EXPLORING ADULT PATIENTS' PERCEPTIONS OF WHAT ENABLES THEM TO MAKE SENSE OF THEIR INTENSIVE CARE EXPERIENCE

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DECLARATION

I, the undersigned, hereby declare that the work contained in this thesis is my own original work and that I have not previously in its entirety or in part submitted it at any university for a degree.

Signature:

Date: April 2019

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DEDICATION

To my mother who, with her unconditional love and devotion, equipped me with my life's armour and taught me that even the largest task can be accomplished if it is done, one step at a time.

To Huibre, my moral compass with her rare, humble, patient, wise, kind and gentle soul, throughout this journey and every day.

To my sister who forever carries my heart in hers.

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ABSTRACT

Critical illness requiring admission into an intensive care environment is a significant stressful event in any person's life. Good caregiving in an intensive care environment is supported by appropriate, correct assessment and monitoring, drug and organ support interventions, patient comfort measures, psychological support, and early detection of complications. All these interventions and activities create experiences the critically ill person must make sense of in order to manage long-term consequences of this traumatic encounter (Leach, 2004:13).

Critically ill patients' experiences are an important component of a person's perceptions of the quality of care provided in the intensive care unit (Wahlin, Ek & Idvall, 2009:332). During my clinical experiences as a critical care nurse and through listening to patients' and colleagues' accounts of their experiences of intensive care, it appears that in many instances the person's negative experiences outweigh the positive ones.

I was keen to explore adult patient's perceptions of what aspects of the intensive care experience had an enabling influence on them making sense of their intensive care encounter and how these aspects enabled the patient to make sense of their experience of intensive care in order to move through the experience and make the experience tolerable.

A qualitative descriptive phenomenological research approach was used. This study aimed to explore a participant's own lived intensive care experience through their personal recollections in the intensive care unit. The participant's experience of their time in an intensive care unit was the key event.

A purposive sampling strategy using a network sampling method was applied to identify and include participants who had experienced an ICU admission, had recovered and moved from ICU to the ward or home, was able to give informed consent and able to talk with me about their admission and journey through their ICU stay.

It was found that participants were enabled to make sense of their ICU experience when they were part of a trusting relationship with their caregiver. A trusting relationship also encompassed the patient knowing that they mattered to their caregiver and allowed the patient to feel at ease and in turn feel safe. Distrust in the caregiver erodes this notion of feeling safe and hindered the patient being able to make sense of their experience of ICU.

It is recommended that education and training programmes should include specific content and application of trying to live in a critically ill person's shoes in order to enable a nurse or doctor to have some insight as to what this experience means to a critically ill person.

The study will be beneficial to nurses and other healthcare personnel who can offer care that is influenced by insights from this work and optimize a patient's sense of being able to make sense of, tolerate and move through an experience of intensive care.

Keywords: Intensive care experience, caregiver, patient experiences of ICU

ABSTRAK

Kritieke siekte wat toelating tot 'n intensiewe sorgomgewing vereis, is 'n beduidende stresvolle gebeurtenis in enige persoon se lewe. Goeie versorging in 'n intensiewe sorgomgewing word ondersteun deur toepaslike, korrekte assessering en monitering, middels en orgaanondersteuningsintervensies, pasiënt gemaksmaatreëls, sielkundige ondersteuning en vroeë opsporing van komplikasies. Al hierdie intervensies en aktiwiteite skep ervarings wat die kritiek siek persoon sin van moet maak om langtermyn gevolge van hierdie traumatiese ontmoeting te kan hanteer (Leach, 2004: 13).

Kritiek siek pasiënte se ervarings is 'n belangrike komponent van 'n persoon se persepsies van die gehalte van sorg wat in die intensiewe sorgeenheid verskaf word (Wahlin, Ek & Idvall, 2009: 332). Tydens die navorser se kliniese ervarings as 'n kritieke sorg verpleegkundige en deur na die pasiënt- en kollegas se weergawes van hul ervarings van intensiewe sorg te luister, blyk dit dat die negatiewe ervarings van die persoon in baie gevalle die positiewe ervarings oorskadu.

Ek was daarop uit om die volwasse pasiënt se persepsies te verken oor watter aspekte van die intensiewe ervaarervaring 'n invloed gehad het op hulle insig in hul intensiewe versorgings ervaring. Ook hoe hierdie aspekte die pasiënt in staat gestel het om sin te maak van hul ervaring in die intensiewe sorg eenheid, om sodoende aan te beweeg deur die ervaring en die ervaring verdraagsaam te maak.

'n Kwalitatiewe, beskrywende fenomenologiese navorsings ontwerp is gebruik. Hierdie studie het ten doel om 'n deelnemer se eie lewende intensiewe ervaring te verken deur middel van hul persoonlike herinneringe in die intensiewe sorgeenheid. Die deelnemer se ervaring van hul tyd in 'n intensiewe sorgeenheid was die belangrikste gebeurtenis.

'n Doelgerigte steekproef strategie met behulp van 'n network steekproefmetode is toegepas om deelnemers te identifiseer en in te sluit wat 'n toelating in die waakeenheid beleef het, herstel het en verskuif was vanaf ISE na die saal of 'n huis.

Die person moes ook in staat wees om ingeligte toestemming te gee en met my te praat oor hul toelating en reis gedurende hul ISE tydperk.

Daar is bevind dat deelnemers in staat gestel word om sin van hul ISE-ervaring te maak wanneer hulle deel was van 'n vertrouens verhouding met hul versorger. 'n Vertrouens verhouding het ook ingesluit dat die pasiënt geweet het dat hul versorger vir hul omgee, want dit het dan tot gevolg gehad dat die pasiënt gemaklik en veilig voel. Wantroue in die versorger verhinder die idee om veilig te voel en die pasiënt word dan verhoed om sin te maak van hul ondervinding van die ISE.

Daar is aanbeveel dat opvoedings en opleidingsprogramme spesifieke inhoud en toepassing moet insluit om in 'n kritiek siek persoon se skoene te staan om sodoende 'n verpleegkundige of dokter in staat te stel om insig te hê wat hierdie ervaring beteken vir 'n kritiek siek persoon.

Die studie sal voordelig wees vir verpleegkundiges en ander gesondheidsorg-personeel wat sorg kan bied wat deur insigte vanuit hierdie werk beïnvloed word. Dit kan ook die pasiënt se gevoel om sin te kan maak van die intensiewe sorg ervaring, dit te verdra en dan aan te beweeg optimaliseer.

Sleutelwoorde: Intensiewe sorg ervaring, versorger, pasiënt ervarings van die ISE

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CHAPTER 1
INTRODUCTION AND OVERVIEW OF THE RESEARCH STUDY

1.1   INTRODUCTION

Critical illness requiring admission into an intensive care environment is a significant stressful event in any person's life. Good nursing care in an intensive care environment is supported by appropriate, correct assessment and monitoring, drug and organ support interventions, patient comfort measures, psychological support, and early detection of complications. All these interventions and activities create experiences the critically ill person must make sense of in order to manage long-term consequences of this traumatic encounter (Leach, 2004:13; Kowalczyk, Nestorowicz, Fijalkowska & Kwiatosz-Muc, 2013:111).

Critically ill patients' experiences are an important component of a person's perceptions of the quality of care provided in the intensive care unit (Wahlin, Ek & Idvall, 2009:332). During my clinical experiences as a critical care nurse and through listening to patients' and colleagues' accounts of their experiences of intensive care, it appears that in many instances the person's negative experiences outweigh the positive ones.

A discussion follows highlighting the background and rationale for the study, the problem statement, the research question and the research purpose in the sections that follow. An explanation of the key terms is given, along with a discussion of the research approach and design. The chapter concludes with an in-depth look at rigor and ethical considerations followed by the chapter headings and the research summary.

1.2   BACKGROUND AND RATIONALE FOR THE STUDY

Critical illness requiring intensive care is a significant, stressful and frightening event in any person's life. The effect of an admission to an intensive care unit is well documented in literature. Much of the research conducted shows the intensive care

unit is experienced negatively; being unable to communicate easily, the noisy unit and feeling pain are just a few of the main stressors with which a patient must cope during the course of their ICU stay (Hweidi 2007:231). A traditional ICU setting places the critically ill patient within a sea of monitors, equipment, cords, tubes and wires; she/he is connected to various devices, exposed to unsettling noises, smells, lighting and uncomfortable temperatures. Patients are not only compromised by illness, they also endure reduced personal dignity and the loss of interaction with family and friends (Lee, Chung, Chan & Chan, 2004:610). These along with their perceptions of other patients' experiences, can cause physical and mental stress for a patient (Mariläinen, Kyngäs & Ala-Kokko, 2013:79).

A stressor experienced by many critically ill patients is the inability to communicate. Communication is a universal need which assists us in constructing and reflecting our social world (Marilainen *et al.*, 2013:84). The normal methods of communication are disrupted by sedation, opiates, endotracheal and tracheostomy tubes, fluctuating levels of consciousness, and fear. The challenges to normal methods of communication create difficulties for both patient and nurses in intensive care units.

The majority of patients in intensive care units have a compromised ability to communicate, an example being patients who require mechanical ventilation. Mechanically ventilated patients experience swollen vocal cords, difficulty swallowing, a painful throat, excessive thirst, and are unable to communicate with words. Being unable to speak leaves patients feeling frustrated or scared, they are less able to participate in decision-making or express their feelings, thoughts, hopes and needs (Urden, Stacy & Lough, 2006:668; Baggs & Gray, 2017:1424). Ventilated patients attempt to interact with the environment by cringing, squirming, wincing, and with distressed and pained facial expressions and movements, turning and lifting their heads towards noise and activity (Marilainen *et al.*, 2013:84).

Drugs such as muscle relaxants and sedatives may be used to allow for treatment plans to be carried out effectively, leaving the patient feeling dazed, confused and helpless. The ICU environment can be incomprehensible to a patient who is waking up from sedation and moving in and out of consciousness. They are unable to determine time, place and events (Marilainen et al., 2013:84). A lack of high quality

and satisfying communication could have implications for the physical and psychological health of critically ill patients. All patients desire to be understood and have their concerns and fears validated. This can be difficult for patients who are critically ill and whose ability to communicate is impaired (Urden *et al.,* 2006:52). Good communication is important to patients in intensive care and can improve recovery (Marilainen *et al.*, 2013:84).

In addition to experiencing challenges in communicating, the patient also experiences loss of their ability to take care of and be in control of their self. Hweidi (2007:233) identified the loss of having control over oneself as a stressor for a patient admitted into intensive care. According to Hweidi (2007:233), patients within the ICU setting rely on nurses in particular to perform tasks like changing position, activities of personal hygiene, and even eating. This state of dependency and depersonalisation can trigger a state of distress and helplessness for an ICU patient.

Hweidi (2007:231) revealed that the experience of pain is very discomforting to the critically ill patient and is considered to be a significant stressor. Invasive procedures are commonplace in the management of a patient for the purpose of diagnosis, monitoring or treatment and these procedures may be very painful. Patients identify pain as one of the biggest stressors associated with intensive care, also revealing that analgesia did not result in total relief from pain (Hweidi, 2007:233).

The critically ill patient's experiences of pain and discomfort are worsened by an environment that does not readily support effective rest and sleep. A lack of sleep can lead to confused reactions, decreased pain tolerance, respiratory dysfunction and increased irritability, tiredness and aggression (Mariläinen *et al.,* 2013:84). Sleep deprivation and sensory overload from loud and unfamiliar noises, flashing lights, noxious smells and light 24 hours a day hinders the patient's recovery process (Hweidi, 2007:232).

Patients in a state of physiological chaos become almost entirely dependent on the caregiver to assist them through the experience of intensive care. Basic nursing care like promoting comfortable positioning, ensuring effective pain relief, providing periods of uninterrupted sleep, reducing environmental noise and lighting, ensuring patient

privacy and effective communication could all assist in reducing the stressors with which a patient has to cope (Hatchett, Langley & Schmollgruber, 2010:57).

According to Samuelson, Lundberg and Fridlund (2007:94), experiences of discomfort and stressful memories in the ICU have been associated with the development of acute post-traumatic-stress-disorder related symptoms. These symptoms include anxiety, depression, and impaired quality of life. The critically ill patient's memories of stressful experiences in the ICU can be very disturbing and might cause psychological problems, thus affecting their sense of wellbeing and the rehabilitation process. Patients in intensive care perceive events in the ICU in different ways; their memories of experiences in ICU vary from nothing to remembering everything.

1.3   PROBLEM STATEMENT AND RESEARCH QUESTION

The discussion in the previous section illuminates a few of the many identified stressors a critically ill patient experiences, demonstrating that a stay in an intensive care unit is potentially traumatic for patients across emotional, social and psychological spheres (Adam & Osbourne, 2005:18). However, in conversations with people who have experienced being admitted to and cared for in an intensive care unit it seems that despite the overwhelming number of negative stressors affecting a critically ill patient, people are in some way able to make sense of the experiences of their ICU admission.

1.4   RESEARCH PURPOSE & QUESTION

While research has demonstrated what stressors are present in the environment and how these stressors affect critically ill patients, there is little known about what enabled people to make sense of their experience and, in some way, make their encounter with intensive care tolerable. By applying a qualitative approach to gain insight into the attributes or qualities of an intensive care experience that enabled a patient to make sense of and endure the encounter, caregivers may be better able to adapt care and interventions to facilitate a more tolerable experience of intensive care for a patient.

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This gave rise to the following research question posed for the study, namely:

What enabled patients to make sense of their experiences in an intensive care unit?

The aim of this study was to explore adult patients' perceptions of what in their intensive care encounter enabled them to make sense of the experience of intensive care and move through it.

I intended to explore adult patients' perceptions of what aspects of the intensive care experience had an enabling influence on them making sense of their intensive care encounter and how these aspects enabled the patient to make sense of their experience of intensive care.

1.5   PARADIGMATIC PERSPECTIVE

Paradigms are powerful because they create the lens through which we see the world (Covey, 2004:32). A paradigm is a researcher's set of assumptions and ways of knowing that guide and influence the researcher's investigation (Brink, Van der Walt & Van Rensburg, 2006:22). My worldview is based on my values and beliefs and embraces how I choose to live. I recognise that my paradigm embraces the way I acquire knowledge and what I regard as knowledge. My paradigm and worldview shape my personal frame of reference described in the way I view human beings, health and the caregiver.

An important element of Husserlian phenomenology is that the researcher attempts to shed prior personal knowledge to grasp the essential lived experiences of those being studied (Lopez & Willis, 2004:727). I aimed to achieve reflexivity through ongoing critical reflection of my biases and assumptions and how these have influenced all stages of the research process in an attempt to limit their influence into the study. During the period of data collection and analysis I continually reflected on my impressions, hunches and meanings in relation to specific contexts and experiences. Through this approach I intended to become more aware of the interconnectivity between and amongst myself, the participants, the data and the methods as I interpreted and represented the study findings (Begoray & Banister, 2012).

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1.5.1   Meta-theoretical statements

A meta-theoretical statement is a subjective and personal frame of reference held dear to the researcher (Brink *et al.*, 2006:23). Lor (2010:3) notes that in choosing a research method best fitted for this research study a researcher is influenced by many diverse dimensions such as where the researcher is coming from (sociological dimension), what the researcher aims to achieve through the research (teleological dimension), the phenomena under study (ontological dimension) and how the researcher comes to knowledge of it (epistemological dimension). In order to provide some insight into my lens that holds influence in this study, my broad beliefs about human beings, health and the caregiver unfold below.

1.5.1.1 Human beings

My frame of reference comes from an Ubuntu framework and Christian faith. I believe in what Ubuntu tells us. According to Ubuntu, there exists a common bond between us all and it is through this bond and our interaction with fellow human beings that we discover our own human qualities. Ubuntu speaks about interconnectedness. You cannot be human all by yourself. The essence of being human is in our interconnectedness (Boudreau, 2012). From within this framing, my view of human beings is connected to Psalm 139, verse 13-16.

> *God placed us on this planet and we are born by His purpose and for His purpose. You shaped me first inside, then out. You formed me in my mother's womb. You know me inside and out. You know every bone in my body. You know exactly how I was made, bit by bit. How I was sculpted from nothing into something. Like an open book, you watched me grow from conception to birth. All the stages of my life were spread out before you. The days of my life all prepared before I'd even lived one day (Psalm 139:13-16).*

For this study, the term 'human beings' refers to the study participants and their caregivers.

1.5.1.2 Health

My perception of health echoes that as defined by the World Health Organisation (WHO). Health is a state of complete physical, mental and social wellbeing, and not merely the absence of disease or infirmity (WHO, 1946).

1.5.1.3 The caregiver

I believe that the term 'caregiver' encompasses nurses, doctors and all of the members of the multidisciplinary team. The researcher is passionate about quality patient care and the unique value the multidisciplinary care team brings to their relationships with patients, their significant others and their colleagues. The researcher believes that any caregiving act or interaction should be founded on kindness, concern, care, competence, commitment and a love and respect of self and others. The researcher believes that being a caregiver is a God given gift and talent.

1.6   CONCEPTUAL FRAMEWORK

A conceptual framework is the abstract, logical structure of meaning that guides the development of the study and enables the researcher to link the findings to the body of knowledge used in nursing (Burns & Grove, 2009:155).

This study will be underpinned by the Person-Centred Nursing Framework (PCNF) (McCormack & McCance, 2006:473). McCormack and McCance (2006) ascribe the following meaning to person-centred care: it is an approach to practice that is established through the formation and fostering of therapeutic relationships between all care providers, people and others significant to them in their lives. It is underpinned by values of respect for persons, individual right to self-determination, mutual respect and understanding. This approach places the person, which includes their experience and understanding of a healthcare situation, at the centre of nursing care. The PCNF speaks to my study aim as well as my worldview and personal frame of reference.

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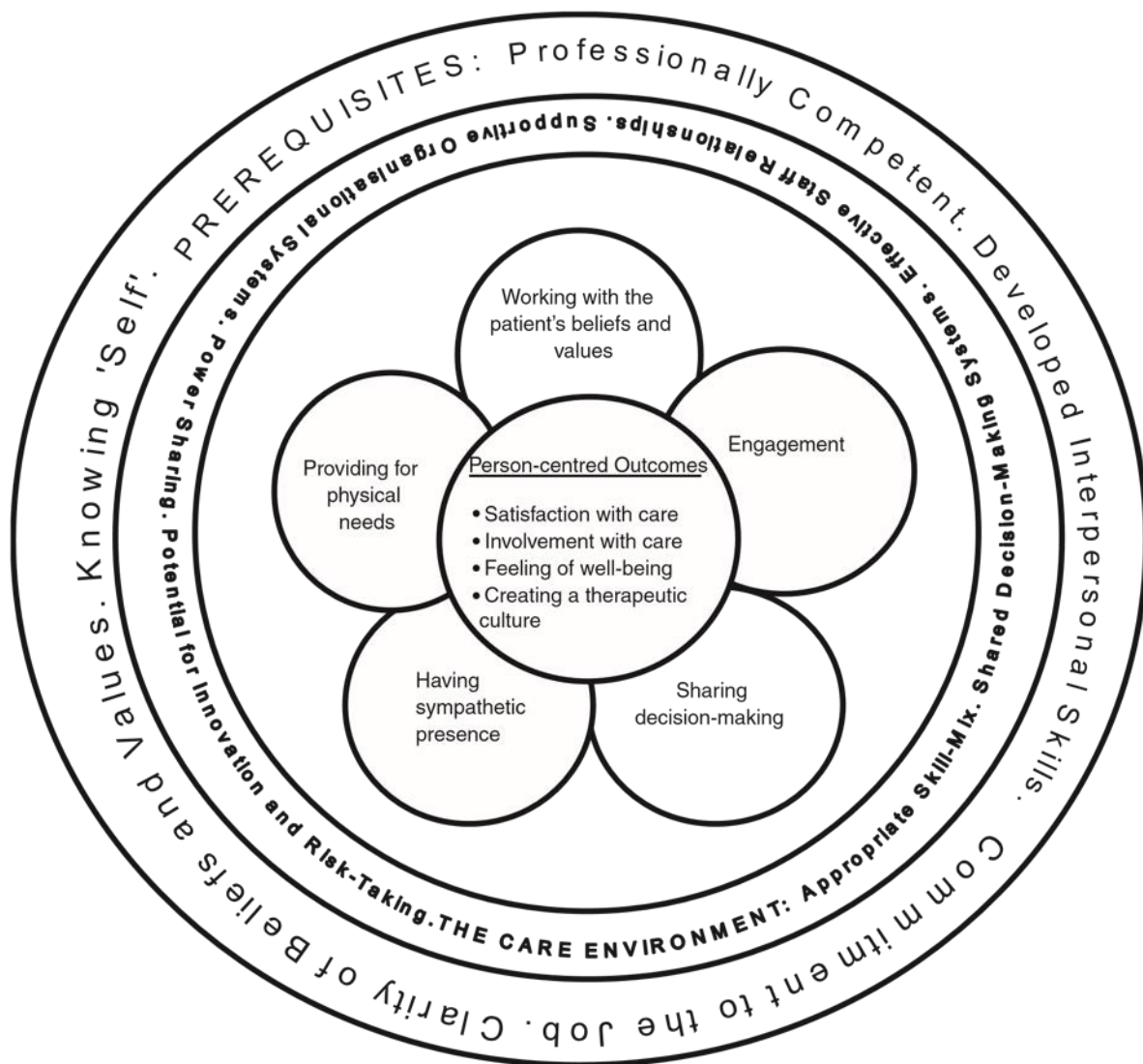
Figure 1.1:   A framework for person-centred nursing (McCormack & McCance, 2017:37)

Prerequisites, the outer ring of the figure, focus on the attributes of staff and are considered the key building blocks in the development of healthcare professionals who can deliver effective person-centred care. Attributes include being professionally competent, having developed interpersonal skills, being committed to the job, being able to demonstrate clarity of beliefs and values, and knowing self. It is the combination of these attributes that reflects a person-centred caregiver who can manage the challenges of a constantly changing context (McCormack & McCance, 2017:46).

