itself and the mechanical ventilator. The impact of these stressors, such as mechanical ventilators,

machines, physical and environmental factors, and the experiences of individual patients to these stressors are important in this study.

- **Health**

Health is a dynamic state of being which results from the interaction of an individual with the environment. It varies from optimum health to illness, disease and dysfunction and changes throughout the individual life span. The World Health Organization defines health as the state of complete physical, mental and social well-being and not merely the absence of disease or infirmity (World Health Organization, 2016). Wellness can be described as an active process of becoming aware of and making choices toward a more successful existence (National Wellness Institute, 2016). Wellness is viewed as multidimensional and holistic which encompasses lifestyle, mental and spiritual well-being and the environment. Health and illness continuum describes how the absence of illness does not indicate well-being, rather the individual mental and emotional health is incorporated into well-being. The continuum indicates that in the absence of physical illness an individual can suffer from various conditions, such as anxiety, depression and emotional breakdown, which point to lack of wellness.

- **Nursing**

Henderson's definition of nursing states "The unique function of the nurse is to assist the individual, sick or well, in the performance of those activities contributing to health or its recovery (or to peaceful death) that he would perform unaided if he had the necessary strength, will, or knowledge doing such in a way to help the patient gain independence as rapidly as possible (Henderson, 1991). In any Intensive Care Unit setting, the goal of the ICU nurses is to provide specialised nursing care for the critically ill patient with actual or potential dysfunction of the vital organs (WFCCN, 2005). The ICU nurse, caring for a critically ill patient, should therefore possess the necessary skills, knowledge, experience, attitudes and knowledge of highly technological equipment. The integration of these knowledge into the care and management of the critically ill, will assist in rendering holistic and patient-centred care to the patient as well as contributing knowledge to the

multidisciplinary team involved. This attitude and knowledge will help to promote a caring relationship between the caregivers and the patient.

### **1.6.2 Theoretical Assumptions**

The terms of reference for this study are:

- **Patient**

A patient is described as a recipient of care from health care professionals (Brooker *et al.*, 2009) In this study, a patient will refer to the adult recipient of care from a professional nurse within the Intensive Care Unit whilst connected to a mechanical ventilator.

- **Mechanical ventilation**

This refers to the use of an artificial device to assist a patient to breathe. A mechanical ventilator is the device or machine specifically designed to provide ventilation assistance to the patient (Urden *et al.*, 2008). Mechanical ventilation can be categorised as invasive or non-invasive, where the ventilator support is provided with or without the use of a tracheal tube. In this study, mechanical ventilation will refer to the use of an oral or nasal endotracheal tube inserted into the trachea of a critically ill patient and connected to a mechanical ventilator.

- **Intensive Care Unit**

This is a specialised unit within a hospital which provides care for severely ill patients with potentially reversible conditions. It also provides care for patients who require close observation and/or treatment which cannot be provided in a general ward (Adam and Osborne, 2005). In this study, two Intensive Care Units will make up the study selected site.

- **Experiences**

The Oxford English Dictionary (2009) defines “experiences as the practical contact and observation of facts or events and knowledge or skill gained over time”. In this study, experience will refer to the meanings and patterns of relating that create a person’s unique process of life during short and long-term mechanical ventilation in the Intensive Care Unit.

### **1.6.3 Methodological Assumptions**

Methodological assumptions are assumptions made by the researcher about the methodology and methods used in the process of qualitative research and in line with this study, the methodological assumptions are qualitative research and evidence based practice.

The researcher practice caring for the total being, spirit, soul and body, of a patient hence health personnel should ensure that the physiological, psychological, social, cultural and spiritual aspect of the patients’ life are included in the planning of care.

Acquisition of knowledge from education and individual experiences in line with the phenomena under study helps in enhancing caring for the patient in nursing practice. The researcher believes nursing care and management of critically ill patients must be evidenced based. Evidence based practice is the process of making shared decisions between the healthcare provider or the multidisciplinary team, the patient and significant others based on research findings and clinical expertise.

Evidence based practice is important as it helps in improving the outcome of patients illness. This takes what is known or found out via research and incorporating this into patients’ management or line of care to achieve the best possible outcomes, bearing in mind that the evidence has to be critically evaluated (Morton and Fontaine, 2013).

As such, the researcher undertook this study in an attempt to generate understanding of patient lived experience of mechanical ventilation and useful knowledge that can improve or inform nursing practice as well as patient care.

The study intended to explore and describe the experiences of patients' on mechanical ventilation, as lived by the patients placed on this treatment modality. Their experiences, which would be their feelings, views about the Intensive Care environment, the ventilator, mode of communication, experiences of pain and sedation and their opinion of the health personnel working in the units would be obtained.

A qualitative descriptive method, which focuses on exploring the lived experiences of the study participants, was used for obtaining the information. This study intended to explore subjective information from the patient as it is believed to be a more reliable means of obtaining people's views of a phenomenon.

## **1.7 OVERVIEW OF RESEARCH METHODOLOGY**

### **1.7.1 Research Design**

A qualitative, exploratory, descriptive and contextual design was used to explore the patient's experiences of mechanical ventilation in the Intensive Care Unit of one public sector tertiary hospital in Johannesburg. This method was chosen to address a specific research question and to fill an empirical gap in literature about the South African context. The study utilised a qualitative approach as the researcher focused on describing the experiences of mechanical ventilation from the perspective of the participants without any form of manipulation (Creswell, 2013). A descriptive approach was used, as the study sought to describe participants' views of their experience of mechanical ventilation (Polit and Beck, 2012). The study was also contextual, as it only explored the experiences of patients on mechanical ventilation who were admitted to the Intensive Care Units of the academic hospital under study.

### **1.7.2 Sample size**

The target population for this study was critically ill patients who experienced mechanical ventilation during their admission in the Intensive Care Unit. A purposive sampling

method was utilised for sample selection, and a minimum of eight the participants (n=8) who met the inclusion criteria were targeted.

### **1.7.3 Setting**

The study was conducted in a natural setting namely the intensive care unit of one public sector tertiary hospital in Johannesburg. The hospital is a tertiary and academic hospital which has 1,088 beds and over 4000 members of staff. The hospital has more than four intensive care units with 39 beds in all. The cardiothoracic ICU and the multidisciplinary ICU were used for this study.

### **1.7.4 Data Collection**

Data was collected using audio-taped in-depth interviews to ensure an accurate record of the participants' experiences or information was secured (well kept). The interviews were analysed and the transcription of the audio-taped interviews was done verbatim using Clarke and Braun (2013) method of data analysis (Clarke and Braun, 2013).

The participants were patients who had experienced mechanical ventilation for a period greater than 24 hours but not more than three weeks, as they were expected to have an in-depth understanding of their experiences. The use of in-depth interviews is to allow the participants freedom in expressing their views and feelings of being connected to a machine (ventilator)

## **1.8 TRUSTWORTHINESS**

The term trustworthiness refers to the degree of confidence qualitative researchers have in their data assessed using criteria of credibility, transferability, dependability and confirmability, as described by Lincoln and Guba (Lincoln and Guba, 1985; Shenton, 2004; Polit and Beck, 2013).

### **1.8.1 Credibility**

The term refers to confidence in the truth of data and interpretations as the researcher attempts to demonstrate that a true picture of the phenomenon under study is being presented (Polit and Beck, 2013).

### **1.8.2 Dependability**

The term refers to stability or reliability of data over time and conditions (Polit and Beck, 2013).

### **1.8.3 Transferability**

This refers to the potential for extrapolation, or the extent to which the findings can be transferred or have applicability in other settings (Polit and Beck, 2013).

### **1.8.4 Confirmability**

Shenton (2004) suggests researchers must take steps to demonstrate that findings emerge from the data and not their own predispositions or inclinations.

## **1.9 ETHICAL CONSIDERATIONS**

Ethical issues in research are standards of ethical conduct to safeguard the study subjects and integrity of the research process (Polit and Beck, 2013). Declaration of Helsinki (2013) was upheld in this conduction of this study. The following ethical principles was applied in this study (Brink *et al.* 2012):

- The research proposal was submitted and presented for peer review to the Department of Nursing Education and the Postgraduate Committee of the University for feasibility and approval.
- Ethical approval was sought and obtained from the Human Research Ethics Committee (Medical) of the University of the Witwatersrand, as well as the Gauteng Department of Health.



- All the participants who met the inclusion criteria of the research population were approached and invited to voluntarily participate. Data was gathered until all categories were saturated.
- Informed consent was obtained from the participants and the participants were reminded that participation was voluntary and withdrawal, at any stage of the interview process, was allowed. Should the participants agree to participate in the interview being audio-taped, a separate consent was signed.
- The participants' names were replaced with code numbers for confidentiality and anonymity.
- Although no harm was intended, provision for emotional support was made available should any of the participants experience discomfort during the interview process.
- The participants who experienced physical discomfort during the interview were referred for counselling and were automatically withdrawn from the study. The study setting has experienced specialist health personnel and social workers who assisted further in addressing emotional distress of participant.
- To ensure privacy, the interview was conducted privately with only one participant and the researcher present. Time was allowed at the end of the interview for the participant to raise questions.

## **1.10 SUMMARY**

In this chapter, an overview of the study was given, the background of the study, the research rationale and questions were detailed. The researcher's assumptions were discussed and the research methodology and methods described. The ethical considerations pertaining to the study were given and measures of trustworthiness were presented.

In the next chapter, the literature review will be discussed in greater detail and will be followed by the methodology and methods utilised for this study.

# **CHAPTER TWO**

## **LITERATURE REVIEW**

### **2.1 INTRODUCTION**

In the previous chapter, an overview of the study was presented which included the background to the study, the problem statement, significance, objectives, aim, research question and meta-theoretical assumptions. A brief overview of the research methodology and ethical considerations were also presented.

In this chapter, the review of previous research or studies on this topic will be discussed in addition to a brief history of the ICU, mechanical ventilation and the development of intensive care in South Africa.

An ICU is a specialised unit designed for the management and close monitoring of critically ill patients with life threatening conditions; well equipped with highly specialised trained health personnel, special equipment/facilities for the support of vital functions it provides high dependency and Intensive Care (Urden *et al.*, 2008).

### **2.2 HISTORY OF INTENSIVE CARE**

The history of the ICU began as far back as in the 18<sup>th</sup> century, when Florence Nightingale discovered a post-operative recovery room, designed to care for patients post-surgery until they were stable. Patients from surgery were placed here and monitored immediately after surgery to recover from the immediate effect of the operation and to reduce post-operative complications and mortality (Hilberman, 1975; Weil and Tang, 2011). During the Crimean War (1850s), injured soldiers were placed and nursed on the bed closest to the nursing station for close monitoring. Seventy years later, Dandy, in 1923, created a three-bed unit for the Intensive Care of critically ill post-operative neurosurgical patients at Johns Hopkins Hospital in Baltimore, MD, USA where specially trained health personnel were used to monitor, render care and manage patients (Hilberman, 1975; Weil and Tang, 2011).

Kirschner of Germany, in 1930, also created a combined post-operative recovery room and Intensive Care ward in the surgical unit of the University of Tübingen, Germany, when he determined a serious need for specialisation in the care of the patient in which application of clinically expanding knowledge and special techniques in surgery were essential. This helped to monitor and manage critically ill patients as well as those recovering from surgery (Hilberman, 1975 and Vincent, 2013) and led to the establishment of recovery rooms in all hospitals by 1960.

High mortality rates from respiratory paralysis, secondary to a polio epidemic and the desperate attempt at saving a 12 year old girl which occurred in Denmark 1952, led to the establishment of the first Intensive Care Unit in the world and the introduction of manual mechanical ventilation for non-surgical patients (Reisner-Sénélar, 2011). Ibsen, the senior anaesthetist at Blegdam Hospital, performed a tracheostomy by inserting a cuffed endotracheal tube into the airway and the patient was manually ventilated (positive pressure mechanical ventilation), with the use of a vented rubber bag, which delivered oxygen mixtures when compressed manually thus improving the patient's condition (Hilberman, 1975; Reisner-Sénélar, 2011; Weil and Tang, 2011). The modernised ICUs began in the late 1950s, followed by recruitment and training of specialised (health personnel) and medical expertise in the mid-20<sup>th</sup> century. Sophisticated haemodynamic and respiratory monitoring was introduced to better care for the critically ill patient and this was followed by recruitment of health professionals (health personnel) who were ready to use life support interventions. Since then, several other improvements have been introduced into the Intensive Care Unit (Weil and Tang, 2011).

The development of Intensive Care in South Africa began in 1960, with the post-operative ventilation of cardiothoracic patients and development of a neonatal tetanus unit in King Edward VIII Hospital in Durban and a pulmonary unit in Cape Town for ventilating patients with respiratory problems. The need to create a resuscitation centre for the management of patients with respiratory problems and to improve post-operative nursing and emergency services led to the advent of a post-registration course in anaesthetics for (health personnel) (Scribante *et al.*, 2004). The post-basic diploma Intensive Care nursing was approved in 1964, with the first course offered in 1966 in Johannesburg Hospital. The first multidisciplinary unit was founded in Addington Hospital, Durban (1970), and the

first full time intensivist on the African continent, Dr Neil Goodwin from Sweden, was appointed to help manage the unit which later led to the establishment of various ICUs throughout South Africa (Scribante *et al.*, 2004; CCSSA, 2015). As a result of the growth of this discipline, the Critical Care Society of Southern Africa (CCSSA) was established in 1978 in order to develop a constitution for the discipline (Scribante *et al.*, 2004). Intensive Care health personnel were empowered to be independent practitioners, accountable for all actions taken in caring for critically ill patients. Despite the commencement of intensive care courses since 1964, South Africa faces the challenge of a shortage of intensive care personnel. In an audit done by the Critical Care Society of Southern Africa in 2004, it was discovered that only 25.6% of the health personnel working in the Intensive Unit were trained critical care health personnel (Scribante *et al.*, 2004).

### **2.2.1 MECHANICAL VENTILATION**

A mechanical ventilator is the device or machine that is specifically designed to provide ventilatory assistance to the patient (Urden *et al.*, 2008). Mechanical ventilation can be categorised as invasive and non-invasive, where the ventilator support is provided with or without the use of a tracheal tube. Initially, an iron lung called a “spirophore,” developed by Alfred Woillez (1876), was used for ventilating drowning patients and this was replaced by another iron lung developed by Drinker and Shaw in 1929, to treat polio patients. The iron lung is an elongated tank, which encloses the patient’s whole body from the neck downwards, with the neck enclosed in a rubber gasket exposing the head, face and airway to room air. In normal mechanics, negative pressure is generated in the pleural cavity by the respiratory muscles resulting in a gradient between the atmospheric pressure and the pressure in the thorax to generate a flow of air (Slutsky, 2015). Followed by the polio conference in Copenhagen, the polio epidemic of 1952, gave rise to the development and use of positive pressure ventilation, as there was a high mortality of more than 80% of polio patients during the epidemic. Ibsen realised that the high mortality experienced was as a result of respiratory failure, hence he recommended positive pressure ventilation and the use of a tracheostomy. The amount of oxygen supplied to the patient lung manually through the insertion of a tracheostomy tube is 50% (fifty percent) oxygen which resulted in a reduction of the mortality rate during the outbreak (Slutsky, 2015)

Positive pressure ventilation works by causing an increase in the airway pressure of the lungs/intrathoracic cavity through an endotracheal/tracheostomy tube. It allows air to move into the airway until the ventilator breath is stopped, once this happens, airway pressure drops and the elastic recoil of the lungs and the chest wall pushes the breath out through passive exhalation. The two types and modes of positive pressure ventilator used during this period were the Pressure Cycled Ventilator (PCV) and the Volume Cycled Ventilator (VCV) (Kotur, 2004). Over the years, improvement has been made to the ventilation used in the ICU, resulting in new modes and new ventilators.

The above aspect highlighted the history of Intensive Care as a development in medicine where critically ill patients are monitored effectively and cared. This is achieved by the use of highly developed and complex instruments and equipment necessary for promoting survival and prompt management.

The use of mechanical ventilation in the ICU distinct this unit from others and the health personnel, with a nurse ratio of 1:1 makes this unit unique, with the purpose of giving individualised and holistic care to both the patient and family. This section also describes the use of negative pressure ventilation as the first type of ventilation available, which has now been replaced with the use of positive pressure ventilation.

## **2.3 EFFECTS OF MECHANICAL VENTILATION ON THE PATIENT**

The establishment of an artificial airway (endotracheal tube) is important for the management of patients with respiratory insufficiency or failure. However, mechanical ventilation and intubation have diverse effects on the patients and these are presented in the table below. I will then highlight the respiratory system as the focus of this study is mechanical ventilation and thereafter, effects related to the respiratory system will be discussed, as the focus of this study is mechanical ventilation.

**Table 2.1:** Effects of Positive Pressure Ventilation on the body's system

<b>SYSTEMS</b>	<b>EFFECTS OF POSITIVE PRESSURE VENTILATION (PPV)</b>
Cardiovascular	<ul style="list-style-type: none"><li>• Reduction in venous return due to alteration in skeletal pump, respiratory pump and intra-thoracic pressure.</li><li>• PPV also causes increase in the mean airway pressure and a decrease in the cardiac output.</li><li>• PPV increases the intra-thoracic pressure, which results in a decrease in venous return, with a resultant decrease in pulmonary blood flow.</li><li>• Reduction in right and left ventricular preload also occurs resulting in reduction in stroke volume, impacting on the cardiac output (Chang, 2013; Robb, 1997a).</li></ul>
Hepatic	<ul style="list-style-type: none"><li>• Reduction in cardiac output as a result of positive pressure ventilation and positive end-expiratory pressure causes a resultant decrease in blood flow to the liver.</li><li>• An increase in hepatic vascular resistance and mechanical compression from increased intra-thoracic pressure causes a reduction in hepatic blood flow.</li><li>• , the reduction in hepatic perfusion majorly occurs with the introduction of positive end-expiratory pressure (Chang, 2013).</li></ul>
Nervous	<ul style="list-style-type: none"><li>• An increase in intra-thoracic pressure, as a result of positive pressure ventilation increases the jugular vein, superior vena cava and the extra-thoracic pressure which then result in a decrease in cerebral venous return and consequently increases the intracranial pressure and intracranial blood volume (Robb, 1997a; Cairo, 2012).</li></ul>
Renal	<ul style="list-style-type: none"><li>• The kidney receives about 25% () of the cardiac output, hence with positive pressure ventilation, a decrease in cardiac output causes a reduction in the glomeruli perfusion, a decrease in filtration process efficiency and a resultant decrease in urine output (Chang, 2013).</li><li>• Introduction of positive end-expiratory pressure causes a further decrease in urine output and consequent fluid retention (Robb, 1997b).</li></ul>

SYSTEMS	EFFECTS OF POSITIVE PRESSURE VENTILATION (PPV)
Haemo-dynamic measurement	<ul style="list-style-type: none"> <li>• With positive pressure ventilation, compression of the lung parenchyma against the chest wall causes an increase in intra-thoracic pressure and compression of the pulmonary blood vessels causes a decrease in the ventricular output and stroke volume (Chang, 2013).</li> <li>• The increased intra-thoracic pressure thus limits the flow of blood to the right ventricle, resulting in a decrease in the right ventricular output which leads to a decrease in the blood volume in the pulmonary arteries and a resultant decrease in the left and right ventricular input and output (Chang, 2013).</li> </ul>
Abdominal considerations	<ul style="list-style-type: none"> <li>• The introduction of mechanical ventilation in these patients increases intra-abdominal pressure causing a decrease in cardiac output as a result of transmission of pressure across the diaphragm to the heart and great vessels.</li> <li>• The use of positive end-expiratory pressure in patients with elevated intra-abdominal pressure also results in increased peripheral vascular resistance, a decrease in compliance of ventricles and a decrease in cardiac output (Cardiovascular effect) (Chang, 2013).</li> </ul>
Infection (Risks)	<ul style="list-style-type: none"> <li>• There is an increased risk of developing nosocomial infection as a result of suppression of the patients' immune function and invasive procedures. The risk of developing nosocomial pneumonia, according to Robb (1997b), in ventilated patient is increased six to twenty one times more than in non-ventilated patients.</li> </ul>

### 2.3.1 Alteration in Respiratory Mechanics

Alteration in the normal respiratory or pulmonary mechanics occurs with the introduction of positive pressure ventilation. With negative pressure ventilation, the diaphragm and other respiratory muscles allow gas flow by decreasing the pleural, alveolar and the airway pressures below the atmospheric pressure allowing air to flow into the lungs during inspiration (Chang, 2013).

However, with positive pressure ventilation, the flow of air is delivered under a positive pressure gradient to the lungs whereby the airway pressure is greater than the atmospheric pressure during inspiration (Chang, 2013).

Decreased lung compliance, increased alveolar dead space, positive end-expiratory pressure, increased ventilation perfusion mismatch, barotrauma, oxygen toxicity and respiratory alkalosis are altered during positive pressure ventilation. The elasticity of the lungs (compliance) becomes decreased during positive pressure ventilation as a result of uneven distribution of gases (mal-distribution), decrease in surfactant production, increase in pulmonary oedema and progressive atelectasis with increased functional residual capacity which results in a decrease in lung volume resulting in stiff lungs (Chang, 2013; Robb, 1997b).

During mechanical ventilation, over inflation of the alveoli and the inhibition of the capillary perfusion occurs as a result of either administration of large tidal volumes and/or high alveolar pressures, which then cause an increase in the physiological dead space (Robb, 1997b).

Also there are changes in the distribution of gas to the lung areas during mechanical ventilation in which the central alveoli is ventilated first. This is contrary to the sequence of events during a spontaneous ventilation where the peripheral alveoli becomes ventilated first because of their closeness to the expanding chest wall.

The ventilation of the central alveoli first resulted in ventilation perfusion mismatch, resulting in a further increase in the physiological dead space (anatomical and alveolar dead space) (Robb, 1997b).

Several complications emanate as a result of positive pressure ventilation and intubation and even with the use of some medication whilst being ventilated, such as morphine sulphate which is a respiratory depressant.

The complications associated with PPV and intubation will be addressed in the next section.



### **2.3.2 Complications of Mechanical Ventilation and Intubation**

Complications may occur at any stage of mechanical ventilation, either during and after intubation or at extubation.

Complications that can occur during intubation are soft tissue damage, trauma to the teeth during an emergency intubation and oesophageal intubation problems. This complication can occur if intubation is carried out by an inexperienced practitioner which can lead to aspiration or induced vomiting.

With prolonged intubation, hypoxia can occur which, if left uncorrected may result in arrhythmias. Bradycardia may occur from excessive vagal nerve stimulation. Although some of these complications are life threatening, others are minor and can be reversible.

Complications can also occur whilst intubated, depending on the length of time the patient is intubated and the techniques of airway management employed. Secretions can obstruct the airway (Chang, 2013), kinking of the tube can also occur and as such, the endotracheal tube and the ventilator circuit should be repositioned to prevent such occurrence. Self-extubation can also occur, which should be prevented as this can cause tracheal damage. Complications such as barotrauma, volutrauma and biotrauma are also associated with positive pressure ventilation (Chang, 2013),.

### **2.3.3 Communication Impairment**

Communication impairment has been reported by various researchers as one of the major challenges faced by mechanically ventilated patients. In a study conducted in USA, approximately 2.7 million patients admitted to the ICU per year experience inability to communicate largely due to the presence of the endotracheal tube for assisted ventilation (Happ *et al.*, 2011).

In exploring the lived experiences of patients on mechanical ventilation by Jordan *et al.* (2002), the participants described experiencing the feeling of fear, anxiety, stress,

loneliness and frustration as a result of the inability to communicate verbally caused by the placement of the endotracheal tube.

In a descriptive study exploring the level of frustration of mechanically ventilated patients and the intervention of health care professionals regarding communication, Patak *et al.* (2004) interviewed 29 patients using both a qualitative and quantitative approach. In this study, data analysis revealed that 62% of the participants expressed high levels of frustration in communicating their needs. With regard to interventions provided by the health personnel in promoting communication of needs, 66% of the patients applauded the professional intervention as being helpful, 24% said the intervention wasn't useful to them and 10% indicated the professionals were never helpful when it came to communication.

In a related scenario, the participants in Schou and Egerod (2008) described the inability to communicate as a life threatening challenge as they experienced soreness of the throat, inflammation of the vocal cords and difficulty swallowing post-extubation. Despite the inability to communicate, the patients credited the health personnel for their ability to anticipate the patients' needs and communicate with them. The patients found the alternative means of communicating with the health personnel helpful though not easy, especially when sedated (Schou and Egerod, 2008).

In another study by Karlsson *et al.* (2012), the inability to communicate was expressed as the worst experience, as patients felt annoyed when they could not be understood by the health care professionals. However, an interesting outcome, was the fact that years of experience of professionals was seen to make a difference in their ability to understand and predict patients' needs. Being out of control was linked to disorientation and a feeling of powerlessness due to lack of information regarding their plan of care and what to expect.

Findings from Engström *et al.* (2013) showed that the inability to communicate by the participants was experienced as hard, especially with their inability to use any of the alternative means of communication or sign language due to the weakness of their muscles and body, resulting in frustration and panic. Tapping of the bed rails with probes was the only alternative they could explore to call attention to themselves. Meanwhile, the

participants applauded their family and health personnel for understanding their mimes and attending to their needs even though it was not an easy task for them.

The participants also experienced feelings of hopelessness and anger as a result of lack of information regarding their condition and treatment (Engström *et al.*, 2013). However, receipt of information by the participants regarding their health and management made them trust the health personnel, gain confidence and a sense of safety associated with information regarding suction and how to breathe.

Guttormson *et al.* (2015), in a descriptive, correlational study of communication during mechanical ventilation in the USA, conveniently selected 31 participants from a medical-surgical ICU and interviewed the participants about their experience of communication while on mechanical ventilation.

Data analysis revealed that the inability to communicate was described as horrid and the worst thing that had ever happened to the participants. Among the participants, found it extremely difficult to express their needs while 35% could not understand the information they were given, resulting in a feeling of helplessness (Rattray *et al.*, 2010), (Happ *et al.*, 2011), (Patak *et al.*, 2004).

This was contrary to the findings by Karlsson and Forsberg (2008), where the issue of communication was viewed as a minor problem by the participants.

Furthermore, Guttormson *et al.* (2015) described the problem encountered by the participants with communication. He highlighted the problems in terms of failed communication or receipt of information, methods of communication and the measures they believed could be effective in communicating whilst on mechanical ventilation. Failed communication was expressed by the participants as the inability of the healthcare workers to understand their messages of distress, wishes or needs.

Some participants viewed it as lack of response from the health personnel, while adequate information given to the participants regarding their health and the treatment modalities was seen to be beneficial as some described it as helpful in coping with their illness, management and the strange ICU environment.

However, the participants described receiving information from healthcare professionals as “sucking out information from healthcare workers”; they could only obtain information from healthcare workers through persistence (Guttormson *et al.*, 2015).

The participants described alternative method used to communicate with the health personnel and their family such as (i) the use of alphabet boards, (ii) picture boards, (iii) pointing, (iv) body gestures, (v) writing on a pad, (vi) gesticulating with their hands and lip movements to describe their needs and to communicate with health personnel and family were methods described by the participants in Hurtig and Downey (2008), Holm and Dreyer, (2015) and Guttormson *et al.* (2015) as alternative methods to communicating in an ICU. Although many of the participants described difficulties with some of these measures including a difficulty in writing, others indicated the usefulness of them.

A major setback from the report of Guttormson *et al.* (2015) was that the study was a secondary analysis which was not entirely focused on communication and also the sample size was small for a quantitative study. Nevertheless, the study suggested the need to lay more emphasis on the development of communication skills amongst health personnel and healthcare workers who are the primary communication partners to the patients (Guttormson *et al.*, 2015).

From the perspectives above, it was evident that the ability to communicate and the provision of information for patients are very important aspects of patient experiences on mechanical ventilation and as such, this current study seeks to explore the experiences of patients whilst mechanically ventilated.

## **2.4 PATIENTS EXPERIENCE OF CRITICAL ILLNESS**

Critical care patients are those at high risk of actual or potential life threatening conditions, which require intensive nursing care. The Intensive Care environment is a high-technology environment created specifically for the treatment and monitoring of life-threatening conditions in critically ill patients (Meriläinen *et al.*, 2010; Urden *et al.*, 2008). The health personnel therefore need to pay attention to the technology and the treatment necessary for ensuring the stability in the physiological functioning of the patient. This section will deal

with the patients' experiences of critical illness stressors they endure in the ICU during their critical illness.

#### **2.4.1 Stressors in the ICU**

Critical illness, trauma and severe disease situations are viewed as life-threatening conditions, experienced as stressful for the individual and the family. The relocation from home to the hospital environment and then to ICU also constitutes stress for the patient.

The experiences of patients regarding critical illness are varied from one individual to another. Each individual has to cope with one or more stressors such as the fear of death, fear of survival, discomfort, lack of sleep, loss of control over self, inability to communicate with intubation and loneliness as a result of separation from families and friends.

The responses of each individual to these stressors are dependent on their age, social support, gender, cultural background, medical diagnosis and prognosis (Urden *et al.*, 2008). Stress occurs as a result of disequilibrium between the physiological and psychological functioning of an individual.

Following admission into the ICU, patients are confronted with multiple stressors from physical, psychological and environmental factors. In response to these stressors, several adaptation methods are activated, such as the hypothalamic-pituitary-adrenal axis (Morton and Fontaine, 2013).

- **Physical Stressors**

Fredriksen and Ringsberg (2007), in regarding living with situation stress-experiences amongst Intensive Care patients in Sweden, ten articles were reviewed and stress related to the body, relationship and the room were discussed.

Being a patient and admitted to the ICU environment affects the body and creates stress for everyone, especially the critically ill. This causes physical and psychological alterations in the state of humans.

Experiences such as hyperventilation, excessive sweating, tachycardia and restlessness were described as responses to stressful situations. The inability to sleep also adds to stress for a patient, as sleep has a healing effect on the body and since man's perception of the world around him is achieved by his body and senses, alteration in sleep forces the senses into action and prevents the body from perceiving the world.

- **Intensive Care Unit Environment**

The environment of a patient in the ICU can either be the physical, social, psychological or symbolic environment, which can affect the patient and their recovery or health directly or indirectly. The physical environment of a patient in the ICU is referred to as the patient room, which on its own can be a source of stress (Meriläinen *et al.*, 2010). The ICU is a special environment and the room carries no meaning on its own except within the social and cultural contexts. Lights, sounds (noises) and the absence of family integration into a patients' care all result in stress for the patient. Fredriksen and Ringsberg (2007) alluded to the fact that when lightning becomes disturbing, the patient became stressed.

In an observational study in Finland, Meriläinen *et al.* (2010), reported that the physical environment can either be a direct or non-direct environment where equipment connected to the patient, such as monitors, ventilation, IV cannulas, infusion devices, light, noise and beds, are the direct environment while the indirect environment are the hospital and the patient's room (ward). This physical environment, referred to as the patient's intimate space, was violated several times by nursing activities resulting in stress, worry and anxiety for the patient. Although the patients' feelings of being closely monitored helped in increasing their sense of safety, their reaction to noises in the physical environment was enormous. This varies from opening of eyes, limb movement, fidgeting in bed, turning of head and eyes to head lifting, all of which were linked to the problem encountered with sleep, development of delirium and slow recovery of the patient (Fontaine *et al.*, 2001; Pun and Ely, 2007; Wang *et al.*, 2009; Engström *et al.*, 2013).

Several studies have reported that patients felt strange, frustrated and frightened by the Intensive Care environment and the technology in the unit (Jablonski, 1994; Wang *et al.*, 2009). For them to feel safe and comfortable, the health personnel has a role to play which includes the provision of information, trust, hope and the ability to maintain control for the patient.

Jordan *et al.* (2002), on the lived experiences of patients on mechanical ventilation, the patient's experience of the physical environment was described in terms of noise levels in the ICU as disturbing, affecting their emotional state and sleep patterns. The alarms from all gadgets, other patients and health personnel were also a source of disturbance.

The lighting of the ICU reportedly affected the sleep patterns of the patients, resulting in disorientation, the ward rounds were seen as depressing to the long term patients, especially when recovery was not evident. The presence of other patients was seen as disturbing as the participants saw themselves in the light of others and felt they may be dying, especially if other patients are not recovering at all. Deprivation of sleep was experienced as disturbing, resulting in feelings of anxiety (Jordan *et al.*, 2002).

Concurring with Meriläinen *et al.* (2010), Johansson *et al.*, (2012) describe the sound environment in an ICU patient's room as being related to the settings, health personnel, other patients in the room, technical equipment and dreams. Thirteen patients were interviewed, of which two had no recall or memory of sound or other events in the ICU and five reported not being disturbed by noises even though they had memories of sound in different ways. The room was reported as calm and peaceful for the patient to sleep and rest, only to some it was too calm and silent, especially in the middle of the night, making the participant feel scared, lonely and abandoned. The sound of helicopters landing and explosions were also reported by some of the patients but was not at all disturbing to them.

The participants heard talking, chatting and whispering amongst health personnel, but it was regarded as low, continuous and not disturbing, in fact, it gave the participants a sense of security and safety. The sounds from the technical equipment were also regarded as disturbing and annoying, such as sounds from machine alarms (ventilator, food pump, infusion pumps and monitor). This negatively affect the participant night's sleep and made

some of them frightened as they felt the machine was going to stop thus affecting their breathing. The noise level in the patient's room was regarded as higher than the recommended level by WHO (WHO, 1999), thus making the room uncondusive for sleep or rest.

- **The Experience of Technology (Equipment)**

The presence of machines and equipment alongside nursing procedures performed on critically ill patients are viewed as sources of stress for the patient. Nevertheless, the mechanical ventilation are regarded as helpful in restoring hope of recovery and security. For some patients, this was seen as triggering fear and for others, it triggered experiences of trauma which then resulted in the alteration of the emotional state of the patient.

The experience of helplessness, the inability to make decisions, vulnerability and confusion, trigger emotional reactions in a patient, whilst the inability to make sense of the environment, as a result of the critical illness and confinement to a hospital bed, all affect the body's life and future.

The observation of nursing procedures in the ICU by the patient is described as more stressful than noise and light and the organisation of care activities were seen to affect the satisfaction of the patient's physical and emotional needs (Fredriksen and Ringsberg, 2007).

- **Social Environment**

The social environment, as described by Meriläinen *et al.* (2010), includes the health personnel, relatives and other patients who can directly or indirectly come in contact with the patient. Poor communication/relationships with these social elements also causes stress and fear for the patient.

Isolation from families and friends, the lack of information regarding procedures and disturbances of sleep, as a result of activities without concrete information, were also



regarded as sources of stress which can eventually result in delirium and disorientation for the patient.

In Hupcey (2002), on the identification of ICU patients' experience when their needs were not met and the role of the families and health personnel in meeting their needs, the receipt of information was discovered to be helpful in reassuring participants. Less information received by the participants about their condition led to either refusal of treatment or ripping out of endotracheal tubes and other invasive lines attached to them.

These aspects have shown the effect of critical illness and mechanical ventilation on the critically ill patient. The next section will discuss the experiences of patients on mechanical ventilation in the ICU from a number of research studies in this area.

## **2.5 PATIENTS EXPERIENCE OF MECHANICAL VENTILATION**

Experience is the knowledge of an individual regarding a phenomenon or an event in which the individual is involved. As such, literature regarding experiences of critically ill patients on mechanical ventilation will be discussed in this section.

In Turner *et al.*, (1990) 100 participants were evaluated post ICU admission. The participants were from different race, religion, occupation and educational levels. The ICU environment was described as friendly or relaxed by 94% of the participants while the remaining 6% either had no recollection or described it as hostile.

The participants described the experience of tracheal suctioning (30 participants out of 68) and arterial blood gas sampling (48%) as an unpleasant experience. Experience of pain, noise, ward rounds and family worries were all highlighted by the participants as moderately to severely disturbing (Turner *et al.*, 1990).

This study was one of the studies conducted in South Africa and a further motivation for this study.

In a quantitative study conducted by Rotondi *et al.* (2002), 150 patients out of the 817 enrolled, who were mechanically ventilated for more than 48 hrs, from four ICUs in Pittsburgh were selected and a questionnaire on their experiences of mechanical ventilation and the Intensive Care Unit (ICU) was distributed to each of them. Of these 150 participants, 50 (33%) had no memories of ICU or the endotracheal tube (ETT), while 97 (67%) the participants remembered their admission in the ICU and 75 remembered being intubated.

The experiences of pain, the inability to communicate and anxiety regarding the endotracheal tube were the most terrible of all the experiences elicited by those who remembered being intubated, while amongst those who remembered being in an ICU, feeling tense, loss of control, inability to communicate, thirst and swallowing difficulties were described as bothersome.

More than 90% of the participants described spells of terror or fear (panic) as the most terrible experience. The severity of illness was seen to play a part in the recollection ability of the patients as they were most likely heavily sedated and paralysed (Rotondi *et al.*, 2002). There were also experiences of sleep disturbance, ranging from difficulty falling asleep to waking up in the middle of the night, which were all related to discomfort and a choking sensation as a result of the endotracheal tube (Bergbom-Engberg and Haljamae, 1989).

Rotondi *et al.* (2002) concluded that the provision of information to patients of what to expect whilst on mechanical ventilation and the appropriate assessment of patients' level of comfort and reaction to an endotracheal tube might help in reducing the stressful experience of the ICU and mechanical ventilation.

Despite the accuracy of the method used in this study, the researcher could not guarantee the generalisability of the findings. Hence it was suggested that the study be carried out in other institutions with a greater number of the participants from both short and long-term ventilation to obtain richer information regarding patients' experiences.

This study therefore intends to find out if provision of information has helped in the reduction of stressful experiences of patients on mechanical ventilation.

### **2.5.1 Experience of Endotracheal Tube**

In a descriptive study by Grap *et al.* (2002), on patients' report of endotracheal tube discomfort in USA, 22 the participants who had experienced mechanical ventilation for at least six hours were identified and interviewed using the semi-structured interview method. Data analysis acknowledges the feeling of discomfort, sharp pain, choking, gagging and sore throat, which were as a result of the presence of an endotracheal tube. In Grap *et al.* (2002) study, 27% (n= 6) of the participants described experiencing pain in the chest region as opposed the throat and they felt relieving the dryness in their mouth would have relieved the pain felt in the throat.

This study provided information regarding the location and type of the discomfort experienced with an endotracheal tube, which was not evident in previous research. The participants agreed that ETT was very uncomfortable and movement was identified as one of the causes of the discomfort. The administration of medication has not been shown to reduce this discomfort, therefore focus must be on relieving the discomfort in the chest and throat as well as in the mouth. This study by Grap *et al.* (2002) was limited to a small sample of the participants and was drawn only from surgical patients. Hence, this study seeks to explore further into the location of pain in mechanically ventilated patient.

Jordan *et al.* (2002) explored the lived experiences of patients on mechanical ventilation in Port Elizabeth, South Africa. Purposive selection (sampling) of five participants was done and unstructured audio-taped interview method was used to elicit information from the participants. The data was analysed using phenomenological approach and two themes were identified with several sub themes. The two themes are:

- The experiences of patients related to the process of ventilation and
- The patients' experience of the environment whilst connected to the mechanical ventilator.

The process of ventilation was experienced as uncomfortable with experience of pain as a result of strapping used to secure the tube. Sore throat post extubation, thirst and frustration from lack of information regarding why water was not allowed were all described by the participants (Jordan *et al.*, 2002).

Suctioning was experienced in different ways by these participants; some felt it was helpful as it helped them to breathe better once it was done, others felt it was painful and discomforting. It was even regarded as a feeling of suffocation by some patients and referred to as a terrible experience.

This study was limited to one ICU and there was no suitable place for the interview due to interruptions and privacy not being fully ensured. There was also difficulty in selecting the participants for the study, as most of them could not remember their ordeal on the ventilator. This was one of the two studies that could be found to have explored the experiences of the critically ill patient on mechanical ventilation in South Africa.

The unpleasant experience of endotracheal intubation was also expressed by the participants in Holm and Dreyer (2015). The participants described the presence of the tube as having a foreign object in the throat resulting in a strange feeling and the displacement of the tube led to feeling of discomfort. The experience of pain was described in a continuum from constant to overwhelming and they felt strangled with the presence of the endotracheal tube.

As such, stabilising the tube was seen to decrease the discomfort experienced by the participant and providing them with mirror or sample of the endotracheal tube was discovered to minimise their anxiety. The feeling of being rid of the tube overwhelmed the participants and despite their recognition of its need for survival, they just wanted to be free of it and since they could not, they had to endure the discomfort and pain.

### **2.5.2 Psychological Experience**

Arsanian-Engoren and Scott (2003), in Michigan, described the experience of patients who survived prolonged mechanical ventilation and identified factors, which contributed to

their successful liberation from the ventilator. A phenomenological approach was used to explore the experiences of seven participants who were conveniently invited and interviewed two years post discharge from the ICU. From the analysed data, six themes were identified which included (i) enduring a traumatic experience where the participants described surviving the ventilator as a traumatic, frustrating and depressing experience. (ii) Emotions such as anger, fear and fright were reported by the participants and anguish and distress were felt as a result of not being able to communicate and breathe on their own. The participants in this study were motivated to recover better and return to their families, which was seen as one of the factors that contributed to their survival.

In contrast to the findings by Arslanian-Engoren and Scott, (2003), Adamson *et al.* (2004) interviewed six participants on their memories of Intensive Care and the effect of their experience of critical illness on their recovery in Australia. The study was conducted six months post discharge from the ICU, where the participants highlighted recollections, responses and comfort/discomfort as the major themes.

The majority of the participants experienced comfort in terms of ease and freedom from pain, whilst others alluded to experiencing severe pain. The participants in this study had few recollections of their experiences of the health personnel, the technology used, noises and the ICU environment.

Although the participants had little or no recollection of their stay in the ICU, the effect of the critical illness on them was evident six months after their discharge. The participants described experiencing pain, physical fatigue, weakness and psychological distress.

The issue of continuity of care for critically ill patients, following transfer to the ward until after their discharge from the hospital, became evident in this study as rehabilitative services and integration of critical care services can assist with recovery of both physical and psychological aspect of life.

In another study conducted in Australia by Johnson *et al.* (2006), patients described their experience of long term mechanical ventilation as unpleasant and problematic. The study was conducted two weeks to two months post discharge from the ICU, where the participants described experiencing hallucinations, nightmares and disorientation to time

and place. However, these experiences were attributed to ICU syndrome, which can be defined as a state of severe mental disorder developed in some of the Intensive Care patients.

This syndrome may be characterised by disorientation, disturbance of consciousness, confusion, hallucinations and change in cognition that develops within a short period of time which, according to Granberg-Axell (2001), can be attributed to the effects of pharmacological substance, sleep deprivation and the severity of patient's condition.

These findings, regarding disorientation of time, also reflected in Schou and Egerod's (2008), study where the participants described losing track of time and place as they were not well orientated. The participants felt helpless, had decreased self-confidence and loss of control resulting in feelings of loneliness and as such, they desired the constant presence of the health personnel.

According to Samuelson (2011), emotional distress and well-being was the second theme discussed, where the participants saw their illness as terrifying and gave rise to fear of dying and this fear/shock was attributed to the inability to breathe.

The participants were so anxious, angry and frustrated in their situation. Some of the participants wanted to escape, they had episodes of depression, sadness and loneliness. Their lack of information, dependence, vulnerability and powerlessness resulted in an unpleasant experience leading to loss of control. The participants overcame all these feelings of emotional distress with a sense of relief after receipt of professional help, feeling of safety with the presence of the health personnel and their sense of recovery.

Terrifying dreams, memories that were horrible and hallucinations of all kinds were expressed by some of these the participants as perceptual distress, whilst others expressed having pleasant hallucinations and dreams (Rotondi *et al.*, 2002; Adamson *et al.*, 2004; Johnson *et al.*, 2006; Samuelson *et al.*, 2007; Samuelson, 2011; Holm and Dreyer, 2015).

According to Zetterlund *et al.* (2012), regarding memories from the ICU persisting for several years, a longitudinal prospective design was used to conduct the study and five

hospitals in Sweden were involved. Questionnaires were sent to 41 participants who were placed on mechanical ventilation during their ICU admission one and five years post illness/injury. The participants experienced nightmares and dreams, with other experiences of the ICU environment were becoming clearer as time passed.

The Memories of peoples' faces and alarm noises increased over time (over the years), whilst memories of voices and relatives decreased; memories of lighting, suctioning, pain, nightmares and dreams increased over the years.

Among the participants, 61% (n=25) had emotional memories (Pain), 24% (n=10) had delusional memories (hallucinations, nightmares, dreams) and 66% (n=27) had factual memories (voices and family members) four years after their admission into the unit. This study was limited by the small sample and the fact that not all of the patients could be reached five years after the event.

From the above perspective, emotional consequences or psychological experiences, such as hallucinations, dreams and nightmares, were evident as consequences following mechanical ventilation and admission to the ICU. Although several interventions, such as the use of diaries and follow up in clinics, have been undertaken in some countries to help reduce these experiences, this study seeks to explore the occurrence of these psychological effects and the interventions used from a South African perspective.

### **2.5.3 Family Member on a Ventilator in an ICU**

The presence of the family is very important when it comes to taking care of patients in an ICU. The patient as well as the family are confronted with the critical illness and since this illness and admission into the critical unit is stressful, it alters the wellbeing, social balance and is viewed as a sign of impending death by both the patient and the relatives (Morton and Fontaine, 2013).

Some of the effects of family presence by the patient's bedside by Miracle (2005) are:

- Expression of happiness
- Decrease in the feeling of loneliness and anxiety

- Physiological impact, such as decrease in intracranial pressure.

The experience of loneliness has been a constant finding (Schou and Egerod, 2008; Samuelson, 2011), in studies regarding experiences of patients in ICU and this feeling has been attributed to the absence of relatives and families and even short visiting times. The participants feel their family is their life, hence separation from the family as a result of critical illness has already led to stress for the family (Johnson, 2004; Johnson *et al.*, 2006; Schou and Egerod, 2008). Incorporating the family into the care of the patient is essential and caring for the family becomes a part of the critical care nursing responsibility. As such, a family-centred care approach becomes essential in caring for the critically ill patient (Morton and Fontaine, 2013).

The relatives and family presence, according to Hupcey (2002) and Johnson (2004), were helpful in reorienting the participants to place, time and person which gave them a sense of safety, hope, comfort and recovery (Schou and Egerod, 2008; Zetterlund *et al.*, 2012; Cutler *et al.*, 2013).

Also, the presence of the family was described as helpful in alleviating the feeling of isolation and meaninglessness and as such, created a friendship atmosphere and promoted a sense of yearning for recovery, health and eventual discharge (Arslanian-Engoren and Scott, 2003; Karlsson and Forsberg, 2008; Wang *et al.*, 2009; Karlsson *et al.*, 2012; Engström *et al.*, 2013).

From the above, it is evident that the presence of family and relatives during the period of critical illness is important in helping the patient cope and hope for recovery. The current study therefore seeks to find out more about the patient's perception of family presence during their period on mechanical ventilation and in the ICU from the African context.

#### **2.5.4 Spirituality**

Spirituality, according to Morton and Fontaine (2013), refers to the way an individual seeks meaning to his/her life and experiences connected with the universe. Spirituality relates to the belief, religion and values of an individual. The aspect of spirituality of a



critically ill patient has been identified to be essential in assisting them through the period of critical illness (Morton and Fontaine, 2013; Arslanian-Engoren and Scott, 2003). The critically ill patient has alluded to finding strength in prayer as a powerful instrument that enables them cope with the stressful situation of ICU admission, critical illness and impending death.

Also, in line with Arslanian-Engoren and Scott (2003), religion and prayer has been identified by patients to be helpful in gaining successful liberation from prolonged mechanical ventilation. The participants expressed that faith in God (higher being), incessant prayer and belief in prayer helped them through the illness ordeal and attributed recovery to “something more powerful” than the health workers (Arslanian-Engoren and Scott, 2003 pg 332; Hupcey, 2002).

These participants also alluded to receiving reassurance from “angelic encounters”, which was helpful in bringing hope and reassurance to them (Arslanian-Engoren and Scott, 2003 pg 332).

Since the spirituality of the participants was seen as helpful in their recovery, alongside the presence of family members. In this study, Arslanian-Engoren and Scott, (2003) suggested that restriction of visitors should be removed to allow family members to spend quality time at the bedside and an opportunity for expression of their spiritual belief (Arslanian-Engoren and Scott, 2003).

Prayer was important to some of these participants as they viewed themselves as dying and saw prayer as their only hope. (Jordan *et al.*, 2002; Jenabzadeh and Chlan, 2011; Karlsson *et al.*, 2012).

From the above findings, the spirituality of the critically ill patient is essential to their recovery and safety, as prayers and faith in God has been demonstrated in several studies to be helpful in their path to recovery. The current study was carried out to explore the importance of spirituality on the road to recovery of the critically ill patient.

### **2.5.5 The Attitude of the ICU Staff.**

The attitude of Intensive Care health personnel has been a recurring aspect of the experiences of patients on mechanical ventilation and in the Intensive Care Unit. According to Jordan *et al.* (2002), the connection of the participants to machines and lines made them dependent on the health personnel for the activities of daily living and care. The nursing care received was described as caring and supportive and the timely response of the health personnel to certain situations was also commended.

The participants in Turner *et al.*, (1990) described their confidence in the doctors (89%) and nurses (90%) as good and excellent while 4% of the participants described their confidence in doctors and nurses as poor.

The receiving of information regarding care and procedures was seen as reassuring by the participants, although the inability of the health personnel to understand the alternative means of communication employed by the participants were viewed as dissatisfying.

The patients' felt that the health personnel could do better to improve their communication skills, especially in the care of ventilated patients (Jordan *et al.*, 2002). Similarly, the participants in Engström *et al.* (2013) reported to having confidence and trust in the health personnel for their safety and security and also received motivation to breathe on their own from the health personnel.

The participants in Engstrom *et al.* (2013) had the sense of being cared for and under the control of the health personnel which helped them to remain calm and develop a relationship with the health personnel (Karlsson *et al.*, 2012). The participation and companionship with the health personnel also gave the patients hope of recovery and made them feel less critical as they began to fight for survival.

The participants in Johnson *et al.* (2006) felt more reliant/dependent on technology and the critical care health personnel to help them through their period of critical illness, as the role of critical care health personnel in terms of provision of comfort and support was emphasised. Samuelson (2011), discovered unpleasant and pleasant memories of Intensive

Care and both negative and positive attitudes of health personnel were commented on by the participants and the pleasant comments were seen to have balanced the unpleasant memories. The participants described the health personnel as caring, pleasant, wonderful and comforting. The ability of the health personnel to remain attentive to the patients and rendering care when needed was also regarded as good.