The inner ring of the figure, the care environment focusses on the context within which care is delivered and encompasses characteristics like appropriate skill mx, systems that facilitate shared decision making, sharing of power, effective staff relationships, supportive organizational systems, the potential for innovation and the physical environment.

Person-centred process makes up the petals of the flower in the figure. These processes focus on delivering person-centred practice which include working with patients' beliefs and values, engaging authentically, being empathetically present, sharing decision-making and providing holistic care. This component focusses specifically on the patient.

The centre of the flower, person-centred outcomes, represent the results expected from effective person-centred practice which include a good experience of care, involvement in care, feeling of wellbeing and the existence of a healthful culture.

The prerequisites and the care environment for providing effective care through the care processes need to be considered in order to reach the person-centred outcomes at the center of the flower. This ordering leads to the achievement of positive patient outcomes which form the central component of the framework. It is also acknowledged that there are relationships between the constructs (McCormack & McCance, 2006:475).

1.7   OPERATIONAL DEFINITIONS

The following operational definitions are clarified as below for the purpose of this study.

Intensive care: constant, complex health care as provided in various acute life-threatening conditions such as multiple trauma, severe burns, myocardial infarction or after certain kinds of surgery (Mosby's Medical, Nursing & Allied Health Dictionary, 2002:904). Care which provides a level of constant and complex monitoring and treatment to patients with potentially reversible, life-threatening conditions (Leach, 2004:13).

Intensive care nursing: highly specialized, skilled nursing personnel who have vital nursing roles such as patient assessment, continuous monitoring, drug administration, patient comfort, psychological support, assistance with communication, advocacy, skin care, positioning, feeding, and early detection of complications. These nursing roles have a profound effect on patient outcome. Nurses also provide essential support for relatives, doctors, physiotherapists, and other caregivers (Leach, 2004:13).

Intensive care unit (ICU): a specially equipped hospital area designated for the treatment of patients with sudden, life-threatening conditions. Intensive care units contain resuscitation and monitoring equipment and are staffed by personnel specially trained and skilled in recognizing and immediately responding to cardiac and other emergencies (Mosby's Medical, Nursing & Allied Health Dictionary, 2002:449).

Critically ill patients: patients who have an immediate or potential life-threatening illness or injury causing compromise to one or more organ systems (Elliot, Aitken & Chaboyer, 2012:785).

ICU Admission: the critically ill patient's length of stay in an intensive care unit. Patients remain in ICU for varying lengths of time depending on the nature of their illness.

Make sense of: the way in which the patient interprets or comprehends their experience of intensive care. The way in which a patient finds meaning and understands their experience of intensive care.

Enable: to empower, provide and equip someone with the ability, the means and the knowledge to make something possible (Merriam-Webster Dictionary, 2005, s.v. 'enable').

Tolerable: something that is unpleasant but able to be accepted to exist or to happen to a person, to accept and to bare (Merriam-Webster Dictionary, 2005, s.v. 'tolerable').

Perception: the way we try to understand and interpret the world around us in order to give that world meaning. Our perceptions can be vastly different (Covey, 2004:23).

1.8   RESEARCH DESIGN AND APPROACH

The best research design is the one most appropriate to the research problem and purpose (LiBiondo-Wood & Haber, 2010:90).

A qualitative approach applying descriptive phenomenology was used in this study. Descriptive phenomenology enables the participant's own meaning of a phenomenon to be described (Thompson, Grocke & Dileo, 2017:325). This study aimed to explore a participant's own lived intensive care experience through their personal recollections in the intensive care unit. The participants' experience of their time in an intensive care unit was the key event being explored to elicit the meaning held in this event for the person.

Through using a qualitative approach, my intention was to seek a better understanding through exploring this complex situation of a person becoming able to make sense of their experience in an intensive care unit (De Vos, Strydom, Fouche & Delport, 2011:64). Qualitative research answers questions about the complex nature of phenomena, with the purpose of describing and understanding the phenomena from the participant's point of view. In exploring this phenomenon through a phenomenological design, the discipline knowledge foundation of critical care nursing expands and enriches our understanding of everyday occurrences in this environment (Thompson *et al.,* 2017:325).

1.8.1   Context of the research

Participants were purposively accessed within one private hospital in the Cape Metropole offering multidisciplinary intensive care services across two ICUs, and via a network sample method using word of mouth about the study amongst nursing colleagues and study participants. Between these two methods a more heterogeneous study sample resulted which supported the study's trustworthiness and contributed towards but is still self-limited to enhancing transferability of the study findings.

1.9   RESEARCH METHOD

The research method informs the reader of how the investigation was carried out and what the researcher did to answer the research question (Brink, van der Walt & van Rensburg, 2006:191). In this section, an overview of the research approach, design and methods is provided with a more detailed explanation offered in Chapter 2.

1.9.1   Population and sample

People choosing to engage in qualitative studies are known as the study participants and need to meet certain criteria set by the researcher first in order to engage with and participate in the research study (Burns & Grove, 2011:51). For this study, the research population embraced adult people who had been admitted to an intensive care unit as a result of a critical illness, experienced the intensive care admission and journey as a patient, and had recovered sufficiently to have moved out of ICU and into the ward or discharged home from the hospital.

Sampling allows the researcher to select a sample of study participants from a population in order to obtain information regarding a phenomenon in a way that represents the population of interest (Brink *et al.,* 2006:124).

Participant selection must have a clear rationale and fulfill a specific purpose related to the research question. A purposive sampling strategy using a network sampling method was applied to identify and include participants which allowed the researcher to handpick participants that had lived and experienced the phenomenon under study and could thus give a rich in-depth account of the lived phenomenon (Creswell, 2007:125). LoBiondo-Wood and Haber (2010:234), note that network sampling also allows the researcher to identify participants who can provide rich data about the phenomenon being studied. Through intentionally selecting adult patients who had received intensive care for a critical illness, I was confident that the participants were knowledgeable and able to talk about their experience, and in this way, access to rich and relevant data was gained.

Participant sampling continued until data saturation was reached. Data saturation is the point at which no new information or themes emerge from the data (Crabtree, 2006:1). I achieved a final sample size of 6 participants. Thomson (2011:50) identifies that a sample size of between 6 – 10 participants will most likely provide saturation when individual interviews are utilized.

1.9.2   Data collection

According to Brink *et al,* (2006:141), the process of data collection is of critical importance to the success of a study. Without high quality data collection techniques, the accuracy of the research conclusions is easily challenged.

Once informed consent had been obtained, data collection took the form of individual, unstructured interviews guided by an open-ended question to initiate the conversation between participant and researcher. The goal was to obtain genuine insight into the participant's experiences. An unstructured interview is a conversation with a purpose and encourages the participant to do the talking and tell their story. I invited participants to reflect on their feelings and recollections about what enabled them to make sense of their ICU experience by initiating the interview with an open-ended question. Pilot interviews were conducted to assess the interview questions and analysis process. No changes were made after this process had been completed and the pilot interview data was included in the main study

Reflexivity forms an important part of descriptive phenomenology (Shosha, 2012:32). Here, the researcher must recognise their own personal bias and beliefs about the phenomenon under study, and deliberately work to put these aside. The aim of this it to keep what is already known about the description of the phenomenon separately from the participant's description. I kept a reflexive journal throughout the data collection process. In this journal, I reflected on my own personal beliefs and assumptions about the phenomenon under study. Reflexivity helps to gain insight into the common features of any lived experience and eradicates bias inherent in researcher beliefs and attitude (Shosha, 2012:41).

In this way I worked to limit imposing my assumptions on the data collection process or the structure of the data. In this way, validity of data collection and data analysis was supported and the participants' voice in describing the phenomenon was maintained.

1.9.3   Data analysis

The method of data analysis in qualitative research is determined by the purpose of the study. I intended to obtain genuine and reliable insight into the participant's lived experiences and to uncover trends or patterns that recurred in the collected data, therefor I chose to use Colaizzi's method of thematic content analysis. Colaizzi (1978) states that thematic content analysis allows for the description of lived experiences through the building of words with similar meanings into themes to elicit an exhaustive description about the phenomena being studied. Colaizzi's seven step method includes validating results by returning to study participants, thus enhancing credibility and trustworthiness of data and minimizing the possibility of researcher bias (Polit & Beck, 2010:473).

1.9.4   Literature integration

In qualitative phenomenological studies, a literature review *after* data collection and analysis assists the researcher in limiting preconceived ideas about the phenomenon under study and to set aside biases that might influence the research (Botma, Greef, Mulaudzi & Wright, 2010:196; Creswell, 2014:29; Burns & Grove, 2009:91; Speziale & Carpenter, 2007:97).

Therefore, literature integration was done after data analysis in order to compare, contrast and situate the unique findings of this research with similar studies. Ebscohost, Google Advanced Search and Science Direct were some of the search engines used for articles, theses and dissertations. The literature also included journals and books relevant to the phenomena under study. A full explanation of this process is provided in Chapter 3.

1.10   TRUSTWORTHINESS

Trustworthiness in qualitative research is also known as rigor. Rigor influences the perceived worth of research findings. Without rigor, the research is worthless (Burns & Grove, 2009:54). It is the qualitative researcher's responsibility to illustrate the richness of the data and to convey to the audience the relationship between the themes identified. This is essential in order to document the rigor of the research (LoBiondo-Wood & Haber, 2010:105).

The elements of trustworthiness as explained by Lincoln and Guba (1999), described by Brink *et al,* (2006:118), and De Vos *et al,* (2011:421), were consistently applied throughout this study. A detailed discussion of how each of the elements, namely credibility, transferability, dependability and confirmability, were attended through the study is provided in Chapter 2.

1.11   ETHICAL CONSIDERATIONS

Ethical codes and regulations have been developed to provide guidelines for the selection of the study purpose, design and subjects; the collection and analysis of data; the interpretation of results; and the presentation and publication of the study (Burns & Grove, 2009:184).

Inherent in all research is the demand for the protection of human subjects (LoBiondo-Wood & Haber, 2010:117). The Nuremberg Code and the Declaration of Helsinki provide the foundation for numerous ethical research guidelines developed by government and professional organizations involved in the conduct of research on human subjects all over the world (Brink *et al.,* 2006:30).

Permission to conduct the research was obtained from the Health Research Ethics Committee at the Faculty of Health Sciences, Stellenbosch University (see Annexures 1 & 2), and the Ethics Committee of the chosen private hospital group's head-office and their nursing education institution (see Annexures 3, 4 & 5). Permission to access the private hospital was obtained from the hospital manager, the nursing manager and the unit managers of both the ICUs and the wards. Permission to gain access to the

participants outside of the hospital setting was given via word of mouth from the participants to my nursing colleagues.

Informed consent included written disclosure of essential study information to the study participants (see Annexure 6). Participation in the study was voluntary and the participant was assured they could withdraw from the study at any point without any repercussions.

By signing the consent form, the participant agreed to me audiotaping the discussions with an audio-tape-recorder and a cellular telephone. Verbal permission was also obtained from participants prior to the interviews being held. I believed that using two separate devices to record the interviews would aid well should one of the recording devices fail during the interviews.

The interview recordings were immediately deleted from the cellular telephone and the audio-tape recorder once the transcriptions were completed.

There are three fundamental ethical principles that guide researchers, namely, respect for persons, beneficence and justice. These principles were strictly adhered to and applied throughout the course of the research study. These principles are based on the human rights that need to be protected in research, namely, the right to self-determination, to privacy, to anonymity and confidentiality, to fair treatment and to being protected from discomfort and harm (Brink *et al.,* 2006:31). These principles and the application thereof in this study are explained in Chapter 2.

1.12   RESEARCHER EXPERTISE AND COMPETENCE TO CONDUCT THE RESEARCH

I completed a research methodology module first in my Honours degree programme and again as part of the first year of my structured Masters programme, both which I passed with distinction. My supervisor has experience in conducting qualitative research, has supervised a number of other students and has published work in discipline journals. Together, we worked closely through every step of the research process.

1.13   REMUNERATION

Participants were not paid to take part in the research study. Refreshments in the form of coffee or cold non-alcoholic drinks were provided to the participant by the researcher during the interviews.

1.14   RELEVANCE AND VALUE OF THE RESEARCH

The study is relevant to the whole of the multidisciplinary care team looking after a patient in the ICU setting and aims to contribute to every health care professional's understanding of what the patient moving through an intensive care experience has to endure and what enables the patient to make it through this state of chaos they have been faced with. The study offers healthcare professionals an understanding of the ways to support the patient to move through the experience and make the experience more tolerable. The study will be beneficial to all healthcare personnel who offer care that is influenced by insights from this work and enable a patient to make sense of, tolerate and move through an experience of intensive care.

1.15   MANAGEMENT AND DISSEMINATION OF RESEARCH RESULTS

Results were not posed or fabricated and all of the participants were acknowledged. Policies regarding plagiarism and copyright as described by Stellenbosch University were taken into account. The findings of the research are available in the form of a dissertation and the researcher aims to publish an article in a relevant peer-reviewed journal.

1.16   PROGRESS REPORT

The progress of the research and adherence to ethical aspects as set out in the HREC ethical guidelines were adhered to both by myself and my study supervisor, with HREC approval S14/10/208. I received an invitation to travel and work abroad in 2015 and thus discontinued the research study as it was not feasible to continue while I was abroad. I registered for the Masters programme again in 2018 and HREC approval

was granted, S19/01/019, and extended from 2015 to 2018. Refer to annexures 1 & 2.

1.17   CONFLICT OF INTEREST

There was no personal or financial conflict of interest in this study.

1.18   DISSERTATION LAYOUT

The division of chapters is the common structure used for a dissertation that involves empirical research (Burns & Grove, 2009:111). A literature review was conducted to identify relevant published scholarship once the data analysis had been completed. The findings from the literature review were integrated into Chapter 3 and used to contrast, highlight and situate the study findings within the current body of discipline knowledge related to the study topic. I critically examined my own role, potential bias and influence during this process. Galdas (2017:1) affirms that qualitative research allows for the researcher to become an integral part of the process and final product and that separation from this is neither possible nor desirable. I strived to always be transparent and critically self-reflective about my own preconceptions.

The chapters are thus divided as follows:

Chapter 1: Introduction and overview of the research study
Chapter 2: Design and approach
Chapter 3: Discussion of results and literature integration
Chapter 4: Conclusions, evaluation of the study, recommendations and limitations

1.19   SUMMARY

This chapter gave the reader a broad orientation and rationale to the research study including the research purpose and paradigmatic perspective. The design, data collection methods and data analysis were also highlighted, followed by an overview of the measures taken to ensure trustworthiness and ethical behaviour. Chapter 2 discusses the research design and approach to the research study in detail.

CHAPTER 2
RESEARCH DESIGN AND APPROACH

2.1   INTRODUCTION

This chapter provides a detailed description of the research methodology and methods applied in the study. According to De Vos et al, (2011), and Burns and Grove (2017), it is important that the research methodology be described comprehensively so that the reader develops confidence in the research methods used. A researcher relies on a pre-established plan relating to the phenomenon being studied. This plan is a way of gaining knowledge via scientific enquiry and follows a detailed and precise path irrespective of what you want to discover or which facts you anticipate to learn (Burns & Grove, 2009:719). The choice of methodology is guided by the research question, aims and objectives. As stated in Chapter 1, the aim of this study was to explore adult patients' perceptions of what enabled them to make sense of their experience of intensive care. A qualitative descriptive phenomenological research approach and design was chosen to best provide insight and understanding into this topic area. In this way the study can contribute to creating a discussion document to guide practice change in the intensive care units in the effort to enhance a person's making sense of their ICU experience.

2.2   RESEARCH APPROACH, DESIGN AND METHOD

The research approach, design and method inform the reader about how the investigation was carried out and what the researcher did to best answer the research question (Brink *et al.,* 2006:191). A qualitative approach was used to explore and gain insight into patients' perceptions of what in their intensive care encounter enabled them to make sense of their intensive care experience in order to make that experience tolerable. Qualitative research generates knowledge about meaning and discovery and is a systematic, interactive, subjective approach best used to describe life experiences and give them meaning (Burns & Grove, 2009:23). It allows the research design to grow and develop as the study grows and develops. This approach allowed for genuine, honest and open interaction between myself and the participant, through

individual unstructured interviews to gain sincere and reliable insight into the participant's experience and generate rich, valuable data. As there is little known about what enables a patient to make sense of an intensive care experience in order to make this tolerable, a qualitative approach was appropriate to elicit the meaning held for participants about the study phenomenon. In coming to an understanding of what enables a patient to make sense of their experience, we become better able to influence and guide practice change with the study findings in the effort to enhance a person's making sense of ICU.

Within a qualitative approach, phenomenology enables research designed to explore and understand people's everyday lived experiences (Shosha, 2012:31). The design of a study is the end result of a series of decisions the researcher will make concerning how best to implement the study (Burns & Grove, 2009:218).

Husserl believed that human experience of a phenomenon as perceived by human consciousness should be scientifically studied (Shosha, 2012:32). His belief that phenomena could not be condensed into objective reality, but rather that the individual experience was valuable and should become the central focus (Pallikkathanyil & Morgan, 1990:195), underpins phenomenology, the exploring and developing knowledge of human experience. Phenomenology embraces a process of learning and constructing the meaning of human experience through intensive dialogue with persons who are living the experience. The phenomenological design provides a sense of the "whole". Emphasis is not on parts or pieces but on the wholeness of the lived experience (LiBiondo-Wood & Haber, 2010:102). After considering the underpinnings and intended purpose of descriptive phenomenology I chose this the most appropriate research design to achieve the study's research question and aims.

Phenomenology has many advantages:

- discovery of the essence of the phenomenon, that is, the deepest understanding of the structure of the experience;
- richness of the data gathered - it is through the experiencing individual that the wonders and mysteries of life are disclosed;

- allows for a "recognition of the other as a unique individual with a unique set of experiences";

- provide an opportunity for gaining insight into the self - awareness of one's own spirituality and of one's own intuitive caring nature empowers one to respond with increased understanding when encountering the phenomenon in the future (Pallikkathayil & Morgan, 1990:198); and

- for human sciences such as nursing, an approach that suspends all judgments about reality until they can be founded on something more certain is critical.

Descriptive phenomenology situates study participants as instrumental in uncovering the meaning of their experiences. With the study focused on the patient's experience of their time in an intensive care unit as the key event, participants were asked to share their personal reflections and thoughts about their experiences of an ICU admission and journey through ICU. In this way knowledge was generated through participants recounting experiences, these meaningful experiences of individuals understood within their particular situation and context (Creswell, 2014:206).

2.3   LITERATURE REVIEW AND INTEGRATION

I made a choice to integrate published and relevant literature with the study findings. As such, no separate chapter detailing the literature review chapter forms part of this dissertation. While no separate chapter is offered, a focused and rigorous literature review was conducted. The process is described in Chapter 3.

A broad-based literature review was conducted during the proposal development in order to substantiate the need for this study to be done. However, a more focussed review was conducted once the data analysis had been completed to contrast, highlight and situate the study findings within the current body of discipline knowledge related to the study topic.

My intention with the literature review was to identify, explore and describe similar studies and subjective health experiences relevant to the study focus in order to gain a deeper understanding of their shared meaning. The literature review was conducted

to identify relevant published scholarship. A literature review is a broad search of relevant, fitting literature related to the research topic at hand and aims to provide a strong knowledge base and theoretical foundation for the conduct of the study (Burns & Grove, 2009:545).

Both national and international literature concerning adult patient perceptions and experiences of an intensive care admission within an adult intensive care environment and how these patients endured and overcame these experiences were included in the review.

Literature was identified through conventional searches of the library at the Faculty of Medicine the Medical Library (Stellenbosch University), a public library and computerised literature searches of electronic databases. Keywords used in the initial search included: intensive care patient, intensive care unit, intensive care nursing, intensive care experiences, critically ill patient, ICU admission, make sense of, enable, tolerate, mechanical ventilation, sedation, analgesia, intensive care stressors, communication, patient interventions, family. The material selected for the literature review consisted of books and journal articles covering a period of 33 years from 1985 to 2018.

2.4   STUDY SETTING

The borders of this study's setting are provided by a critical care environment in a private sector hospital of a metropolitan area in the Western Cape, South Africa. Hospitals in this metropolitan area have well established critical care units which provide specialised nursing, medical and allied services and care to people affected by acute or life-threatening consequences of an illness or injury. The hospital has both a medical and a surgical intensive care unit with an average of 140 medical patients and 118 surgical patients with diverse admission diagnoses being admitted to these units each month.