#### **2.5.6 Experience of Weaning**

Schou and Egerod (2008) conducted a qualitative study on the experience of post-CABG (Cardiopulmonary artery by-pass graft) patients during mechanical ventilation weaning in Denmark (Copenhagen). Semi-structured depth interviews approach was used to interview ten participants who were ventilated for more than or equal to 24 hours post-surgery, on a one-on-one basis at two to five weeks post discharge.

The data retrieved were analysed using a hermeneutic phenomenological approach, where three themes were identified namely: (i) general phenomena, (ii) psychological phenomena and (iii) existential phenomena. The participants described the ventilator as unpleasant, strange and uncomfortable though bearable, with several experiences such as choking, discomfort and overheating as a result of endotracheal tube. The challenge of weaning forms the most distressing experience as the participants were not confident of their ability to breathe on their own which was similar to the findings by Jordan *et al.* (2002).

Despite the fear and anxiety regarding weaning, the participants in Schou and Egerod (2008)'s study viewed the process of weaning as helpful in restoring their sense of independence and control. The study however, found that the participants lacked information regarding the weaning process and as such, felt their survival and ability to breathe was dependent on the ventilator.

From the above perspective, it became obvious that weaning was experienced as stressful and hard and accordingly, the provision of information, regarding weaning and what to expect during and after, is beneficial in providing comfort for the patient. This study, therefore, seeks to explore the experiences of patients towards weaning.

The reviewed study by Jenabzadeh and Chlan (2011), in Minneapolis, was a reflective study of a nurse's experience of being intubated and mechanically ventilated in an Intensive Care Unit. The study described the experience of being conscious but not being able to do anything and being frightened, as the patient was chemically paralysed and had weakened muscles.

The presence of the nurse's mother was viewed as being very comforting, reassuring and supportive. The playing of music was viewed as therapeutic for the participant. The process of communication was not easy and frustrating as the patient wished to verbalise her feelings and needs but obviously could not. Although an alternative means of communication was devised such as the use of charts, pictures, paper and pen, this was difficult due to the weakness experienced.

The health personnel were credited for their ability to anticipate and meet the patient's needs. The patient felt anxious and frustrated with the attitude of some of the health personnel, while the willingness to chat and the receipt of information from others fostered a sense of comfort. The patient experienced discussions amongst the health personnel, which did not include her, which in her opinion as a patient, imposed on her dignity. A feeling of vulnerability was also expressed when she was lifted up in the bed.

Despite having undergone several intubations, the patient described the sixth intubation as traumatising due to being conscious throughout the procedure. Experiences such as coughing, vomiting, feeling of suffocation were felt during the intubation process before sedation. Scleral haemorrhages, mouth dryness and throat irritation were experienced post intubation.

The experience of suctioning was uncomfortable and extubation was exhausting and uncomfortable though relieving; there was an experience of soreness of the throat post extubation and pain whilst coughing.

The patient claimed her religious belief served as a source of strength, hope and endurance throughout the illness. The study highlights that health personnel caring for ventilated patients should be empathetic in their dealings, re-orient the patient to time, place and date

frequently as they lose track of time, communicate with the patient often as it helps to reassure them, address the patient directly to enhance their dignity and should ensure that necessary information regarding the patient's health and procedures are communicated to them to gain participation and cooperation (Jenabzadeh and Chlan, 2011).

Samuelson (2011) conducted a descriptive qualitative study on the unpleasant and pleasant memories of patients placed on mechanical ventilation for more than 24 hours in two general ICUs in Sweden. Following discharge five days from the ICU, two hundred and fifty participants were interviewed, using two open ended questions. The data analysed identified five sub-themes of which pleasant and unpleasant memories were the main themes. The five sub-themes are:

- Physical distress and relief of physical distress. The participants described the inability to breathe, vomiting of blood, the inability to receive enough air, the inability to communicate their needs despite all efforts made, restriction of movement, the inability to sleep, change in bodily restrictions, pain and thirst as an extremely unpleasant experience.

The pleasant experiences such as seeing the ventilator as a life-saving machine, receiving help when needed especially with the removal of secretions, the ability to talk again post extubation, administration of analgesics for pain and administration of ice cube or sips of water to quench their thirst, helped the participants in alleviating their unpleasant experiences.

- Emotional distress and wellbeing
- Perceptual distress and well being
- Environmental distress and comfort
- Stress-inducing care and caring service

This study by Samuelson (2011) was important as a large number of the participants were interviewed. This gave rich and valuable information regarding their experiences of mechanical ventilation, unfortunately the data was too voluminous and the interviews were written down, rather than audio-taped, resulting in fragmentation of data and loss of some information.

The findings, however, revealed that the numerous unpleasant memories experienced by the participants were relieved by the pleasant memories they had and therefore, promotion of positive experiences during ventilation and Intensive Care stay is essential to reduce the traumatic experiences.

- **Experiences of conscious patients on mechanical ventilation.**

In Karlsson *et al.* (2012), exploring the lived experiences of conscious adult patients who were mechanically ventilated in the ICU in Sweden. Following discharge a week from the ICU, 25 participants were interviewed and data was analysed using phenomenological-hermeneutics approach. It was discovered that being dependent on the ventilator made the participants feel breathless although they wanted to breathe on their own but could not, hence, they became fearful and feared the ventilator may stop working or they may die.

Being forced to submit to the will of others, in which they had to depend on the health personnel to assist in performing activities such as toileting, personal hygiene, suctioning mucus from their throat, made them feel they had lost their personal dignity (Engström *et al.*, 2013). The presence of the health personnel was also seen as problematic as the participants could not discuss private matters with their families or make informed decisions regarding sedation.

The participants in this study also experienced a sense of regaining control as a result of being conscious, being able to receive information when necessary and they were aware of their surroundings. The participants also anticipated quick recovery, freedom from all machines, tubes and lines and yearned for independence.

Although, the experience of breathlessness, voicelessness and dependence on others were regarded as the worst experience and difficult, as it led to feeling of panic or fear, yearning for independence; presence of health personnel and relatives were comforting and supportive as the participants regained hope of recovery. However, the timeframe for the interviews was short in some cases, which was not in-depth enough to reveal the meaning ascribed to being conscious during mechanical ventilation.

Similarly, Holm and Dreyer (2015) conducted a study to explore the adult ICU experience of being conscious during mechanical ventilation in two multidisciplinary ICUs in Denmark. A phenomenological-hermeneutic approach was utilized and four participants were enrolled for the study.

A semi-structured interview method was used to elicit information from the participants', one to two days post extubation, where the tube in the throat, to be conscious but doped and where the passing of time was dragging were the themes developed.

The participants in this study wanted to participate in routines and care regarding their health, which gave them a sense of control and comfort. The feeling of thirst meant the inability to fulfil an essential need, which resulted in yearning and sense of deprivation. To be conscious but feeling doped was another theme identified in this study where the participants, though not sedated, had no memory of a part of their ventilation experience or ICU stay.

The participants, though conscious, experienced hallucinations, surreal experiences, incoherent thoughts, but also good dreams that gave them a place to escape in their thoughts.

Despite these traumatic and painful experiences, the participants still preferred to be conscious to know what was occurring around them as this gave them a sense of control and a feeling of participation in their own care. With light or no sedation, the participant's ability to contribute and be involved in their care is enhanced and as such, this gives them a sense of controlling time.

Although the methodology used in this study seems appropriate, the number of the participants was limited due to the strict inclusion criteria for selection. Also, the time interval before the interview was conducted was short, hence the researcher suggested follow-up interviews at three and six months for deeper information.

This study therefore suggested the need to develop further clinical nursing practice to better meet the patients' needs, such as communication and participation, and also to revise

the ICU setting in order to meet the need of a conscious ventilated patient (Holm and Dreyer, 2015).

Having dealt with various experiences regarding patient stay on ventilators and the problem or challenges in communication experienced by the patients who are mechanically ventilated will be dealt with in the next section alongside issues regarding the provision of information to patients.

### **2.5.7 Sedation**

Caring for a critically ill patient in the ICU often demands the use of sedatives and analgesics, especially for the patient in need of mechanical ventilation. Sedatives are mostly used to manage the discomfort experienced by the ventilated patient so as to help them adapt to the machine and prevent any form of harm (Shinotsuka, 2013). Various pharmacologic agents are used for sedation and analgesic purposes, such as benzodiazepines and narcotics, as the goal includes the relief of anxiety, the treatment of intracranial hypertension and the improvement of patient–ventilator synchrony amongst others (Gradwohl-Matis *et al.*, 2015). Despite the objectives of sedation, studies have suggested that sedation has effects on the course of critical illness.

Excessive (over) sedation has been associated with prolonged mechanical ventilation, increased hospital stay, increased delirium rates and increased mortality (Kress *et al.*, 2000; Urden *et al.*, 2008; Reade and Finfer, 2014).

In a study by Kress *et al.*, (2000), protocol of daily awakening was associated with reduction in the duration of mechanical ventilation, length of stay in the ICU, decrease in the need for CT scans of the brain and reduction in the occurrence of post-traumatic stress disorders.

Lower dose sedation during mechanical ventilation has been proved to have multiple benefits besides improving the survival rates of the patient.



Strøm *et al.* (2010) conducted a study, in Denmark, on the outcome of no sedation protocol in place of daily interruptions of sedation with 140 participants who were ventilated for more than 24 hours. The participants were distributed into 'no' sedation and 'daily' interruption groups.

The data analysis revealed that the participants who received no sedation experienced more days without ventilation than those sedated; they also had reduced length of stay in the ICU than the sedated group and experienced less days in hospital as a whole, with a difference of 9.7 days.

However, there was no difference in occurrence of complications such as ventilator associated pneumonia, accidental removal of endotracheal tube or the need for brain scans (MRI and CT), which does not conform to the findings by Schweickert *et al.* (2004).

In Schweickert *et al.*, (2004) daily interruptions of sedation resulted in a reduction in the occurrence of ventilator associated pneumonia and the need for brain scans (MRI and CT scans).

Irrespective of these findings, sedation of mechanically ventilated patients is still the standard practise in most institutions (Mehta *et al.*, 2006). As a result of these effects of over sedation, sedation protocols were introduced. The use of daily interruptions of sedation, symptom-based approaches focusing on pain and delirium control while preventing sedation and use of sedation protocol were all strategies employed to minimise sedation.

The next aspect will discuss the specialisation of intensive care health personnel and the concept of balancing comfort and safety as an essential role of intensive care health personnel.

## **2.6 SPECIALISATION**

Nursing, as a profession, offers a variety of specialisations with critical care nursing being one of them, in addition to the basic qualification of a registered nurse. The critical care nursing programme is provided as a post-registration diploma course and as a post-

graduate (Masters) degree for a period of 1 to 2 years (Scribante *et al.*, 2004). This form of specialisation allows a registered nurse to be an independent practitioner, as is the case in South Africa, and held accountable for their decisions and actions. The ICU nurse in South Africa is thus guided by both the scope of practice (SANC, 1991) and the acts and omission regulation (SANC, 1990). In Scribante *et al.* (2004), only 26% of nursing personnel working in the ICU environment are registered/trained ICU nurses or registered nurses with post basic qualification in Intensive care nursing, while the remaining nursing personnel are either enrolled nurses or professional nurses who receive “on the job training”.

As a result of the complexity of critical illness, health personnel working in the ICU environment must possess an in-depth understanding of critical illness, multi system organ failure and psychosocial skills, as well as being familiar with the protocol of the ICU. The health personnel must be able to manage multiple stressors encountered by the critically ill patient and their families, and also manage both the patients and the highly sophisticated technology in the ICU. According to *Surviving Critical Illness, Intensive Care and Beyond*, by Kean and Smith (2014), there is no survival of patients in the ICU without involvement of skilled professional nursing care.

## **2.7 BALANCING COMFORT AND SAFETY**

The concept of balancing safety and comfort in the management of critically ill patients is essential to the critical care nurse. Florence Nightingale stressed the importance of holism in nursing, which is caring for the total being, and insisted on creating an environment that promotes healing for critically ill patients. The promotion of patient’s safety, according to Couchman *et al.* (2007), is through the use of a health assessment framework. The emergency care cycle is one health assessment framework that can be utilised for the assessment of the patient. It has two components, the primary survey that identifies life-threatening situations and the secondary survey that uses the head-to-toe systems approach in assessing the functionality of the body’s organs. Critically ill patients receiving mechanical ventilation require close monitoring and continuous observation as part of safety considerations, thus, the intensive care unit is operated on a one patient to one nurse ratio to ensure close monitoring of patients and prompt attention to alarms (ACCCN, 2005;

Bray *et al.*, 2010). Ensuring the emergency trolley or equipment are available at all times is also essential in promoting patient's safety. Observing routine safety measures in critical care environment is another important aspect of promoting safety, which includes checking patient equipment, the alarm settings, checking of intravenous infusions, resuscitation equipment and proper attachment of monitoring devices.

The primary survey focuses on the mnemonics ABCDE, which is Airway, Breathing, Circulation, Disability and Exposure, while the secondary survey entails assessment of the functionality of each organ of the body. In critically ill patients, the introduction of an artificial airway alters the normal physiological homeostasis of the body. As such, the assessment of the organs of the body essential for early identification and intervention to prevent complications and maintain safety of mechanically ventilated patient requires the critical care nurse's ability to demonstrate in-depth knowledge of pharmacology, technology and procedural advances.

The progressive assessment of respiratory function in mechanically ventilated patients is important in ensuring safety of the patient. Monitoring of artificial airways, patency of the airway and breathing are essential components to be examined in assessment of the respiratory function. This ranges from assessment of tube location, cuff pressure and tube security to lung secretions. In maintaining patency, endotracheal suctioning is essential in removing excess secretions and assessing the secretions for colour, amount and consistency.

Although suctioning can be dangerous to the patient, it should be done with care and only when necessary in line with a review by Day *et al.* (2002), where it was indicated that suctioning should be done in accordance with patient's needs and not routinely. Proper assessment of patient airways, either by palpation or auscultation of the chest, or as evidenced on the ventilator, will indicate the need for suctioning rather than by routine practice.

The concept of the "ventilator care bundle" has been incorporated into the care of mechanically ventilated patients in the United States and United Kingdom to support the

issue of evidence based caring for mechanically ventilated patients. The bundle has four interventions namely:

- the elevation of the head of the bed to 30 degrees;
- the sedation management;
- prophylaxis for peptic ulcer and
- deep vein prophylaxis (Institute for Healthcare Improvement, 2006).

All of these measures were to improve the safety of the patients.

Promoting comfort in critically ill, ventilated patients is also an essential part of the nursing management of patients. The ability to manage both the patient's environment as well as to provide comfort is an integral part of alleviating patient's stress. Several measures, as described by Coyer *et al.* (2007) in ensuring comfort and reducing patient's psychological experiences, are promoted in the care of the ventilated patient. Measures, such as proper positioning of the ventilated patient, have been described helpful in reducing myocardial workload and improving the patient's comfort (Stiller, 2000). Semi-recumbent, prone, supine and side-lying are some of the positions supported by evidence that health personnel can use to promote comfort for a ventilated patients, taking into consideration the patient's haemodynamic status and lung pathology (Bonten, 2005; Grap *et al.*, 2005). Continuous evaluation of patients' physiological response to positioning is thus an essential duty of the critical care nurse to prevent complications and promote comfort.

Another important measure in promoting patients' comfort by the Intensive Care nurse is by meeting the hygienic needs of the patient such as bathing and care of the eyes and mouth. Management of stressors, which is meeting the psychosocial needs of ventilated patients, is another measure to promote comfort in ventilated patients. Many (reference) researchers have reported pain, difficulty in communication (Holm and Dreyer, 2015), sleep difficulty, sedation management, feeling of loneliness (Schou and Egerod, 2008), isolation and experiencing nightmares as stressors experienced by ventilated patients, which impact on their safety and comfort. Several interventions have been reported in previous studies as helpful in promoting safety and comfort amongst ventilated patients and managing stressors. Measures such as lip-reading, non-verbal communication methods, eye contact and use of simple technological devices, were measures employed to

communicate with ventilated patients Magnus and Turkington (2006) and Happ *et al.* (2011),.

Individualising care, carrying out patients' care at once, reducing noise and dimming lights are a few of the interventions recommended in previous studies to reduce sleep disturbance and promote patient comfort. Although the provision of care for ventilated patients is demanding and challenging, care provides an opportunity for the critical care nurse to render quality, expert and evidence based care, which in turn promotes comfort and safety for the patient (Coyer *et al.*, 2007).

## **2.8 SUMMARY**

This chapter has discussed the literature in relation to the study at hand. The brief history of the development of the Intensive Care Unit from post-operative recovery room to the hospital was examined. Discussion, regarding the development of mechanical ventilation as the basis of Intensive Care, was included which involved the initial use of negative pressure ventilators in maintaining gaseous exchange and with subsequent advances in technology. Positive pressure ventilation (PPV) came into the limelight because of its ability to apply greater pressure in facilitating gaseous exchange (Slutsky, 2015). The development of Intensive Care in South Africa was also briefly discussed.

The main issue of discussion circled around the experiences of patients on mechanical ventilation in the Intensive Care Unit. The effects and complications of positive pressure ventilation, such as reduction in venous return, reduction in renal perfusion, liver perfusion and cerebral perfusion (Robb, 1997a), and the Intensive Care environment were reported to have impacted on the experiences of patients in the unit.

Complications related to ventilation, intubation and extubation, such as kinking of the tube, airway obstruction by mucus, ventilator associated pneumonia, barotrauma, biotrauma, volutrauma, as adverse effects of positive pressure ventilation on the patient were examined.

The literature also reveals that the Intensive Care environment carried with it some stress induced conditions, which could alter the physiological functioning of the patient and as such, had an impact on the recovery of the patient. Physical, psychological and environmental factors were described as responsible for the development of stress in patients and the inability of the patient to cope with these stressors further complicate their conditions. The effect and impact of these stressors varied amongst individuals. In this case, it would be appropriate that further research should be conducted to explore these differences in patient's experiences.

The presence of machines, equipment, noise, light, nurse's procedures, inability to communicate, lack of information and isolation from families (short visiting time) were also analysed in the literature as sources of stress for the patients. This needed to be explored further due to differences in protocols and ward routines across the world. The social environment, and the health care professionals, relatives and family members as well as friends, were also identified as a source of stress for the patient, which impacted on their emotional state.

The experiences of patients on mechanical ventilation, which forms the bulk of the review, was explored from the quantitative, qualitative and mixed point of views. Quantitatively, Hupcey (2002) and Rotondi *et al.* (2002) explored the experiences of patients and discovered that most of the patients had no recollection of their experience, whilst some remembered being intubated and admitted into the Intensive Care unit. Experience of pain, inability to communicate, thirst, spells of terror and sleep disturbances were highlighted by these participants. The literature reviewed described the location of discomfort and pain experienced by the participants as not only located in the mouth/throat, but also in the chest, hence the suggestion that the focus should be placed on identifying ways of relieving such discomfort as it also impacts on the stress experienced by the patient (Grap *et al.*, 2002). This study seeks to explore further the experiences and measures used by the patients and health personnel in relieving discomfort.

The literature analysed also revealed that the psychological effect of the ICU admission and mechanical ventilation not only occurs or lasts within the period of illness/injury, but

evidently lasts for a period of time ranging from days, weeks, months to years (Arslanian-Engoren and Scott, 2003; Adamson *et al.*, 2004; Samuelson, 2011; Zetterlund *et al.*, 2012).

The reviewed literature highlights the importance of family presence during Intensive Care admission. Although, the visiting hour policies might have affected the impact of the family on the patient and led to stress for the family as well, literature still indicated that the family presence was of utmost importance in the recovery process of the patient. Therefore, in this study, the experiences of the patient, with regard to the presence of their family in the ICU during their admission, was elicited from the African point of view.

Spirituality was also discussed in the reviewed literature as an important aspect of care of the mechanically ventilated patient. The participants alluded to their incessant prayer was helpful in coping with their illness and the environment at large (Arslanian-Engoren and Scott, 2003; Karlsson *et al.*, 2012). This current study explored how the participants' spiritual lives impacted on their admission and experiences of mechanical ventilation and ICU.

The health workers' attitude was highlighted as important in exploring the experiences of the patient on mechanical ventilation, both in the qualitative study and the quantitative study. The participants described health workers' attitude to their care as both negative and positive.

Weaning has presently become an important aspect of the experience of mechanical ventilation, especially among cardiothoracic patients where the intubation process was carried out during anaesthesia and they awoke to discover they have been intubated. According to Schou and Egerod (2008), the participants described the experience of weaning as the most distressing experience ever, stirring up fear of survival post extubation despite their desire to be off the ventilator. This study seeks to understand patients' experiences of weaning from the mechanical ventilator in South Africa.

The feeling of frustration and helplessness has been associated with the inability to receive information and communicate regarding their condition and management, as reviewed in literature. The use of communication aids were reported as essential in assisting

communication though not often explored. Therefore, this study explored the experiences of patients with regard to communication and the alternative procedures practised explored whilst on mechanical ventilation.

This section presents studies relating to the patients' subjective experiences of mechanical ventilation and the Intensive Care Unit. The findings in the reviewed literature revealed experiences of comfort and discomfort in relation to endotracheal tubes, psychological experiences such as hallucinations, dreams and unreal experiences, inability to communicate and sleep disturbances, as highlighted by the participants. Weaning was also reported as part of the unpleasant experience that mechanically ventilated patients experienced in their ordeal in the Intensive Care Unit. Therefore, this study seeks to explore and understand the experiences of patients on mechanical ventilation in the Intensive Care Unit of an academic hospital in South Africa, in view of the fact only one study has been carried out on this aspect of care in the country.

The next section will deal with the methodology employed in carrying out this study.



# **CHAPTER THREE**

## **RESEARCH DESIGN AND METHODS**

### **3.1 INTRODUCTION**

The previous chapter dealt with the review of literature related to the topic. This chapter describes the research methodology used in this study including the research design, the research setting and the research methods (population, sampling method, data collection and data analysis). The research design was qualitative, explorative and descriptive. The method of analysis employed in analysing the data collected in this study is the Clarke and Braun (2013) method of data analysis. This chapter also describes the ethical consideration taken into consideration in this study.

### **3.2 OBJECTIVES**

The objectives of the study were:

- To identify and describe the experiences of patients on mechanical ventilation in the Intensive Care Unit.
- To explore the physical and psychological experiences of patients on mechanical ventilation in the Intensive Care Unit.

### **3.3 RESEARCH SETTING**

Polit and Beck, (2013) describe a study setting as the place where research is undertaken, or a specific place where information is gathered. This study was conducted in a tertiary academic hospital located in Johannesburg, Gauteng Province, South Africa. South Africa has a population of 54.96 million from all nine provinces, in which Gauteng Province comprises 13.20 million (24%) of this population (Statistics South Africa, 2015). The South African health sector comprises both a large public health sector, which caters for 80% of the populace and a small, but fast growing, private health sector responsible for

only 20% of the population. The healthcare services operate on a three-tier level ranging from the basic primary healthcare to a hi-tech health service operated in both the private and public sector (South Africa Info, 2012).

This study was undertaken in a natural setting, namely the Intensive Care Unit of one public sector tertiary hospital in Johannesburg. The hospital has 1,088 beds and over 4000 members of health personnel and is the main teaching hospital for both undergraduate and postgraduate training of all health professionals of the Faculty of Health Sciences, University of the Witwatersrand. The hospital offers a wide range of specialised services and it's a referral centre for several hospitals, having more than four Intensive Care Units with 39 beds in all. For the purpose of this study, the Intensive Care Units were used. This facility is funded by the government, hence patients who make use of it are unemployed with co-morbidities and no medical aid. The health personnel in this unit comprises intensivists, medical/surgical specialists, Intensive Care health personnel and professional health personnel without a specialist certificate, and the nurse-patient ratio in this unit is one to one.

According to one study by Schmollgruber, (2015), the average level of illness severity (SAPS II score) of patients admitted to this unit is 34.72 (SD 12.53), and average length of stay is 8.54 (SD 17.01) days. The research settings discussed is also the contextual design for this study.

### **3.4 RESEARCH DESIGN**

A research design is a plan, which helps the researcher in planning and implementing the study to achieve the desired objective. For the purpose of this study, qualitative, exploratory and descriptive design was used to explore the patient's experiences of mechanical ventilation in the Intensive Care Unit of one public sector tertiary hospital in Johannesburg. This method was chosen to address a specific research question and to fill an empirical gap in literature, based on the South African context.

### **3.4.1 Qualitative Approach**

A qualitative approach is a method of exploring meaning, describing and providing an in-depth understanding of life experiences. It deals with direct description of a phenomenon from peoples perspectives (Polit and Beck, 2013). For the purpose of this study, the qualitative approach was utilised, as little knowledge is known of the experiences of patients on mechanical ventilation in the South African context. Bothma *et al.* (2010) focused on understanding the concept as a whole and placed emphasis on the importance of people's interpretation of the events and situation rather than the researcher's interpretation. This method thus helped the researcher to gain understanding and receive rich description of the experiences of patients on mechanical ventilation in an academic hospital in Johannesburg.

### **3.4.2 Exploratory study**

These are studies which focus on increasing the knowledge of the researcher about a phenomena or area of study (Polit and Beck, 2013). Several studies have been conducted in the area of patients' experiences of mechanical ventilation in the first world countries, but little has been explored in the South African context.

### **3.4.3 Descriptive Design**

A descriptive design is employed to gain an in-depth knowledge of the phenomenon under study and it does not give room for manipulation of the variables (Burns and Grove, 2009). It entails collection of information from a representative of the population. A descriptive design was employed as the main aim of the study was for patients to explain and describe their experiences on mechanical ventilation, in the Intensive Care Unit, as it naturally happened to them.

## **3.5 RESEARCH METHODS**

This is a strategy of enquiry, which proceeds from underlying assumptions to research design and data collection. It allows the researcher to collect samples, data and find a

solution to the problem at hand (Burns and Grove, 2009). The research methods include target population, sample and sampling procedures, data collection and data analysis.

### **3.5.1 Population**

Population refers to the entire aggregation of the participants in which a researcher is interested (Polit and Beck, 2013). The population for this study was all patients placed on mechanical ventilation, in the Intensive Care Unit in one public sector hospital in Johannesburg.

**Target population:** In this study, the target population are patients who experienced mechanical ventilation in the multidisciplinary Intensive Care Unit of an academic hospital in Johannesburg.

### **3.5.2 Sampling method**

Sampling refers to the process of selecting the participants to represent the entire population so that inferences about the population can be made (Polit and Beck, 2013). In this study, a non-probability purposive sampling method was chosen to obtain in-depth information and understanding of the participants' experience (Burns and Grove, 2009). Mechanically ventilated patients, who met the requirements of the sampling criteria set out by the researcher, were consciously selected to participate in the study. It was anticipated that ten to fifteen the participants would be targeted. Data collection was continued until saturation of information was achieved.

For this study, the inclusion criteria, was as follows:

- MAAS score of 3-4 (Devlin *et al.*, 1999) whilst on mechanical ventilation.
- Aged 18 years and above.
- Able to communicate in English in order to avoid the loss of important information elicited during the process of interpretation.

- Be interviewed 48 to 96 hours (Karlsson *et al.*, 2012) after discharge from the ICU to ensure privacy and a relaxing environment conducive for interviewing the participants comfortably.

The exclusion criteria for this study were patients who have been connected to a mechanical ventilator in the study selected ICU for >3 weeks. The critically ill patient admitted for more than 3 weeks represent about 3% of the total ICU population and fall within the category of prolonged mechanical ventilation, and their care needs are complicated by processes of attempting to discontinue mechanical ventilation.

### 3.5.3 Data Collection

Data collection refers to the gathering of information to address a research problem (Polit and Beck, 2012). In a qualitative study, an interview is one of the most commonly used methods of data collection (Burns and Grove, 2011). In this study, data was collected using an in-depth audio-taped interview and the researcher coordinated the discussion in-line with the objectives of the study.

- **Data Collection process**

After receiving clearance to conduct the study from the Post-graduate Committee and Ethics committee of the University of the Witwatersrand (see **Appendix G**) and approval from the Chief Executive Officer of the hospital (see **Appendix H**), permission to conduct the study at the unit was obtained from the Unit Manager of the ward after briefing the manager of the intended study and handing her a copy of the information letter (see **Appendix A**)

With the Unit Manager's permission, the participants were invited to participate in the study post discharge from the Intensive Care Unit. The participants were given an information sheet, which contained all the necessary information (**Appendix A**). Voluntary participation was stressed to the participants and those who signified intent were asked to sign the letters for informed consent and audio-taping. Written consent was also obtained from the participants (**Appendix B**). Key/specific patient data were extrapolated from the

ICU records (**Appendix D**). One open-ended question was asked with additional probes when necessary (**Appendix E**). In addition, contact details were obtained should a follow-up interview be needed for clarification. The first interview was conducted as a pilot interview together with the researcher's supervisor to allow the researcher to clarify questions and her interviewing techniques. The interviews were tape-recorded and field notes on all the interviews were taken. All interviews were conducted in the general ward post discharge of the patient from ICU. A convenient time for the interview was agreed upon by both the researcher and the participants. The Unit Manager was informed of the decision and the approximated time for the interview was stated.

At the beginning of the interviews, the participants were asked to relax and they were reminded they could withdraw from the interview at any point in time. An interview guide with one open-ended question and probes was used to keep the interview focused (see Appendix E), which allowed the researcher to obtain detailed data as well as giving the participants opportunity to talk about their experiences should they so wish.

The interview was tailored towards the sharing of the participants' experiences, feelings about being mechanically ventilated in the Intensive Care Unit. Information regarding awareness of the Intensive Care admission, pain, communication methods, sedation levels, physical challenges, feelings about leaving the Intensive Care Unit, and effects of the admission on family relationships were explored. Individual interviews continued until no new information emerged, signifying data saturation (Polit and Beck, 2012).

Field notes were taken during the interviews after receiving written consent from the participants. The use of pseudonyms ensured the participants' anonymity and confidentiality. Information regarding participants' gender, age (in range), admission date, reason for admission, period of stay on mechanical ventilation was sought.

At the end of the interview, the participants were thanked for their cooperation, openness and input. The audio-taped interviews and field notes were kept under lock and key and only accessed by the researcher.

A total of ten interviews were conducted by the researcher and the audio-taped information, together with the field notes were transcribed within 48 to 72 hours of the interviews.

### **3.5.4 Data Analysis**

In qualitative studies, the purpose of data analysis is to organise, provide structure to and elicit meaning about data (Polit and Beck, 2013). In this study, listening to verbal descriptions and paying attention to non-verbal expressions during the interview began the data analysis process. Issues of interest were clarified during the interview. Data analysis was initiated after the participants had been interviewed. The interviews were transcribed verbatim and analysed using Clarke and Braun, (2013) method of data. The remainder of the transcripts, as well as the field notes, were then analysed in the same manner.

The essential steps followed are discussed under the practical approach employed for the analysis.

The essential steps are:

- Step one: Reading the transcribed data to acquire a sense of the information.
- Step two: Extracting significant statements from each transcript.
- Step three: Formulating meanings for each extracted significant statement.
- Step four: Organising the formulated meanings into a cluster of themes.
- Step five: Integrating results into an exhaustive description of the phenomenon.
- Step six: Formulating an exhaustive description of the phenomenon/event.
- Step seven: Validating the formulated exhaustive description.

#### **3.5.4.1 The practical approach employed in this study for the data analysis process**

Each transcribed interview was cross checked with the original audio-taped recording before data analysis was commenced to ensure accuracy of the information. The following steps were employed during data analysis of this study:

- Step one: Reading the transcribed data/interview

Each audio-taped interview was listened to several times and cross examined by the supervisor and the participants with the transcribed data for accuracy and understanding of the content of the data. The assumptions and opinions of the researcher, regarding the phenomenon, were laid aside to enable the researcher to explore the participants' experiences as described by them. This was made possible by bracketing, which entails identifying and holding in confidence temporarily (abeyance) every preconceived idea and opinion regarding the phenomenon under study in an attempt to convey the data in its pure form (Polit and Beck, 2012).

- Step two: Extracting significant statement from each transcript

This step involves extracting significant statements in relation to the objectives of the study and the phenomenon under study from the transcript. Each transcript was analysed to give a sense of the individual experience. The significant statements were cut, pasted on a different page and highlighted to assist in immersing oneself in the data and in identifying themes emerging from the data quickly. An extract from one transcribed interview, showing the significance of the statement, is highlighted below:

Participant: **'Hummmm probably I got up with it yes I went in for anaesthetics and when I got up the tube was in my mouth'....'It was uncomfortable but I was warned before it I mean they they they informed me that when I get up I will have it in my mouth. It was manageable I think ehhhhhhhh it was uncomfortable but manageable but the problem was the real challenge was when the time came to take it out it was very very stressful aaaaaa I felt very was the word very prudent, when they try to clean up the lungs it was a horrible feeling'**



**‘...It was terrible I mean at some point it feels like you were dying men its very very the word Is very invasive it was hectics ahhhhhhhhhhh it was tough’**

**‘...Like I said it was uncomfortable but manageable it wasn’t so bad except when the time came to get out it yah that was hard’**

There was a total of 59 significant statements with detailed descriptions were extracted from the transcribed data. For a complete list of the significant statements, see Appendix I.

**Table 3.1:** List of selected significant statements from the transcribed interview

NO	SIGNIFICANT STATEMENT
1	...one thing that was not allowed was food, no food no water only that water up there (IVT).
2	Water I wanted a glass of water, I wanted a glass of water so desperately.
3	I was using the pipes... I could not talk to anyone.
4	I had to use plates on bed I felt bad when I soiled the sheet.
5	Especially when they do the washing a lot it can chokes, choke, choke (Suctioning).
6	My mouth started to have scales.
7	I wasn’t feeling okay... I’m not use to sign language that is the main problem and when I grow up I was not using I didn’t grow up using sign language but I ended up using sign language because I wanted help.
8	Yes there was pain you know something that is not that was not born with you it always bring pain in your body...it was minimal but it was, you know the pain is pain it doesn’t matter it doesn’t matter is a terrible or very low or what it doesn’t matter.
9	They were allowed to visit but not for a very long time... When they come they will just say oh they will just say you just have to pray now just for a few minute... it was totally unacceptable because when you are sick the families must be together.

- Step three: Formulating meanings for each extracted significant statements

Each extracted statement was carefully observed and examined within the context of their expression to formulate meaning in line with the phenomenon under study. Fifty-nine meanings were formulated from the extracted significant statement as shown in the table below. For a complete list of the formulated meanings, see Appendix J.

**Table 3.2:** Selected lists of significant statements and their formulated meanings

NO	SIGNIFICANT STATEMENT	FORMULATED MEANINGS
1	...One thing that was not allowed was food, no food no water only that water up there (IVT).	The participants complained of not being allowed to eat or drink because of the tube, and water is a physiological need.
2	Water I wanted a glass of water, I wanted a glass of water so desperately.	This is a physiological need - water was needed desperately by the participant but the need could not be met.
3	I was using the pipes (ETT)... I could not talk to anyone.	The Participant linked the inability to talk to the presence of the tube.
4	I had to use plates (Bedpan) on bed I felt bad when I soiled the sheet.	The participants felt loss of personal dignity when he soiled the bed.
5	Especially when they do the washing (suctioning) a lot it can chokes, choke, choke.	Experience of choking expressed due to suctioning.
6	My mouth started to have scales (cracks).	The Participant complained that he started to have scales (cracks) in his mouth due to the endotracheal tube and dryness of the mouth.
7	I wasn't feeling okay... I'm not use to sign language that is the main problem and when I grow up I was not using I didn't grow up using sign language but I ended up using sign language because I wanted help.	The participants felt bad about the use of alternative means of communication but had to accept it because he needed help/he's incapable.

- Step four: Organising the formulated meanings into a cluster of themes

This step involves arranging similar formulated meaning into categories, which are then incorporated into clusters of themes. A total of sixteen clusters of themes were developed depending on the commonalities. An example is shown below and in appendix K.

**Table 3.3: Selected lists of some formulated meanings grouped into clusters**

<b>FORMULATED MEANINGS</b>	<b>CLUSTERS THEMES</b>
<p>The experience of inability to breathe was evident both during suctioning and with intubation (49); The participants attributed difficulty and shortness in breathing to the presence of the tube (39).</p> <p>The participants complained of not being allowed to eat or drink because of the tube and water is a physiological need (1); This physiological need for water was needed desperately by the participants but the need could not be met (2).</p> <p>Pain, a subjective experience was expressed by the participants, although it was not clear if it was attributed to the disease process or the presence of the tube (9); The participants describe the experience of the ventilator as being pathetic and unpleasant, which encouraged them to quickly try to breathe on their own in an attempt to rid themselves of the tube (18);</p> <p>Experience of soreness due to presence of ETT (51); Experience of choking expressed due to suctioning (5); Experience of nauseous sensation as a result of insertion of tubes causing a feeling of embarrassment (19); The use of saline during suctioning was described as traumatic and made the patient feel helpless (22); The participants wished there was an alternative method as the ventilation experience was traumatic (23).</p>	<p>Feeling of breathlessness.</p> <p>Mouth Dryness.</p> <p>Experience of pain.</p> <p>Physical discomfort.</p>

- Step five: Integrating result into an exhaustive description of the phenomenon

This step involves organising all clusters of themes into emergent themes depending on the commonalities as these emergent themes provide the fundamental structure of the experiences of patients on mechanical ventilation. See appendix K for a complete list of the cluster of themes and emergent themes.

**Table 3.4: List of selected formulated meanings, cluster themes and emergent themes**

<b>FORMULATED MEANINGS</b>	<b>CLUSTERS THEMES</b>	<b>EMERGENT THEMES</b>
<p>The experience of the inability to breathe was evident during suctioning and with intubation (49)</p> <p>Patients complained of not being allowed to eat or drink because of the tube and water is a physiological need (1); This physiological need; water was needed desperately by the participant but the need could not be met (2).</p> <p>Pain, a subjective experience was expressed by the participants though it was not clear if it was attributed to the disease process or the presence of the tube (9); The participants described the experience of the ventilator as being pathetic and unpleasant which encouraged them to quickly try to breathe on their own in an attempt to rid themselves of the tube (18); The participants only experienced swallowing pain with the presence of the tube (20).</p> <p>Experience of soreness due to presence of ETT (51); Experience of nauseous sensation as a result of insertion of tubes causing a feeling of embarrassment (19); The use of saline during suctioning was described as traumatic and made the patient feel helpless (22); the participant wished there was an alternative method as the ventilation experience was traumatic (23).</p>	<p>Feeling of breathlessness.</p> <p>Mouth Dryness.</p> <p>Experience of pain.</p> <p>Physical discomfort.</p>	<p>Physical Experience.</p>

- Step six: Formulating an exhaustive description of the phenomenon/event

The exhaustive description of the experiences of the participants on mechanical ventilation was developed from the emergent themes described above. This was attainable by integration of the result into an exhaustive description of the event under probe.

- Step seven: Validating the formulated exhaustive description

This step is the final stage of the analysis process, where the study findings need to be validated by the participants in order to verify if the results presented were a true reflection of the experiences and feelings expressed.

### **3.6 TRUSTWORTHINESS OF THE STUDY**

The term trustworthiness refers to the degree of confidence qualitative researchers have in their data assessed using criteria of credibility, transferability, dependability and confirmability (Polit and Beck, 2012). In this context, the core issue in establishing trustworthiness of the study was to ensure that measures used in the research process can produce data that reflects the truthfulness of the event under study. As described by Lincoln and Guba, (1985) in, four defining criteria are described to ensure trustworthiness.

#### **3.6.1 Credibility**

The term refers to confidence in the truth of data and interpretations as the researcher attempts to demonstrate a true picture of the phenomenon under study is being presented (Polit and Beck, 2013). The researcher ensured this criterion was achieved by spending a considerable amount of time, up to eight months or more, in the field in order to develop an adequate understanding of the phenomenon under study and to establish a relationship of trust with the participants in the natural setting to ensure accurate data findings.

### **3.6.2 Dependability**

The term refers to stability or reliability of data over time and conditions (Polit and Beck, 2013). Relevant literature on studies carried out in a similar context were reviewed by the researcher. The researcher gave a detailed report of processes followed in this study in order to enable other researchers to repeat the study in future, although not necessarily to yield the same result. Individual interviews and member checking were done soon after the interview.

### **3.6.3 Transferability**

This refers to the potential for extrapolation, or the extent to which the findings can be transferred or have applicability in other settings (Polit and Beck, 2013). The researcher ensured achievement of this criterion by the use of rich and thick description of participants' experiences obtained in the audio-taped interviews and by provision of the result findings.

### **3.6.4 Confirmability**

Shenton (2004) suggests researchers must take steps to demonstrate that findings emerge from the data and not from their own predispositions or inclinations. The researcher ensured this criterion was achieved by recording the interview to demonstrate the findings were the result of the participant's experiences as told by them and by a rigorous audit trail. Transcripts of interviews, field notes and rough copies of data analysis were presented for peer review and member checking for validation of how the results were obtained. Data triangulation may also be used by comparing themes reflected in the literature review.

In ensuring the above, the table 3.5 present the measures of trustworthiness employed in this study.

**Table 3.5:** Measures of trustworthiness applied in this study

Strategy	Criteria	Application
Credibility	<ul style="list-style-type: none"> <li>➤ Peer examination</li> <li>➤ Prolonged engagement</li> <li>➤ Triangulation Follow up interviews</li> <li>➤ Authority of the researcher</li> <li>➤ Interview technique</li> </ul>	<ul style="list-style-type: none"> <li>➤ Peer examination was done by discussing the research process with the supervisor, who is an experienced researcher, and availability of the analysed data in the report was ensured.</li> <li>➤ The researcher has been working over a period of time in the units where the participants were recruited, to allow for the participants to become accustomed to the researcher during the course for the master's programme.</li> <li>➤ This is ensured by the use of individual interview which was audio-taped.</li> <li>➤ The researcher has been working (engaged) in the unit in the course of her master's programme, familiarising herself with the phenomenon and the participants to be interviewed in order to establish a relationship and gain trust. She also attended workshop on mechanical ventilation.</li> <li>➤ All interviews were conducted by the researcher, utilising an interview guide for obtaining depth of information; the unclear information was made by reframing and repeating questions for clarity and consistency.</li> <li>➤ The interviews were all audio-taped.</li> </ul>

Dependability	<ul style="list-style-type: none"> <li>➤ Dense description</li> <li>➤ Peer examination</li> </ul>	<ul style="list-style-type: none"> <li>➤ The detailed description of the processes, research method and design used were provided to allow for the study to be repeated.</li> <li>➤ The research plan and implementation were also examined by the supervisor and coding and re-coding done with the supervisor.</li> </ul>
Confirmability	<ul style="list-style-type: none"> <li>➤ Verbatim transcription</li> <li>➤ Audit trail</li> <li>Feedback from participants</li> </ul>	<ul style="list-style-type: none"> <li>➤ All audio-taped interviews were transcribed verbatim with the involvement of the supervisor who is an experienced researcher.</li> <li>➤ Detailed methodological description was given to allow for an audit trail.</li> <li>➤ Complete description of the steps undertaken in the design, data collection and analysis, conclusions were given.</li> </ul>
Transferability	<ul style="list-style-type: none"> <li>➤ Thick description</li> <li>➤ Contextual information and nominated sample</li> </ul>	<ul style="list-style-type: none"> <li>➤ Detailed description of the phenomenon under study, the analysed data and method were presented in the report for proper understanding.</li> <li>➤ The study was conducted amongst mechanically ventilated patients in the Intensive Care Units of an academic hospital in South Africa.</li> </ul>



### **3.7 ETHICAL CONSIDERATIONS**

Ethical considerations are discussed, taking into account the University's rules and regulations and the declaration of Helsinki (2013) under the following headings: permission to conduct research, informed consent and measures to ensure confidentiality and anonymity.

#### **3.7.1 Permission to Conduct Research**

The research proposal was written and presented for peer review in the Department of Nursing Education, where it was refined. The refined protocol was then submitted to the University Postgraduate Committee for assessment of the feasibility of the study. The protocol was assessed and corrections made. The protocol was further submitted for review and clearance to the Ethics Committee for Research on Human Subjects of the University of the Witwatersrand. Approval to conduct the study was then received (see **Appendix G**). Upon receipt of ethics permission, approval to conduct the study was sought from the hospital authorities, where the study was to be carried out (see **Appendix H**). Permission to conduct the research in the Intensive Care Unit was also sought from the Unit Manager in order to gain access to the participants.

#### **3.7.2 Informed Consent**

After obtaining approval from the appropriate authorities, eligible the participants were invited and briefed of the study. Those who met the inclusion criteria were approached and given the information letter, which explained the intended study in detail (see **Appendix A**). Informed written consent was then obtained from those who expressed their willingness to participate in the study. Also, a separate consent for audio-taping the interview was received from the participants. The right of the participants to withdraw from the study at any time, without any penalties, was emphasised.

### **3.7.3 Anonymity and Confidentiality**

Anonymity in qualitative research entails keeping the participants' identity confidential, while confidentiality entails the researcher keeping confident information that the participants do not want divulged to others (Holloway and Wheeler, 2013).

Anonymity, in this study, was ensured by the use of codes during data collection and to maintain confidentiality, the following procedures were ensured:

- The audio-taped interview was destroyed post transcription.
- The transcribed interview was saved with a password known only to the researcher.
- Codes and integration of identifiable data were used.
- Identifiable written scripts were kept in a sealed envelope in a safe with the supervisor (password enclosed).
- The data is kept for three to five years after final submission, then it will be shredded and destroyed.

## **3.8 SUMMARY**

This chapter provides a detailed discussion of the study's research design and methods, the target population, sample and sampling methods, data collection and data analysis procedures which were followed. Measures of trustworthiness are discussed. Ethical considerations were addressed.

A purposive sampling method was used for selecting the study the participants and data was collected using an in-depth audio-taped interview tool. Data analysis was carried out using Braun and Clarke (2013) thematic analysis approach. Lincoln and Guba's (1985) measures of trustworthiness which includes credibility, dependability, confirmability and transferability were utilised.

In the next chapter, the results of the patients' experiences of short and long-term mechanical ventilation will be addressed.

## **CHAPTER FOUR**

### **PRESENTATION OF FINDINGS**

#### **4.1 INTRODUCTION**

This study was designed to investigate the experiences of critically ill patients, on mechanical ventilation, at a tertiary academic hospital in Johannesburg. An exploratory, qualitative and descriptive design was used to gather information from the participants. An audio-taped unstructured interview method was employed to elicit information from ten (10) patients who participated in the study. The collected data were analysed using Clarke and Braun's (2013) method of data analysis.

The chapter presents the demographic profile of the study participants, followed by the themes that emerged from the interviews (expressions) of the participants' experiences of mechanical ventilation in the Intensive Care Unit, with quoted words for clarification purposes. The description of the phenomenon under study, which provides a fundamental structure of the patients' experiences of mechanical ventilation, will then be presented. Discussion, integration and referencing of the existing literature is done in line with the themes and sub-themes discovered in this study to support the research findings. Finally, the summary of the experiences of patients on mechanical ventilation in the Intensive Care Unit was presented.

#### **4.2 DESCRIPTION OF SAMPLE**

Purposive sampling method was employed to select ten (n=10) patients who participated in this study. The participants were interviewed individually, post intensive care discharge, as described in Chapter Three. These participants had recovered from their illness and had been extubated from the ventilator. Some of the participants have been transferred to the general ward while others to high care where the interview took place.

### 4.3 DEMOGRAPHIC PROFILE

The demographic characteristics of the patients comprised of

- Gender,
- Age,
- Reason for admission,
- Period of stay on mechanical ventilation
- Length of stay in the ICU (see Appendix D).

A total of ten (n=10) mechanically ventilated patients in the Intensive Care Unit of an academic hospital in Johannesburg participated in the study. Table 4.1 illustrates the characteristics of the 10 (n=10) the participants for discussion of data of the study.

Table 4.1: Demographic profile of the ten participants (n=10)

ITEM	DEMOGRAPHIC VARIABLES	FREQUENCY (n)	PERCENTAGE (%)
	Research code		
1	Gender : Male Female	6 4	60 40
2	Age : 18 – 28 29 – 38 39 – 48 49 and above	1 3 4 2	10 30 40 20
3	Reason for admission: Medical Surgical elective Surgical emergency	3 5 2	30 50 20
4	Period of time on mechanical ventilation	Mean 57.45	Range 25 to 120
5	Length of stay in ICU	Mean 4.9	Range 2 – 8

Amidst the total number of the participants for this study (n=10), the male the participants had the highest percentage of numbers (n=6). The highest age range of the participants was between 39 to 48 years. Half of the participants (50%) were admitted for elective surgery,

while the remaining were for medical reasons (30%) and emergency surgery (20%). The mean period of time spent on mechanical ventilation and length of stay in ICU was 4.9 days and 57.45 hours, respectively.

#### **4.4 DATA COLLECTION AND ANALYSIS**

The data collection procedure was carried out in the general wards after the participants were discharged from the ICU and only a few interviews were conducted in high care. The Unit Manager and Chief Leader of each ward were informed of the interview process to gain their cooperation and prevent disturbance or interference. The participants' curtains were pulled for privacy and confidentiality purposes. The following question was used to kick-start the conversation after greetings were done:

*Can you please tell me about your experiences on the breathing machine?*

The participants were allowed to reflect on their thoughts before the conversation began. The conversation was kept informal to allow for the free flow of conversation between the participants and the interviewer. The interviewer attentively listened to the responses from the participants by maintaining eye contact and taking notes at intervals. Non-verbal communication techniques, such as nodding of the head, eye contact, 'okay', 'yes' and 'uh-huh,' were used to encourage the participants, with repetition and para-phrasing also used. Probes such as 'how' and 'what' were used to obtain clarity from the participants. Reflection was used to confirm statements made by the participants and summarising was performed at the end of the interview. The interviews lasted between 20 and 25 minutes and the participants were thanked for their time.

The individual interviews were conducted, audio-taped and transcribed word for word. Data analysis was done following the transcription of the audio taped interviews. Themes and sub-themes were identified and developed, as described in Chapter Three. Initial data analysis occurred in conjunction with the interview, as the participants described their experiences on the ventilator and in the Intensive Care environment.

The details of the findings are discussed in the next section, with statements made by the participants presented in italics.

#### **4.5 DISCUSSION OF THEMES EMERGING FROM THE INTERVIEWS**

This section focuses on the findings from the participants expressions of their experiences on mechanical ventilation in the Intensive Care Unit. Three broad themes were identified with 13 sub-themes from the study. The prevailing issues were (i) the feeling of breathlessness, (ii) mouth dryness, (iii) experience of pain, (iv) physical discomfort, (v) experience of fear, (vi) feeling of being bothered, (vii) near death experience, (viii) inability to endure, (ix) powerlessness, (x) knowledge deficit, (xi) sense of safety and unsafe, (xii) body image and (xiii) spirituality.