2.5   ETHICS APPROVAL

I received approval from the HREC for the study (S14/10/208), on 16 March 2015 (Annexure 1) and initiated data collection processes in May 2015 in which I completed in-depth interviews with three participants, the first interview serving as the pilot interview for the study. The first interview done in 2015 was regarded as a pilot interview for the next two interviews done in 2015. When recommencing my studies again in 2018, I then regarded the three interviews done in 2015 as my pilot interviews for the interviews conducted in 2018. We included all six interviews into the data set due to the richness of the data collected in the interviews. In 2016, I received an invitation to travel and work abroad. I decided to discontinue my studies at that point in time as it was not feasible to continue with the research while I was abroad. I registered for the M Nursing programme and requested HREC approval again in 2018 (Annexure 2) which was granted to me (S18/01/019).

2.6   RESEARCH POPULATION

The research population encompasses all those individuals that meet certain specific criteria for inclusion in a study (Burns & Grove, 2011:51). For this study, the research population were adult people who had been admitted to an intensive care unit as a result of a critical illness, had experienced the intensive care admission and journey as a patient, and had recovered sufficiently to have moved out of ICU and into the ward or be discharged home from the hospital.

2.7   SAMPLING

Sampling allows the researcher to select a sample of study participants from a population in order to obtain information regarding a phenomenon in a way that represents the population of interest (Brink *et al.,* 2006:124). People choosing to engage in qualitative studies are known as the study participants and must meet certain criteria set by the researcher first in order to engage with and participate in the research study (Burns & Grove, 2011:51).

A purposive sampling strategy using a network sampling method was applied to identify and include participants which allowed me to handpick participants that had lived and experienced the phenomenon under study and could thus give a rich in-depth account of the lived phenomenon (Creswell, 2007:125). Through intentionally selecting adult patients who had received intensive care for a critical illness, I was confident that the participants were knowledgeable and able to talk about their experience, and in this way, access to rich and relevant data was gained. LoBiondo-Wood and Haber (2010:234), note that network sampling also allows the researcher to identify patients who can provide rich data about the phenomenon being studied.

2.8   INCLUSION CRITERIA

Inclusion criteria are those characteristics that a participant must possess to be part of the target population (Burns & Grove, 2009:345). Participants who had experienced an ICU admission, had recovered and moved from ICU to the ward or home, was able to give informed consent and able to talk about their admission and journey through their ICU stay, were invited to participate in the research study.

Ethical approval was received from Stellenbosch University and the Ethics Committee of the chosen private hospital group's head-office and their nursing education institution (Annexures 3, 4 & 5). Permission to gain access to the ICUs was then obtained from the Nursing Manager. I visited the adult medical and surgical intensive care units to meet with the respective unit managers and peruse through the ICU patient admission registers to identify patients who I thought best met the inclusion criteria for the study and determined which wards the patients had been transferred to.

On arrival in the ward, I introduced myself to the unit manager and described the research topic and reason for my visit. Meyer, Naude and Van Niekerk (2004:135) describe the patient as a receiver of care and a unique, holistic human being with dignity worthy of respect and high-quality nursing care. The unit manager has a responsibility to facilitate the process of being responsible and accountable for the wellbeing of the patient by taking on the role of gate-keeper and exercising patient advocacy. I requested permission to speak directly with the patient to invite them to

participate in the study. The unit manager directed me to where the potential participant was in the ward but was not present during any interaction between the participant and I. This enabled me to establish a relationship with the participant in a confidential and protected way. I introduced myself to the participant, briefly described why I was excited to meet the patient and gained verbal and written consent from the patient while in conversation about the research topic.

Outside of this hospital environment participants were recruited by word of mouth amongst nursing colleagues and people who had already contributed as study participants.   All in all, this captured the essence of a network sampling strategy which is a type of purposive sampling. The network sampling strategy assisted me in acquiring otherwise difficult to locate subjects. Between these two methods a more heterogeneous study sample resulted which in turn supported the study's trustworthiness and transferability of the study findings (LoBiondo-Wood & Haber, 2010:235).

Participant sampling continued until data saturation was reached. Data saturation is considered to be the point at which no new information or themes emerge from the data (Crabtree, 2006:1). A final sample size of six participants provided sufficient data to determine that data saturation had been achieved. After six in-depth interviews common and repeated ideas, explanations and descriptions were noted in the data. A sample size of 6 participants is congruent with what Thomson (2011:50) identifies as most probably, providing data saturation when individual interviews are utilized.

Table 2.1:   Participant summary table

Participant summary table					
Participant	**Pseudonym**	**Gender**	**Where found**	**Admission diagnosis**	**ICU length of stay**
1	Allison	Female	Hospital	Elective surgery	5 days
2	Matthew	Male	Hospital	Stroke	2 days
3	Shelley	Female	Hospital	Chest pain	2 days

Participant summary table					
Participant	Pseudonym	Gender	Where found	Admission diagnosis	ICU length of stay
4	Mark	Male	External network	Motorbike accident/Polytrauma	2 months
5	Luke	Male	External network	Cardiac arrhythmias	2 weeks
6	John	Male	External network	Motor vehicle accident/Head injury	2 months

2.9   DATA COLLECTION

2.9.1   Accessing participants

After receiving ethical approval from the Stellenbosch Health Research Ethics Committee, reference S14/10/208 in 2015 and reference S18/01/019 in 2017, and the hospital group's ethics committee, I gained permission from the nursing manager to access the ICUs.

In 2015, I visited the adult medical and surgical intensive care units, met with the respective unit managers and presented them with a brief overview of the study. I perused through the ICU patient admission registers and identified and purposively selected patients who had suffered a critical illness, recovered sufficiently from that illness and had been discharged from the ICU to the ward.

The admission register indicated which wards the possible participants had been transferred to. On arrival in the wards, I introduced myself to the respective unit managers, gave each of them a brief overview of the study and asked for their permission to speak with the prospective patient who met the inclusion criteria for the study. I then asked the respective unit managers to direct me to the prospective participant. Once at the bedside, I introduced myself to the patient, gave them a brief overview of the study and asked for informed consent before initiating further

conversation about the interview process with the prospective participant. Each person invited to participate was able to give informed consent and converse with the researcher. Three participants agreed to participate at this stage. The first interview was used as the initial pilot interview for the study (see Section 2.8.3).

In 2017, participants were identified by word of mouth and a network sampling process through nursing colleagues and study participants. I communicated via my nursing colleagues and other study participants from which I had come to know of the potential participants. Using the person who identified a person who may agree to participate in the study, I obtained consent to contact each person individually via telephone and approached each of them to participate. Another 3 participants agreed to participate in the study at this stage.

Data collection involves the most relevant method of obtaining data for the research study (De Vos *et al.,* 2011:73).

2.9.2   Interviews

Data collection took the form of individual, unstructured interviews guided by an open-ended question to initiate conversation between participant and researcher. The goal was to obtain genuine insight into the participant's experiences. Informed consent was obtained from participants. This process included providing information to the person about the study, providing an opportunity for them to clarify any aspects they wished to and to make them aware they should feel comfortable and at ease to withdraw from the study at any time. The participant read through the study information and signed the consent form before participating in the interview (see Annexure 6 & 7). By signing the consent form, the participant agreed to me audiotaping the discussions with an audio-tape-recorder and a cellular telephone as well as make contact again with them at a later stage to validate the findings with their experiences. Verbal permission was also obtained from participants prior to the interviews being held. I believed that using two separate devices to record the interviews would aid well should one of the recording devices fail during the interviews.

An unstructured interview is a conversation with a purpose and encourages the participant to do the talking and tell their story (Brink *et al.,* 2006:152). I invited participants to reflect on their feelings and recollections about what enabled them to make sense of their ICU experience by initiating the interview with an open-ended question. The aim of an open-ended question is to encourage participants to tell their stories with minimal input from the researcher. Open-ended questions provide richer, more diverse data than can be obtained with the use of closed-ended questions (Brink *et al.,* 2006:149).

The interview recordings were immediately deleted from the cellular telephone and the audio-tape recorder once the transcriptions were completed.

Three of the interviews took place in the hospital setting, one being outside in the garden in the shade under an umbrella and the other two in a quiet room in the hospital building. The interviews were conducted in a non-threatening, quiet, private space with natural light, warmth and good ventilation. The participant chose a place where they felt most comfortable to sit and have the interview which was also depended on how restricted their activities were. Each interview lasted a maximum time of one hour. The interviews were conducted at a convenient time for the patient, in a private venue and the timing was managed to have the least impact on the participant and their patient care activities. Three interviews were done with participants outside of the hospital setting, two in the participants' homes in the living area sitting comfortably at a dinner table and on couches in the lounge. The third interview happened in the participant's office space during a break. These three interviews were carried out at a time most convenient for them and in a space they chose and found to be safe, comfortable, quiet and private. Participants were given the choice to freely withdraw at any time from the interview process if they wished to do so. None of the participants became distressed or emotional during the time of the interview.

An audio-tape recorder and cellular telephone with recording capabilities were used to record the interviews with permission from the study participants. This allowed for a much fuller record than notes taken during the interview (De Vos *et al.*, 2009:298), and I believed that using two separate devices to record the interviews would aid well should one of the recording devices fail during the interviews. Participants were

identified during the recordings using the pseudonyms they had chosen for themselves which ensured the participant's personal information was kept confidential. Recording the interviews allowed to limit the distraction of note taking. I made notes on the transcriptions, which allowed me to immerse myself in the data analysis phase.

Three interviews (including the pilot interview) were conducted in 2015 and a further three in 2017 culminating in a data sample of six interviews. The first interview done in 2015 was regarded as a pilot interview for the next two interviews done in 2015. When recommencing my studies again in 2018, I then regarded the three interviews done in 2015 as my pilot interviews for the interviews conducted in 2018. We included all six interviews into the data set due to the richness of the data collected in the interviews. Data saturation determined the end point of data collection for the study. Data saturation happens when information being shared with the researcher becomes repetitive. Ideas conveyed by the participant have been shared by other participants and the inclusion of additional participants does not result in new ideas (LiBiondo-Wood & Haber, 2010:577).

2.9.3   Pilot interview

A pilot interview is a small-scale version, a trial run, an initial attempt, an exploratory attempt in preparation for the research interview to ascertain whether the subject being investigated is being adequately captured (Social Research Glossary, online). This allows me to find any difficulties the participants may experience during the interview process, which could possibly have a negative impact on the data collection process. A pilot interview was conducted in May 2015 (as part of the HREC approved study S14/10/208). Based on this interview as well as its analysis, no changes were made to the open-ended questions used to initiate conversation between myself and the participant and the researcher. This data was included in the main study.

2.9.4   Interview preparation

I met with each purposively selected patient, gave them a brief overview of the study and invited them to participate. I felt that this contact session was very important to discuss the research topic with the patient, create a bond with the patient and take

consent from the patient to have the interviews tape-recorded. I asked each participant to choose a pseudonym. The pseudonym ensured the patients their identities would be kept anonymous. I also informed each participant that they could feel comfortable and free to withdraw at any time should they feel the need to do so. The interview sessions were held at a time and place most convenient for the patient and the nursing staff involved with patient care activities. Most of the hospital-based interview sessions occurred between 2pm and 4pm in the afternoons. The 2pm medication round had been completed by then and the patients were usually awake, waiting in anticipation for visiting hours with family and friends at 4pm. I brought along stationery, a hand-out giving a detailed overview of the study and a consent form for the patient to peruse through and sign if they wished to participate. Interviews done with participants outside of the hospital setting were carried out at their homes, in the evening time after they had completed their working day and were relaxed in their familiar surroundings, either in front of a fireplace on a comfortable couch or at the dinner table with a cup of tea in hand. One of the participants felt comfortable having his spouse taking part in the interview as well.

2.9.5   Interview process

Once a participant indicated they were comfortable to begin, I used the following open-ended questions to initiate the interviews:

- When you think about your time in ICU, tell me about the things that enabled you to make sense of the ICU experience and in so doing, move through it.
- Tell me about the things that made your experience more positive and what made your experience more negative.
- Tell me about your experiences of being cared for during your time in ICU.

I was guided by the responses of the participant and where I felt it necessary, used communication skills to gain deeper insight into the participant's answers.

I aimed to encourage the participant to elaborate on the topic at hand. Following the knowledge gained from Lloyd, Bor and Noble (2010:20), I focussed on listening

effectively in order to encourage the participant to explain what they had come to talk about during the interview. Clarification is asking a person to clarify what has been said. I clarified statements made by the participant in order to be sure I understood what the participant was saying. I also reflected back on what the participant was saying which allowed the participant to really know I was listening and engaging attentively.

Reflection in an interview context means to reflect back what a person has said, which shows that you are listening and thus encourages the participant to continue. This is helpful particularly when a person might be finding it difficult to go on because of their feelings. Silent periods may make us feel uncomfortable and there can be a temptation to rush in to fill the gap. However, silences give both myself and the participant the time to reflect on what has been said. Pauses in a conversation help people to remember what they want to say, or what they want to ask. Taking a moment to take stock also helps in making the transition into the next stage of the conversation. People generally want to feel listened to and understood. I aimed to accurately identify another person's feelings and experiences and communicate that understanding back to the person.

An audio recording device and a cellular telephone with recording capabilities were used to record the interviews with permission from the study participants. This allowed a much fuller record than notes taken during the interview (De Vos *et al.*, 2009:298). It also allowed me to limit the distraction of note taking. Both the audio recording device and the cellular device were placed in a space that was easily seen by and accessible to both the researcher and the participant. Verbal and written permission had been obtained from each participant for the recording to occur prior to the recorder being switched on. The audio-recorded interviews were transcribed word for word, verbatim, solely by myself into a Microsoft Word document from the tape recordings. No transcribing programme or technology was used for this process other than a laptop and a Microsoft Word document. I am fluent in reading, writing and speaking both Afrikaans and English. I listened to the recordings while reading the written transcripts and in so doing, began the process of becoming immersed in the data being collected.

The interview recordings were immediately deleted from the cellular telephone and the audio-tape recorder once the transcriptions were completed. A copy of all the transcribed material and related documents were kept in a safe, locked cabinet my home to ensure privacy and confidentiality. Data and related documents were kept until the research study was completed after which they were destroyed. My study supervisor and I were the only ones with access to the locked cabinet.

2.9.6   Reflection

According to Shosha (2012:32), one of the important rules of descriptive phenomenology is reflection by a researcher during the research process. Here, a researcher must affirm their own personal prejudice and beliefs about the phenomenon under study and put them aside. The aim of this it to keep what is already known about the description of the phenomenon by the researcher separate to the participant's description. This process assists a researcher to limit imposing their assumptions on the data collection and analysis processes or the structure of the data.

I am a critical care trained registered nurse with ten years of intensive care nursing experience. Adjacent to the interviews taking place, my mother experienced a hospital admission and stay for elective surgery and I became intimately and personally involved with her treatment plan and recovery phase.

I used a reflective diary to write about my own personal beliefs, experiences and assumptions about the phenomena under study. In this diary, I described how it felt having my mother looked after in hospital, reflecting on the intensive care my mother received and the work ethic I experienced while my mother was in the ICU. Reflection helps to gain insight into the common features of any lived experience and limits bias inherent in researcher beliefs and attitude (Shosha, 2012:41). According to Mortari (2015:2), no impartial observer can enter the research field without an interpretive frame of reference. What I see and hear as the researcher depends on my pre-understandings. I felt connected with each participant during the interview process, while they were telling their stories and for this reason, made use of a reflective diary to reflect on these interview sessions and as a way to disconnect from the experience. Reflection is a way to ensure validity of data collection and analysis, maintain the

objectivity of the phenomenon and to make the politics of research transparent (Mortari, 2015:2).

2.10   DATA ANALYSIS

The analysis of data in qualitative research is determined by the purpose of the study. The researcher used Colaizzi's method of thematic content analysis. Phenomenology wants to discover the essential elements of a particular phenomenon. Colaizzi (1978) argues that thematic content analysis allows for the description of lived experiences which serves as the foundation for discovering the essential elements of the phenomena being studied. The description of the lived experience occurs through the building of words with similar meanings into themes (Saldana, 2009:13). The aim in applying Colaizzi's strategy in this descriptive phenomenology study was to elicit an exhaustive description about the phenomena being studied.

I used Colaizzi's method of thematic content analysis as a coding process. A coding process is the building of words with similar meanings into themes. A theme is a phrase or sentence that identifies what a unit of data is about and what it means. It describes and organizes possible conversations and interprets aspects of the phenomenon under study. A theme functions as a way to categorize a set of data into an implicit topic that organizes a group of repeating ideas (Saldana, 2009:139).

The coding process for this study was guided by Colaizzi's seven-step method to analyse data included the following (Colaizzi, 1978:48-59):

- Each transcript was must be read and re-read to acquire a feeling for the content.
- Review each transcript and extract significant statements.
- Formulate meanings from each significant statement.
- Organize the formulated meanings into clusters of themes.
  - Refer these clusters back to the original transcripts to validate them
  - Note discrepancies among or between the various clusters avoiding the temptation of ignoring data or themes that do not fit
- Integrate results into an exhaustive description of the phenomenon under study.

- Formulate an exhaustive description of the phenomenon under study in as unequivocal a statement of identification as possible.

- Ask the participants about the findings thus far as a final validating step to compare the researcher's descriptive results with their experiences. This step aims to validate study findings using a "member checking" technique. Participants' views on the study results are obtained and discussed via telephone. Where necessary, new findings from these conversations should be integrated into the final description of the interviewee's experience.

The first three interviews were transcribed in 2015 and analysed by myself before travelling abroad and discontinuing the research. The last 3 interviews were transcribed and analysed by myself after the last interview transcription was completed in 2018. The first 3 interview transcriptions were analysed again along with the last 3 transcriptions which allowed me to become immersed in their content and reinforced this immersion in the data while transcribing the first 3 interviews back in 2015 (Images 2.1, 2.2 & 2.3). The above described steps were applied to the data collected from the six participants. Each interview transcript was read line by line to elicit "what's happening here" (Schlegel, Bonvin, Rethans & Van der Vleuten, 2016:280). This was important in order to become familiar with the story the participant was sharing with me. I made notes in my reflective diary and on the interview transcripts on ideas as they emerged from the data. Through iterative reading and re-reading of the transcripts a number of significant statements emerged from the data. A significant statement is a quote taken from the interview transcript describing something significant that either enabled the participant or hindered the participant making sense of their ICU experience.

These significant statements were clustered into groups of similar statements that spoke to different ideas around what enabled a patient to make sense of their ICU experience, which were forming from the interview transcripts. From this process, meanings from the significant statements were formulated and ultimately these coalesced into three overarching themes. Saldana (2009:139) explains that a theme is an outcome of coding, in this instance the significant statements and clustering

process, thus a theme is a phrase or sentence that identifies what a unit of data is about and what it means.

Table 2.2:   Examples from the significant statements coding table

Significant statements coding table			
Significant statement	**Transcript (T)**	**Page (Pg)**	**Paragraph (Pr)**
"Once I was reassured I wasn't going to die, I felt fine" (ShelleyT3Pg2Pr6). "It was comforting to know that this little bump is blimping across there comfortably and it wasn't flat-lining or anything" (ShelleyT3Pg10Pr72).	T3	Pg10	Pr72
"Well emotionally I think I was putting on a brave face. I was to a certain extent putting up a front of trying to be brave" (MatthewT2Pg2Pr20).	T2	Pg2	Pr20
"The anaesthetist spoke to me slowly and very carefully, through every step. I'm going to remove this pipe now. I'm going to change this setting and what you will feel is this. There was that reassurance of ok, cool, I'm conscious of the fact that you may be worried about these things, but don't worry, I've got you" (JohnT6Pg1Pr5).	T6	Pg1	Pr5

I searched for words or codes in the interview transcriptions that spoke to the lived experience being studied. Codes were drawn from quotes or significant statements participants made within the interview transcriptions. Meanings were formulated from the significant statements drawn from the participants' descriptions of their lived experiences and then arranged into sub-themes and then themes.   Significant

statements triggered formulated meanings.   The following table describes this process:

Table 2.3:   **Examples of formulated meanings created from significant statements**

Formulated meanings created from significant statements	
Significant statement	**Formulated meaning**
"*I was happy and confident that if anything was going to happen there was staff that could look after me in an efficient manner*" (MatthewT2Pg6Pr56). "*I was a bit anxious at night but I was reassured because the shift leader or one of the senior people was working*" (MatthewT2Pg3Pr26). "*I felt safe. I didn't feel unsafe. I didn't feel concerned. I didn't feel frightened. I did feel cared for*" (ShelleyT3Pg6Pr26).	<u>The safe space</u> The safe space seems to be a space where the participant felt cared for, felt at ease, felt protected, felt strengthened, felt they were able to make sense of their ICU experience and move through it
"*You can take the positive out of it and you can say man, there's a reason for me to be there and it's good. That's the difference*" (MarkT4Pg15Pr196). "*It's all about the person and how you treat yourself in there. It's actually quite simple. I always knew that I was sick but I wasn't sick. Verstaan jy?*" (LukeT5Pg10Pr102). "*Well emotionally I think I was putting on a brave face. I was to a certain extent putting up a front of trying to be brave*" (MatthewT2Pg2Pr20).	<u>My headspace</u> My headspace described the participant's attitude towards being in ICU and having to endure the experience. This formulated meaning spoke to the participant's willpower and emotional and psychological tools they used to enable them to make sense of their experience.
"*I can't speak to you. I can't tell you what's wrong with me and what kind of special needs I may have. I know that you won't*	<u>The darker side</u> The darker side encompassed the things that hindered the participant making sense

Formulated meanings created from significant statements	
Significant statement	**Formulated meaning**
know because to you I'm just another patient. And it's terrifying. Because you are helpless in ICU. You can't fight back. You are a passive receiver of action" *(JohnT6Pg6Pr41).* *"You go into a ward, they don't care or they don't appear to care. They're all running past themselves" (ShelleyT3Pg8Pr48).* *"People don't touch you. And I'm saying please come and touch me. Once I was lying there crying one day and I couldn't move and just crying, crying"* *(MarkT4Pg7Pr82)*	of their ICU experience and moving through it in a more positive way. This included moving from ICU to the ward setting.

Table 2.4:   Example of how "the safe space" theme was constructed

Theme: The safe space		
Theme clusters built from formulated meanings	**Examples of codes building to theme cluster**	**Example of significant statement from data**
Feeling safe More care in ICU Feeling at ease	Reassurance Hope Faith Informed	*"I felt safe. I didn't feel unsafe. I didn't feel concerned. I didn't feel frightened. I did feel cared for" (ShelleyT3Pg6Pr26).*
I've got you Encourage a feeling of normal	Feeling cared for Trust Grace	*"The anaesthetist spoke to me slowly and very carefully, through every step. There was that reassurance of ok cool, I'm conscious of the fact that you may be worried about these things but don't worry, I've got you" (JohnT6Pg2Pr5).*

Once the coding process was completed and confirmed with the co-coder, I made contact with four of the participants telephonically to validate whether the emergent themes represented those things that enabled them to make sense of their ICU experience. The participants confirmed that the themes and descriptions offered did capture their lived experiences.

"The safe space" describes the patient's perceptions of being cared for while moving through their ICU experience and encompassed aspects that allowed the patient to feel safe, feel cared for, feel protected and feel at ease, thus enabling them to make sense of their experience of ICU.

"I know I matter" described the patient's perceptions of the care received from the caregiver and by the different and continuous evidence of how involved the people caring for them were, and how this enabled them to make sense of their experience.

"The darker side", describes patients' perceptions of the things that hindered them making sense of their experience, thus making it more difficult to move through their experience. The findings within these three emergent themes will be further elaborated on in the next chapter.

From the findings of this study, discussed in detail in Chapter 3, it seems that people make sense of the experiences in ICU through coming to know that they are safe despite the often overwhelming and chaotic ICU environment. Their knowing they were safe was mostly held in the various ways and means that they felt cared for. This feeling of being safe is reinforced through their coming to know that they matter by the different and continuous evidence of how involved the people caring for them were in their situation and health status quo. There are also particular aspects that undermine a person being able to make sense of their experience, the darker sides of an ICU experience.

The study offers healthcare professionals an understanding of the ways to support the patient to move through the experience and make the experience more tolerable. The study will be beneficial to all healthcare personnel who offer care that is influenced by

insights from this work and enable a patient to make sense of, tolerate and move through an experience of intensive care.

2.11   DEMONSTRATING TRUSTWORTHINESS

Trustworthiness in qualitative research is also known as rigor, which influences the perceived worth of research findings. Without rigor, research is worthless (Burns & Grove, 2009:54).   It is the qualitative researcher's responsibility to illustrate the richness of the data and to convey to the audience the relationship between the themes identified. This is essential in order to document the rigor of the research (LoBiondo-Wood & Haber, 2010:105).

Lincoln and Guba (1999) outline the following concepts of trustworthiness as described by Brink *et al,* (2006:118), and De Vos *et al,* (2011:421), which were consistently applied throughout this study.

2.11.1   Credibility

Credibility, also known as internal validity, is concerned with the accuracy and truthfulness of scientific findings (Brink *et al.,* 2006:118). I ensured the credibility of the study or the strength of the study by choosing study participants firstly purposively from the two intensive care units and secondly, by word of mouth about the study amongst nursing colleagues and study participants, thus making use of network sampling. These two broad ways allowed me to obtain a more heterogeneous sample which supported the study's trustworthiness and in particular transferability of the study findings. The participants all experienced an ICU admission and a variety of stressors during their ICU stay. My study supervisor was consulted to ensure that the topic was accurately identified and described according to content, research process and outcome.

One of the best methods to establish credibility is through prolonged engagement with the subject matter (Streubert & Carpenter, 2011:48) and this occurred during the individual unstructured interviews I held with each of the participants. The interviews were recorded and transcribed word for word from the tape recordings and I became

immersed in the content of the transcriptions while reading and re-reading them. I also listened to the recordings and read the written transcribed text simultaneously, making notations of observations on the transcript (Burns & Grove, 2011:85). I then went back to the participants telephonically to ask their perspective as to whether the data analysis remained true to their experiences, reflecting what they had said. I aimed to elicit context rich and meaningful descriptions from the study participants with the posed questions and the advantages of the interactive processes in the interviews.

2.11.2 Transferability

Transferability or fittingness in qualitative research is concerned with providing a detailed thick description of the data so that someone else can determine whether the findings of the study are applicable in another context or setting (Brink *et al.,* 2006:119). This is also known as external validity.

In order to acquire a sense of transferability, I provided a rich description and explanation to illuminate the context, data sources, data management and analysis. In this way the research becomes open to others reading it and allows them to determine whether they can transfer the study findings to their own context. I referred back to the person-centred nursing conceptual framework which is the foundation for this study, with the hope of creating a discussion document with the content explored in the interviews. Limitations in this study were clearly described which aids transferability.

2.11.3 Dependability

Dependability is important to trustworthiness because it establishes the research findings as consistent and repeatable. Researchers aim to ensure that their findings are consistent with the raw data they collected. They want to make sure that if other researchers look at the data, they would arrive at similar findings about the data.

Establishing dependability in a study requires an audit. To facilitate dependability, an enquiry auditor or assessor, usually a peer, will follow the development and

procedures used by the researcher in the study and establish whether they are acceptable, in other words, dependable and trustworthy (Brink *et al.,* 2006:119).

In order to do this a clear and detailed description of the study was provided to allow the actions and processes applied in the study to be transparent and open to discussion. My supervisor functioned as the auditor throughout the process of this study.

A dense description was given about the research methodology and the data collected. Data was organised into themes and subthemes. All interview materials, transcriptions, documents, findings, interpretations and recommendations were kept, and any other material relevant to the study made available and accessible to the supervisor and any other researcher, for the purpose of conducting an audit trail.

2.11.4 Confirmability

According to Brink *et al*, (2006:119), confirmability guarantees that the findings, conclusions and recommendations are supported by the data and that there is internal agreement between the investigator's interpretation and the actual evidence. This is also accomplished by incorporating an audit. I developed and maintained a detailed record of the raw data, analysis, and notes taken. Transcribed data was verified between myself and my supervisor by "member-checking" to ensure the accuracy of their data.

2.12   ETHICAL CONSIDERATIONS

Ethical codes and regulations have been developed to provide guidelines for the selection of the study purpose, design and subjects; the collection and analysis of data; the interpretation of results; and the presentation and publication of the study (Burns & Grove, 2009:184).

Inherent in all research is the demand for the protection of human subjects (LoBiondo-Wood & Haber, 2010:117). The Nuremberg Code and the Declaration of Helsinki provide the foundation for numerous ethical research guidelines developed by

government and professional organizations involved in the conduct of research on human subjects all over the world (Brink *et al.*, 2006:30).

Permission to conduct the research was obtained from the Health Research Ethics Committee at the Faculty of Health Sciences, Stellenbosch University (see Annexures 1 & 2), and the Ethics Committee of the chosen private hospital group's head-office and their nursing education institution (see Annexures 3, 4 & 5). Permission to access the private hospital was obtained from the hospital manager, the nursing manager and the unit managers of both the ICUs and the wards. Permission to gain access to the participants outside of the hospital setting was given via word of mouth from the participants to the researcher's nursing colleagues.

Informed consent included written disclosure of essential study information to the study participants (see Annexure 6). I ensured that the participants understood the research study, what is expected of them in participating and what I aimed to achieve by conducting the research prior to their signing consent. By signing the consent form, participants consented to audio-tape recordings and cellular device recordings of the interviews. The participant chose where they felt most comfortable having the interview which was also dependent on the participant's mobility and recovery process. Participation in the study was voluntary and the participant was assured they could withdraw from the study at any point without any repercussions.

There are three fundamental ethical principles that guide researchers, namely, respect for persons, beneficence and justice. I adhered to these principles strictly throughout the course of the research study. These principles are based on the human rights that need to be protected in research, namely, the right to self-determination, to privacy, to anonymity and confidentiality, to fair treatment and to being protected from discomfort and harm (Brink *et al.,* 2006:31).

2.12.1   Respect for the autonomy of participants

Participants are autonomous beings and have a right to decide whether or not they want to participate in the study, without the risk of penalty or prejudice. Participants took part and contributed to this study voluntarily. All of the participants were treated

with respect for their dignity as individuals. The identity of the participant was protected to respect the principles of confidentiality and privacy. I asked each participant to provide me with a pseudonym during the interview process which I used to identify all data relevant to that person. Only the participant and I knew the identity of the person labelled with the particular pseudonym. Study participants indicated their willingness to participate in the study privately.

2.12.2 Justice

This principle includes the participant's right to fair selection and treatment (Brink *et al.*, 2006:33). The participants were selected for reasons directly related to the study phenomena and not because they were readily available or easily manipulated. Participants had to meet a certain set of inclusion criteria before they were invited to participate in the study. Participants were provided with clear information regarding the study and chose to participate by their signing an informed consent document. No incentive was offered for participation. The interviews were conducted in an area the participant felt most comfortable in.

2.12.3 Beneficence

The participant has a right to protection from discomfort and harm and the wellbeing of the participant will always remain secure (Brink *et al.,* 2006:32). I respected this principle by ensuring that no discomfort or harm came to any of the participants during the course of the study. Although qualitative research is often regarded as "non-invasive" because it involves neither interventions nor treatment, qualitative researchers nevertheless enter the participants' lives (Brink *et al.*, 2006:33). All data collected during the study remained confidential and the participant's right to privacy was always respected. I ensured the participants' identities were kept secret with regard to their participation in the research. The transcribed voice recordings were saved and labelled with a pseudonym in order to hide the participant's true identity. A copy of all the transcribed material and related documents is still kept in a safe, locked cabinet at my home to ensure privacy and confidentiality. The cellular telephone used to record the interviews belonged solely to me and was kept safe on my person at all times. The cellular telephone was never used by any other persons except myself

throughout the duration of the data collection and data transcription phases. This is how I strived to protect the recordings. The interview recordings were immediately deleted from the cellular telephone and the audio-tape recorder once the transcriptions were completed. I also ensured that a comfortable and welcoming space was created and maintained for the interview process.

2.13   QUALITY OF THE RESEARCH

I adhered to standards of evaluation, planning and implementation of the project as approved by the HREC. The research was conducted meaningfully with a contribution to the improvement of nursing practice. Permission was given from the Health Research Ethics Committee at the Faculty of Health Science, Stellenbosch University. I successfully completed Research Methods and Contemporary Health Nursing Practice modules at Stellenbosch University and full supervision was available throughout the research process.

2.14   CONCLUSION

By gaining insight into the attributes or qualities of an intensive care experience that enabled a patient to make sense of and endure the encounter, critical care nurses will be better able to adapt care and interventions to facilitate a more tolerable experience of intensive care for a patient.

Chapter 2 described the research design and method, population and sampling, data collection approach and instrument, data analysis, ethical considerations and demonstration of trustworthiness of the research data. In this study, attributes and qualities of an intensive care experience that enabled a patient to make sense of and endure that encounter were explored. Chapter 3 presents the research findings and literature integration.

CHAPTER 3
FINDINGS AND LITERATURE INTEGRATION

3.1   INTRODUCTION

In this chapter, the findings drawn from the study are presented. A detailed discussion as to how these findings were elicited through applying descriptive phenomenology as the research approach and design, and the methods that were applied in this study were provided in Chapter 2.

In qualitative data, some interpretive leeway is necessary (Saldana, 2009:150). Meanings were formulated from the significant statements taken out of the interview transcriptions which described the participant's lived experience of what enabled them to make sense of their ICU experience. My goal was to be the instrument through which the participant could tell their story. The findings presented in this chapter are supported by quotes from the participants and are integrated with relevant and accessible literature.

3.2   LITERATURE INTEGRATION

Literature integration is the process of incorporating literature that speaks to and supports the study findings. In this study a broad-based literature review was conducted during the proposal development in order to substantiate the need for this study to be done. However, a more focussed review was conducted once the data analysis had been completed because I looked to find literature that would speak to the study findings. The findings from this latter more focussed literature review were used to contrast, highlight and situate the study findings within the current body of discipline knowledge related to the study topic. In this chapter the relevant literature is integrated into the discussion of each theme to provide a substantial and expanded understanding of the study findings.

My intention in this literature review was to identify, explore and describe similar studies and subjective health experiences relevant to the study focus in order to gain

a deeper understanding of their shared meaning. A literature review was conducted to identify relevant published scholarship. A literature review is a broad search of relevant, fitting literature related to the research topic at hand and aims to provide a strong knowledge base and theoretical foundation for the conduct of the study (Burns & Grove, 2007:545). Researchers are confronted with a vast amount of literature and are tasked with making a specific selection and focussing on only that which is relevant to their particular research project (Brynard, Hanekom & Brynard, 2014:33). This involves searching, collating and summarising results of the studies to establish if there were links (Smiddy, O'Connell & Creedon, 2015:269).

Both national and international literature concerning adult patient perceptions and experiences of an intensive care admission within an adult intensive care environment and how these patients endured and overcame these experiences were included in the review.

Literature was identified through conventional searches of the library at the Faculty of Medicine the Medical Library (Stellenbosch University), a public library and computerised literature searches of electronic databases. Keywords used in the initial search included: intensive care patient, intensive care unit, intensive care nursing, intensive care experiences, critically ill patient, ICU admission, make sense of, enable, tolerate, mechanical ventilation, sedation, analgesia, intensive care stressors, communication, patient interventions, family. The material selected for the literature review consisted of books and journal articles covering a period of 33 years from 1985 to 2018.

To meet the objectives of this literature integration review, the relevant literature was approached from two distinct but interwoven pathways that were informed by the themes and sub-themes that emerged from the data. Firstly, I wanted to understand the obstacles or challenges the patient was faced with when admitted to an intensive care unit. Secondly, I wanted to discover what enabled the patient to face, endure and overcome those challenges.

The relevant literature is presented within the discussion of each emergent theme that follows.

3.3   EMERGENT THEMES

As explained in Chapter 2, the research findings from this study emerged from the data provided in interviews with the participants. The interviews' transcriptions were analysed using Colaizzi's approach to data analysis and poured over multiple times by myself in order to become immersed in the value of their content.

Significant statements were drawn from the transcriptions which the researcher found supported the research phenomena under study. Codes or words with similar meanings were drawn from the significant statements and grouped together into formulated meanings and eventually into emergent themes.

A theme is an outcome of coding, categorisation and analytic reflection (Saldana, 2009:139). Through this process, the emergent themes offer a rich and extensive description of what enabled participants to make sense of their ICU experience. Three themes emerged to describe how participants are able to make sense of their ICU experience. Table 3.2 summarises these themes with their related subthemes, formulated meanings and codes drawn from significant statements in the data.

In the following discussion, the emergent themes are presented with an overview description of the theme and contributing elements with supporting quotes drawn from the transcriptions and an integration of relevant literature. In the discussion, quotes from the transcripts are referred to with the following demarcations which guide the reader to where the quote can be found in the relevant transcript:

Table 3.1:   Demarcation table

Transcript	T
Page	Pg
Paragraph	Pr

The final thematic map illustrating the themes for this study is presented below:

Table 3.2:   Final thematic map

EMERGENT THEME 1: THE SAFE SPACE		
Subthemes	**Formulated meaning**	**Codes**
Inside the safe space	Walk their talk and talk their walk Trusting the caregiver "I've got you" Feeling at ease Feeling cared for Family presence	Feeling safe Relationships ICU environment More care in ICU Time bound stay Reassurance Comfort Hope Faith Information Empowered Strength Brave
Outside the safe space	"Going from the fat into the fire" Being sucked into a vacuum Don't appear to care Time-space disconnect Putting on a brave face and "fake it until you make it" Feeling vulnerable and helpless Being released	Running Brave face Scared Helpless vulnerable
EMERGENT THEME 2: I KNOW I MATTER		
Subthemes	**Formulated meanings**	**Codes**
Feeling cared for **My headspace**	Relationships and connection "It's all about the people" "It's humbling without being humiliated" Grace and recalibration "I've got you"	Comfort Informed patient Being nice At ease People Relationships

		Connection
		Humility
		Mind-set
		Pep-talk
EMERGENT THEME 3: THE DARKER SIDE		
Subtheme	**Formulated meanings**	**Codes**
Caring fails	At the mercy of the caregiver Feeling powerless "You're just a blob" "I can't tell you what's wrong with me"	Discrimination Powerless Depersonalised Loss of identity Prejudice Intolerance

These significant statements were clustered into groups of similar statements that spoke to different ideas around what enabled a patient to make sense of their ICU experience, which were forming from the interview transcripts. From this process, meanings from the significant statements were formulated and ultimately these coalesced into three overarching themes. Saldana (2009:139) explains that a theme is an outcome of coding, in this instance the significant statements and clustering process, thus a theme is a phrase or sentence that identifies what a unit of data is about and what it means.

It is evident from these main themes that the data generated from the participant interviews gave a rich and in-depth description of the research question, "What enabled you to make sense of your ICU experience and move through it?" The findings are presented in the following discussion.

The discussion that follows will take form and be set out in a specific structure so as not to lose the reader and also provide a way of keeping the golden thread flow of the discussion, flowing in the most congruent way possible. Each theme will be discussed noting the emergent theme first, then the subthemes the emergent theme grew from, and finally the codes and formulated meanings that evolved out of the significant statements drawn from the participant interview transcripts. By setting out the

discussion this way, I hope to keep the reader involved with the content and keep the golden thread flowing through the discussion so that the reader is able to grasp exactly what the participant is telling them.

Code words were drawn from significant statements or quotes taken from the interview transcripts describing something significant that either enabled the participant or hindered the participant making sense of their ICU experience. Grouping code words together created formulated meanings which will be discussed in detail.

3.3.1   Emergent theme 1: The safe space

The safe space seems to be a space where participants felt cared for, felt at ease, felt protected, felt strengthened, felt they were able to make sense of their ICU experience and move through it. This theme is described by the two subthemes it was built up by, namely "inside the safe space" and "outside the safe space". According to Mollon (2014:1729), feeling safe is an emotional state where perceptions of care contribute to a sense of security and freedom from harm. Participants voiced their need to feel cared for and by feeling cared for, they felt safe. Feeling cared for became a formulated meaning encompassing many code words which supported this growing theme. These codes included feeling reassured, feeling comforted, feeling secure, feeling hopeful and being kept informed.

3.3.1.1 Subtheme: Inside the safe space

This subtheme describes the participants' experiences whilst being cared for within the ICU environment and how they perceived the ICU to be a safe space and describes what they found helped them recognise the ICU as a safe space. A number of code words were drawn from the transcriptions which, when grouped together, grew into formulated meanings which in turn grew into the subtheme of "inside the safe space" and eventually the theme of "the safe space" as a whole. Code words included relationships, feeling safe, the ICU environment, the perception of more care in ICU, the ICU stay being time bound, reassurance, being kept informed, feeling empowered, strengthened and brave, and the awareness of family presence.

- Formulated meaning: Walk their talk and talk their walk

Walking their talk and talking their walk encompassed the relationship building between the caregiver and the participant. Trust was established between participant and caregiver, allowing the participant to feel at ease. Feeling at ease strengthens and enables the participant to make sense of their experience and move through it.

Patients relate competency to the technical skills staff perform as part of their job, in addition to their knowledge demonstrated in their interactions and relationships with the patient (Mollon, 2014:1731). Feeling safe meant that they were cared for by members of staff who had a high level of training and skill, seniority and experience. Staff members were recognised as people who knew what they were doing, able to walk their talk. Here, the formulated meaning of "walking their talk and talking their walk" came into being. This assumption is supported by the quotes that follow.

"*I was happy and confident that if anything was going to happen there was staff that could look after me in an efficient manner*" (MatthewT2Pg6Pr56).

"*I was a bit anxious at night but I was reassured because the shift leader or one of the senior people was working*" (MatthewT2Pg3Pr26).

"*I felt safe. I didn't feel unsafe. I didn't feel concerned. I didn't feel frightened. I did feel cared for*" (ShelleyT3Pg6Pr26).

"*The physician would come and speak to me and say this is the plan. He turns around and the nurse would come and she turns around and she says, just wanna make sure that you heard what he said, the plan is this and, you know, it was just, she's on board, she knows what he's saying. I can ask questions and she's up to date and she knows the environment and she knows the routine. There's just so, you know, that communication. The skill level was very positive*" (MarkT4Pg9Pr88).

"*I'd seen this sister in action with the doctor, you know, she's not scared of anyone. So that was cool. It's like having a feeling of a mother bear as a protector*" (JohnT6Pg3Pr15).