The focus of this study was not on communication, but communication came out strong hence it became a theme on its own. These 13 sub-themes generated three themes, physical experience, emotional experience and communication, which form the fundamental structure of this study.

Significant statements (quotes) from the transcribed interviews were cited to illustrate the findings and to allow the reader to evaluate the responses and the credibility of the findings. The researcher cited statements made by two or three of the participants, as examples under each theme and sub-theme from the transcripts, to illustrate the aspects under discussion. Each quotation was followed by the code P, which is the statement made by the participants (P) in the individual interviews. The codes are followed by a number to indicate which the participants made statement, for instance P2 indicates the second participant interviewed made the said statement.

An overview of the themes and sub-themes from the interviews with the participants is provided in table 4.2.

**Table 4.2:** Themes and Sub-themes from the interviews with the participants

THEME	SUB-THEME	
4.5.1 Physical Experiences	4.5.1.1	Feelings of breathlessness
	4.5.1.2	Mouth dryness
	4.5.1.3	Experiences of pain
	4.5.1.4	Physical discomfort
4.5.2 Emotional Experiences	4.5.2.1	Experience of fear (shock)
	4.5.2.2	Feelings of bothering
	4.5.2.3	Near death
	4.5.2.4	Inability to endure
	4.5.2.5	Powerlessness
	4.5.2.6	Knowledge deficit
	4.5.2.7	Sense of safe/ unsafe
	4.5.2.8	Body image
	4.5.2.9	Spirituality
4.5.3 Communication		

#### **4.5.1 THEME ONE: PHYSICAL EXPERIENCES**

##### **4.5.1.1 Feeling of breathlessness**

The participants in this study described having the experience of breathlessness, which was expressed as a feeling of inability to breathe on their own or shortness of breath, as expressed in the statement below:

*“...is not the nicest thing because you can’t breathe it breathes for you, you have to wait for it to breathe so that is the and that is something that I must say something I won’t like to do again.”*

(P4, P5,)

Another participant added:

*“For the breathing apparatus things I think am I don’t know how it works how they set it up to do your breathing for you but I think the time you know I don’t know how this machine works but it’s a vacuum pump and what happens is that it put the air in your throat but only in a short time it doesn’t allow you to breathe because the time I actually breathe is very short.”* (P9)

The participants also described experiencing breathlessness in relation to the suctioning procedure:

*“They didn’t take too much but it’s painful it’s like you are dying you can’t breathe.”*

(P5)

The experience of breathlessness was further described as upsetting and associated with the suctioning procedure:

*“That’s the breathing one, it was okay because they put some fluid in and they pump it down your lungs at that time you can’t breathe it was very upsetting.”*

(P9)

The above were the expressions of the participants with regard to their experiences of breathlessness whilst connected to the ventilator. This conforms to the findings by Karlsson *et al.* (2012) and Engström *et al.* (2013), where the participants described the experience of breathlessness as the inability to fill their lungs with air which led to feelings of panic. They identified the need to breathe on their own, but they could not because of the tube. The participants also described their inability to breath as unpleasant and life-threatening, although some of the participants in Samuelson, (2011) expressed satisfaction with the assistance they received in removing secretions from the throat, help with the ventilator and experience of prompt attention when needed, despite their feeling of breathlessness (Schou and Egerod, 2008).



#### 4.5.1.2 Mouth dryness

Mouth dryness is referred to as an expression of the inability to take in any fluid for the period of endotracheal intubation or mechanical ventilation. The experiences of thirst and hunger were feelings that resulted in mouth dryness, according to the participants in this study:

*“But one thing that was not allowed was food, no food no water only that water up there [IV fluid] when I got there.”* (P1)

Another participant’s response to what he would have loved to do if not connected to the machine was:

*“Water I wanted a glass of water, I wanted a glass of water so desperately.”* (P4)

This need for a glass of water and food were spoken of by these the participants as an essential need; one participant saw it as the only problem he had whilst on the ventilator.

*“...the only problem though was no food, that’s all.”* (P1)

There is a hierarchy of needs described by Abraham Maslow (Janice and Kerry, 2013:5) where the physiological needs form the foundation of the ladder (pyramid) where water and food are basic needs that must be met and without which, man may not survive. The participants in this study exhibited dissatisfaction in meeting these needs.

This feeling of not being able to take in water, or the demand for such, was described by Magnus and Turkington (2006) in their study as frightening and cruel as the participants described it as loss of control and was a negative emotional response to mechanical ventilation.

It was an unclear indication if the participants received any information as to why water was not allowed, however one participant (P4) saw the need to follow whatever the nursing

health personnel told him, as he saw the nursing health personnel were only performing their duties:

*“Like I said the people that side were so nice it’s not I went out for health personnel they put in there I won’t and they are straight they are straight forward you know sometimes other people will take the route of that I have seen them tell you straight forward listen to me don’t do this listen carefully and in the mean time they are just doing their job, if you listen to them yes and if you don’t it’s your own problem.”* (P4)

In contrast with this finding, the participants in Jordan *et al.*, (2002) study were frustrated as their need for water was not met, coupled with the fact they were not informed by the nurses of the reason why water was not allowed whilst on the mechanical ventilator. Landström *et al.* (2009), Arai *et al.* (2013) and Holm and Dreyer (2015) described thirst not only as a physiological need, but also as an existential need that could not be met because of the presence of the endotracheal tube. As such, this resulted in a feeling of yearning and deprivation, as described by Karlsson and Forsberg (2008).

The development of cracks in the mouth was also because of mouth dryness, which was expressed by one of the participants as being due to the inability to take water or even rinse the mouth because of the endotracheal tube. The participant said:

*“My mouth started to have scales (cracks).”* (P1)

This finding are similar to those of Holm and Dreyer (2015), where the participants saw the tube as a foreign object and described experiencing scarring or having sores in the roof of the mouth as a result of the endotracheal tube.

The inability to speak clearly and loudly was also attributed to the presence of the endotracheal tube and the participants described this as voice change, as expressed below:

*“....and they had to pull this thing out that’s why my voice is still not right.”*  
(P7; P9)

Therefore, it can be concluded that the participants in this study suffered from mouth dryness as a result of placement of the endotracheal tube and it became evident that they yearned for a drink of water, which became their first and urgent need especially immediately after disconnection from the ventilator.

#### 4.5.1.3 Experience of pain

Pain is a subjective feeling that can only be expressed by the person experiencing it. It can be defined as a physical suffering or an unpleasant experience or feeling resulting from illness, disease or accident (Free Dictionary). In this study, it was noted that the participants' experiences of pain were at different levels of care during their Intensive Care admission. Some the participants admitted to having pain just because of the presence of the endotracheal tube, as reflected in the below statement:

*"Yes there was pain you know something that is not that was not born with you it always bring pain in your body... It was minimal but it was you know the pain is pain it doesn't matter it doesn't matter is a terrible or very low or what it doesn't matter."*

(P2)

Although the participant agreed it was minimal, he expressed further to the fact that pain is pain no matter how serious or minimal it may be, confirming the fact it is a subjective matter. Some of the participants attributed pain to the suctioning procedure, as expressed below:

*"When they (nursing staff) try to clean up the lungs it was a horrible feeling."*

(P3)

*"Yoh they take it when they take the tube the put something to clean my chest, Ohhhhhhhh its painful, its painful, ...they didn't take too much but it's painful."*

(P5)

*"I just wanted to take it out it was so painful to breathe with the machine."*

(P7)

*“I felt pretty whats it that place is sensitive because once they pour the stuff down I mean it was like it was its traumatising.”* (P3, P5, P8, P9)

The participants in this study used expressions such as difficult, horrible and irritating to depict their expression of pain (feeling of pain and being on the ventilator), as expressed thus:

*“(Sigh), I don’t know what can I say because it was so difficult.”* (P5)

Some of the participants in this study alluded to the fact that the endotracheal tube and being on a ventilator was a horrible experience they never want to experience again:

*“It’s the most horrible irritating feeling... Once it settles in your throat its very painful.”* (P7)

*“When they try to clean up the lungs it was a horrible feeling ...oh God I rather not I rather not it’s horrible I’m sure I’m not the first patient.”* (P3)

*“So apart from that I can’t say is a bad experience in total but for me it was difficult cos I can’t keep things in my face then they tried twice to put the pipe back in my nose.”* (P9)

Other forms of pain reported by the participants in this study were related to swallowing and pain in the throat, as reflected below:

*“... I had a little swallowing pain.”* (P7)

*“It makes it difficult to swallow... ‘the pain only happened when you swallow to clear your throat the thing goes around and has to move around the two pipe and that the only thing...”* (P9)

These experiences of pain in relation to the endotracheal tube were supported by Holm and Dreyer (2015: pg 4), as the participants in their study described pain on a scale of zero to

constant overwhelming experience, describing it as *'agonising all the way through.'* Karlsson *et al.* (2012) confirmed this experience of pain due to suctioning, as their participants described the experience as painful and unpleasant.

Holm and Dreyer (2015) attributed the experience of pain on mechanical ventilation to insufficient pain management or the instability of the endotracheal tube and as such, supported the motion that pain management must be taken seriously when patients go through endotracheal intubation and the use of a reliable observational tool to evaluate patient's pain to enable adequate management to be provided.

This experience of pain in relation to swallowing was supported by findings from Schou and Egerod (2008), who stated that despite feeling uncomfortable with the presence of the tube and having swallowing difficulties, mechanical ventilation was bearable. This feeling that the ventilator was bearable was also reflected in this current study, as indicated by the statement below:

*"I won't say it's uncomfortable though ahh it is uncomfortable but it's not intolerable...Yah it's bearable."* (P9)

Jordan *et al.*, (2002), Johnson *et al.*, (2006) and Wang *et al.*, (2009) discovered that mechanical ventilation and suctioning were extremely uncomfortable, as expressed by the participants in their studies, where the pain and discomfort was described as continual and unendurable.

The experience of pain in relation to suctioning was described as traumatising in this study. This was contrary to the findings of Karlsson and Forsberg (2008), where suctioning and alarms were rated as non-bothersome to the participant rather the feeling of relief that the mucus was removed from their airways was evident.

Although Johnson *et al.* (2006), Wang *et al.* (2009) and Baumgarten and Poulsen, (2015) supported these findings, as experience of pain due to suctioning was described as awful, severe, unendurable and unpleasant. The participant attributed the pain experienced to the

skills used by different nursing health personnel while performing the suctioning procedure (Jordan et al., 2002) the participants.

In this study, two of the participants remarked that although the procedure was ‘*hectic*’, they felt good and the nurses worked very fast, whilst another participant said she felt good because she wanted to be alive and go back to her normal life.

#### 4.5.1.4 Physical discomfort

This can be referred to as a sense of distress, something that disturbs the comfort of a person (Free Dictionary). The participants in this study related their feelings of soreness to the presence of the endotracheal tube and this made them scared. Participant said:

*“I was so scared because the tube they put was so sore, ... sore I feel sore.”*

(P6, P7)

Some related their experience of discomfort to the feeling of vomiting while they were being suctioned.

*“Imagine someone sticking some things in your throat you feel like vomiting so embarrassing.”*

(P8; P9)

One participant even attributed the experience of vomiting to the nasogastric tube that was placed in his nose and the presence of all the tubes in his face made him feel nauseous:

*“I couldn’t keep it down I had to bring it out so all my stomach juices I had to vomit out so it was rather difficult for me to keep all the stuff in my face and keep on pump like pumping.”*

(P9)

Experience of choking was also paramount in this study, as some of the participants expressed feelings of being choked mainly during suctioning and being traumatised.

*“Especially when they do the washing a lot it can choke, choke, choke.”*

(P1)

*“Yah sometime when you wanna cough or so it is basically there when you get something stuck in your throat automatically it’s going to want to choke.”*

(P4)

*“Yah it was very traumatising. It was tough.”*

(P3)

These experiences culminated into physical discomfort experienced by this participant.

From the above perspectives, the experience of suctioning was horrible and traumatising.

The physical discomfort, such as

- (i) experiences of a sore throat,
- (ii) nauseousness,
- (iii) choking sensations,
- (iv) experiences of pain as a result of the presence of the endotracheal tube described as an irritating feeling,
- (v) swallowing pain,
- (vi) mouth dryness
- (vii) the desperate need for a glass of water
- (viii) feelings of breathlessness, where the participants felt they had to wait for the machine to breathe for them, which was described as “not the nicest thing,” all culminated into the physical experiences these participants expressed.

#### **4.5.2 THEME TWO: EMOTIONAL EXPERIENCES**

Emotional experiences are the knowledge gained by an individual as a result of his/her engagement in that event or occurrence, with mental involvement such as perceptions, will, emotion and thoughts (Free dictionary).

The participants in this study described some level of emotional experiences as a result of their placement on mechanical ventilation such as

- (i) having feelings of fear,
- (ii) being bothered,
- (iii) near death experiences,
- (iv) inability to endure some occurrences whilst on the ventilator,
- (v) powerlessness,

- (vi) lack of adequate knowledge regarding the treatment and procedures carried out while connected to this machine,
- (vii) sense of being safe and unsafe in relation to health personnel attitudes,
- (viii) how they felt about their bodies
- (ix) spirituality.

#### 4.5.2.1 Experience of fear

Experience of fear is the knowledge of unpleasant, disturbing feelings, which can be caused by the presence of danger. It means to be frightened or afraid.

In this study, the participants described feeling shocked and frightened, especially at the moment of waking-up from anaesthesia and discovering they are connected to the mechanical ventilator (their experience of fear in terms of being shocked when they woke up and discovered they had a tube stuck to their throat). The feelings of shock may even continue in some cases for the entire period of connection to the ventilator affecting the participants' acceptance of the ventilator as a treatment regimen and as such, negatively affecting the whole experience.

Other participants, despite being informed on the way to the theatre, still felt very anxious with the presence of the tube and wanted to rip the tube out, as reflected in one participant's statement: *'scared too much of both the presence of the tube and the inability to talk.'*

Some of the statements made by the participants were:

*"Yes I did feel anxious."* (P4, P8)

*"...ehhhhhh you know why you become very anxious."* (P3)

Another participant added:



*“The time I discover I was on that pipe I was so scared neh but I told myself God is the one who can make me succeed as you see me today, ... At that time I couldn’t stop I was just scared too much that’s why I was praying inside me.”*

(P5)

Waking up post anaesthesia and finding the endotracheal tube in the mouth frightened one of the participants:

*“Shocked shocked luckily they are strange to me because normally your first reaction they taught me is not because of your root it’s because first when you woke up your reaction is to pull out so they warned me before to say listen look your hands are tied down that is not very permanent.”*

(P4)

The experience of fear was attributed to the nature of the illness, which led to shock and the fear of dying. Some of the participants attributed their fear to the presence of the endotracheal tube and their inability to participate in their own breathing, which led to anxiety, anger and frustration (Samuelson, 2011). This confirms the findings in this study, as the participants acknowledged being shocked and scared with the presence of the tube.

*“I was so scared because the tube they put was so sore.”*

(P6)

According to the participants in Karlsson *et al.* (2012), their experience of fear was attributed to being connected to the ventilator and which led to the fear of death as they feared the ventilator could stop working while they were still connected to it, as they felt that they are living because of the ventilator, also the painful and unpleasant experience of suctioning resulted in feelings of fear for some of the participants.

The experience of fear from the participants in Karlsson *et al* 2012 was attributed to being connected to the ventilator. The participants feared death as they felt they are living because of the ventilator and feared the ventilator could stop working while they are still connected to it.

#### 4.5.2.2 Feelings of bothering

Bothering can be described as an act of annoying, provoking or disturbing a person, while feeling is an emotion that can only be expressed by the person involved; it is a subjective expression. In the context of this study, the feeling of bothering was expressed by the participants in relation to disturbances from alarms, machines, suctioning procedures and even the environment (Free dictionary). These disturbances were described as upsetting, the worst feeling ever and the presence of the tube as uncomfortable as expressed below:

*“...No just that it was uncomfortable and so”* (P3, P7, P9)

Another participant added:

*“I won’t say it’s uncomfortable though ahh it is uncomfortable but it’s not intolerable”* (P3, P9)

The experience of suctioning as related to bothering was expressed as:

*“Ammmm, Its just uncomfortable relying and watching...during that time you felt eh and they work quickly it’s a worst feeling.”* (P4)

Other participants added:

*“That’s the breathing one, it was okay because they put some fluid in and they pump it down your lungs at that time you can’t breathe it was very upsetting.”* (P3, P7)

*“...there were sometimes maybe you woke up and you start hearing the machines alarming.”* (P8)

The frequent disturbances by the nursing health personnel, as experienced by the participants, was felt as bothering (Samuelson, 2011) and the alarms were described as disturbing by Wang *et al.* (2009), which was contrary to the findings in Karlsson and

Forsberg (2008), where the participants were not bothered by the suctioning procedure nor by the alarms of the machines. According to the findings of this study, the participants were disturbed by the sounds of the alarms as well as the ICU environment thus, making their stay in the unit uncomfortable.

Consequently, to decrease the feeling of bothering for these patients, it is of important that critical care nurses arrange procedures in order of priority and perform such activities timeously so that the patients can have enough time to rest and relax.

#### 4.5.2.3 Near death

This is the experience of almost dying, but surviving; it is comparable to seeing death face-to-face and miraculously surviving (Free dictionary). In this study, the participants described their experiences of ventilation as the worst experience ever; they described the ventilator as a “*torture machine*” (P4) and at some point they felt they were fighting for their lives or felt like dying. They related the experience of near death to the ventilator, suctioning or extubation. These are some of the statements made by the participants:

*“It was terrible I mean at some point it feels like you were dying men it’s very very the word is very invasive.”* (P3, P5)

*“Ohhhhhh it’s a miserable feeling if you ask me now all about the operation that’s probably the worst part seriously because ehhhhh you know why you become very anxious it is like you are fighting for your life, you understand you just getting instructions push, breath or whatever it is eh you know throw up or whatever.”* (P3)

*“Torture that’s a torture machine that is not the nicest thing because you can’t breathe it breathes for you, you have to wait for it to breathe so that is something that I must say something I won’t like to do again.”* (P4)

In line with the findings by Samuelson (2011), the experience of being acutely ill resulted in a scary feeling which threatened the chances of survival and caused an overwhelming feeling and fear of dying for the participants . Johnson *et al.* (2006) further confirm this

finding by describing participants' experience of doom and fear of death due to being connected to a ventilator.

Furthermore, Johnson *et al.* (2006), Rattray *et al.* (2010) and Engström *et al.* (2013) confirmed the participant's thoughts of death and their grateful expressions on survival. The participants initially queried their ability to survive outside the ventilator, despite the unpleasant experiences, but eventually, after their survival and extubation, they were grateful and very happy.

Critical care nurses therefore need to be mindful of the supportive and informative role to critically ill patients as this can provide them with a sense of hope.

#### 4.5.2.4 Inability to endure

The inability to endure is the lack of means of coping with a situation or incapacity to do something (Free Dictionary). The participants in this study claimed that the process of ventilation was tough and hectic for them, they even felt as though they drowning. They felt they might not be able to survive the ordeal of suctioning and extubation, as expressed below:

*"Like I said it was uncomfortable but manageable it wasn't so bad except when the time came to get out it yah that was hard ...but ehnnnnnnnnnn I was okay with it until the point came where we needed to get it out."* (P3)

*"It's understandable like I said I can understand it I think it's just that when they are taking it out and flush it yoh that's hectic u feel like drowning u know what I mean it's very invasive...it was tough though I wish there could be other way to do it."* (P3, P4, P8)

*"I was happy because that time when they take it out I know how to breathe and I know how to talk I saw everybody."* (P5)

In line with Holm and Dreyer (2015), the participants described the endotracheal tube as foreign and wanted to rid themselves of it, but because it was expedient for their survival they had to devise means of coping with it by suppressing the urge for removal.

Jenabzadeh and Chlan (2011) also described the process of extubation as exhausting, especially the last suctioning before extubation. The suctioning was experienced as terrible and uncomfortable even though post extubation, the participants' experienced a sense of relief but still had to battle with soreness in the throat.

In this study, the participants described the extubation process as hard, hectic, stressful and difficult.

#### 4.5.2.5 Powerlessness

Powerlessness is a feeling of not being capable, or lack of ability, to perform a task resulting from weakness or being feeble (Free dictionary). In the context of this study, powerlessness resulted from the lack of strength and feelings of helplessness experienced by the participants as a result of their condition.

The participants in this study fought with the presence of the tube and the ventilator as they could not breathe on their own, but they eventually accepted it since they could not get rid of it on their own. The participants said:

*"I just needed the machine to come out for me, ...I was drawing the machine pulling it out yahhhhhhhh."*

(P8)

*"All I can remember was the me and machine was battling so they had to put me out again they had to sedate me they put me back to sleep to put another pipe inside."*

(P4)

This confirms the findings of Samuelson (2011), where the participants felt powerless, vulnerable and helpless leading to the feeling of loss of control. In Karlsson *et al.* (2012),

the feeling of powerlessness was attributed to the inability to communicate and not to the ventilator itself, although the presence of the endotracheal tube caused the inability to talk. In this study, the participants wanted to get rid of the machine and the tube and inability to do so led to the feeling of powerlessness.

*“Yes I had to endure it because it was a lifesaving machine.”* (P8)

The feeling of loneliness was attributed to being powerless, as the participants felt lonely in the Intensive Care Unit and also when health personnel concentrated more on the technology rather than on the patient, which can be attributed to loss of control (Olausson *et al.*, 2013). Schou and Egerod (2008) confirmed these findings in their study describing the lived experiences of post-CABG patients during mechanical ventilator weaning, where the feeling of loneliness was attributed to the Intensive Care environment being strange and the participants felt the need to engage more with the nursing health personnel in the unit.

The participants in this study also described the feeling of loneliness, except that it was attributed to the absence of family members and friends, which was supported by Bergbom-Engberg and Haljamae (1989). When asked how he was treated in the ICU, one participant said:

*“I feel lonely at that time you know that’s why they say you can die in bed because of those situations like that you will die in bed because you won’t be able because if you look if you look on my blood pressure it was going up and down then go up again (loud) you see.”*

(P2)

He attributed the fluctuation in his blood pressure reading to the fact that he felt so lonely because his family was not allowed to visit for the full length of the visiting hour.

Although only one of the ten participants’ complained of experiencing short visiting times, it became imperative as this participant spent a considerable time in the Intensive Care

Unit and on mechanical ventilation, and he felt it was important for family to be there for each other, as reflected in this statement:

*“...They were allowed to visit but not for a very long time, when they come oh they will just say you just have to pray now just for a few minute. About that one like the way I was talking ,say the families is visiting you they were not allowed to stay for very long time you see do you know the time frame was from three – five pm you see so they just come and some time they stay for 10 minute then they were gone.”*

(P2)

This implied that the family visit was too short hence it impacted on the experiences of the patient in the unit. This same participant went on further to make this statement:

*“...Because you know as a family you have to talk to find a solution say you know guys I’ve got a difficulty this is my problem how can we solve this problem you see then they will help you to say know who can solve this problem in such a way that nothing will stop us from coming to see you, you see but if they just to say when they are coming they say no you guys you are not allowed this guy is coming from ICU you are not allowed to come here you are allowed to stay home you see that way is not good.”*

(P2)

Other participants in this study were also visited by their family members, but most of them were visited after the endotracheal tube had been taken out. A few relatives saw their family member on the ventilator and this statement was made by one of the participants:

*“I didn’t feel anything it was them who felt bad they were telling me after that the way you were looking you were this thin.”*

(P10)

Family presence in the Intensive Care Unit has been reported several times in previous findings with differing opinions.

According to Schou and Egerod (2008), family presence is very important as it helps to quicken the recovery of some patients, although some felt it was disturbing especially if they are in a two-bedded cubicle (room), basically because of individual differences.

The participants in Schou and Egerod (2008: pg 176) referred to the family presence as a “lifeline” and this study suggested that patients preferences should be taken into consideration in term of length of visiting time and number of visitors. It is worth noting that institutions have protocols or guidelines (rules) governing number and length of visits per time.

In line with Karlsson and Forsberg (2008), family and relatives involvement in patients care is important as it helps in promoting yearning, patients’ health in the ICU, as well as participation in their care and reduction in feeling of loneliness and isolation. Wang *et al.*, (2009) also acknowledge family support as important and helpful in the patient recovery process.

The participants in this study attributed their sense of optimism and hope to the presence and visits of their family members and relatives, although the visiting time was short lived, their presence was well appreciated. This confirms the findings in this study, that the presence of the family cannot be over emphasised. Samuelson (2011) attested to the findings that relatives’ presence helps with emotional security of the patients.

Jenabzadeh and Chlan (2011), in a nurse’s experience of being intubated and receiving mechanical ventilation, described the presence of the family, especially the participant’s mother, as being comforting and reassuring.

Arsanian-Engoren and Scott (2003) supported this finding, where the participants attributed their quick withdrawal from the ventilator to the support and encouragement received from their family. The participants believed that they got the energy and strength to move on from the constant presence of their relatives.



#### 4.5.2.6 Knowledge deficit

A knowledge deficit is the lack of information or knowledge about a particular phenomenon or situation; lack of information about a disease condition, a procedure, treatment modality, or a situation in which one finds oneself (free dictionary). In regards to this study, the participants reflected having knowledge deficit in three areas:

- (i) the connection to mechanical ventilation as an important component of the recovery period,
- (ii) the benefit of purpose of connection during this period and
- (iii) the weaning process.