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"I was reassured because I knew there was someone I could rely on. Someone I knew I could rely on and was keeping an eye out" (MatthewT2Pg3Pr30).

The transcriptions gave me a sense of what the participants saw in a caregiver who was able to walk their talk and talk their walk. From the participants it seems that trust forms when a patient can see that a caregiver is competent and at ease in fulfilling their role and being who they are when they are content within themselves. Participants felt safe when their psychosocial needs were met by the caregiver and when caregivers could intuitively understand what needed to be done for the patient. Trust is related to a patient's perception of safety (Schaepe & Ewers, 2017:951).

It is essential for the caregiver to be familiar with the perceived needs of the critically ill patient. Nurses who approach patients only to deal with administrative or functional activities may adversely affect the development of a positive nurse patient relationship that is essential for the provision of quality patient care (McCabe, 2004:42). This is important in preventing tedious experiences and providing patient-centred care. "Being there is grounded in the caregiver's attentive attitude towards the patient and can be understood as an answer to a need expressed by the patient (Schaepe & Ewers, 2017:953). ICU patients consider the nurses' expertise and technical skill as important (Wassenaar, evan den Boogaard, van der Hooft, Pickkers & Schoonhoven, 2015:3234).

"It's got a lot to do with the people and yourself obviously, and the doctors. Everyone knew what they were doing. They were genuinely well trained, doing their thing and being available and people just said aaaaah and they would be there" (LukeT5Pg17Pr186).

- Formulated meaning: Trusting the caregiver

The transcriptions elicited a sense of trust in a caregiver when they were able to show the participant they could walk their talk and talk their walk. The caregiver showed confidence in their ability and behaved in a way that made the participant believe they were comfortable in their own skin or role of being a caregiver, knowing where they fit and knowing how to hold themselves. It showed in how they interacted with people around them. The participant could see that the caregiver was confident and

competent in their ability through the way they worked and through their way of being. Seeing this, the participant decided to give the caregiver a chance to convince them that he or she actually was competent. This in turn created a need for the patient to connect with the caregiver and then the relationship strengthened.

The participant did not automatically trust their caregiver, but did allow their caregiver the opportunity to convince them they could be trusted. The trust at this stage seemed tenuous and fragile. When the caregiver knew what they were doing, could explain to the patient what they were doing and did explain to the patient what they were doing, the patient felt reassured that the caregiver could talk their walk and walk their talk.

- <u>Formulated meaning: "I've got you"</u>

It would appear that trusting the caregiver enabled the participant to make sense of their ICU experience and move through it. Receiving information constantly from caregivers who had proved to the patient they knew what they were doing, telling the patient that they were going to be ok was very important for the patient to know that they were safe and could feel at ease and enabled to make sense of the experience. This was illustrated beautifully in the quotes that follow.

> *"The anaesthetist spoke to me slowly and very carefully, through every step. I'm going to remove this pipe now. I'm going to change this setting and what you will feel is… But then I will take over with the ambubag. There was that reassurance of, ok cook, I'm conscious of the fat that you may be worried about these things but don't worry, I've got you" (JohnT6Pg1Pr5).*

> *"Try to mirror the heartbeat in your interaction with the patient. If you speak to them, try to get a taupe that's kind of the same measuredness as a heartbeat. It instils comfort or reassurance" (JohnT6Pg9Pr55).*

- <u>Formulated meaning: Feeling at ease</u>

Once the participant was assured of their caregiver's ability and sense of being comfortably and competent in their own skin, they could feel at ease and start to trust them so it seems as though trust may be interwoven with feeling at ease. Drawing

these threads together it's possible to assume that the overwhelming experience that helps participants make sense of this seems to be held in the notion of I am safe.

"The anaesthetist spoke to me slowly and very carefully, through every step. I'm going to remove this pipe now. I'm going to change this setting and what you will feel is… But then I will take over with the ambubag. There was that reassurance of, ok cook, I'm conscious of the fat that you may be worried about these things but don't worry, I've got you" (JohnT6Pg1Pr5).

"Try to mirror the heartbeat in your interaction with the patient. If you speak to them, try to get a taupe that's kind of the same measuredness as a heartbeat. It instils comfort or reassurance" (JohnT6Pg9Pr55).

"Mens moet net almal at ease laat voel. Want as jy in ICU le, is dit in elk geval baie sleg" (LukeT5pg13pr136).

Complex care is inherent to treatment in an intensive care unit due to the combination of its invasive nature and the use of extensive technical equipment (Wassenaar *et al.*, 2015:3234). Environmental elements in the ICU reassured the patient that they were alive and gave them tangible proof that they were going to be ok which in turn made them feel at ease. Being attached to monitoring devices and being watched also created a sense of security and safety. This assumption is supported by the following quotes.

"Once I was reassured I wasn't going to die, I felt fine" (ShelleyT3Pg2Pr6).

"It was comforting to know that this little bump is blimping across there comfortably and it wasn't flat-lining or anything" (ShelleyT3Pg10Pr72).

"Hearing alarms in the background was comforting" (ShelleyT3Pg10Pr61).

"I must admit, you know, in some sense, the constancy of the sounds is quite comforting. The sound of the machine is a sign that that person is alive" (AllisonT1Pg8P108).

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> *"You know how you get that feeling, I knew I was going to be ok"* *(ShelleyT3Pg2Pr6).*

> *"There's something comforting that in this space of total uncertainty there's something that's measured about the beating of a heart and the sats monitor's blip, blip, blip. I was in an isolation room so I couldn't hear any other monitors except my own and that was comforting"* *(JohnT6Pg6Pr31).*

An ICU sets the tone of a rushed sense of pace in a crowded space. The ICU setting holds many physical features like blinking monitors, ventilators, intravenous infusion pumps, noise from equipment and the many disciplines talking at the bedside, bright lights, and a rushed sense of pace in a crowded space (Fontaine & Gonce Morton, 2009:37)

The participants in this study said they felt safe in this crowded space, as described by Fontaine and Gonce Morton (2009:37). Elements in the environment acted as confirmation for the patient and reassured the patient that they were still alive. Seeing, hearing and being attached to something physical acted as a safety rope to a notion of feeling safe and that they would make it through the experience of ICU.

Creating an environment where patients feel safe and secure is a major goal and the nurse is in charge of creating that physical and emotional tone (Fontaine & Gonce Morton, 2009:36). The original concept of the healing environment was developed by Florence Nightingale whose theory of nursing called for nurses to manipulate the environment minimize suffering, and optimize the capacity of a patient to recover, including quiet, warmth, clean air, light and good diet. She claimed that sounds that create anticipation, expectation, waiting, and fear of surprise damage the patient (Healing Environments, 2014). Patients experience a positive outcome in an environment that incorporates natural light, elements of nature, soothing colours, meaningful and varied stimuli, peaceful sounds and pleasant views. Less pain medication is needed and a faster recovery may occur when careful attention is given to providing a soothing environment (Fontaine & Gonce Morton, 2009:38).

- <u>Formulated meaning: Feeling cared for</u>

The value of the presence of another human being is closely linked to the concept of feeling safe (Mollon, 2014:1731). Intensive care nurses are always at their patients' bedside looking after them and coordinating their care. ICU patients are almost entirely dependent on them during their treatment, monitoring and care (Wassenaar *et al.,* 2015:3234). Participants said they felt reassured and strengthened when caregivers talked to them. This gave them a more positive mind-set and outlook on what they were going through, making them think that maybe they could do this after all and actually get through this chaotic event. The quotes that follow illuminate this element clearly.

"Die groot ding is jy moet op jou gemak wees en jy was. Jy't interaksie gehad met die mense en dit gaan absoluut oor die verhouding wat jy opbou met die personeel" (LukeT5Pg10Pr94).

"Dit is belangrik dat die pasient weet wat gaan gebeur en wat kom. Jy het nie a cooking clue wat daar aangaan nie want jy's so bekommerd oor wat gebeur het. Sy't presies verduidelik wat gaan hulle doen, wat gaan met jou gebeur, wat kom volgende" (LukeT5Pg12Pr116).

"And this nurse would phone her two, three 'o clock at night and say, listen the blood results are out, this is where we are, this is the plan and you know" (MarkT4Pg8Pr86).

"Weet jy as hy net gese het, het almal aangehardloop gekom en gehelp. Dit is so belangrik om nice te wees" (LukeT5pg13pr140).

"Dit maak dit lekker. Dit is soveel makliker. Jy is in 'n meer positief mindset. Hulle laat jou spesiaal voel. Jy is nou siek en kop onder die vlerk maar hulle laat jou sesiaal voel" (LukeT5pg13pr131).

Providing knowledge to the patient and their family about their current situation alleviates their fears and increases their feeling of emotional safety (Mollon, 2014:1731). Participants voiced that caregivers would allay their fears through talking,

keeping the patient informed about what was to happen next, keeping the family informed and up to date with the treatment plan and showing genuine care and concern created a sense of trust between them and their caregiver. Patient-centred communication invites and encourages the patient to participate and negotiate in decision making regarding their own care (McCabe, 2004:42).

"I was a participant in the conversation" (JohnT6Pg11Pr71).

Nurses play a vital role in alleviating patients' fears by facilitating familiarity, orientation, trust and security for them. Nurses can diminish negative effects of ICU stay through manipulating undesirable experiences in a therapeutic way and providing knowledgeable care to achieve optimal physical and psychological health (Alasad, Abu Tabar & Ahmad, 2015:859). The quote that follows supports this finding.

"The wall in front of me was all I could look at and they made sure that the wall was full of pictures of happy memories of my past, friends. And then someone would always be there and when they'd come to visit they'd ask me, what happened in this picture? What was the story here?" Having those links with what happened in the past was like an anchor, just made the whole chaos of ICU into something substantially positive" (JohnT6Pg3Pr17).

- Formulated meaning: Family presence

Critical illness combined with a family's lack of contact with the technology-laden ICU environment and the medical vocabulary and expressions used by the ICU-care team make the ICU admission of a family member an extremely stressful experience for the whole family (Chatzaki, Klimathianaki, Anastasaki, Chatzakis, Apostolakou & Georgopoulus, 2012:1832).   Family members often have difficulty coping with this stressful experience and they experience emotional turmoil worrying about the patient's recovery (Ågård, Egerod, Tønnesen & Lomborg, 2015:1893). The quote that follows supports the literature.

"Toe hy in die teater vir daai flippen elf ure operasie, ek sit by daai deur, ek gaan nerens nie. Maar weet jy, sy het binne teater to gebel en se vir my hulle het die gedoen en dit gekry, hy's ok. Dan gaan daar weer 'n uur verby dan se

sy maar gaan drink koffie dan wil ek net hier bly sit, dan se sy vir my wat gebeur het, dan bel sy, dan se sy vir hulle gaan nou dit doen, hulle het dat gedoen. So jy wil net die heeltyd op hoogte bly. Jy wil net weet alles gaan ok wees en dis erg maar dit gaan ok wees" (LukeT5Pg12Pr122).

The ICU environment is stressful to family members because of fear of the unknown, fear of death, fear of loss of a loved one, fear of recurrence of untoward events and loss of control in the setting of a life-threatening disease (Shukar & Khamaisi, 2018:99). The following quote supports the literature.

"On top of that, then an extra child in the house that can't walk. I couldn't go to the loo, you know. She had to do all the nursing care. So I think family support is something that is underestimated. How do we actually care for the family? Everybody came to visit at home and they said, how's Jack, how's Jack? And at some stage, she was just screaming. She says, what about me? What about me? Who's looking after me?" (MarkT4Pg12Pr138).

It appeared that the patient was enabled to make sense of their intensive care experience when they knew there was a certain time period linked to their stay in the ICU. Knowing the experience would end soon, being time bound created a sense of knowing that the experience was being broken down into manageable chunks and would end soon, that it would pass, and therefore, the patient was able to endure and make it through. This did not seem to be elicited in other studies and offers a new insight into what helps to make sense of the intensive care experience. This is supported by the quote that follows.

"I knew that it would only be 24 hours. I knew it was only going to be till the next morning. So I was reassured I'd be getting out shortly" (MatthewT2Pg6Pr56).

Empowering patients by promoting their self-care capability and autonomy reduced anxiety and fear amidst the noise and hustle of the ICU (Shukar & Khamaisi, 2018:99). This is echoed in the quote that follows:

there and that nobody came to talk to them. It seemed they felt they were being sucked into a vacuum which lead them to believe that people did not care. This hindered the patient being able to make sense of their experience, making it less tolerable for the participant.

- Formulated meaning: They don't appear to care

There was a sense that there was more care in an ICU and leaving the ICU, going from the fat into the fire, as one of the participants mentioned, was very disconcerting for them, leaving the perceived comfort of highly skilled caregiver and the sea of monitoring equipment they found themselves in and going to a place where the nurses were seen to be running and where there were many more patients than nurses in the care area, creating a sense for the patient that the nurse did not seem caring.

> *"I think you're going from the fat into the fire" (ShelleyT3Pg8Pr46)*.

> *"You go into a ward, they don't care or they don't appear to care. They're all running past themselves" (ShelleyT3Pg8Pr48)*.

> "*Wanneer ons in die gewone saal was het jy nie geweet wie's aan diens nie. Jy't daai mense nooit gesien nie. Niemand het vir jou kom se wat gebeur nou volgende nie. Ek dink dit is belangrik" (LukeT5Pg11Pr114)*.

- Formulated meaning: Time-space disconnect

It seems as though there was a delayed reaction to leaving, like a strange time-space disconnect between when the patient left the ICU and started to make sense of the experience. This created a barrier to making sense of her experience of ICU. Unresolved psychological distress affects a patient's motivation to engage in interventions to promote recovery after a critical illness (Choi, Tate, Rogers, Donahoe & Hoffman, 2016:145). One of the participants was overwhelmed at having no time before or during her experience to process what had happened to her.

> *"I don't really know, you see all the things that lead up to my operation, I had been diagnosed with cancer, I knew I was going for surgery. I had to get my*

life in order before I went for surgery. Everything up to the operation was just go, go, go. I never really had the time to kind of process everything and I think once I was in hospital, had the surgery, and now had time on my hands, you know, it gave me time to actually sit and think about everything that had happened over the last few weeks" (AllisonT1Pg12Pr171).

- Formulated meaning: "Putting on a brave face" and "fake it until you make it"

Another participant described a complete state of vulnerability when having to leave the ICU and transition to the ward. By feeling vulnerable, the participant put on a brave face and took on a brave persona which enabled him to make sense of his ICU experience, move through it and know that everything will be ok. He needed to know that he would be fine. The brave persona was strengthened when staff provided information and reassurance.

"Well emotionally I think I was putting on a brave face. I was to a certain extent putting up a front of trying to be brave" (MatthewT2Pg2Pr20).

Putting up a front and putting on a brave face, enabled participants to make sense of and move through their ICU experience. This is supported in the quotes that follow.

"I knew what was going on and I knew what the outcome would be. I knew what the potential dangers were" (MatthewT2Pg4Pr32).

Participants voiced their feelings of being scared and pretended to put on a brave face in order to convince themselves that they would make it through the chaotic and horrible time of being in the ICU. It seems as though putting on a brave face created a positive headspace and enabled the participant to make sense of the experience of being in ICU. "Fake it until you make it". Participants believed that if they were able to convince themselves that they would be ok, they could convince others they would be ok and because they were able to do that, they knew they were enabled to make it through the chaotic time. It came through in the transcriptions that when participants were kept informed and knew the outcomes and dangers of the current space they found themselves in, the more they could convince themselves that it was likely for them to make it through.

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Participants felt enabled to make sense of their experience when they were able to talk to others who had similar experiences helping them to understand that they were not alone and that their physical and psychological experiences were common among ICU survivors. Simply talking about what they went through helped them to come to terms with the experience.

- Formulated meaning: Feeling vulnerable and helpless

Participants who felt vulnerable also experienced an anxiety provoking feeling of being helpless. Learned helplessness is the acquired belief that one is unable to affect one's own fate or environment positively, leading to inaction and a feeling of absolute vulnerability (Brown, Azoulay, Benoit, Payne-Butler, Folcarelli, Geller, Rozenblum, Sands, Sokol-Hessner, Talmor, Turner & Howell, 2018:1389). Some participants seemed to experience a weakened sense of self-ability or "learned helplessness" when having all of their ICU support withdrawn in preparation for their moving to the ward. The participant struggled with the immense and overwhelming feeling of being vulnerable which in turn hindered them making sense of the event.

> *"What was much more traumatic was the discharge from ICU to the ward and being extubated, and the absolute vulnerability post. Like suddenly the anaesthetist decides, ok, you're going back to the ward, all the pipes out. I'm naked when the NG tube is out, the urethral catheter is out, the ET tube is out, the drip's out. You feel very vulnerable. And suddenly you're not on a 24 hour monitor. You're like, who knows what's going on in my body?" (JohnT6Pg2Pr5).*

Having lines removed overwhelmed some of the participants making them feel vulnerable. Other participants felt relieved having lines removed was a step in the right direction of going home and getting well and saw this as an improvement to their overall health and wellbeing. Being released from being tied down by invasive lines and tubes and monitor cables created a sense of relief for the participant.

> *"It's encouraging when you make those jumps. Improvements, you know. Things come off and out so it's a release. It's good" (MarkT4Pg19Pr254).*

> *"For me it was like slow progress, slow progress and then boom and a jump, and slow progress, slow progress, boom, you're going home!" (MarkT4Pg19Pr250).*

One of the participants felt ready to leave the ICU environment and was relieved to go home. He regarded going home as going back to a space of normalcy where he take on his normal duties again. What enabled him to make sense of his experience in ICU was knowing that when he was ill in ICU, his wife was at home looking after their house and their children and all he wanted to do was get well and strong to help her and take on his father figure and caretaker role again, looking after his family. It seems as though this gave him an innate strength and drive to want to get better. This seems as though it was enabling factor for him to make it through his ICU experience in order to get back to his family.

> *"No, no, I was ready. Ready to go home and see the kids. The important things in life and things that you've been missing" (MarkT4Pg11Pr124).*

> *"It was good to go home. I think it's very hard on the wife because she was then having to pick up all my duties" (MarkT4Pg11Pr132).*

Leaving the ICU enabled participants to eat food again. Food brought immense comfort to one of the participants. Being able to eat food again gave the participant a feeling of returning back to a space of being normal. Food is a basic need in life and being able to fulfil that basic need again on their own encouraged a sense of getting back to what was normal before the chaotic event of being in ICU. This in turn strengthens the patient's ability to achieve that sense of normal again.

> *"So now I'm fully conscious. I'm conscious and all the tubes are out. They pushed me through the ICU doors and I smelled a pepper steak pie. And that's all I wanted was a pepper steak pie and a coke. Remember, I haven't eaten something substantial for a month. Yes, I've been fed through an NG tube and intravenously but that's not feeding. So I asked my mom to please bring me a pepper steak pie (laughing). It was heaven" (JohnT6Pg2Pr7).*

3.3.2   Emergent theme 2: I know I matter

It is essential for critically ill patients to know they are valued as a person and not just as a patient. It seems as though participants were enabled to made sense of their experience and move through it intact when they knew they mattered to the people working there, caring for them. They mattered to their caregivers. This theme is described by the two subthemes it was built up by, namely "feeling cared for" and "feeling at ease". Participants voiced their need to feel cared for by their caregivers to enable them to make sense of their experience of ICU. Caregivers who encouraged a sense of normal and were regarded as professional human beings to them made them feel connected to the caregiver. A sense of relationship and feeling connected to their caregiver was seen to be a very important aspect, enabling the participant to make sense of their ICU experience. By feeling cared for, the participant felt protected which in turn allowed them to relax and feel at ease in the care of their caregivers. Feeling at ease allowed them to feel safe. "It's all about the people", professionals as human beings; encourage a feeling of normal; relationships and connection and "my headspace" were some of the formulated meanings which grew from code words drawn from the participant transcriptions.   Code words building up to this subtheme included reassurance, comfort, being kept informed, being nice, feeling reassured, people, relationships and connection.

3.3.2.1 Subtheme: Feeling cared for

- <u>Formulated meaning: Relationships and connection. "It's all about the people".</u>

Caregivers took the time to treat participants as real people and spoke honestly to them. They continually provided participants with information and support. Having a relationship with their caregiver and having sense of connectedness allowed the participant to know they mattered. Ubuntu says there exists a common bond between us all and it is through this bond and our interaction with fellow human beings that we discover our own human qualities. Ubuntu speaks about interconnectedness. You cannot be human all by yourself.   The essence of being human is in our interconnectedness (Boudreau, 2012).

Nurses are the people who spend the greatest amount of time with individual patients and who therefore establish deep and trusting relationships with patients. It is essential for nurses to provide patients with information. This can help to diminish the patients' misconceptions in delusional periods and nurture feelings of safety and yearning to be healthy again (Zetterlund, Plos, Bergbom, & Ringdal, 2011:164). Patients spoke of feelings of security and comfort knowing that the nurses listened without prejudice (Hofhuis, Spronk, Van Stel, Schrijvers, Rommes & Bakker, 2008:310).

The caring behaviour of the nurse and their continuous support relieved their fears and worries in a way that they could concentrate on their recovery and rehabilitation. Caring behaviour was also described as sweet, nice, compassionate, showing personal interest in the patient as well as the family (Hofhuis *et al.,* 2008:310).

I believe that the term "caregiver" encompasses nurses, doctors and all of the members of the multidisciplinary team giving quality care to their patients and their significant others. Any caregiving act or interaction should be founded on kindness, concern, care, competence, commitment and a love and respect of self and others. I believe that being a caregiver is a God given gift and talent.

> *"The small things. It's the small loving detail which is absolutely huge. It made such a difference. The experience is less stressful. The experience is just beautiful you know. It's just, this is good, you know. Let's say that this is bad, but, this is good" (MarkT4Pg15Pr194).*

Staff able to walk their talk and talk their walk enabled a connection which allayed the participant's and strengthened their trust. The participant trusted the caregiver because they could see how skilled and experienced they were, always communicating with the them and working towards the same goal of getting the participant better and closer to a state of normalcy. Experiencing a state of normalcy again strengthened the participant and enabled them to make sense of their experience. Having their significant others around them encouraged a familiar feeling of normal.

"You're irreplaceable to your family. And just to realise that, I could have gone on for twenty more years and totally missed it. You know my wife says I've totally changed. Before this accident you were an ass and it's true. It's the truth. So it was good" (MarkT4Pg7P82).

"You're replaceable just like that, in an instant. But for your family you're not. And that recalibration was just the best thing that could have happened" (MarkT4Pg3P34).

From a patient's perspective, suffering from a critical condition can result in feelings of neglect and insignificance. However, the presence of a patient's loved ones decreases this threatening feeling and allows the patient to feel protected. Families that are involved in care and who are able to communicate with healthcare providers are more reassured, optimistic and satisfied. Healthcare providers have a positive perception of the impact it may have on patient outcomes (Liput, Kane-Gill, Seybert & Smithburger, 2016:1192).

"Some of them even walked with her to her car afterwards in the evenings when she would leave. It's got to do with the type of person you are. I think it's about a positive attitude" (LukeT5pg8pr70).

"It's got a lot to do with the people and yourself obviously, and the doctors. Everyone knew what they were doing. They were genuinely well trained, doing their thing and being available and people just said aaah and they would be there" (LukeT5Pg17Pr186).

- Formulated meaning: Humility. "It's humbling without being humiliated".

Within the hustle and bustle of a never-ending business in ICU, caregivers very easily become wrapped up in treating the presenting illness, forgetting about the actual patient behind that illness they are both confronted with. Caregivers need to remember to treat the person first because when you do that, treating the illness becomes somewhat easier for both the caregiver and the patient.

Patients in ICU are in a state of physiological chaos and become almost entirely dependent on the caregiver to support them through the experience of intensive care. Basic nursing care like promoting comfortable positioning, ensuring effective pain relief, providing periods of uninterrupted sleep, reducing environmental noise and lighting, ensuring patient privacy and effective communication assists in reducing the stressors with which a patient has to cope (Hatchett *et al.,* 2010:57).

> *"Issues using the bedpan. I knew I had to. Somebody's going to lift me and it's going to be very painful. Just the professionalism, it's humbling without being humiliated. And the response of the staff to what's actually happening is what brings the dignity back. It's humiliating but could be humbling if dealt with appropriately. It was a wonderful experience. It was just the way they did it. Good communication" (MarkT4Pg8Pr86).*

> *"What do you say to a person that feels constipated? You can say no just give an enema and get it over and done with, or you can address the fears, can address their, how do you feel about it, are you anxious about it, what worries you about it, you know and that's the difference" (MarkT4Pg14Pr174).*

> *"That's the thing. If you haven't been there, you don't understand" (MarkT4Pg14Pr178).*

> *"There were two nurses that were specifically looking after me, angels! You need to make something about these nurses. They just, you know, they just changed perspective" (MarkT4Pg4Pr40).*

> *"It's humbling without being humiliated" (MarkT4Pg8Pr86).*

Participants spoke of feeling valuable and acknowledged when the nursing staff exchanged conversation and praised their progress made. Being reminded about things that were important in ordinary life strengthened the participants' motivation to fight. This could be thinking about their home, friends, family, workmates, or something that would be waiting for them when they recovered. It was important for patients to feel that someone cared for them (Wahlin *et al.*, 2009:375).

"The doctor cleared his whole day just to look after me" (LukeT5Pg5Pr46).

"He's in touch with all his patients. Hy's in Joburg, elf uur die nag, vir kongres, dan ly daai foon in ICU dan wil hy weet hoe gaan dit met my hoe gaan dit met dit, wat het dit en dat gedoen wat is dit, dit moet gedoen word" (LukeT5Pg16Pr177).

Encouragement and interaction with the patient are essential to promote a patient's self-ability. Promoting the patient's own ability requires a lot of persuasion and sensitive interactions with the patient (Häggström & Bäckström, 2014:4). By doing this, the trusting relationship between the participant and the caregiver was strengthened and enhanced the participant's feeling of being safe and at ease.

"The anaesthetist spoke to me slowly and very carefully, through every step. I'm going to remove this pipe now. I'm going to change this setting and what you will feel is this. There was that reassurance of ok, cool, I'm conscious of the fact that you may be worried about these things, but don't worry, I've got you" (JohnT6Pg1Pr5).

"They respected my personhood in that interaction. I was a participant in the conversation" (JohnT6Pg11Pr71).

3.3.2.2 Subtheme: My headspace

- Formulated meaning: "It's what you make of it"

My headspace described the participant's attitude towards being in ICU and having to endure the experience. This formulated meaning spoke to the participant's willpower and emotional and psychological tools they used to enable them to make sense of their experience. This concept became interwoven in knowing that a patient mattered to the person looking after them. It seemed as though having a positive mind set and attitude enabled the patient to make sense of their experience of ICU. This particular mind set was almost like a strict pep talk they had with themselves in order to process the experience and make it through this chaotic time in their lives.

"As jy daar in 'n bondeltjie wil le en sulk, dan gaan hulle jou net los" (LukeT5Pg10Pr96).

"It's all about the person and how you treat yourself in there. It's actually quite simple.   I always knew I was sick but I wasn't sick.   Verstaan jy?" (LukeT5Pg10Pr102).

"I should have been down under the ground a few times. I got over it every time. I've got an expression, my kop sit nou weer in my gat and I have to get it out. If you're down in a hole, no one's going to take you out, you have to get yourself out and I think daai attitude het my gehelp" (LukeT5Pg11Pr105).

Having a positive attitude and seeing the positive in what was happening around them was instilled into a patient knowing that they mattered to the caregiver and thus enabled the patient to make sense of their experience. Attitudes and belief systems play a significant role in the way a patient is able to remain positive amongst all the negativity around them. Again, this sense of having a strict pep talk, saying I am sick but I am not sick, had much to do with personal attitude and how the participant treated and looked after themselves.

- <u>Formulated meaning: Grace. A sense of recalibration</u>

It seems as though participants made sense of their ICU experiences knowing that the experience had changed their perspective and their make up for the better. Participants voiced that if they were to live their lives over again, they would not change what happened to them. It seems as though the experience of ICU enabled them to make it through because the experience was seen as a life lesson, a change of perspective, a new lease on life. This enabled the participant to make sense of this somewhat chaotic and terrible place they had found themselves in and eventually it turned into something positive.

"So for me it's the recalibration that happened" (MarkT4Pg2Pr30).

"It was horrible to go through but the lesson was invaluable, priceless" (MarkT4Pg9Pr92).

"No, I mean, some people still, some people live and they learn this lesson when it's too late when they're on their death bed. You know I was on my death bed but I didn't die and I've got a second chance. And the question now is, what do you do with that? What are the things that are important? How do you live, you know? We judge others by what they do to us but we judge ourselves by our intentions" (MarkT4Pg5Pr56).

"I tell you a doctor needs to be in the ICU. There was one colleague as well, the specialist physician that looked after me and towards the second week I told him, listen, your bedside manner and everything is just different, as if you know what I want. And he says, ja, when he was a sixth year medical student he was admitted to ICU with a serious neck injury and he just, so I think you cannot be a proper doctor if you haven't been a patient" (MarkT4Pg5Pr70).

"I tell you a doctor needs to be in the ICU. There was one doctor that looked after me and towards the second week I told him, listen, your bedside manner and everything is just different, as if you know what I want. And he says, ja, when he was a 6th year medical student he was admitted to ICU with a serious neck injury. I think you cannot be a proper doctor if you haven't been a patient" (MarkT4:g6Pr70).

Another thing that enabled a patient to make sense of their experience was the notion of taking things slow. This was illustrated in the following quote:

"The cool thing about ICU is that people talk to you in your face. She's right here and she talks slowly and clearly, and very measured. There's a measuredness about the whole thing. And I wonder if, as a suggestion, on could maybe try to mirror the heartbeat in your interaction with the patient. If you speak to them, try to get a taupe that's kind of the same measuredness as a heartbeat. It instils comfort or reassurance. And just move slowly because everything is going way too fast for the brain to process so go slow. It would be cool if the environment could slow down equally" (JohnT6Pg9Pr55).

3.3.3   Emergent theme 3: The darker side

The darker side encompassed the things that hindered the participant making sense of their ICU experience and moving through it in a more positive way.   The transcriptions brought about a number of aspects the researcher assumed may have hindered the patient being able to make sense of their intensive care encounter, making the encounter less tolerable and more difficult to bear. These negative aspects mainly highlighted the caregiver looking after the patient and not as much the space they found themselves in, which ties into the previous finding of how important positive relationships between the caregiver and the patient are.

3.3.3.1 Subtheme: Caring fails

- Formulated meaning: At the mercy of the caregiver

Patients did not feel at ease when they did not trust their caregiver.

"I starting having concerns about the staff looking after me, their competency and those type of things" (MatthewT2Pg2Pr20).

"I don't suffer fools lightly" (ShelleyT3Pg5Pr22).

"I will have the world's patience with a nurse who's nursing me, who's trying to do the right thing. But if you are not willing to learn or question why you are doing something or your patient's required to do something, I would get irritated" (ShelleyT3Pg5Pr22).

"They don't care or they don't appear to care" (ShelleyT3Pg8Pr48).

The nurse-patient relationship is threatened by the ever-demanding technical skills that nurses are expected to master. Although the nurses' expertise, technical skills and medical equipment are perceived as important to patients, as they are part of necessary life-saving interventions, caring behaviour, relieving the patient of fear and worries, may help them to concentrate on their recovery and is regarded as most valuable. Nurses should be aware that patients sometimes perceive that increased

attention to technical equipment decreases the patients' trust (Hofhuis *et al.,* 2008:311).

When patients develop distrust in the staff's ability to competently care for them, their feelings of safety and security are eroded. This made it more complicated for the patient to make sense of and move through their ICU experience. The development of a positive caregiver-patient relationship is essential for the delivery of quality patient care (McCabe, 2004:42). Caregivers are in constant contact with patients in the intensive care environment and they are in an ideal position to influence the stressors that patients are exposed to during an admission. The caregiver-patient relationship is an intimate and trusting relationship which forms the basis of nursing and sets the climate for the patient's experience within the healthcare institution. In this relationship, caregivers are committed to caring for patients and their families during periods of intense vulnerability (Pera & Van Tonder, 2011:109).

"How much I can pick up in the voice, in the body language. That rushedness whey they come into the, you know, ok, ons gaan jou gou gou was, you know? And even if you're not in a coma, that's terrifying. Versus, hello, ek gaan gou kom om jou net bietjie skoon te maak. Ons gaan jou so bietjie rondrol in die bed. Like, just talk" (JohnT6Pg10Pr67).

Participants felt sensitive to the attitudes and behaviour of the carer and expressed distrust when they did not feel safe. They became watchful and wary of their care and expressed concern about the ability and skill of the staff. Some participants voiced their fears of being at the mercy of the caregiver, saying that staff were not looking out for their best interests and as a result always remained on guard. This is echoed in the quotes that follow:

"He hurt me. He pinched my arm. And that was a jarring experience. The pinching was, I mean, it was just a pinch. But the whole business of being pinched, you know, you're a grown man and another grown man pinches you and you can do nothing about it" (JohnT6Pg7Pr41).

Participants spoke of a rushed sense of pace in the ICU environment.

> *"I appreciate the fact that often the environment cannot slow down but in all those cases that it can, why not?" (JohnT6Pg9Pr55).*

> *"Just move slowly because everything is going way too fast for the brain to process" (JohnT6Pg9Pr55).*

- <u>Formulated meaning: Feeling powerless. "You're just a blob</u>

Participants experienced a feeling of being powerless and losing their identity when in ICU which hindered enabling them making sense of their ICU experience. The formulated meaning that arose from the codes in the transcripts was that of "you're just a blob". This is supported by the quotes that follow:

> *"I had with the medication, I had some constipation and the surgeon walked in and said, you know, I'm really concerned about this and I was crying about this… Oh, ok sister, just give an enema, turned around and walked out, you know. Of course he's right but he's so wrong. He's so wrong" (MarkT4Pg13Pr160).*

Participants felt hampered by caregivers making them feel as though they were a burden to them. Participants felt ignored and became more dependent on the staff member looking after them, a staff member with a poor attitude with arrogance and lack of insight. This reinforced their reality of being sick and hindered the patient being enabled to make sense of their experience and so move through it and tolerate it.

> *"Nurses get uppity and say I know, I'm coming to you, so don't bother me. Don't tell me what to do. It doesn't help either them or the patient. Our biggest worry is the attitudes of the staff" (ShelleyT3Pg21Pr188).*

> *"A lot of them are arrogant and do not have the insight they need" (T3Pg26Pr233).*

It is quite common for ICU patients to be surrounded by equipment and staff. Having tubes in your nose or mouth was classified as one of the principal stressors in the study by Hweidi (2007:231). Tubes and monitoring equipment effectively lock the patient to the bed, preventing movement and contributing to feelings of powerlessness. In addition, patients are often unable to communicate verbally, due to the presence of an ET tube facilitating ventilation. Drugs such as muscle relaxants and sedatives may be used to allow for treatment plans to be carried out effectively, leaving the patient feeling dazed, confused and helpless. The patients are often rendered powerless and this powerlessness combined with the inability to communicate is extremely isolating. Many of the participants feared that this powerlessness would last forever (Hweidi, 2007:231).

"Being in isolation is horrible. They call that isolation room the 'glaskas' or the fish bowl. It's terrifying when you're alone in a room when someone else is there that you don't know" (JohnT6Pg6Pr35).

"I was in isolation. It's the most horrible thing that can happen to you. People don't touch you or they don't want to come in because it's gloving and all. And I'm saying please come and touch me. Once I lay there crying one day and I couldn't move and just crying, crying and people asked, you know, are you ok, and I couldn't speak and I was itching on my arm, this side. I just couldn't do this and scratch it. I couldn't tell anybody that my arm was itching" (MarkT4Pg7Pr82).

Hweidi (2007:233) identified another stressor as not having control over oneself. It is easily understood that patients within the ICU setting rely on health care personnel, especially the nurses, in performing tasks like changing position, personal hygiene, and even eating. This state of dependency and depersonalization can trigger a state of distress and helplessness already existing among the ICU patients. The loss of independence in the ICU was reported to be the principal cause of psychological instability among ICU patients.

- Formulated meaning: "I can't tell you what's wrong with me"

Communication is a universal need and the challenges to normal methods of communication create difficulties for both patients and nurses in intensive care units. Seriously ill patients cared for in an intensive care unit usually suffer failure of vital body functions like the respiratory system (Torpy, Campbell & Glass, 2010:902). Mechanical ventilation is required when a patient is unable to breathe on their own. Normal methods of communication are disrupted by sedation, opiates, endotracheal and tracheostomy tubes, fluctuating levels of consciousness, and fear. Mechanical ventilation may sustain life but offers no cure. It allows time for other treatments to take effect and for the body to recover (Engström, Nyström, Sundelin & Rattray, 2013:89). Communication assists us in constructing and reflecting our social world (Mariläinen *et al.,* 2013:84).

Patients' experiences being cared for while intubated and mechanically ventilated show that impaired speech and communication difficulties lead to a sense of vulnerability and powerlessness. Not being fully in control creates a stressful, fearful and emotionally chaotic state the patient must encounter. All patients want to be understood and have their concerns and fears validated. This can be difficult for patients who are critically ill and whose ability to communicate is impaired (Urden *et al.,* 2006:52). Being unable to speak leads to patients feeling frustrated or scared, they are less able to participate in decision-making or express their feelings, thoughts, hopes and needs (Urden *et al*., 2006:668). The literature supports the quote that follows:

> *"I can't speak to you. I can't tell you what's wrong with me and what kind of special needs I may have. I know that you won't know because to you I'm just another patient. And it's terrifying. Because you are helpless in ICU. You can't fight back. You are a passive receiver of action" (JohnT6Pg6Pr41).*

> *"Then he took my whole foot in both hands and the comfort of that warmth and then I realised that he doesn't know I recognise him and he turned to leave and I remember the panic of not having that contact, knowing that he doesn't know whether or not I knew he was there, and as he turned to leave, all I wanted to say was "Pappa", but I couldn't generate enough force and I couldn't pass air*

over my vocal cords because there was this thing and the terror of not being able to make that contact, just that recognition, that was terrifying" (JohnT6Pg11Pr73).

Ventilated patients attempt to interact with the environment by cringing, squirming, wincing, and with distressed and pained facial expressions and movements, turning and lifting their heads towards noise and activity (Mariläinen *et al.*, 2013:84). Drugs such as muscle relaxants and sedatives may be used to allow for treatment plans to be carried out effectively, leaving the patient feeling dazed, confused and helpless. The ICU environment can be incomprehensible to a patient who is waking up from sedation and moving in and out of consciousness. They are unable to determine time, place and events (Mariläinen *et al.*, 2013:84). Good communication is important to patients in intensive care and can improve recovery (Mariläinen *et al.*, 2013:84).

Patients experience discomfort and pain due to the endotracheal tube, swollen vocal cords, difficulty swallowing, a painful throat and excessive thirst (Engström *et al.,* 2013:89). Despite various forms of discomfort, the patients did not find mechanical ventilation unbearable. Suctioning of the airways and machine alarms did not bother them and caused no prolonged suffering. The participants in this study contradicted this literature finding in the quote that follows:

"The absolute worst experience was having my ET tube suctioned. The chest physio tried to make the experience as soft as possible. She'd do the percussion on the chest which was painful. Trying to communicate that to her was difficult. Then she pushed the suction tube through the trachy all the way down until I could feel it hit my carina and then she says, "cough", and I think to myself, f*** bitch, I can't do anything else! You know you are eliciting the deepest most primitive reflexes. I can't do anything else" (JohnT6Pg8Pr51).

Patients identify pain as one of the biggest stressors associated with intensive care, also revealing that analgesia did not result in total relief from pain (Hweidi, 2007:233). Diagnosis, monitoring and treatment activities are commonplace in managing a critically ill patient, many of these activities cause pain and discomfort for the person. Poorly managed pain increases the anxiety felt by patients and causes harm to a

patient regardless of the nature, pattern or cause of the experienced pain. Increased anxiety activates the sympathetic nervous system, manifested by an increased heart rate, blood pressure, respiratory rate and neurohumoral responses, possibly leading to a destructive anxiety syndrome (Lee *et al.,* 2004:610). Hweidi (2007:231) revealed that the experience of pain is very discomforting to the critically ill patient and is considered to be a significant stressor.

> *"There was just fractures all over the place so movements were sore and the difficulty was the change-over of staff, you know, you have to teach each one, no this is sore, don't do it like this etc. But they allowed my wife to stay long times and my wife did most of these things which also helped"* *(MarkT4Pg10Pr104).*

According to Parry, Knight, Connolly, Baldwin, Puthucheary, Morris, Mortimore, Hart, Denehy and Granger (2017:532), adverse effects of critical illness on muscles and nerves, prolonged bed rest and reduced physical activity all lead to inability and impairment. The detrimental effects of critical illness myopathy and polyneuropathy are well documented although the mechanism remains unclear. Exercise and physical activity as an intervention is safe, feasible and potentially efficacious in survivors of critical illness at improving patient outcomes especially when applied early in the ICU.

Psychological chaos shadows a critically ill patient nursed in an intensive care environment and any patient who is ill enough to be admitted to an ICU will react emotionally if they are able to do so. This initial reaction is usually expressed as fear and panic. When the patient controls this emotional response, it still often gives the impression of overwhelming anxiety, depression and denial. Occasionally there is a complete withdrawal into a psychotic state (Grandberg, Engberg & Lundberg, 1998:294).

Critical illness requiring intensive care treatment is a significant stressful event in any person's life and can be potentially traumatic for patients across emotional, social and psychological spheres (Adam & Osbourne, 2005:18). Critical care nursing practice occurs at the interface of the nurse with the patient and family during this significant stressful event and in an environment that requires humanism and compassion

(Fontaine & Gonce Morton, 2009:36).   Meeting patient needs through continuous monitoring is the hallmark of all critical care (Fontaine & Gonce Morton, 2009:37).

Appropriate, correct patient assessment and monitoring, drug and organ support interventions, patient comfort measures, psychological support, and early detection of complications all underpin the provision of quality nursing care for critically ill patients. These necessary interventions or activities create experiences that the critically ill patient must make sense of in order to manage long term consequences of this traumatic encounter (Leach, 2004:13).