The lack of information was associated with mechanical ventilation and procedures, such as suctioning, oral care and treatment modalities done for the participants whilst in the Intensive Care Unit. The participants in this study described their lack of in-depth knowledge, with regards to mechanical ventilation, as tough and believed that if they had been given enough information as to what to expect this would have enabled them to prepare themselves better. The said:

*“...but all they said was you will have a pipe in your mouth they didn’t say more than that and I don’t blame them you know but it was tough.”* (P3)

*“I don’t really have time to think about it you have no knowledge about what the purpose of it and you just get up and it’s there and nobody sits and give you a full run down on it probably because I suppose they don’t want to answer to you.”*

(P3)

*“...No they didn’t tell me, ... Nothing no information.”*

(P8)

*“I think ahhhhhhhhhhh one thing about the whole operation from start to finish is that ehhhhhhh they told me before that they gonna put that thing in my lungs they gonna put those pipe in my nose but they don’t explain the purpose of it you understand so if the doctor or whoever does it explained it in more common or normal language you people are used to medical term so if you explain to me in a*

*normal term that okay this might be uncomfortable, it might be sore and it might be difficult to breathe then you have your mind set on it so if it happens you know it's going to happen."* (P9)

The participant who made the above statement (P9) said () that pre-information was given about the endotracheal tube, but it was not detailed enough. The information only entailed the presence of the tube in the mouth post-surgery; the patient was only told once he awoke he would find the tube in his mouth.

The participant confirmed that the little information they received helped to an extent, but deeper and more concrete information about everything to expect, in simple language, would have been better for coping with the ventilator. In Engström *et al.* (2013), the participants confirmed that knowledge about the treatment regimen, procedure or what would happen helped in preparation.

Karlsson *et al.* (2012) studied the lived experiences of adult Intensive Care patients and found that the participants described a lack of information about planned management and what to expect resulted in feelings of being powerless. This also gave a sense of uncertainty about their condition, whether they were recovering or getting worse.

The participants in this study also described receiving minimal information regarding what to expect, but this information was not detailed enough for them, although some said it helped them to cope with the situation. These are some of the statements by the participants in relation to pre-information:

*"It was uncomfortable but I was warned before it I mean they informed me that when I get up I will have it in my mouth."* (P3)

*"...Yes before going to the theatre there was a nurse she talk to me she said I'm your sleeping nurse I'm taking you to the theatre this is what will happen as we talk we talk you will sleep...Oh yes because they talked to me I was relaxed."*

(P10, P4, P3)

This confirms the findings of Guttormson *et al.* (2015), where information was only given to the participants when nurses felt it was needed. The participants were not fully informed of all the processes happening to them and felt being given enough information would have been beneficial to them rather than having to force the information from the nurses.

#### 4.5.2.7 Sense of safe/unsafe

This is the feeling of freedom from danger and harm, while the sense of being unsafe is the feeling of danger, harm or risk to a person (free dictionary). Most of the participants in this study admitted that the health personnel were friendly and described the experience as good, although not all the participants commented about the health personnel:

*“Oh yah I had good conversation I had good conversation with some of them freelance little basically ... and like I said it went all out all the way to make my stay visit that side comfortable.”* (P4)

Another participant said:

*“Actually I remember the one state that they actually bring a fan the one night the lady actually took the blanket because I was sweating and my temperature was running so they actually took the blanket waited a bit and put it on me they are very disciplined...they were brilliant.”* (P4, P9, P10)

Whereas another participant responded with this statement when asked about his relationship with the health personnel:

*“Ahhhhhh just minding my own business as patient.”* (P1)

Hofhuis *et al.* (2008) and Engström *et al.* (2013) confirmed the sense of safety experienced by the participants as they trusted and believed in the health personnel for their safety in the unit. The receipt of information, support and motivation from the health personnel also assisted their participants in feeling safe. The participants in the above mentioned studies further appreciated the constant presence of the health personnel, which gave them a sense

of safety in case their condition deteriorated. The participants also feared transfer to another unit as they had developed a relationship with the health personnel.

Hupcey (2002) claims that the presence of ICU health personnel, family and religious belief was also helpful in feeling safe.

Concurring to findings from Jenabzadeh and Chlan (2011) study, the participants described the receipt of nursing care as helpful, comforting and gave a sense of safety by engaging in chat and receiving of information from the health personnel. This study then suggested that nursing personnel should remember that their patients can hear them, even when sedated. Therefore, provision of maximum care and addressing the patient directly is important as it shows respect for the dignity of the patient.

Furthermore, the need to be empathetic and trying to meet both the physiological and psychological needs of the patients is important for their recovery or peaceful death.

In this study, the participants also described a sense of relief or comfort when they were taken off the ventilator and out of the Intensive Care Unit.

*“But I mean I suppose now that when you pass that mark then you are okay because you survived it and then you realised that you don’t have a choice in the matter ohhhhh that was hard but at least now I’m breathing and in the long term you accept it.”* (P3)

*“I was happy because that time when they take it out I know how to breathe and I know how to talk I saw everybody”* (P4, P5, P9)

One participant described the experience of being discharged from the ICU in this statement:

*“I felt very happy.”* (P2)

According to Samuelson (2011), the participants felt relieved when they discovered they were recovering well and the constant and prompt help received from the health workers

supported them and made them feel relaxed, which eventually gave them a sense of safety. Extubation was described as a moment of relief, which remained in the participants' memories. Karlsson and Forsberg (2008) confirmed the sense of relief and happiness experienced by the participants in this study.

Furthermore, in this study the participants described the feeling of happiness and their reluctance to return to the unit and the ventilator ever again, whereas contrary to our findings, the participants in Adamson *et al.* (2004) agreed to readmission into the unit if need be. A participant said he would only agree to go to the unit if there was a need for a procedure, otherwise he did not wish to go back there ever again:

*"No I won't like it...: I felt very happy... I would go back there not that I want to go but I will go there is in there are procedure maybe which I needed to be finished."*

(P2)

*"Oh God I rather not I rather not it's horrible I'm sure I'm not the first patient."*

(P3)

The Intensive Care environment was described in different ways. While some described the environment as clean and very comfortable, others claimed that it was a busy place. To sleep, eat and breathe well was difficult, culminating in the experience of the unit being a bad one. The participants' views are expressed below:

*"It's clean and there was no disturbance no noise,"*

(P8)

*"The environment was very comfortable."*

(P4)

*"Nooooooo I mean the ICU is a busy place so you can't sleep properly you can't eat properly and you can't breathe properly you can't I mean there is a lot of can't you can't do you understand so all of these accumulate to a bad experience when I found myself out of the place I feel no I'm much better."*

(P9)

This confirms the findings by Samuelson (2011), where the presence of people in and out of the unit and high activity levels all culminated in disturbance for the participants, including the presence of different intravenous lines and tubes.

The participants in this study did not elicit further on the reason why the unit was regarded as comfortable. However, in line with Samuelson (2011), the removal of tubes, intravenous lines and restraining devices was acknowledged as a relief for the participants which agreed with the findings in this study, (where the participants reported a sense of relief with removal of the tubes and transfer out of the unit.)

Johnson (2004) and Wang *et al.* (2009) described the experiences of patients in the Intensive Care Unit environment as unfamiliar, strange and frightening. The participants described it as a jail and as being in a separate world, which was in contrast to the feeling of being comfortable and cleanliness as expressed by the participants in this study.

#### 4.5.2.8 Body image

This can be defined as an individual's personal perception of his or her appearance. The participants felt uneasy when they could not perform activities, such as going to the toilet, eating and drinking, which rid them of their sense of personal dignity. Having to go to the toilet in bed was eventually accepted as they were connected to the machine and felt weak. A participant reported feeling ashamed when he soiled the bed as he could not get out of bed and had not devised a means of communicating with the health personnel. He said:

*"I had to use plates on bed I felt bad when I soiled the sheet."* (P1)

This was consistent with the findings by Karlsson *et al.* (2012), where toileting in bed was seen as a loss of personal dignity. The participants in Wang *et al.* (2009) and Engström *et al.* (2013) described experiencing the feeling of helplessness and dependent on others as a result of body weakness and the inability to use their arms and hands. The inability to go to toilet was also viewed as "demanding" (Engstrom et al., 2013: 91).

The “limited possibilities to act,” by Johansson and Fjellman-Wiklund, (2005:154), described the inability of the participants to perform activities and not being in contact with their normal body. They felt the body was no longer responsive in the usual way anymore and as such, they thought they were living in an unfamiliar body. One participant said:

*“Okay so I don’t know whether my legs were going to go back normally...I can’t remember, everything changed after going to surgery my mind changed some things I forget.”* (P6)

A participant from this study expressed a feeling of embarrassment related to the process of suctioning; she said:

*“Imagine someone sticking some things in your throat you feel like vomiting so embarrassing.”* (P8)

In Jenabzadeh and Chlan (2011), the participant felt like drowning in her secretions and had different bodily experiences, such as having a sense of convulsion, eye tearing up and a sense of emptiness inside. The participants in Johnson (2004) felt like vegetables on the bed as a result of their inability to perform any function resulting in an altered their sense of personal dignity.

#### 4.5.2.9 Spirituality

Spirituality has to do with one’s beliefs and values. It is the realm of invisibility that influences our thoughts and behaviour (Morton and Fontaine, 2013). In this study, the participants described their reliance on God as the bedrock of their strength, as they depended more on God in their state of helplessness:

*“... that’s why I was praying inside me”* (P5)

This same participant described being fearful while on the ventilator, but believed God was more than able to help her:

*“The time I discover I was on that pipe I was so scared neh but I told myself God is the one who can make me succeed as you see me today.”* (P5)

These findings confirm those of Karlsson *et al.* (2012) where the participants described the ability to rid themselves of thoughts of dying because of their reliance on a religious spirit.

This finding was also supported by Jenabzadeh and Chlan's (2011) , where the participants alluded to drawing strength from spiritual belief and described it as a source of hope and perseverance. The participant suggested that nurses should enquire on how they can be spiritually supportive to their clients.

Arslanian-Engoren and Scott (2003) corroborated this finding in the lived experiences of survivors of prolonged mechanical ventilation, where the participants claimed that incessant prayers and belief in God helped them get through the ordeal and also assisted in recovery

Jordan et al (2002) also attested to this finding that trust in God and incessant prayer is essential in overcoming illness and the ICU environment.

This aspect was not so evident in this study, but because of the emphasis placed on it by the participants it became imperative that the result be presented.

It became clear that the participants in this study had so many experiences impacting on their emotions. Experiences such as the feeling of fear, loss of control, lack of sufficient information regarding the ventilator and other procedures. Also the experience of powerlessness brought about by loneliness and their struggle with the ventilator, difficulty experienced with extubation, near death experience and feeling of being disturbed by the health personnel and the machines.



### 4.5.3 THEME THREE: COMMUNICATION

This is the interchange of words, thought, opinion and information by speech, writing or signs (Free Dictionary). Communication can be either verbal or non-verbal and it is a two-way phenomenon. With endotracheal intubation, a patient's ability to communicate is impaired because of the placement of the tube obstructing the larynx and voice production hence, the participants in this study expressed feelings of difficulty and awkwardness due to their inability to communicate. Although they found alternative means to communicate their needs to the health personnel, they still expressed their feeling of dissatisfaction communicating non-verbally. The following quotations support the above statement:

*"I beckon to them and whisper to them to give me bedpan."* (P1)

*"...ah sign language, I wasn't feeling okay, I'm not use to sign language that is the main problem and when I grow up I was not using I didn't grow up using sign language but I ended up using sign language because I wanted help."* (P2)

*"...Sigh I don't know what can I say because it was so difficult."* (P5)

*"...Sign language, I feel so awkward I must say it was so awkward."* (P8)

*"All those thing down your throat it makes it difficult to swallow and communicate."* (P9)

The findings in this current study were in contradiction to those of Khalaila *et al.* (2011), Karlsson *et al.* (2012) and Holm and Dreyer (2015), where the inability to communicate was acknowledged as one of the worst experiences. Being mechanically ventilated was a frustrating experience for the participants as they could not express themselves verbally resulting in a feeling of despair and helplessness (Karlsson *et al.*, 2012). The inability to talk was described as more discomforting and worse than the endotracheal tube or the ventilator itself (Schou and Egerod, 2008).

Approximately 30% of the participants in Guttormson *et al.*, (2015) recalled the inability to communicate their needs whilst ventilated and 35% said they could not comprehend information given to them and since these the participants couldn't communicate their needs, they felt helpless. The inability to communicate and to comprehend information resulted in feelings of dissatisfaction by the participants.

The attitude of the nursing health personnel towards the inability of the patient to talk is a very important aspect of care, as it either worsens or relieves the anxiety/frustration of the patients. Holm and Dreyer (2015) concluded that clear and professional communication is regarded as being of great advantage to the patients, as it helps them to better understand and accept their condition.

In an attempt for patients to cope with their inability to communicate, alternative means of communication were explored. These may be the use of gestures, pointing, hand signals, alphabet boards, amongst others (Khalaila *et al.*, 2011; Holm and Dreyer, 2015; Guttormson *et al.*, 2015). As useful as these alternative measures may be, the participants are still faced with challenges in using them and they become frustrated when they are unable to complete their messages or write clearly.

In this study, the participants described the use of sign language as their alternative means of communicating with the nursing health personnel and their relatives and although they felt unhappy and uneasy in not being able to talk, these measures were helpful to them.

Lip reading was described by one participant with a previous hearing problem, as the alternative means of communicating that he explored. Although he could not successfully use it as there was hardly any direct contact with the health personnel, he described the inability to talk as very difficult for him to cope with:

*“All those thing down your throat it makes it difficult to swallow and communicate and for me with my hearing aid not being here since they don't want me to take my hearing aid with me so communication was difficult because without it my hearing is 20% very small hence communication is difficult once you have it down your throat... I get use to if I can't hear somebody I try to lip read I can do it very well*

*ahhhh but then somebody must look at me so I can lip read not looking around then I can't follow."* (P9)

The participants also described writing on pads/paper to express their needs and messages to the health personnel and their families:

*"I couldn't speak though but I tried to understand them they actually brought me piece of paper to write down."* (P4)

These alternative modes of communication were also supported by Magnus and Turkington, (2006) where the use of alphabet boards, writing and lip reading were regarded as assistors of communication. Meanwhile the health personnel's ability (skills) was highlighted as an important issue to measure the success of these assistors. The participants in this study expressed a positive attitude towards the nursing personnel responses by the use of the alternative means of communication as expressed in these statements:

*"Oh yah I had good conversation I had good conversation with some of them freelance little basically ... if I understand them and like I said it went all out all the way to make my stay visit that side comfortable."* (P4)

*"I used my hands, I didn't feel alright but I know I'm talking and I know they want to help me to talk so anything they ask me to do I'm doing because I want to be well."* (P6)

These findings were supported by Schou and Egerod (2008), where the participants credited the health personnel for their ability to communicate with them and anticipate their needs with the use of aids and gestures.

From all these, it is apparent that the participants still struggled with the inability to communicate with the (nursing) health personnel and family. The participants described this as hard and difficult and because they wanted help, they devised alternative means of communication in forms of writing, scrabbling on paper, lip reading and use of sign language.

## 4.6 SUMMARY

From the above findings, the feeling of breathlessness was described by the participants in this study as '*not the nicest thing*,' as the participants could not breathe on their own due to the presence of the tube. The participants even described experiencing short breathe because of the ventilator. The experience of the inability to drink or eat was also expressed as unpleasant by the participants and was related to the experience of cracks in the mouth. Cracking of the voice post extubation was also described by the participant as not being able to talk clearly.

The experience of pain, from the findings of this study, was only related to suctioning and swallowing pain experienced post extubation, which was contrary to various findings from previous studies. The participants in this study complained of pain as a result of suctioning and described it as a horrible and irritating experience/feeling.

Physical discomfort was also experienced by the participants due to the presence of the endotracheal tube, as the participants described feeling sore and vomiting during suctioning, as well as a choking experience while being suctioned. All of these experiences were regarded to as traumatising by the participant.

The experiences of patients on mechanical ventilation, in the ICU of an academic hospital in Johannesburg, was explored where the participants described their physical experiences, emotional experiences and communication impairment as factors that affected or impacted both positively and negatively on their experience or stay in the Intensive Care Unit in the South African context.

In this chapter, the demographic profile of the participants and the results from the study were presented. The three themes which emerged from the collected data were discussed alongside the sub-themes and literature control.

The next chapter presents the discussion of the findings, limitations, recommendations and conclusion.

## **CHAPTER FIVE**

### **DISCUSSION OF FINDINGS, LIMITATIONS AND RECOMMENDATIONS**

#### **5.1 INTRODUCTION**

This chapter provides the discussion of the findings of the study together with the limitations involved in conducting the research work. The recommendations for nursing practice, education, management, further research and conclusion are also presented.

#### **5.2 DISCUSSION OF FINDINGS**

This study dealt with the experiences of patients on mechanical ventilation in the Intensive Care Unit of an academic hospital in Johannesburg. Physical, emotional and communication experiences emerged as the three major themes in this study, as the participants described both pleasant and unpleasant experiences in relation to these themes.

The findings of this study indicated the physical experiences of these participants were described in the form of things that happened around them, which affected them but did not necessarily involve their psychological state. The participant's description of the endotracheal tube and mechanical ventilation ranges from feelings of breathlessness to physical discomfort.

The participants in this study described the feeling of inability to breathe, as a result of the endotracheal tube and the mechanical ventilation, when discovering the machine was breathing for them. A participant alluded to the fact that the machine was not allowing him to breathe as it was set at a short cycle. This feeling of breathlessness was supported in the findings from Karlsson *et al.* (2012), where the participants described breathlessness as a bad experience. The inability to breathe and get enough air was also expressed by the participants in Samuelson (2011) as an unpleasant experience, except the participants saw the machine as a life-saving machine and became calm even while still connected to it.

This was supported by the findings in this study where the participant endured the machine because it was a life-saving machine (P8).

This was supported by the findings of one of the participants in this study, who alluded to enduring the machine because it was a life-saving machine (P8).

The experience of dryness of mouth, as a result of not being able to take water due to the endotracheal tube placement, forms an unpleasant physical experience for the participants in this study. This feeling of dryness in the mouth was described as a desperate need that could not be met, basically because of the presence of the tube and the participants felt terrible.

In comparison to the findings by Grap *et al.* (2002), the participants described the experience of mouth dryness as a discomfort and suggested that relieving this discomfort can be brought about by wetting the mouth. This experience of thirst was also expressed in Landström *et al.* (2009), Samuelson (2011), Arai *et al.* (2013) and Holm and Dreyer, (2015), where thirst was described as not just a physiological need but also an existential need which could not be met, resulting in a feeling of being deprived and yearning (Karlsson and Forsberg 2008).

The experience of thirst, according to Engström *et al.* (2013), was unpleasant as the participants felt tortured not being able to drink, but when the nurse wet their mouth with swabs they felt satisfied this was contrary to the findings in this study as the participants never experienced wetness of their mouth at any point during mechanical ventilation.

The development of scales, or cracks, in the mouth was also associated with mouth dryness in this current study, where the participants attributed it to the presence of the tube and inability to take water. This was in line with the findings by Holm and Dreyer (2015), where the experiences of scarring was described by the participants.

Experience of pain has been a major finding in studies exploring the experiences of patients on mechanical ventilation and in ICU. The experience of pain by the participants in this study occurred at different levels of their Intensive Care admission. While some

attributed the experience of pain to the presence of the endotracheal tube, others linked it to suctioning, extubation and swallowing.

According to Karlsson *et al.* (2012), the experience of pain was attributed to the endotracheal tube and was described as '*beyond the patient control*' (Karlsson *et al.* 2012:11)) Holm and Dreyer (2015) describe the experience of pain on a rating scale of zero to constant and as overwhelming, with the participants alluding to it being agonizing all the way through, which could be attributed to insufficient pain management.

There was a level of physical discomfort that was associated with the use of sophisticated technology, as the participants in Wang *et al.* (2009) saw it as a source of suffering and unpleasantness. The presence of the endotracheal tube resulted in feelings of soreness in the mouth and this soreness was associated with tracheal suctioning, according to Wang *et al.* (2009). The participants in this study described experiencing soreness in their mouths which was related to the presence of the tube, corroborating the findings of Johnson *et al.* (2006) and Wang *et al.* (2009).

According to Jenabzadeh and Chlan (2011), the tube was irritating to the throat. Experiences such as gagging, choking (Samuelson 2011), sore throat and uncontrolled coughing were discomfort associated with the endotracheal tube and suctioning (Johnson *et al.*, 2006). The discomfort experienced by patients was regarded as continuous, ranging from a sore throat, difficulty in breathing, dry mouth and difficulty in sleeping (Wang *et al.*, 2009), this was in line with the findings from this study, where the participants experienced choking and a feeling of vomiting, especially during suctioning.

Suctioning the removal of phlegm and secretions from the patient's airway was described as extremely painful and unendurable (Wang *et al.*, 2009; Karlsson *et al.*, 2012) and the participants felt as though they were drowning in their own secretions (Jenabzadeh and Chlan, 2011). The experience of suctioning was also described as unpleasant, although the presence of phlegm in the throat and even in the tube increased the participants anxiety, nevertheless the participants felt terrible when needed to be suctioned (the need for suctioning arose)(Engström *et al.*, 2013). The participants in this study had mixed feelings/expressions when it came to the issue of suctioning; some described it as terrible,

corroborating with the findings of Wang *et al.* (2009) and Karlsson *et al.* (2012), whilst others saw it as helpful, which was in line with the findings in Karlsson and Forsberg (2008) where the participants experienced relief with suctioning and therefore were not bothered by the procedure.

From these perspectives, it became evident that these experiences of breathlessness, mouth dryness, pain and suctioning (affected the level of comfort experienced by mechanically ventilated patient) impacted on the comfort of mechanically ventilated patients, which should form the basis of nursing care.

The impact of mechanical ventilation has been reported in previous studies as having an effect on the emotional state of an individual. The experience of fear, feeling of bothering, near death, inability to endure, powerlessness, knowledge deficit, sense of safe and unsafe, body image and spirituality are the sub-themes developed under the emotional experiences, as they can impact on the psychological state of an individual.

The experience of fear/panic was evident during mechanical ventilation treatment amongst the participants in the study by Karlsson and Forsberg (2008), which was also confirmed by Karlsson *et al.* (2012), where the inability to breathe led to a state of panic, which lasted for the period of their ICU admission.

In this study, the participants were shocked with the presence of the endotracheal tube, as most of them awoke from anaesthesia to discover they were connected to the machine, even those who were pre-informed were still anxious with the presence of the tube in their mouth.

This was in tandem with the findings by Samuelson (2011), where the participants also attributed their fears to the presence of the endotracheal tube and the inability to breathe on their own.

In this study, the disturbance by alarms, machines and the environment was described as upsetting and the worst feeling ever, which impacted on the sleep patterns of the participants. Wang *et al.* (2009) and Karlsson *et al.* (2012) supported this finding, as the



participants in their study expressed the inability to sleep for long periods was due to being disturbed by the alarms and the ICU environment. This was in contrast to the study by Karlsson and Forsberg (2008), where the sound of the alarms was not an issue to the patients.

Most of the participants in this study did not have an issue sleeping as they were sedated almost throughout their stay in the ICU; however those who were not sedated for long found the sounds of alarms disturbing. The frequency of nurses being at the patient's bedside was viewed as disturbing and distressing and all of the devices connected to the patient were regarded as irritating (Samuelson, 2011). This supported one of the findings in this study, as one participant described the awfulness of the tubes and gadgets around his face.

The procedure of suctioning was regarded as a disturbance and expressed also as the worst feeling ever by another participant in this study. According to Hofhuis *et al.* (2008), noises from healthcare professionals were reported to lead to feelings of discomfort and disturbance, which is contrary to the findings in this study, as the participants described the health personnel as being competent, with no report of disturbance from the healthcare professionals in relation to their chatting or talking.

Near death experience was a feeling expressed by the participants in this study, as they described the ventilator as a torture machine and at some point, some felt as though they were fighting for their lives, or rather felt like dying either due to the ventilator itself, the suctioning procedure or the extubation process.

This finding is in agreement with the study conducted by Samuelson (2011), where the experience of critical illness was seen as a threat to the existence of the participants, which resulted in shock and the feeling of dying. According to Jordan *et al.* (2002), the participants were aware of their own mortality, as they felt close to death as a result of being connected to the ventilator, but later saw the ventilator as essential for their survival and healing. The experience of the inability to endure was reflected in this study as a form of not being capable to perform certain things. The participants in this study expressed the ventilator as being 'hectic' and 'tough'.

The participants had problems coping with the ventilator especially the process of extubation, which was 'tough' for the majority of the participants as they were not conscious during the intubation process thus, they regarded extubation as 'hectic', hard, difficult and stressful.

This is consistent with the findings by Holm and Dreyer (2015), as the participants saw the tube as a foreign object and wanted to rid themselves of it but eventually had to suppress their urge and manage the tube for longer.

The participants in this study described the experience of powerlessness in the form of a lack of strength and helplessness, which led to them feeling out of control.

The urge to rid themselves of the machine, as they wanted to breathe on their own but could not, led to feelings of helplessness, which is consistent with the findings by Samuelson (2011), where the feeling of powerlessness, vulnerability and helplessness was regarded as distressing for the participants, which made them feel they had loss control.

The inability to communicate in Karlsson *et al.* (2012) led to the feeling of powerlessness and not the presence of the ventilator, which is in contrast to the findings in this study. The struggle of the participants, in this study, with the ventilator, their feeling of loneliness, reduced visiting time and their experiences of the ICU as a unit led to the feeling of powerlessness.