Sven-Tore and Ringsberg (2006:124) note that serious disease or severe trauma often leads to life threatening conditions, exposing a person to circumstances which are far beyond everyday experience. These circumstances can be experienced as stressful, particularly when a person is removed from the safety of their known environment and admitted into an intensive care unit, an environment which can be experienced as unfamiliar, strange and scary.

Critically ill patients experience tension because of the psychological stress involved in the unexpected admission to the ICU. The patient realises there is an immediate danger of death and the response in this situation can range from mild anxiety to severe panic. Even if thoughts of death or dying have not entered the immediate consciousness, it remains a constant reality which may show itself in various ways from acute fear to delirium. Acute confusion is often triggered by a psychologically stressful event (Grandberg *et al.,* 1998:294).

According to Samuelson *et al,* (2007:94), experiences of discomfort and stressful memories in the ICU have been associated with the development of acute post-traumatic-stress-disorder related symptoms.   These symptoms include anxiety, depression, and impaired quality of life. The critically ill patient's memories of stressful experiences in the ICU can be very disturbing and might cause psychological problems, thus affecting their sense of wellbeing and the rehabilitation process.

According to Rattray, Johnston and Wildsmith (2004:65), patients suffer psychological and emotional consequences and have little or no recall of factual events of their

intensive care experiences. Recollections of unpleasant events, delusions and dreams, or "odd perceptual experiences", are described. Studies emphasizing psychological experiences in ICU show that patients may experience panic, nightmares, flashbacks, anxiety and fear when remembering their stay in ICU (Abdalrahim & Zeilani, 2014:571). The majority of these studies focused on psychological problems such as severe anxiety, depression or delusional memories which persisted years after the patient had been discharged from the ICU and manifested into post-traumatic stress disorder.

3.4   CONCLUSION

This chapter explained the realisation of the data collection and discussed the research findings of the study, exploring and describing the lived experience of the ICU patient. The results were presented according to the themes that emerged from the interview transcriptions. I integrated existing literature with the analysed data to support the results of this study. I further supported the findings with direct quotations from the transcripts as shared by the participants. The exhaustive description of the phenomena under study provided an idea of the experience as expressed by the participants in this study. In addition, the exhaustive description and fundamental structure were validated by the participants as a true reflection of their lived experiences, as expressed by Colaizzi's method for phenomenological data analysis. The next chapter concludes the research by evaluating the study, acknowledging the limitations of this study, situating the findings in relation to the PCNF, and offering conclusions drawn from the study findings.

CHAPTER 4
CONCLUSIONS, RECOMMENDATIONS & LIMITATIONS

4.1   INTRODUCTION

Chapter 4 serves up a discussion about the conclusions drawn from the results obtained in this study. The conclusions drawn from the data are discussed first and then recommendations from these conclusions will be presented. The evaluation of the study determines whether the study's objectives have been accomplished. Recommendations include information is relevant to the whole of the multidisciplinary care team looking after a patient in the ICU setting and aim to contribute to every health care professional's understanding of what the patient moving through an intensive care experience has to endure, thus adding value to healthcare professionals' every day practise within the healthcare setting. The study's limitations create opportunity for future research in the same field of interest. I have described the limitations I came across while implementing the study. The chapter concludes with a summary.

The purpose of this study was to learn more about how a patient makes sense of an admission to an intensive care unit in order to gain insight into how and what enabled them to endure and move through the encounter. By gaining insight into the attributes or qualities of an intensive care experience that enabled a patient to make sense of and endure the encounter, caregivers may be better able to adapt care and interventions to facilitate a more tolerable experience of intensive care for a patient.

This gave rise to the following research question posed for the study, namely, what enabled patients to make sense of their experiences in an intensive care unit? The aim of this study was to explore adult patients' perceptions of what in their intensive care encounter enabled them to make sense of the experience of intensive care and move through it.

4.2   CONCLUSIONS

4.2.1   Conclusions regarding emergent theme 1: The Safe Space

"It's like having a feeling of a mother bear as a protector" (JohnT6Pg3Pr15).

This theme, the safe space, describes how and what made the intensive care unit a safe space for the participants, and highlighted elements within this space and outside of it that enabled participants to make sense of their ICU journey.

An important element that made the ICU a safe space for participants was being able to trust their caregiver. It was vitally important for a trusting relationship to form between the participant and their caregiver. A trusting relationship enabled the participant to feel safe and at ease which in turn enabled them to move through and make sense of their experience of ICU.

Elements strengthening the trusting relationship included how caregivers walked their talk and talked their walk. Feeling safe meant that they were cared for by members of staff who had a high level of training and skill, seniority and experience. Caregivers were recognised as people who knew what they were doing, felt comfortable in their own skin of being a caregiver and were able to walk their talk and talk their walk. Being taken care of by highly skilled and efficient caregivers was like having a 'mother bear' protector and strengthened the feeling of trust and safety they felt whilst in ICU. Participants felt safe, protected and strengthened which in turn made them feel at ease and enabled them to make sense of their experience and the experience of ICU tolerable and positive.

Prerequisites within the Person-Centred Nursing Framework (PCNF), focus on staff attributes being the key building blocks in the development of healthcare professionals who can deliver effective person-centred care. These attributes, being professionally competent, walking their talk and talking their walk, having developed interpersonal and communication skills, being committed to the job and knowing oneself, reflects a person-centred caregiver who can manage the challenges of a constantly changing context (McCormack & McCance, 2017:46).

Participants found security in being connected to something tangible like an intravenous line or a monitor cable. Environmental elements in the ICU reassured the patient that they were alive and gave them tangible proof that they were going to be ok which in turn made them feel at ease. They felt as though there was something real they could hold on to, hearing their own heart beat or the heartbeat of the patient beside them gave them a sense of security and safety knowing that they were still here and not going to die.

Another element that was necessary for participants to feel that they were able to make sense of their experience and tolerate it was their knowing that their stay in ICU time-bound. They felt they could make sense of their time in ICU as they knew that it would be over soon and they would be discharged home to their loved ones.

Participants were able to make sense of their experience by putting on a brave face for their significant others. Participants believed that having resilience within themselves created a resilience within their loved ones which enabled them to make sense of and tolerate the experience.

Participants took great comfort in knowing their family members were looked after by their caregivers. They voiced their admiration and thankfulness for caregivers who would go the extra mile, taking their loved ones into consideration by reassuring them and keeping them constantly informed about their progress and treatment plans, looking after their physical and psychological needs along with those of the participant.

The safe space as an enabler for a person to make sense of their time in ICU was reinforced when the person was discharged from the environment. Their experiences of feeling safe inside the unit were amplified by their experience of leaving or being outside this safe space. While in a sense they felt progress in their trajectory to becoming well again which was an enabler of making sense of this critical illness experience, leaving the safe space elicited new emotions that ranged from fear, anxiety, and trepidation to excitement, and even joy.

4.2.2   Conclusions regarding emergent theme 2: I know I matter

"What do you say to a person that feels constipated? You can say no just give an enema and get it over and done with, or you can address the fears, can address their, how do you feel about it, are you anxious about it, what worries you about it, you know and that's the difference" (MarkT4Pg14Pr174).

This theme, "I know I matter", described how a participant experienced being totally dependent upon and cared for by another human being. This theme also described the importance of relationship and connection between the participant and their caregiver, enabling them to make sense of their experience of ICU. Participants spoke about the different qualities they found made their caregivers exceptional people, "angels". Grace, humility and professionalism were some of the aspects experienced by participants enabling them to make sense of their experience of ICU.

Patients spoke of humility and being humbled. The experience of having nurses tend to their very personal and intimate needs when they were not able to do their own daily care was a humbling experience. However, the way in which the nurses carried out this care focussing on them as a person made the experience as humane as possible and in that way, the person was able to make sense of this.

Patients spoke of having being in a very specific kind of headspace. It seemed as though having a certain headspace, a positive mind set and attitude enabled the patient to make sense of their experience of ICU. This particular mind set was almost like a strict pep talk they had with themselves in order to process the experience and make it through this chaotic time in their lives. They had a headspace of not feeling sorry for themselves and being their own cheerleader. This related into the patient having a positive attitude about their care plan which was strengthened through the people looking after them and the way in which they were looked after. In essence it seems that people and the relationships with people were pivotal to the person making sense of their experience. A positive headspace encompassed the participant's willpower with emotional and psychological tools they used to enable them to make sense of their experience.

Participants found their experience recalibrated their life and their thought processes. They found their experience of ICU to be a life lesson and said that if they were to have their life lived over again, they would never want to change what happened to them. Participants believed their lives had been changed for the better because of what they have been through.

Participants spoke of how important it was to slow things down. They recognised the need for a rushed sense of pace in the ICU setting but emphasized how important it was that when working with them personally, to just be calm and measured in the interaction with the patient and regard the patient as a person first and not just a passive receiver of care.

These moments in their ICU experiences left patients feeling empowered. They felt as though they mattered. They felt valued. This in turn strengthened them emotionally and mentally to want to make it through the experience of ICU.

Person-centred processes within the PCNF focus on relationship and connection between the caregiver and their patient and engaging authentically with patients and being empathetically present, whilst providing holistic care (McCormack & McCance, 2017:53).

4.2.3   Conclusions regarding emergent theme 3: The darker side

"Everyone just calm the f*** down. While you're busy with this patient, just be busy with this patient" (JohnT6Pg10Pr59).

This theme, the darker side, described elements that hindered participants making sense of their ICU experience and moving through it in a more positive way. The darker side highlighted negative aspects of a patient's intensive care experience. These negative aspects mainly highlighted the caregiver looking after the participant and not as much the space they found themselves in.

Participants spoke about a rushed sense of pace in ICU and stressed how important it was for a caregiver to slow things down for them and interact with them individually

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when caring for them. The participant wanted to be seen as an individual person and stressed that when the caregiver was busy with them, to be busy with them personally and calmly and slowly and measured and intimately. They spoke of feeling like a piece of meat and caregivers just wanting to interact with them to get the job done. Another patient the caregiver needed to get through to make it through their day with all that they had to do.

Participants found it difficult to make sense of their experience when they did not trust their caregiver. Patients experienced a loss of identity and talked about feeling powerless and totally and entirely dependent on the caregiver for their needs. They spoke of how they felt being a burden to their caregiver. When participants developed distrust in the caregiver's ability to competently care for them, their feelings of safety and security became eroded. This made it more complicated for the participant to make sense of and move through their ICU experience.

Patients felt isolated and scared in ICU. They spoke about being nursed in an isolation cubicle and having someone with them in that close vicinity who they did not know yet they were screaming out inside they wanted to be touched and reassured, but could not communicate this to the person looking after them. Patients spoke of times they were physically harmed by their caregivers and were not at all able to fight back and fend for themselves. They spoke of themselves as passive receivers of care. Patients spoke about not being able to communicate with their loved ones. Having their loved ones with them at the bedside was enabling for them yet also troubling due to the fact that some could not communicate

Participants spoke of how important it was for a health care professional to experience ICU as a patient first before becoming a health care professional and provider to be able to know how a patient really feels and what their needs are to get through this terrifying experience.

Person-centred outcomes within the PCNF represent the results expected from effective person-centred practice which include a good experience of care, involvement in care, feeling of wellbeing and the existence of a healthful culture (McCormack & McCance, 2017:58).

4.3   OVERALL CONCLUSION

I intended to explore adult patients' perceptions of what aspects of the intensive care experience had an enabling influence on them making sense of their intensive care encounter and how these aspects enabled the patient to make sense of their experience of intensive care.

The extensive descriptions of the participants' lived experiences highlighted the many stressors patients as passive receivers of care are faced with in ICU. Person-centred care and the relationships that form between the patient and their caregiver seem to be what enables or hinders the patient making sense of their experience.

It is evident the purpose of this research study has been achieved. Chapters 3 and 4 both highlight this achievement in the rich descriptions given by the participants about their lived experiences of an ICU encounter. A qualitative descriptive phenomenological design was chosen to answer the research question posed for this study. The participants' thoughts, feelings, beliefs, raw emotion and their personal realities which flowed from the transcripts allowed for an exhaustive description of the essence of the lived experience. The interviews the researcher had with each of the participants allowed for rich descriptions of the phenomenon under study. Research findings were confirmed when literature integration was applied.

The researcher believes the participants' descriptions have given provided new insights into what enables an adult patient to make sense of their intensive care experience.

4.4   RECOMMENDATIONS

The recommendations will be presented in 3 sections. The first section will speak to critical care nursing practise in order to clarify drivers of person-centred care. The second section is directed at critical care nursing education, focussing on empathic engagement. The third identifies further opportunities for research.

4.4.1   Recommendations for critical care nursing practice

- In this study, it is evident that making sense of the ICU encounter revolved around the relationship and connection between the patient and their caregiver. Conversations need to start amongst the multidisciplinary care team focussing on understanding ways to support the patient and implement and drive person-centred care. This research study serves as the springboard for these conversations to start happening.
- Developing person-centred practitioners doesn't stop at the point of registration. Following registration there is a requirement on practitioners to continue to learn and develop and to acquire skills that enable them to become more expert in practise (McCance & McCormack, 2017:43).

4.4.2   Recommendations for critical care nursing education

- Education and training programmes should include specific content and application of trying to live in a critically ill person's shoes in order to enable a nurse or doctor to have some insight as to what this experience means to a critically ill person. This could take the form of a conversation with a person with critical reflection by the nurse or doctor thereafter.
- Students in critical care nursing programmes should be required to demonstrate competence in empathic engagement and relationship skills which could enable them to create and strengthen the relationship between them and their patients.

4.4.3   Recommendations for future research

- A larger scale study stemming from the same research question would be useful to further elaborate, refine and substantiate the themes and subthemes that emerged from this small study.
- Some aspects such as the importance of food, the significance of the monitoring tones and similar in a person coming to make sense of their experience do offer interesting scope for further investigation as these are elements that have either not

been revealed in previous studies, or else, in the instance of the monitoring tones, are usually seen as adding to stress rather than assisting with the experience.

4.5   LIMITATIONS OF THE RESEARCH

The research study housed a number of limitations. Firstly, research findings cannot be generalised because of the qualitative nature of the study. Secondly, participants were purposively accessed within one private hospital and via a network sample method using word of mouth about the study amongst nursing colleagues and study participants. Between these two methods a more heterogeneous study sample resulted which supported the study's trustworthiness and but only contributed slightly to enhancing transferability of the study findings. The study only reflected the lived experiences of six participants although data saturation was reached. Four participants were male and two were female.

The researcher remains a novice researcher and her knowledge, skill, depth, panache and ability for this complex methodology is still growing and developing.

4.6   SUMMARY

This chapter offered conclusions and an evaluation of the study. The researcher then discussed recommendations and the limitations of the study.

The purpose and goal of this research study has been reached, namely to know about what enables a patient to make sense of their intensive care experience so that we as caregivers can do our very best to make the experience tolerable, bearable and more positive. The study aims to start the conversation of how we as the caregivers can connect with patients and form relationships with our patients in their most vulnerable time of need. The rich insight gained from the lived experiences of ICU patients fuels this conversation. The little things matter.

The study offers healthcare professionals an understanding of the ways to support the patient to move through the experience and make the experience more tolerable. The study will be beneficial to all healthcare personnel who offer care that is influenced by

insights from this work and enable a patient to make sense of, tolerate and move through an experience of intensive care.

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ANNEXURE 1: HRECA APPROVAL 2015

UNIVERSITEIT·STELLENBOSCH·UNIVERSITY
jou kennisvennoot • your knowledge partner

Approval Notice
Response to Modifications- (New Application)

16-Mar-2015
Harmuth, Keryn K

Ethics Reference #: S14/10/208

Title: Exploring adult patients' perceptions of what enables them to make sense of their intensive care experience.

Dear Ms Keryn Harmuth,

The **Response to Modifications - *(New Application)*** received on **21-Jan-2015**, was reviewed by members of **Health Research Ethics Committee 1** via Expedited review procedures on **21-Jan-2015** and was approved.
Please note the following information about your approved research protocol:

Protocol Approval Period: **16-Mar-2015 -16-Mar-2016**

Please remember to use your **protocol number** (S14/10/208) on any documents or correspondence with the HREC concerning your research protocol.

Please note that the HREC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

After Ethical Review:
Please note a template of the progress report is obtainable on www.sun.ac.za/rds and should be submitted to the Committee before the year has expired. The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly for an external audit.
Translation of the consent document to the language applicable to the study participants should be submitted.

Federal Wide Assurance Number: 00001372
Institutional Review Board (IRB) Number: IRB0005239

The Health Research Ethics Committee complies with the SA National Health Act No.61 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 Part 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes 2004 (Department of Health).

Provincial and City of Cape Town Approval

Please note that for research at a primary or secondary healthcare facility permission must still be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Contact persons are Ms Claudette Abrahams at Western Cape Department of Health (healthres@pgwc.gov.za Tel: +27 21 483 9907) and Dr Helene Visser at City Health (Helene.Visser@capetown.gov.za Tel: +27 21 400 3981). Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics approval is required BEFORE approval can be obtained from these health authorities.

We wish you the best as you conduct your research.
For standard HREC forms and documents please visit: www.sun.ac.za/rds

If you have any questions or need further assistance, please contact the HREC office at 219389156.

Included Documents:
MOD_Protocol
MOD_Information leaflet and consent
Informed consent general
MOD_HREC letter modifications required

Information leaflet and informed consent

Declaration J Bell

Protocol

CV K Harmuth

MOD_Cover letter response to Modifications

Checklist

Declaration K Harmuth

Protocol Synopsis

CV J Bell

Application form

Sincerely,

Franklin Weber
HREC Coordinator
Health Research Ethics Committee 1

ANNEXURE 2: HRECA APPROVAL 2018

Health Research Ethics Committee (HREC)

Approval Notice New Application

07/02/2018

Project ID :2045

HREC Reference # S18/01/019

Title: Exploring adult patients' perceptions of what enables them to make sense of their intensive care experience

Dear Miss Keryn Harmuth,

The **New Application** received on 01/02/2018 was reviewed by members of the **Health Research Ethics Committee 2**

(HREC2) via **expedited** review procedures on 07/02/2018 and was approved.

Please note the following information about your approved research protocol:

Protocol Approval Period: **07-Feb-2018 – 06-Feb-2019**

Please remember to use your **Project ID [2045]** on any documents or correspondence with the HREC concerning your research protocol.

Please note that the HREC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

After Ethical Review

Please note you can submit your progress report through the online ethics application process, available at: Links Application Form Direct

Link and the application should be submitted to the HREC before the year has expired. Please see *Forms and Instructions* on our HREC website (www.sun.ac.za/healthresearchethics) for guidance on how to submit a progress report.

The HREC will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly for an external audit.

Provincial and City of Cape Town Approval

Please note that for research at a primary or secondary healthcare facility, permission must still be obtained from the relevant authorities (Western Cape Departement of Health and/or City Health) to conduct the research as stated in the protocol. Please consult the Western Cape Government website for access to the online Health Research Approval Process, see: https://www.westerncape.gov.za/general-publication/health-research-approval-process. Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics approval is required BEFORE approval can be obtained from these health authorities.

We wish you the best as you conduct your research.

For standard HREC forms and instructions, please visit: Forms and Instructions on our HREC website https://applyethics.sun.ac.za/ProjectView/Index/2045

If you have any questions or need further assistance, please contact the HREC office at 021 938 9677.

Yours sincerely,

Francis Masiye,

HREC Coordinator,

Health Research Ethics Committee 2 (HREC2).

National Health Research Ethics Council (NHREC) Registration Number: REC-130408-012 (HREC1)·REC-230208-010 (HREC2)

Federal Wide Assurance Number: 00001372

Office of Human Research Protections (OHRP) Institutional Review Board (IRB) Number: IRB0005240 (HREC1)·IRB0005239 (HREC2)

ANNEXURE 3: LIFE ETHICS APPROVAL 2015
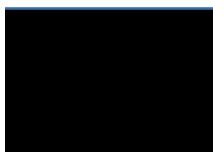
Group

29 April 2015

ATTENTION: Keryn Harmuth

SUBJECT: APPLICATION TO CONDUCT RESEARCH

TITLE: **Exploring adult patients' perceptions of what enables them to make sense of their intensive care experience.**

This letter serves as authorisation from the ▮▮▮▮ Research and Scientific Committee for the conduct of your research within company facilities.

The approval is conditional to your agreement on the following provisos:

1. Presentation of this letter to the Hospital or Nurse Manager when seeking permission at the specific facility you will be using during your research.
2. An electronic copy of your research report is submitted to the ▮▮▮▮ Research and Scientific Committee prior to publication.
3. No direct reference is made to ▮▮▮▮ or its various facilities in your research report or any publications thereafter.
4. The Company and its facilities are not in any way identifiable in the study.
5. The research is conducted within one year of permission being given by the Company.
6. Placement of the research report on the Company's research register after approval by the associated Higher Education Institution.

We wish you the best in your studies and look forward to the results.

Yours sincerely

Anne Roodt
on behalf of the Research and Scientific Committee.

Please sign this letter as indicated below and return to the sender within 2 working days:

I, _____, hereby agree to the provisos (points 1-6) as listed above.