The participants experienced loneliness as a result of not being seen as a human being, or not being paid attention to. Being alone in the ICU and being vigilant to the complex machinery rather than the patient by nursing health personnel made the participants feel lonely (Olausson *et al.*, 2013).

Schou and Egerod (2008) revealed that the feeling of loneliness was attributed to the strange environment in which the participants found themselves and therefore they felt a need to engage with the nursing health personnel in that unit. In this study, the feeling of loneliness was related more to the absence of family, which was confirmed by Bergbom-Engberg and Haljamae (1989).

The importance of a family presence during mechanical ventilation and ICU admission cannot be over emphasised. as according to Karlsson and Forsberg (2008), the presence of the family was not only seen to assist in alleviating feelings of fear, isolation and anxiety, but also in creating a friendly atmosphere for the patient where they could be encouraged to participate in activities regarding themselves and thus maintain their identity, individuality and also promote their yearning for survival (Johnson, 2004; Karlsson *et al.*, 2012).

In Samuelson (2011), the presence of the family enhances the emotional security of the participants. The successful recovery of the participants in Wang *et al.* (2009) was attributed to the presence of their family as they received support and encouragement from them. The participants in the study felt they would have given up on hope and themselves if were not for the presence of their families and indicated the family is most needed during a period of critical illness.

The presence of families has also been helpful in reducing patients' fear in the ICU (Zetterlund *et al.*, 2012). This confirms the findings in this study, where the participants described the need for their family at all times during their stay and admission in the ICU, indicating that when a family member is sick they all needed to be involved with one another to jointly find a solution to the problem.

The issue of visiting time for the patients' relatives was also found, in this study, to be distressing to the patients as they felt their families should be given more time to be with them.

This was supported by Johnson's (2004) study, which suggested that adopting unrestricted visiting times and regular visiting for the families may be essential in helping the patient's recovery, but must be done according to the patient's needs or individualised treatment rather than following rigid protocols.

The issue of limited visits was also evident in Wang *et al.* (2009), where although the visit was helpful and supportive for the participants, they reported it was too limited (short-timed).

The importance of providing information to patients and relatives cannot be over-emphasised. Several studies have identified the need to provide information regarding care and management of patients and their families. In this study, some of the participants claimed that they were pre-informed that they would be intubated and admitted to the ICU, whilst others reported they were not.

Some of the participants of this study came from the cardiothoracic unit where surgery was elective hence, the chances of pre-information was high compared to admission to other Intensive Care Units, where the majority of patients are not aware of their admission or were too critically ill to be pre-informed about the procedure. This therefore may be responsible for the diversity of the results in this study.

According to Karlsson *et al.* (2012), the lack of information regarding the management and plan of care of participants made them felt less humane, powerless and uncertain about their fate. Meijers and Gustafsson (2008) suggested the provision of information to patients and their involvement in their plan of care could be helpful in reinforcing their self-determination. It also encourages the patient to participate in their own care and experience companionship.

Zetterlund *et al.* (2012) also confirms that the provision of continuous information, regarding nursing procedures, plan of care and management, is essential in guiding the patient towards a safe recovery.

In this study, some of the participants claimed they lacked information regarding nursing procedures, such as suctioning and the ventilator, in regard to what to expect, which supported the above findings.

Also the need to orient patients to time, place and person is an essential aspect of patient's care, as lack of orientation to time place and person has become a consistent finding in recent literature, where patients wake up to discover they are in ICU, a strange and frightening environment, without a sense of time resulting in confusion and emotional stress (Schou and Egerod, 2008).

The participants in this study also experienced disorientation and lack of sense of time although this aspect was not fully explored in this study and, it may warrant further research.

The use of visual cues have been suggested by Karlsson and Forsberg (2008) as being helpful in reducing patient stress and in helping to orient them to time and place, thus reducing their suffering. Cues should include a large wall clock, a calendar and a sign describing the unit. The investigation into the usefulness and helpfulness of these cues is essential to ascertain if they have helped in reducing patient stress.

The participants in this study also agreed to receive some measures of information regarding the procedure to be done, but not in a language they understood and not detailed enough hence they felt disadvantaged, although some felt a little better from the small amount of information they had.

This conforms to the finding of Guttormson *et al.* (2015) where the participants alluded to receiving information, although coerced from the nursing health personnel . However, it helped them to cope better and tolerate their condition, treatment and the environment .

Feeling of helplessness and loss of control experienced by the participants was as a result of lack of information regarding their health and progress made. Also disorientation experienced by participants made them feel worse (Schou and Egerod, 2008).

Lack of information regarding patient health and progress resulted in feelings of helplessness and loss of control and the disorientation experienced by the patient made it worse (Schou and Egerod, 2008).

A sense of safety is the feeling of freedom from danger and harm (reference). In the context of this study, the participants expressed a feeling of safety within the presence of the nursing health personnel; they admitted that the nursing health personnel were friendly and that they had a good relationship with them. This mirrors closely to the finding of Hofhuis *et al.* (2008), Jenabzadeh and Chlan (2011) and Engström *et al.* (2013). The constant presence of the nursing health personnel and the receipt of information made the participants feel safe and secure.

Although the participants felt dependent on the nursing health personnel, their presence gave them a sense of security should their condition worsened, even to the extent that the patient feared being transferred to another unit as they were not sure/certain of continuing hospitality and care (Hofhuis *et al.* 2008; Jenabzadeh and Chlan, 2011 and Engström *et al.* 2013).

The participants receipt of information regarding suctioning was appreciated and made them feel safe, which was contrary to the findings of this study, as the participants (confirmed no receipt of any information) to not receiving any information about suctioning hence the procedure was painful for them.

The presence of a person beside the patients, holding their hands and making eye contact made them feel safe and was regarded as extremely valuable (Karlsson and Forsberg, 2008). The participants in this study also described experiencing a sense of relief and comfort brought about by being taken off from the ventilator and being discharged from the ICU.

In this study, the participants had described the extubation process as hard yet relieving, expressing reluctance to return to the ICU ever again, whereas contrary to our findings, the participants in Adamson *et al.* (2004) agreed to re-admission if necessary. The findings of this study are consistent with those of Karlsson and Forsberg (2008), where the participants described the extubation period as a memorable time for them.

The Intensive Care environment has been viewed differently by various participants, while some describe the environment as clean and very comfortable, other participants claimed the environment is too busy for them.

According to Fredriksen and Ringsberg (2007), the ICU environment carries no meaning alone except with the social and cultural context of which the light, noise and absence of family involvement in patient care forms a part, hence the environment has been described as strange, unfamiliar and terrible (Wang *et al.*, 2009).

The noise and light in the ICU environment has been described as disturbing for the patients resulting in a great deal of emotional state and affecting their sleep patterns (Jordan *et al.*, 2002).

Another issue which became evident in this study was the fact that the participants alluded to believing in God for their survival and safety. They trusted God as the only one who can see them through the ordeal of the illness.

This corresponds to the study by Karlsson *et al.* (2012) where the participants alluded got rid of their thoughts of dying as a result of their belief in God and relied on religious spirit. Jenabzadeh and Chlan (2011), confirms this finding by claiming to have drawn strength from spiritual belief, which serves as a source of hope and perseverance for the participants.

There were experiences of a loss of memory, which could be attributed to the administration of drugs in an attempt to sedate the patient and bring about comfort. As such, this sedation made the participants less active during their ICU admission and the recovery of their memory was blurred during this study. Although it was not evident how much sedation the participants in this study had received, it was only evident that they could not remember some of the events that occurred while they were in the ICU.

Communication is an essential aspect of living which affects relationships amongst individuals. . This is the third theme for this study where the participants described their experiences as relating to the difficulty they experienced in passing information to the nursing health personnel and even their families.

Communication can either be verbal or non-verbal and studies have previously been conducted to explore the aspect of communication in respect of mechanically ventilated patients, since the placement of endotracheal tubes prevented the patient's ability to speak (Guttormson *et al.*, 2015; Karlsson and Forsberg, 2008; Schou and Egerod, 2008).

Mechanically ventilated patients have described their inability to communicate as distressing, embarrassing and awful, which was a direct concern for the patient and even

impacted on their health and recovery (Magnus and Turkington, 2006; Wang *et al.*, 2009). Findings from Samuelson (2011) revealed that the participants struggled to communicate because of the presence of the endotracheal tube, which was regarded as a 'distressing bodily restriction'. This was in line with the findings of Schou and Egerod (2008), where the participants were distressed and embarrassed as a result of not being able to communicate their needs. In this study, the participants also found it difficult to communicate and described it as embarrassing.

Although the participants in this study were not comfortable with the use of alternative means of communication, they employed the use of sign language and lip reading, amongst others, to communicate their needs to the nursing health personnel and their families. This concurs with the findings of Magnus and Turkington (2006) and Guttormson *et al.* (2015) where alternative measures of communication were regarded as assistants to communication.

The nursing health personnel's attitude in assisting with communication was also an essential finding in this study. The participants refers to the fact that the healthcare professionals supplied them with materials to communicate, such as paper and pens, which was in line with the findings of Schou and Egerod (2008), where despite the distressing feeling, the participants credited the nurses for their ability to anticipate their needs and communication by providing them alternative means of communication, such as the use of gestures, paper and pencils and computers.

Despite the enormity of this aspect of care, for example communication, the participants in Karlsson and Forsberg (2008) saw the inability to communicate as a minor problem, which was contrary to the findings in this study.

From the above perspectives, it became clear that the issue of communication remains a problem for patients who are mechanically ventilated. Should the patient's need for better communication continue to be an issue, their recovery may be impacted negatively.



### **5.3 SUMMARY OF THE STUDY**

The results of these findings revealed that admission to an ICU and being placed on mechanical ventilation is an immense deal for patients and their families having both physical and emotional/psychological consequences on their wellbeing as well as on the family. The experience of breathlessness or the inability to fill their lungs with air, despite all attempts, resulted in a stressful experience. The experience of suctioning, dryness of the mouth and pain related to endotracheal intubation was evident in this study culminating into a stressful experience for the patients. Therefore, the experience of breathlessness, pain, mouth dryness and suctioning ultimately led to unpleasant physical experiences.

The participants in this study expressed the fear of death, anxiety and being scared within the presence of highly developed and complex machinery, equipment and endotracheal intubation.

The participants felt bothered by the painful experience of suctioning and disturbed by the alarms and the environment itself; some concur to the fact that the nurses and healthcare professionals in the unit were good and helpful yet they felt uncomfortable with the endotracheal tubes, ventilators and the environment as a whole.

The participants described the mechanical ventilator as a torture machine and all they could think of was being freed from the machine. Only a few of the participants stayed calm as they saw the (treatment modality) ventilator as a life-saving machine and endured it. The participants felt they were fighting for their life while they were mechanically ventilated and even when being taken off the ventilator, they felt they were drowning as they were extubated, which resulted in an emotional experience for these participants.

The participants felt powerless as they could not influence their situation nor contribute to their recovery, having to be dependent on the nursing health personnel.

The short visiting times they had with their families was seen as unexpected as they felt they now needed more time with their families than ever before. It is necessary to explore the visiting time protocol so as to accommodate individual patient and family needs. It

also became important that nurses should try and organise their procedures and interventions before and after visiting time so there would be no interruption into these periods, as it is important for the patient as well as the family.

The patients need to know and understand what goes on around them is evident in this study. The participants desire to have an understanding of their condition and even the machinery that were connected was important to them as to be prepared since most of the patients are critically ill during their admission. There is a need for nurses to try and orient the patients to time, place and person, together with informing them of any procedure to be carried to gain their contribution and also make the environment conducive for them.

The spiritual needs of the patients also came up in this study, as the participants believed it was God who helped them and saw them through their ordeal.

Despite the physical and emotional challenges faced by these participants, the caring behaviour of the nursing health personnel was commended as it made them feel safe and welcomed. The participants expressed a feeling of safety in the environment within the presence of the nursing health personnel and saw the environment as comfortable.

The findings also showed that communication for mechanically ventilated patients is still experienced as a challenge, despite alternative measures as highlighted in previous research. The participants in this study experienced challenges in communicating their needs to the nursing health personnel as they saw the use of sign language as awkward and difficult and overall the difficulty in communicating made their stay in the ICU a terrible experience for them.

The findings of this study are consistent with similar studies conducted in other countries. As there is limited research available on this aspect in South Africa, it is hoped these findings will add to the existing body of knowledge of Intensive Care nursing.

## **5.4 LIMITATIONS**

There is no scientific study that does not have shortcomings or failure regarding the application or interpretation of the findings (De Vos *et al.* 2013). This shortcomings could either be from the population or the sampling technique and as such, researchers should be able to explicitly point out such shortcomings as it impacts on the scientific quality of the study. In this study the following limitations were discovered by the researcher:

This study was a qualitative study, which entailed data being collected on a one-to-one basis, with individual expressions of ten participants' experiences. However these views and experiences cannot be completely generalised as a representation of all patients' experiences on mechanical ventilation in the ICU in South Africa.

The interview was conducted in English language by the researcher. Although the questions were asked in simple forms in English language, this could have limited the participants from fully expressing their experiences of mechanical ventilation in the ICU. This might not have been the case if the participants were to speak in their native languages. The researcher is not a South African and could not communicate well in any of the South African languages rather the chosen language was English.

The study site is an academic hospital, a referral centre considered to be one of the best tertiary institutions in the region, with well-equipped Intensive Care Units with an abundance of highly and developed and complex machinery and experienced health personnel. The level of care rendered in this institution cannot be compared with that of other institutions in the region and as such may impact on the experiences of patients on mechanical ventilation in these units. In this context, the experiences of patients on mechanical ventilation cannot be generalised to those admitted to other institutions.

## **5.5 RECOMMENDATIONS**

This study revealed that patients admitted into the Intensive Care Unit experienced both physical and emotional/psychological consequences, which not only impacted on the patient. Based on this evidence, there is a need to improve the quality of care given to

mechanically ventilated patients as well as families to reduce these consequences and to promote pleasant experiences. Recommendations from the findings of this study are presented under the following subheadings: nursing education, nursing practice and further research.

### **5.5.1 Nursing Practice**

The findings of this study indicated that the aspect of providing information to patients was lacking. The participants in this study complained of no in-depth information regarding nursing procedure and nursing care. There appears a need to emphasise the importance of communication and giving of the detailed information to patients regarding their health.

As the ICU environment is a highly technological environment, requiring skilled, competent and knowledgeable nursing health personnel, there is a need to ensure that health personnel are fully trained for this environment. The ability to combine the nursing health personnel theoretical and technological knowledge need be addressed in order to provide / deliver quality nursing care.

Clinical nursing practice needs be developed to accommodate the needs of patients on mechanical ventilation, communication, involvement in care and nursing intervention management of thirst, pain and endotracheal tube management.

### **5.5.2 Nursing Education**

In addressing patients' experiences of mechanical ventilation, which is a reflection of nursing care, it becomes imperative to include the concept of comfort care into the curriculum of nursing training so as to teach young and upcoming nurses the importance and basis of nursing care, especially for patient in the Intensive Care Units (Coyer *et al.*, 2007; Couchman *et al.*, 2007)

Although some of the participants (patients) credited the nursing health personnel's attitude while they were mechanically ventilated some aspects of care were still lacking, which ultimately impacted on their overall experience of the unit. Therefore, there is a

need to ensure that nursing health personnel caring for mechanically ventilated patients are provide with learning opportunities that can better inform them on the management of ventilated patients.

The importance of evidence-based practice should also be stressed to young nurses, both in the undergraduate programme and the specialty programme, in order to incorporate this into their care plan and stress the importance of research in nursing practice and education.

### **5.5.3 Further Research**

This study explored the patient's experiences of mechanical ventilation, of which nursing health personnel attitudes and difficulty in communication were important aspects that emerged from the study. Further studies are needed to be conducted to explore the experiences of ICU nurses caring for ventilated patients and also health personnel attitudes regarding communication with ventilated patients, in order to plan an intervention to ensure the rendering of quality care.

Comparative studies about the experiences of patients on short-term, long-term and prolonged mechanical ventilation need to be compared to see if there are any differences in their experiences to suggest or develop further measures to promote comfort for the patient and their families.

To the best of my knowledge, only two studies were found on the experiences of mechanically ventilated patients in South Africa. Follow up studies could be conducted on a wider scale, with the involvement of more public and private institutions, with comparative studies undertaken to examine the levels of care rendered in the private and the public sectors.

## **5.6 CONCLUSION**

This study explored the experiences of patients on mechanical ventilation in an Intensive Care Unit, which was expressed as unpleasant and scary, in an attempt to improve patients' care. By adding the findings of this study to the present body of knowledge, and

confirming previous findings, will enable healthcare professionals in South Africa to learn to combine physiological, psychological and technological interventions with holistic care of patients. Also ensuring patient-centred and family-oriented care is rendered to reduce these unpleasant experiences.

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**PATIENTS INFORMATION LETTER**

Dear \_\_\_\_\_

**INVITATION TO PARTICIPATE IN THE STUDY TITLED “PATIENTS’ EXPERIENCE OF MECHANICAL VENTILATION IN THE INTENSIVE CARE UNIT OF A PUBLIC SECTOR HOSPITAL IN JOHANNESBURG”**

Hello, my name is Adeyemi Ooreofe Bolanle. I am a professional nurse and currently registered for a Master’s degree in Intensive Care Nursing at the University of Witwatersrand, in the Department of Nursing Education. As part of my course requirements, I am required to conduct a small research project under supervision.

**Area of interest**

I am investigating the experiences of patients on mechanical ventilation in the intensive care unit. I will be most grateful if you agree to participate in this study. You have been selected as a potential participant for this study as you were placed on mechanical ventilation for a while in the intensive care unit. Your experiences, thoughts and feelings will be of most valuable to this project.

**Purpose of the study**

The purpose of this study is to describe the experiences of patients on short and long-term mechanical ventilation in the intensive care unit of one public sector hospital in Johannesburg. I will also like to make recommendations for intensive care health personnel as regards proper understanding and caring for patients placed on mechanical ventilator.

**Choice of participation**

Should you agree to participate, I will request you to complete a biographical questionnaire and also hold an interview with you to find out your experiences and feelings of being mechanically ventilated in the intensive care unit. The interview is planned to be audio-taped with your permission and I will also make notes during the interview. I will schedule an appointment with you as to know the convenient date and time by you. The interview should take about 45 minutes - 1 hour.

**Benefits and Risk to the participants**

This study will give you an opportunity to tell us how you felt and your experiences on mechanical ventilation. The study may not directly benefit you immediately, but you will be helping other prospective patients who will be experiencing mechanical ventilation as the result of this study will be made available to health care workers. As such, your

contributions will help in developing measures to improve patient-centred care and improving quality of health care rendered.

Questions that will be asked during the interview are simple questions just to find out your experiences and feelings while on mechanical ventilation. It is possible that you may remember some unpleasant experiences which may depress you. Should this occur, I have made provision for a counselling opportunity for intervention and debriefing if you so wish.

### **Voluntary participation, Consent and Confidentiality**

Your participation in this study is entirely voluntary as you may choose not to participate or withdraw from the study at any time. This will have no effect on the care you receive in this institution. Should you decide to participate, your identity will be completely hidden so as to uphold confidentiality and privacy. I will also request you to sign a consent form both for participation and for audio-taping. I will be asking you questions in English Language that aim to find out your experiences on mechanical ventilation. There will be no consequences resulting from your answers as it will be tape recorded and transcribe by only me. The audio-taped information will be destroyed after the transcription to ensure that you are not identified with it and the transcribed information will be kept confidential.

Permission has been obtained from the ethics research committee of the University of Witwatersrand and the hospital authorities to conduct this study. Should you have any questions regarding your rights as a study participant, you can contact Professor Cleaton Jones or Ms Zanele Ndlovu the secretary of the Human Research Ethics Committee on 011-717 1234.

Should you wish to know more about the study you may contact me on telephone number 0842224417 or email: [orebolanle@yahoo.com](mailto:orebolanle@yahoo.com)

Should you wish to have a copy of the final research report, please provide me with your detailed postal address.

Thank you for taking the time to read this information sheet. Your voluntary participation will be appreciated.

Yours sincerely,

Adeyemi Ooreofe (Mrs)  
MSc Nursing Student

**CONSENT FORM FOR PARTICIPATION IN THE STUDY**

I \_\_\_\_\_(Name of participant) give permission to be included in this study.

I have read and understood the contents of the information sheet and I have been given the opportunity to ask questions I might have regarding the procedure and my consent to being included in the study.

I am aware that my personal details as well as the result of this study will be treated with utmost confidentiality and I have been informed that I could withdraw from the study at any stage without any form of penalty.

I hereby declare my voluntary participation in the study

\_\_\_\_\_

Date

\_\_\_\_\_

Signature

\_\_\_\_\_ (Witness)

**CONSENT FOR AUDIO-TAPE RECORDING DURING THE STUDY  
INTERVIEW**

I \_\_\_\_\_ (Name) having been well informed on the purpose of audio-taping this interview hereby give my consent to have the interview audio-taped for the study titled “Patients’ Experience of Mechanical Ventilation in the Intensive Care Unit”.

\_\_\_\_\_

Date

\_\_\_\_\_

Signature

\_\_\_\_\_

Researcher’s Name

\_\_\_\_\_

Signature

\_\_\_\_\_

Date

**PATIENTS EXPERIENCES OF MECHANICAL VENTILATION IN THE  
INTENSIVE CARE UNITS OF A PUBLIC SECTOR TERTIARY HOSPITAL IN  
JOHANNESBURG**

**DATA COLLECTION INSTRUMENT**

PARTICIPANT NUMBER\_\_\_\_\_

**1.0 DEMOGRAPHIC DATA**

1.1 Research Code \_\_\_\_\_

1.2 Gender                      Male ☐                      Female ☐

1.3 Age

1.4 Reason for Admission      ☐ Medical      ☐ Surgical elective      ☐ Surgical emergency

1.5 Period of stay on mechanical ventilation

1.6 Length of stay in ICU



## **APPENDIX E**

### **PATIENTS' EXPERIENCES OF MECHANICAL VENTILATION IN THE INTENSIVE CARE UNITS OF A PUBLIC SECTOR TERTIARY HOSPITAL IN JOHANNESBURG**

#### **INDIVIDUAL INTERVIEW GUIDELINES**

##### **UN-STRUCTURED QUESTION**

“What was it like for you to be connected to a breathing machine (mechanical ventilator) in the intensive care unit?”

##### **INFORMATION TO BE ELICITED**

- Admission to ICU
- Awareness of critically illness
- People/equipment used in the care of the patient
- Pain, generally and specifically related to tubes or pipes
- Communication with health care providers; inability to communicate, awareness of tubes hindering this
- Effect on family and family relationships
- Reflection of how sick the patient was and now
- If ill and needed treatment in intensive care, would patient want to go back.
- Discharge from ICU, feelings about leaving the unit
- Is there anything else patient wants to share?

Thank you for your time.

The proceeds of this discussion will be brought to you for validation after transcription of this interview of your shared experiences on mechanical ventilation.

## APPENDIX F

University of Witwatersrand,  
Department of Nursing Education,  
Faculty of Health Sciences,  
7 York Road,  
Parktown 2193,  
Date.....

The Chief Executive Officer,  
Charlotte Maxeke Academic Hospital,  
Johannesburg.

Dear Mrs Mogopodi-Bogoshi,

**RE: REQUEST FOR PERMISSION TO CONDUCT A RESEARCH STUDY IN  
THE INTENSIVE CARE UNIT OF THE CHARLOTTE MAXEKE  
JOHANNESBURG ACADEMIC HOSPITAL.**

I am a registered nurse currently pursuing a Master's degree in Intensive Care Nursing at the University of the Witwatersrand. I hereby apply for permission to conduct the study entitled: "Patients experiences of mechanical ventilation in the Intensive Care Unit of a public sector hospital in Johannesburg"

Critically ill patients cared for in the intensive care unit are majorly placed on mechanical ventilation as many of these patients have impaired respiratory function requiring maintenance of airway, oxygenation and ventilation. As such, invasive type of mechanical ventilation is mainly use in our health care institutions. This treatment is known to be stressful for patients and may result in overwhelming anxiety and discomfort. It is therefore of interest to explore and describe these experiences as viewed by patients on mechanical ventilation in the intensive care unit.

This study aims to explore and describe the experiences of patients on mechanical ventilation in the intensive care unit in other to gain knowledge and understanding of their feelings, state of mind and experiences during their intensive care stay. The understanding of their experience is essential for health workers, especially health personnel, as this will help to develop adequate measures in taking care of patients on mechanical ventilation, promote their recovery as well as improve quality of care.

I intend conducting interview with the patients' who have experience of mechanical ventilation individually as this will allow them ability to express themselves freely. The interview will be audio-taped with permission from the the participantsin order to obtain enough information from them. The audio-taped information will be destroyed after the transcription has been checked to ensure that no identification whatsoever is made to the the participantsand the transcribed information will be kept confidential.

Necessary ethical measures regarding the study will be upheld to safeguard the dignity of the institution, personnel and participants. The study will be conducted after the proposed study has been critically reviewed by the research committee on Human subjects of the

University of Witwatersrand and an approval has been received. Participation in the study will be voluntary and written consent will be provided.

Yours Sincerely,  
Adeyemi Ooreofe B. (Mrs)  
MSc Nursing Student  
email: [orebolanle@yahoo.com](mailto:orebolanle@yahoo.com)



R14/49 Ms Adeyemi O. Bolanle

## HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M150765

NAME: Ms Adeyemi O. Bolanle  
(Principal Investigator)

DEPARTMENT: Nursing Education  
 Charlotte Maxeke Johannesburg Academic Hospital;  
 Adult Intensive Care Unit


PROJECT TITLE: Patients' Experience of Mechanical Ventilation in the  
 Intensive Care Unit of a Public Sector Tertiary Hospital  
 in Johannesburg

DATE CONSIDERED: 31/07/2015

DECISION: Approved unconditionally

CONDITIONS:

SUPERVISOR: Dr Shelley Schmollgruber

APPROVED BY:   
 Professor P Cleaton-Jones, Chairperson, HREC (Medical)


DATE OF APPROVAL: 07/09/2015

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

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Secretary in Room 10004, 10th floor, Senate House, University.

I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. I agree to submit a yearly progress report.

  
 Principal Investigator Signature

Date

08/09/2015

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES



## **GAUTENG PROVINCE**

HEALTH  
REPUBLIC OF SOUTH AFRICA

### **CHARLOTTE MAXEKE JOHANNESBURG ACADEMIC HOSPITAL**

Enquiries:

Ms. G. Ngwenya

Office of the Nursing Director

Tell: (011) 488-4558

Fax: (011) 488-3786

17 September 2015

Mrs. Adeyemi Ooreofe  
Department of Nursing Education  
Faculty of Health Sciences  
University of Witwatersrand

Dear, Mrs. Adeyemi Oorefe

**RE: "Patients experience of mechanical ventilation in the intensive Care Unit of a Public Sector hospital in Johannesburg"**


Permission is granted for you to conduct the above recruitment activities as described in your request provided:

1. Charlotte Maxeke Johannesburg Academic hospital will not in anyway incur or inherit costs as a result of the said study.
2. Your study shall not disrupt services at the study sites.
3. Strict confidentiality shall be observed at all times.
4. Informed consent shall be solicited from patients participating in your study.
- 5.

Please liaise with the Head of Department and Unit Manager or Sister in Charge to agree on the dates and time that would suit all parties.

Kindly forward this office with the results of your study on completion of the research.

~~Supported / not supported~~

  
Ms. M.M Pule

Nursing Director

Date: 2015/09/18

~~Approved / not approved~~

21.09.2015  
Ms. G. Bogoshi  
Chief Executive Officer

## APPENDIX I

### List of extracted significant statements

NO	SIGNIFICANT STATEMENTS
	But one thing that was not allowed was food, no food no water only that water up there
	I had to use plates on bed I felt bad when I soiled the sheet
	Especially when they do the washing a lot it can chokes, choke, choke
	My mouth started to have scales (cracks)
	ah sign language, I wasn't feeling okay, Im not use to sign language that is the main problem.
	Yes there was pain you know something that is not that was not born with you it always bring pain in your body
	<p>They were allowed to visit but not for a very long time, When they come they will just say oh they will just say you just have to pray now just for a few minute. It was totally unacceptable because when you are sick the families must be together. The way I was treated there in that unit I don't like it,</p> <p>About that one like the way I was talking ,say the families is visiting you they were not allowed to stay for very long time you see do you know the time frame was from 3-5pm you see so they just come and some time they stay for 10minute then they were gone.</p>
	I feel lonely at that time you know that's why they say you can die in bed because of those situations like that you will die in bed because you won't be able because if you look if you look on my Bp it was going up and down then go up again (loud) you see
	I felt very happy, Because they say they were taking you to 561 that is your room then I know that room I have never had any problem or if I have to go there let me go there
	There is a they put the machine I don't have a problem with the machine but the only reason which I'm worried about is having problem is you can't say you are connecting me to the machine and say my family is not supposed to visit me the machine is not the problem the problem is the people who are controlling the machine who are saying no don't come because we are connecting our patient you are disturbing us you see why can't you just give them time guys give them 1hr or 2

	hours with your patient talk to your patient how does it feel then you go.
	It was uncomfortable but I was warned before it I mean they they they informed me that when I get up I will have it in my mouth. It was manageable I think ehhhhhhhhh it was uncomfortable but manageable but the problem was the real challenge was when the time came to take it out it was very very stressful aaaaaa I felt very was the word very <b>prudent</b> , when you try to clean up the lungs it was a horrible feeling
	It was terrible I mean at some point it feels like you were dying its very very the word is very invasive it was hectic ahhhhhhhhhhhhhhhhh it was tough
	Like I said it was uncomfortable but manageable it wasn't so bad except when the time came to get out it yah that was hard
	i felt pretty wats it that place is sensitive because once they pour the stuff down I mean it was like it was its traumatising men.
	Yah it was very traumatising It was tough
	I never needed to communicate with anybody I was basically still sedated so when I came thru obviously I found it in my mouth but ehnnnnnnnnnnnn I was okay with it until the point came where we needed to get it out
	Basically yes a sense of comfort knowing that you will anticipate this but all they said was u will have a pipe in your mouth they didn't say more than that and I don't blame them you know but it was tough
	Its was tough though I wish there could be other way to do it
	its just that when they are taking it out and flush it yoh that's hectic u feel like drowning
	Ohhhhhh it's a miserable feeling if you ask me now all about the operation that's probably the worst part seriously because ehhhhhhh you know why you become very anxious its like you are fighting for your life, you understand you just getting instructions push, breath or whatever it is eh you know throw up or whatever
	I don't you don't really have time to think about it you have no knowledge about what the purpose of it and you just get up and its there and nobody sits and give you a full run down on it
	No just that it was uncomfortable and so
	oh God I rather not I rather not its horrible



	I just wish there is something better you know I suppose with time they will find to get a way of doing it because it a bit traumatic very traumatising
	Yah very friendly very helpful I must admit, they went out of there way to get everything out as soon as possible even if I can't sit down they try and calm me down and tell me you don't have to get really excited
	Torture that's a torture machine that is not the nicest thing because you can't breathe it breathes for you, you have to wait for it to breathe so that is the and that is something that I must say something I won't like to do again
	all I can remember was the me and machine was battling so they had to put me out again they had to sedate me
	water I wanted a glass of water, I wanted a glass of water so desperately
	the people that side were so nice its not I went out for staff they put in there I won't and they are straight they are straight forward
	I couldn't speak though but I tried to understand them they actually brought me piece of paper to write down
	shocked shocked luckily they are strange to me because normally your first reaction they taught me is not because of your root its because first when you woke up your reaction is to pull out so they warned me before to say listen look your hands are tied down
	not like sleeping its more relaxing it makes your body more relaxable so you don't get tired
	yah sometime when you wanna cough or so it is basically there when you get something stuck in your throat automatically its going to want to choke
	Yoh that's hectic they pull out the pipe and they suck out all the stuff inside the throat just to keep it clear and they arrange themselves again I think its all the stuff that they clean it out but during that time you felt eh and they work quickly it's a worst feeling
	No now im free
	the environment was very comfortable
	Actually I remember the one state that they actually bring a fan the one night the lady actually took the blanket because I was sweating and my temperature was running so they actually took the blanket waited a bit and put it on me they are very disciplined



	They were brilliant
	Ahhhhhhhhhhhh the other lady told me I know everything and the doctor came too
	I was so scared
	Sigh I don't know what can I say because it was so difficult
	The time I discover I was on that pipe I was so scared neh but I told myself God is the one who can make me succeed as you see me today
	At that time I couldn't stop I was just scared too much that's why I was praying inside me
	Yoh they take it when they take the tube the put something to clean my chest, Ohhhhhhhh its painful , its painful
	they didn't take too much but it's painful it's like you are dying you cant breathe
	I could feel so better, I was feeling better
	I was happy because that time when they take it out I know how to breathe and I know how to talk I saw everybody
	I was so scared because the tube they put was so sore I didn't feel -----
	sore I feel sore
	I did sleep nice because once they put this thing on I could sleep they put the drip every day
	No I cant talk you know there is the tube I cant talk to them with the tube, I used my hands
	I didn't feel alright
	I can't remember, everything changed after going to surgery my mind changed some things I forget
	it's the most horrible irritating feeling but believe me it actually gives u courage to actually start breathing quicker on your own because you want to get rid of it..... Once it settles in your throat its very painful.....its very sore .....uncomfortable comes in..... I had a little swallowing pain
	though the voice changes a bit
	I feel so hectic cos it was my first time of experiencing that
	I just wanted to take it out it was so painful to breathe with the machine

	I was drawing the machine pulling it out yahhhhhhhh
	Sign language, I feel so awkward I must say it was so awkward not able to talk not able to get up the bed.
	I just feel that embarrassed u know it was so embarrassing
	So awkward I must say,
	Imagine someone sticking some things in your throat you feel like vomiting so embarrassing.
	No they didn't tell me, Nothing no information
	Yes I had to endure it because it was a lifesaving machine
	Sometimes I slept on my own and sometimes they put me to sleep
	Yes I did feel anxious
	Its clean and there was no disturbance no noise, they were sometimes maybe you woke up and you start hearing the machines alarming
	for me it was difficult cos I cant keep things in my face then I tried twice to the pipe back in my noise
	That's the breathing one, it was okay becos they put some fluid in and they pump it down your lungs at that time you can't breathe it was very upsetting
	my voice is still not right because of that
	it makes it difficult to swallow and communicate,
	communication is difficult once you have it down your throat
	The pain only happened when you swallow
	ahh it is uncomfortable but its not intolerable
	ehhhhhh they told me before that they gonna put that thing in my lungs they gonna put those pipe in my noise but they don't explain the purpose of it
	Noooooo I mean the ICU is a busy place so you cant sleep properly u can eat properly and u cant breathe properly you cant I mean there is a lot of cant u cant do u understand so all of these accumulate to a bad experience when I found myself out of the place I feel no I'm much better
	I was too unconscious but after they put the tube yah I was talking I was using sigh language to communicate

	Noooooooo, I don't think I remember
	ah nothing I dont think there is much because I think I was relieved because of the pains I had gone through
	Yes I slept quite a lot
	Yah I was sleeping because of the drug they were giving me even the pain drugs

## Formulated meanings of significant statements

NO	SIGNIFICANT STATEMENT	FORMULATED MEANINGS
1	...one thing that was not allowed was food, no food no water only that water up there	Patient complained of not allowed to eat or drink because of the tube and water is a physiological need.
2	water I wanted a glass of water, I wanted a glass of water so desperately	This physiological need water was needed desperately by the participant but the need could not be met.
3	I was using the pipes... I could not talk to anyone	Participant linked the inability to talk to the presence of the tube
4	I had to use plates on bed I felt bad when I soiled the sheet	Patient felt loss of personal dignity when he soiled the bed.
5	Especially when they do the washing a lot it can chokes, choke, choke	Experience of choking expressed due to suctioning
6	My mouth started to have scales	Participants complained that he started to have scales in his mouth due to endotracheal tube and dryness of the mouth
7	I wasn't feeling okay... Im not use to sign language that is the main problem and when I grow up I was not using I didn't grow up using sign language but I ended up using sign language because I wanted help	Participants felt bad with the use of alternative means of communication but had to accept it cos he needed help/ hes incapable
8	I cant remember (days and sedation)	Participant had loss of memory because of sedation
9	Yes there was pain you know something that is not that was not born with you it always bring pain in your body...it was minimal but it was, you know the pain is pain it doesn't matter it doesn't matter is a terrible or very low or what it doesn't matter	Pain, a subjective experience was expressed by the participants though it was not clear if it was attributed to the disease process or the presence of the tube
10	They were allowed to visit but not for a very long time... When they come they will just say oh they will just say you just have to pray now just for a few minute... it was totally unacceptable because when you are sick the families must be together	Minimal visiting hours was seen by the participants as frustrating and not helpful for their recovery
11	The way I was treated there in that unit I don't like it	Participants regarded the reception at the ICU has not friendly
12	I feel lonely at that time you know that's why they say you can die in bed because of those situations like that you will die in bed because you won't be able because if you look if you look on my Bp it was going up and down then go up again (loud) you see.... Because you know as a family you have to talk to find a	Participants felt lonely as a result of short visiting time allowed by the family hence felt helpless



	place is sensitive because once they pour the stuff down I mean it was like it was its traumatising men.	was described as traumatic and made the patient felt helpless
23	just wish there is something better you know I suppose with time they will find to get a way of doing it because it a bit traumatic very traumatising	Participant wished there was an alternative method as the ventilation experience was traumatic
24	I don't you don't really have time to think about it you have no knowledge about what the purpose of it and you just get up and its there and nobody sits and give you a full run down on it probably because I suppose they don't want to answer to you and sometimes less information is better you know what I mean then it can be very and sometimes you just have to deal with it	Participants were not properly educated/informed about the ventilation procedures prior to its commencement and participant felt Staff felt they are not accountable to them
25	Basically yes a sense of comfort knowing that you will anticipate this but all they said was u will have a pipe in your mouth they didn't say more than that and I don't blame them you know but it was tough	The participant felt the information given was not detailed enough to prepare them emotionally although they were pre-informed.
26	It was tough though I wish there could be other way to do it	The experience of mechanical ventilation was regarded as being tough to the extent that participant felt an alternative therapy would have been better
27	Its understandable like I said I can understand it I think its just that when they are taking it out and flush it yoh that's hectic u feel like drowning u know what I mean its very invasive	Participant felt the removal and flushing processes were the most challenging aspects of the ventilation procedures
28	Ohhhhhh it's a miserable feeling if you ask me now all about the operation that's probably the worst part seriously because ehhhhh you know why you become very anxious its like you are fighting for your life, you understand you just getting instructions push, breath or whatever it is eh you know throw up or whatever	Participant felt the ventilation experience was more traumatic than the surgical procedure as patients struggle to fight for their life while being instructed on what to do
29	But I mean I suppose now that when you pass that mark then you are okay because you survived it and then you realised that you don't have a choice in the matter ohhhhhh that was hard but atleast now im breathing and in the long term you accept it	Successful extubation was appreciated by the participants as they felt the intubation was necessary for their survival though hard
30	I think ahhhhhhhhhhhhh one thing about the whole operation from start to finish is that ehhhhhhh they told me before that they gonna put that thing in my lungs they gonna put those pipe in my nose but they don't explain the purpose of it you understand so if the doctor or whoever does it explained it in more common	The participants complained that the information were not given in the language that they can understand coupled with the fact that it was too scanty an information

	or normal language you people are used to medical term so if you explain to me in a normal term that okay this might be uncomfortable, it might be sore and it might be difficult to breathe then you have your mind set on it so if it happens you know its going to happen	
31	Yah very friendly very helpful I must admit, they went out of there way to get everything out as soon as possible even if I can't sit down they try and calm me down and tell me you don't have to get really excited because you have to	The attitude and response of the staff was credited as helpful
32	but like I said the people that side were so nice its not I went out for staff they put in there I won't and they are straight they are straight forward you know sometimes other people will take the route of that I have seen them tell u straight forward listen to me don't do this listen carefully and in the mean time they are just doing their job, if you listen to them yes and if you don't its your own problem	Staff attitude was commendable as they gave instructions to the patient on what they can do and not do.
33	Torture that's a torture machine that is not the nicest thing because you can't breathe it breathes for you, you have to wait for it to breathe so that is the and that is something that I must say something I won't like to do again	The machine was regarded as a torture machine which made the participant unable to breathe by themselves.
34	all I can remember was the me and machine was battling so they had to put me out again they had to sedate me they put me back to sleep to put another pipe inside	Participants struggled to cope with the machine to the extent that they wanted to rid themselves of the machine
35	oh yah I had good conversation I had good conversation with some of them freelance little basically I couldn't speak though but I tried to understand them they actually brought me piece of paper to write down if I understand them and like I said it went all out all the way to make my stay visit that side comfortable	Participant's need to communicate was met with the provision of paper and pen for effective communication
36	shocked shocked luckily they are strange to me	The participant was shocked with the presence of the gadgets around him.
37	Yoh that's hectic they pull out the pipe and they suck out all the stuff inside the throat just to keep it clear and they arrange themselves again I think its all the stuff that they clean it out but during that time you felt eh and they work quickly it's a worst feeling also but you get used to it after the fourth time	Suctioning was experienced as painful, hectic and the worst experience for the participant.
38	Ammmm Its just uncomfortable lying and watching and stand so u can get out and like I	Participant understood that the ventilator was necessary for their

	said at the end of the day its only for your own benefit it not for them but for you	survival though unpleasant
39	For the breathing apparatus things I think am I don't know how it works how they set it up to do your breathing for you but I think the time you know I don't know how this machine works but it's a vacuum pump and what happens is that it put the air in your throat but only in a short time <b>it doesn't allow you to breathe</b> becoss the time I actually breathe is very short	Participant attributed difficulty in breathing to the presence of the tube
40	Yah let them do there job what they are trained for and rather be unpleasant patient then they are not gonna like it anyway because then they are gonna go off and I mean if the sisters don't like you you are gonna suffer and I find out if you are friendly to everybody everybody is friendly back and if you are not so friendly no one will be friendly back to you also applicable to every human being	The participant demonstrated dependency on the staff and felt their attitude as patient is essential also in making their stay in the unit memorable
41	the environment was very comfortable	ICU environment was said to be comfortable
42	though the voice changes a bit... it's a long thing that goes down into your lung pipe and they had to pull this thing out that's why my voice is still not right because of that	The changes in the participant's voice in form of cracking was said to be due to the presence of the endotracheal tube
43	Actually I remember the one state that they actually bring a fan the one night the lady actually took the blanket because I was sweating and my temperature was running so they actually took the blanket waited a bit and put it on me they are very disciplined	The caring attitude of the staff were commended by the participants as important
44	I feel so hectic cos it was my first time of experiencing that	Participant felt it was tough since it was a first time experience
45	I was so scared	Participant was frightened
46	<b>Sigh I don't know what can I say because it was so difficult</b>	The whole experience of the ventilation culminated into a rather difficult situation for the participant
47	<b>The time I discover I was on that pipe I was so scared neh but I told myself God is the one who can make me succeed as you see me today</b> I am proud of all the doctor because the time I was going there I was coughing and at night I would not sleep that's why u saw me everytime I was sleeping	Despite the state of fear participant found themselves their faith in God did not waiver. The assistance and expertise of the staff was positively commended
48	At that time I couldn't stop I was just scared too much that's why I was praying inside me	The religious belief of the patient was held in high esteem during the critical period
49	yoh they take it when they take the tube the put	Suctioning was described as a very



	something to clean my chest ...Ohhhhhhhhhhhh its painful. Its painful ...they didn't take too much but it's painful it's like you are dying you cant breathe	painful experience by these participants to the extent of feeling like dying. The experience of inability to breathe was also evident both during suctioning and with intubation
50	I was happy because that time when they take it out I know how to breathe and I know how to talk I saw everybody... So I know I'm not dying anymore, im not going to die if I can take the medicine im nt going to die	Patient agitation was relieved post extubation as they felt they can now breathe again and talk and they felt relief from the fear of death
51	I was so scared because the tube they put was so sore I didn't feel ----- sore I feel sore	Scared Experience of soreness due to presence of ETT
52	I did sleep nice because once they put this thing on I could sleep they put the drip every day	Participant attributed their ability to sleep to the administration of sedation
53	Noooooo I mean the ICU is a busy place so you cant sleep properly u can eat properly and u cant breathe properly you cant I mean there is a lot of cant u cant do u understand so all of these accumulate to a bad experience when I found myself out of the place I feel no I'm much better	The inability to perform some activities that one can naturally perform culminated to a bad experience for the participant and only when they are discharged out do they feel adequate
54	I just wanted to take it out it was so painful to breathe with the machine	Participants struggled to cope with the machine to the extent that they wanted to rid themselves of the machine
55	Yes I had to endure it because it was a lifesaving machine	Endured the ordeal, life saving-machine
56	I used my hands...I didn't feel alright but I know I'm talking and I know they want to help me to talk so anything they ask me to do I'm doing because I want to be well	Despite the inability to talk and the feeling of unhappiness the participant was submissive to the instruction of the staff
57	oh God I rather not I rather not its horrible im sure im not the first patient	The participant rejected any form of re-admission into the unit

## APPENDIX K

### CLUSTERS OF THEME AND EMERGENT THEMES

FORMULATED MEANINGS	CLUSTERS THEMES	EMERGENT THEMES
The experience of inability to breathe was also evident both during suctioning and with intubation (49),Participant attributed difficulty and shortness in breathing to the presence of the tube (39)	Feeling of breathlessness	Physical Experience

<p>Patient complained of not allowed to eat or drink because of the tube and water is a physiological need (1) This physiological need water was needed desperately by the participant but the need could not be met (2), Participants complained that he started to have scales in his mouth due to endotracheal tube and dryness of the mouth (6), The changes in the participant's voice in form of cracking was said to be due to the presence of the endotracheal tube (42)</p> <p>Pain, a subjective experience was expressed by the participants though it was not clear if it was attributed to the disease process or the presence of the tube (9), The participant describe the experience of the ventilator has being pathetic and unpleasant which encourages them to quickly try to breathe on their own in an attempt to rid themselves of the tube (18) Participant only experienced swallowing pain with the presence of the tube (20), The process of suctioning was seen by the participants as horrible (17), The whole experience of the ventilation culminated into a rather difficult situation for the participant (46)</p> <p>Experience of soreness due to presence of ETT (51), Experience of choking expressed due to suctioning (5), Experience of nauseous sensation as a result of insertion of tubes causing a feeling of embarrassment (19), The use of saline during suctioning was described as traumatic and made the patient felt helpless (22), Participant wished there was an alternative method as the ventilation experience was traumatic (23)</p>	<p>Mouth Dryness</p> <p>Experience of pain</p> <p>Physical discomfort</p>	
<p>Participant linked the inability to talk to the presence of the tube (3), Participants felt bad with the use of alternative means of communication but had to accept it cos he needed help/ hes incapable (7) Despite the inability to talk and the feeling of unhappiness the participant was submissive to the instruction of the staff (56), Participant's need to communicate was met with the provision of paper and pen for effective communication (35), The participants complained that the information were not given in the language that they can understand coupled with the fact that it was too scanty an information (30).</p>	<p>Pre-information helped</p> <p>No in-depth knowledge</p>	<p>Communication</p>

<p>The participant was shocked with the presence of the gadgets around him (36), Participant was frightened (45)</p> <p>Participant understood that the ventilator was necessary for their survival (38), the tube was regarded as not comfortable. Participants had to endure the tube since they had no other alternative (13),</p> <p>Participant felt the removal and flushing processes were the most challenging aspects of the ventilation procedures (21, 27), Participant felt the ventilation experience was more traumatic than the surgical procedure as patients struggle to fight for their life while being instructed on what to do (28), The machine was regarded as a torture machine which made the participant unable to breathe by themselves (33),</p> <p>Participants struggled to cope with the machine to the extent that they wanted to rid themselves of the machine (34)</p> <p>The experience of mechanical ventilation was regarded as being tough to the extent that participant felt an alternative therapy would have been better (26), Participant felt it was tough since it was a first time experience (44), Suctioning was experienced as painful, hectic and the worst experience for the participant (37), Extubation was regarded as very stressful by the participants (16), Endured the ordeal, life-saving machine (55),</p> <p>Participants struggled to cope with the machine to the extent that they wanted to rid themselves of the machine (54), Participants felt lonely as a result of short visiting time allowed by the family hence felt helpless (12), The inability to perform some activities that one can naturally perform culminated to a bad experience for the participant and only when they are discharged out do they feel adequate (53), Minimal visiting hours was seen by the participants as frustrating and not helpful for their recovery (10), Participants regarded the reception at the ICU as not friendly (11)</p> <p>ICU environment was said to be comfortable (41),</p> <p>Pre-information regarding intubation helped the</p>	<p>Experience of fear</p> <p>Feeling of bothering</p> <p>Near death</p> <p>Inability to endure</p> <p>Powerlessness</p> <p>Knowledge deficit</p>	<p>Emotional experiences</p>

<p>participant to an extent to cope with the ordeal (14), Participants were not properly educated/informed about the ventilation procedures prior to its commencement and participant felt Staff felt they are not accountable to them (24), The participant felt the information given was not detailed enough to prepare them emotionally although they were pre-informed (15, 25)</p> <p>Successful extubation was appreciated by the participants as they felt the intubation was necessary for their survival though hard (29)</p> <p>The attitude and response of the staff was credited as helpful (31), Staff attitude was commendable as they gave instructions to the patient on what they can do and not do (32),The caring attitude of the staff were commended by the participants as important (43)</p> <p>Patient agitation was relieved post extubation as they felt they can now breathe again and talk and they felt relief from the fear of death (50)</p> <p>The participant demonstrated dependency on the staff and felt their attitude as patient is essential also in making their stay in the unit memorable (40),</p> <p>Patient felt loss of personal dignity when he soiled the bed (4),</p> <p>Despite the state of fear participant found themselves their faith in God did not waiver(47),The religious belief of the patient was held in high esteem during the critical period (48)</p>	<p>Sense of safe/unsafe</p> <p>Body image</p> <p>Spirituality</p>	
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*Work Certificate*

To	Dr Shelley Schmollgruber
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Date	28/04/2016
Subject	MSc: Chapters 1 – 5 What are the patient's experiences of mechanical ventilation in the Intensive Care Unit? by Grace Adeyemi
Ref	SS/GS/14

**I, Gill Smithies, certify that I have proofed and language edited**

Chapters 1 to 5 by Grace Adeyemi,

What are the patient's experiences of mechanical ventilation in the Intensive Care Unit,

**to the standard as required by Wits Dept. of Nursing Education.**

*Gill Smithies*

28/04/2016