Signature:

Date:

ANNEXURE 4: LIFE ETHICS EXTENSION REQUEST

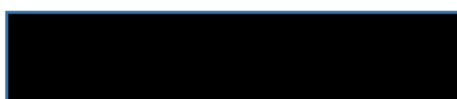<div align="right">

Apartment E208

The Quadrant

Library Square

Wilderness Road

Claremont

7708

27 December 2017

</div>

████████████████████

Oxford Manor

21 Chaplin Road

Illovo

2196

Dear Ms Roodt

RE: REQUEST FOR EXTENSION OF AUTHORIZATION TO CONDUCT RESEARCH WITHIN COMPANY FACILITIES

I received approval from the Life Healthcare Research and Scientific Committee on 29 April 2015 to conduct research within company facilities. The study forms part of the M Nursing programme I was registered for at Stellenbosch University. I initiated data collection processes in July 2015 and completed in-depth interviews with three participants.

In 2016, I received an invitation to travel and work abroad. I decided to discontinue my studies at that point in time as it was not feasible to continue with the M Nursing or the research while I was abroad. I have re-registered for the M Nursing programme in 2018 and would like to request that the Life Healthcare Research and Scientific Committee approval granted for this study in 2015 be extended for 2018. My intention is to complete the M Nursing programme, and therefor, this study in 2018.

Thank you for considering my request.

Warmest regards,

Keryn Harmuth

Research Title: EXPLORING ADULT PATIENTS' PERCEPTIONS OF WHAT ENABLES THEM TO MAKE SENSE OF THEIR INTENSIVE CARE EXPERIENCE

ANNEXURE 5: LIFE ETHICS APPROVAL 2018

Group

Oxford Manor, 21 Chaplin Road, Illovo 2196
Private Bag X13, Northlands 2116, South Africa
Telephone: +27 11 219 9000
Telefax: +27 11 219 9001
www.lifehealthcare.co.za

No.2018/05/01

National Health Research Ethics Committee registration: **REC 251015-048**

11th May 2018

Keryn Harmuth
University of Stellenbosch
Cape Town

Dear Ms Harmuth

RE: APPLICATION TO CONDUCT RESEARCH: ▮▮▮▮▮▮▮

Title of study: Exploring adult patients' perceptions of what enables them to make sense of their intensive care experience

The Research & Ethics Committee of ▮▮▮▮▮▮▮ hereby grants permission with no conditions for your study to be conducted at ▮▮▮▮▮▮▮. Present this letter to the Hospital Manager of the facility to gain permission at hospital level. This approval is valid for the period of the study.

Terms and Conditions:

1. If patient or institutional confidentiality is breached, ▮▮▮▮▮▮ is entitled to withdraw this permission immediately. The Higher Education institution/Research Institution under which the research is taking place will be notified, and ▮▮▮▮▮ reserves the right to take legal action against you, should the company feel that this is warranted.

2. An electronic copy of the research report (except in clinical trials) must be submitted to the ▮▮▮▮▮ Ethics Committee prior to publication.

3. No direct reference may be made to ▮▮▮▮▮ its subsidiaries or any of its facilities or institutions in the research report or any publications thereafter. The Company and its facilities, patients and staff must be de-identified in the study, and remain so for any other studies which may utilise this information.

4. The research must be completed within the time allotted by the Higher Education Institution/Research Institution. If the research is being done in an individual capacity by an employee of the ▮▮▮▮▮ the research must be conducted within one year of permission being given by the Company, OR the proposed time period must be specified in the proposal, and approved. Permission may be withdrawn if the research extends beyond the approved time period.

5. The researcher must provide the Company with an interim report on the progress of the study every six months for the duration of the study.

6. ▮▮▮▮▮ ill not take responsibility for any unforeseen circumstances within its institutions which may materially change the context and potential outcomes of a student's research. Should this occur, the researcher will be required to approach their Higher Education Institution/Research Institution for guidance around alternative sites.

Reg. no. 2003/024367/97 Registered address Oxford Manor, 21 Chaplin Road, Illovo 2196, Private Bag X13, Northlands 2116
Directors: CLW Bekker, CJ Koekemoer, PF Theron, PP van der Westhuizen, SB Viranna, KA Wyke

7. The researcher must provide a copy of the electronic research report or publications for placement on the Company's research register.

8. ██████████ will not be liable for any costs incurred during or related to this study.

Yours sincerely,

Peggy Naicker
On behalf of the Research and Ethics Committee

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ANNEXURE 6: INFORMATION LEAFLET & INFORMED CONSENT – ETHICS APPROVAL 2015

PARTICIPANT INFORMATION LEAFLET

TITLE OF THE RESEARCH PROJECT:

Exploring adult patients' perceptions of what enables them to make sense of their Intensive Care experience.

REFERENCE NUMBER: S14/10/208

PRINCIPAL INVESTIGATOR: Keryn Harmuth

ADDRESS: Division of Nursing, Department of Interdisciplinary Health Sciences, Stellenbosch University, Stellenbosch Central, Stellenbosch, 7600

CONTACT NUMBER: 0760860590

Dear Participant

My name is Keryn Harmuth and I am a Registered Nurse currently completing a Master of Nursing at Stellenbosch University. I would like to invite you to participate in a research project that aims to explore adult patients' perceptions of what enables them to make sense of their Intensive Care experience.

Please take some time to read the information presented here, which will explain the details of this project and contact me if you require further explanation or clarification of any aspect of the study. Your participation in this study is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the **Health Research Ethics Committee (HREC) at Stellenbosch University** and will be conducted according to accepted and applicable National and International ethical guidelines and principles, including those of the international Declaration of Helsinki October 2008.

Critical illness requiring treatment in intensive care is a significant and stressful event in any person's life. Quality nursing care in an intensive care environment is underpinned by appropriate, correct assessment and monitoring, drug and organ support interventions, patient comfort measures, psychological support, and early detection of complications. Previous research has shown that these interventions or activities create experiences that the critically ill patient must make sense of to be able to manage long term consequences of this traumatic encounter.

As critically ill patients' experiences form an important component of her/his perceptions of the quality of care provided in the intensive care unit, the knowledge revealed through this study will be useful to nurses and other healthcare personnel to apply in their interactions with patients and possibly optimize a patient personal feeling of being able to make sense of, tolerate and move through an experience of intensive care.

In this study I will speak to patients who have recovered sufficiently to have been transferred from the intensive care unit to a general ward. I intend to explore their experiences of intensive care with them in order to gain insight into their perceptions of which aspects of this encounter helped them to make sense of their experiences as a patient in intensive care.

Data collection will take the form of individual, unstructured interviews.

A copy of all the transcribed material and related documents will be kept in a safe, locked cabinet at the home of the researcher to ensure privacy and confidentiality. Data and related

documents will be kept until the research study is completed after which these will be destroyed. Only the researcher and the study supervisor will have access to the locked cabinet.

If you are willing to participate in this study please sign the attached Declaration of Consent and hand it to the investigator.

Yours sincerely,

Keryn Harmuth

Principal Investigator

Declaration by participant

By signing below, I ………………………………..…………. agree to take part in a research study entitled: **Exploring adult patients' perceptions of what enables them to make sense of their Intensive Care experience.**

.

I declare that:

- I have read the attached information leaflet and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) ....…........…………….. On (*date*) …………....………….. 2015.

....

Signature of participant

ANNEXURE 7: INFORMATION LEAFLET & INFORMED CONSENT – ETHICS APPROVAL 2018

PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM

TITLE OF THE RESEARCH PROJECT:

Exploring adult patients' perceptions of what enables them to make sense of their Intensive Care experience.

REFERENCE NUMBER: S18/01/019

PRINCIPAL INVESTIGATOR: Keryn Harmuth

ADDRESS: Division of Nursing, Department of Interdisciplinary Health Sciences, Stellenbosch University, Stellenbosch Central, Stellenbosch, 7600

CONTACT NUMBER: 0760860590

Dear Participant

My name is Keryn Harmuth and I am a Registered Nurse currently completing a Master of Nursing at Stellenbosch University. I would like to invite you to participate in a research project that aims to explore adult patients' perceptions of what enables them to make sense of their Intensive Care experience.

Please take some time to read the information presented here, which will explain the details of this project and contact me if you require further explanation or clarification of any aspect of the study. Your participation in this study is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

111

This study has been approved by the **Health Research Ethics Committee (HREC) at Stellenbosch University** and will be conducted according to accepted and applicable National and International ethical guidelines and principles, including those of the international Declaration of Helsinki October 2008.

Critical illness requiring treatment in intensive care is a significant and stressful event in any person's life. Quality nursing care in an intensive care environment is underpinned by appropriate, correct assessment and monitoring, drug and organ support interventions, patient comfort measures, psychological support, and early detection of complications. Previous research has shown that these interventions or activities create experiences that the critically ill patient must make sense of to be able to manage long term consequences of this traumatic encounter.

As critically ill patients' experiences form an important component of her/his perceptions of the quality of care provided in the intensive care unit, the knowledge revealed through this study will be useful to nurses and other healthcare personnel to apply in their interactions with patients and possibly optimize a patient personal feeling of being able to make sense of, tolerate and move through an experience of intensive care.

In this study I will speak to patients who have recovered sufficiently to have been transferred from the intensive care unit to a general ward and/or discharged from hospital. I intend to explore their experiences of intensive care with them in order to gain insight into their perceptions of which aspects of this encounter helped them to make sense of their experiences as a patient in intensive care.

Data collection will take the form of individual, unstructured interviews.

A copy of all the transcribed material and related documents will be kept in a safe, locked cabinet at the home of the researcher to ensure privacy and confidentiality. Data and related documents will be kept until the research study is completed after which these will be destroyed. Only the researcher and the study supervisor will have access to the locked cabinet.

Will you be paid to take part in this study and are there any costs involved?

No you will not be paid to take part in the study. There will be no costs involved for you, if you do take part.

Is there anything else that you should know or do?

> You can contact the Health Research Ethics Committee at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed by your study doctor.

> You will receive a copy of this information and consent form for your own records.

If you are willing to participate in this study please sign the attached Declaration of Consent and hand it to the investigator.

Yours sincerely,

Keryn Harmuth
Principal Investigator

Declaration by participant

By signing below, I …………………………………..…………. agree to take part in a research study entitled, "Exploring adult patients' perceptions of what enables them to make sense of their intensive care experience".

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) ....…........…………….. on (*date*) …………....……….. 2018.

....
Signature of participant

....
Signature of witness

Declaration by investigator

I, Keryn Harmuth, declare that:

- I explained the information in this document to …………………………………..
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did/did not use a interpreter. (*If a interpreter is used then the interpreter must sign the declaration below.*

Signed at (*place*) ....….......…………….. on (*date*) …………....……….. 2018.

………………………………………………   …………………………………………………
Signature of investigator   **Signature of witness**

Declaration by interpreter

I *(name)* …………………………………………..……… declare that:

- I assisted the investigator, Keryn Harmuth, to explain the information in this document to *(name of participant)* …………..…………………………….. using the language medium of Afrikaans/Xhosa.
- We encouraged him/her to ask questions and took adequate time to answer them.
- I conveyed a factually correct version of what was related to me.
- I am satisfied that the participant fully understands the content of this informed consent document and has had all his/her question satisfactorily answered.

Signed at *(place)* ....….......…………….. on *(date)* …………...………………..

....

Signature of interpreter   **Signature of witness**

ANNEXURE 8: EXAMPLES OF THE MIND MAPPING AND TRANSCRIPTION ANALYSIS PROCESSES

Image 2.1: Transcript analysis in 2015

## Image 2.2: Transcription analysis 2018

Left page:

ECG before so, or ~~since~~
me or not. But the long and the short of it w
ICU. Um, what stands out most for me is I'
Pallotti by that stage for about three months a
food complaints. Nothing but food complaints
my food. I found my food was delicious. Um,
that I actually wasn't going to die I felt fine.
good person for you to be trying to do your
part, most of the reason I landed up there
stressful state and secondly I knew I was goi
you get that feeling, I knew I was going to be
I received no IV medication so really I was
wasn't bothered by what was going on aro
have been. I didn't notice about the two pat
took no notice of them at all. I thought, I wa
personality wise. Um, and I read a book. I
didn't have the headphones anyway so I ju
got another couple of books. That was, tha
my space so I could just chill out here and
favourite thing in the whole world. I think
night. I slept but I wasn't aware of noises a
people stood out for me. ▮▮▮ stood o
she had just, she nursed me as well. She
was quite excited about that. ▮▮▮ of c
by then. She was really kind to me. Um,
could not fault the care. I could not fault
concern. I had an angiogram and they
were absolutely, and whether it was bec

Handwritten margin notes:
Good Food
made experience better.
① Stress Theme
② Febld in ICU Theme
③ Reassured Safe There Informed
Coping Theme.
Feeling (need for. Be kind To one another

Right page:

㉜ Ja, ja. So when um, when that happened, um, th
say well I'm not gonna be at the conference,
answer was, oh, no worries, we've got someone
do it, and its just a, its just a um, a slow insidious
I am the head of a unit, um I'm senior consultant
go from there and telling a nurse I think I might
can you come and wash me? And just you kn
you're nothing. Nothing, but for grace, you kno
changes in an instant. Another major turning p
always looking at the academic side of things
from the university phoned, at all. Just my o
with me. No one else phoned or did any
management team of the hospital came in to h

㉝ How you are…

㉞ And, and, and, you know so, so to see who, w
and who don't, and the people you think, ok
and the lies you're telling yourself, you kno
family, I'm working hard for my family, I'm s
etc, etc, and it's a lie, so, so you're replac
instant. But for your family, you're not. And
the best thing that could have happened.
are the priorities.

㉟ Life priorities

㊱ Ja, ja. So um…

㊲ So it just changed your perspective comple

㊳ Yes, yes, and um, just to realise you know
person. You know, I have very good inter
matter. It's what you do. And I mean, wh
expect maybe someone will bring

Handwritten margin notes:
Theme: Reaped this thought
Going from Being. To being (everything) (nothing). Nothing.
Theme!
Grace
Nothing but for grace
The lies you're telling yourself
Theme. you... Reaped!
Theme: eve in an inst
Theme: wh
Theme:

118

Image 2.3: Mind mapping process

Image 2.3: Mind mapping process
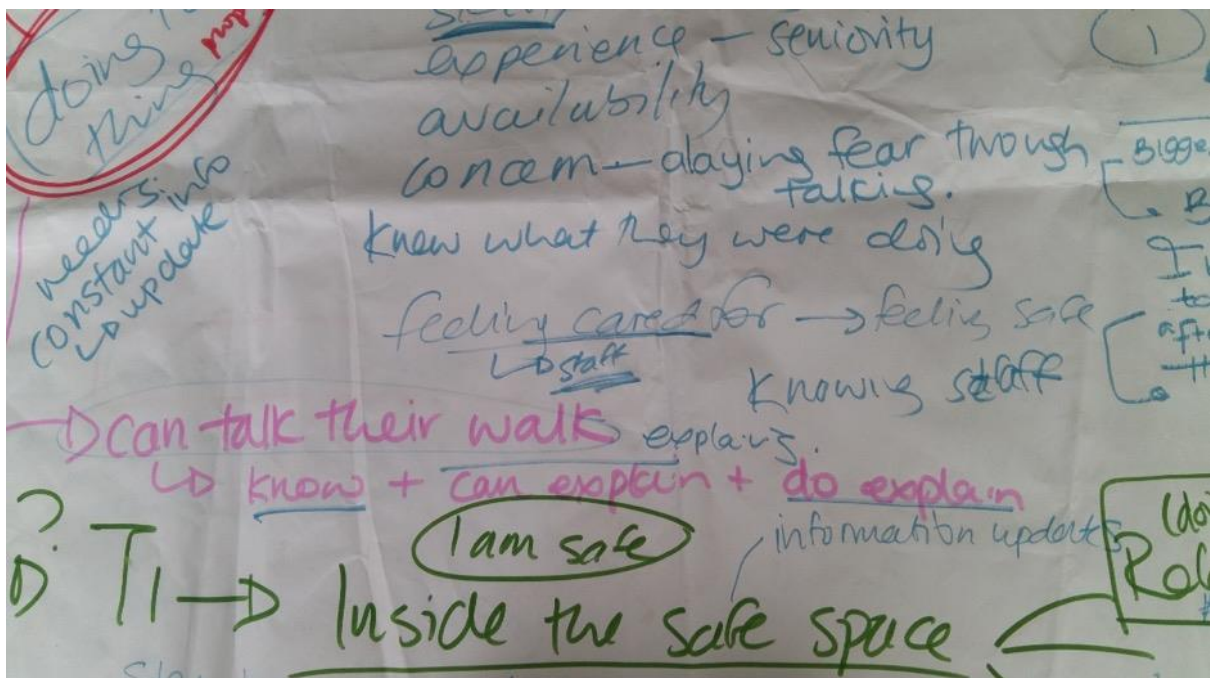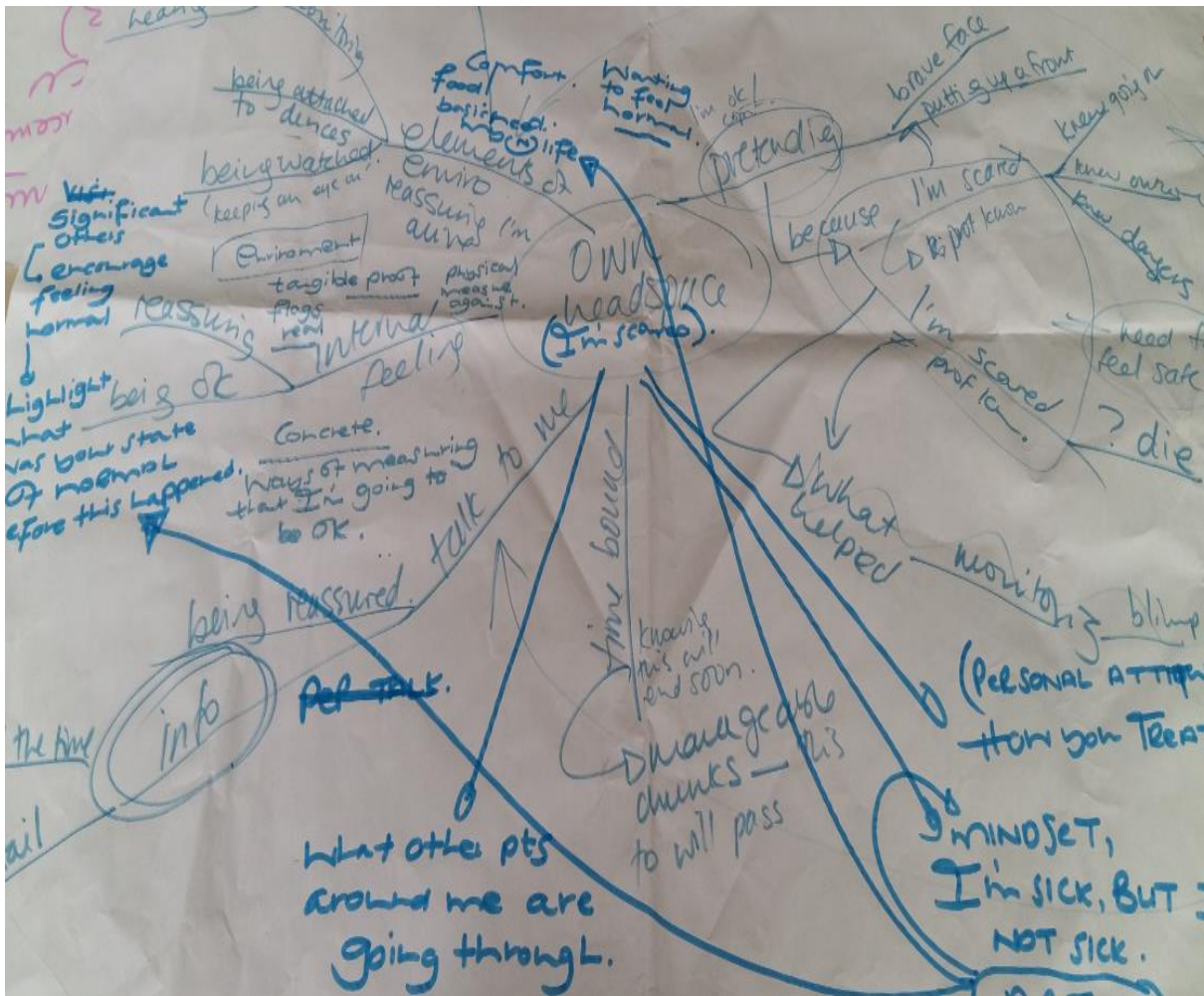
ANNEXURE 9: TECHNICAL EDITING REPORT

Between *the* **lines editing**

Leatitia Romero
Professional Copy-Editor, Translator and Proofreader
(BA HONS)

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26 February 2019

To whom it may concern:

I hereby confirm that I have technically edited the dissertation of KERYN HARMUTH, entitled: "EXPLORING ADULT PATIENTS' PERCEPTIONS OF WHAT ENABLES THEM TO MAKE SENSE OF THEIR INTENSIVE CARE EXPERIENCE". Any amendments introduced by the author or supervisor hereafter, is not covered by this confirmation. The author ultimately decided whether to accept or decline any recommendations made by the editor, and it remains the author's responsibility at all times to confirm the accuracy and originality of the completed work.

Aspects attended to:

- Heading consistency
- Heading and page numbering
- Tables
- Page layout
- Table of contents

Leatitia Romero

(Electronically sent – no signature)

Affiliations

PEG: Professional Editors Group
English Academy of South Africa
SATI: South African Translators' Institute
SfEP: Society for Editors and Proofreaders