BEING IN LIMBO: THE EXPERIENCE OF CRITICAL ILLNESS IN INTENSIVE CARE AND BEYOND

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A thesis presented in fulfilment of the requirements for the Degree of Doctor of Philosophy in Nursing

The University of Newcastle, Australia
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Statement of Originality

The thesis contains no material which has been accepted for the award of any other degree or diploma in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text. I give consent to this copy of my thesis, when deposited in the University Library**, being made available for loan and photocopying subject to the provisions of the Copyright Act 1968.

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This thesis is dedicated to the memory of my dearest father, John Chisanga, whose love and trust kept me focused on my goal.

This thesis is also for my mother Elizabeth Chisanga for her encouragement. Most of all for my dearest husband Elliot for taking up the role of father and mother to our girls so I could get on with the thesis and my dearest children Frederick, Taonga, Lusungu and Elizabeth for their love, support, patience, encouragement and the sacrifices they made in their lives to let me complete this work.

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ABSTRACT

Daily sedation interruption (DSI) has been associated with improved physical outcomes such as short ventilator, intensive care unit (ICU) stay and increased number of survivors. To date, only one cohort study has investigated the long-term effects of DSI on critical illness and ICU survivors. However, numerous studies have argued that many survivors continue to suffer from the effects of their critical illness and the ICU treatment. There are no qualitative studies that have examined the experience of critical illness in ICU and beyond in the context of DSI and the meaning the patients attach to their experience.

The purpose of this study was to describe the lived experience of people who experienced critical illness in ICU and following discharge. The research question for the study asked: What is the experience of critical illness in ICU and how does it affect people’s lives after discharge? Phenomenology was used as the methodological approach to this study. Participants aged between 20 and 76 years with an ICU stay ranging from 3 to 36 days were recruited from a 16 bed ICU in a large regional referral hospital in NSW, Australia. Participants were intubated and mechanically ventilated\(^1\) with DSI during their critical illness in ICU. In-depth face to face interviews with twelve participants were conducted at two weeks after discharge from ICU. A second interview was conducted with eight participants six to eleven months following the first interview. Interviews were audio taped and transcribed. Thematic analysis was conducted using van Manen’s six dynamic interplay activities. The main theme to emerge from the study was ‘being in limbo’. ‘Being disrupted’; ‘being imprisoned’ and ‘being trapped’ comprise the main subthemes of the study.

The findings of this study have the potential to increase understanding of the experiences of people during and following critical illness by nurses and other health care professionals. The experiences of the participants in this study suggest the use of DSI, considered an innovation in the treatment of critically ill patients with improved physiological outcomes, may not improve lived experiences of critical illness in ICU and beyond. Recommendations are made for new models of care and support to mitigate the patients’ experiences.

\(^1\) Being on life support (breathing supported by the breathing machine)
INTRODUCTION

Every sickness has an alien quality, a feeling of invasion and loss of control.

Hustvedt (2011, p. 6)

Critical illness is a sudden traumatising experience that affects not only the sufferer but also their family members throwing them into a crisis situation (Kinrade, Jackson & Tomnay, 2011). Those who are critically ill often discover themselves in an intensive care unit (ICU) when they emerge from a comatose state that may have lasted hours or even days.

Critical illness heralds life threatening complications (Holloway, 1993) and even death (Lubkin & Larsen, 2006). Illness is a highly personal state that impinges on the person’s physical, emotional, intellectual, social, developmental, and spiritual functioning. It is a lived experience that affects the objective (outward/external) and subjective (inward/internal) way of one’s being in the world (Leder, 1992). It disrupts relationships, work and recreation and it thwarts or threatens the individual’s plans for the future (Benner & Wrubel, 1989; Leder, 1992). Living through illness brings into question the person’s future and death (Kralik, Brown & Koch, 2001; Larsen & Lubkin, 2009; Leder, 1992). People who are critically ill are often in pain arising from either their illness or injury or inflicted by nurses and doctors (Granberg, Bergbom-Engberg & Lundberg 1998; Madjar, 1999; Parker, 1997).

In most instances, critical illness occurs in the context of hospitalisation and intensive care. Intensive care is a highly specialised area of medical and nursing practice where treatment and care focuses on continuous monitoring and management of patients for life-threatening or potentially life threatening-conditions or illnesses. An intensive care unit is where patients requiring intensive care are treated and managed (Rolls, 2011). Intensive care units provide care and treatment that supports the physiological functions of critically ill patients and uses the specialist skills of medical, nursing and allied health professionals who are experienced in the management of life-threatening conditions. Ideally, the patients treated and/or managed in ICU are recoverable with hope for an acceptable future quality of life (Faculty of Intensive Care, Australian and New Zealand College of Anaesthetists (FICANZA), 1997; Australian Health Workforce Advisory Committee (AHWAC), 2002). However, ICU hospitalisation is characterised by the use of invasive and painful procedures and rendering patients unconscious with sedatives during mechanical ventilation is central to treatment and
care at this time. As a result, patients are totally dependent on medical treatment and nursing care throughout their stay in ICU. Understanding the experiences of patients under these circumstances is central to good nursing care.

**Background to the study**

The ICU experience has been described variously as complex and difficult to describe by patients because it occurs at a time when they were physically, mentally and emotionally compromised. However, the memories patients have of their experience, together with the physical and psychological sequelae of their illness, affect their recovery and continued well-being. Although technological advances and innovation in intensive care practice have shortened the time patients require mechanical ventilation and their time in ICU, and in some circumstances improved survival rates (Niederman, Craven, Bonten, Chastre, Craig et al, 2005; Mendelsohn & Chelluri, 2003; Kress, Gehlbach, Pliskin, Pohlmans & Hall, 2003; Tonner, Weiler, Paris, & Scholz, 2003), it is not clear whether patient experiences are less traumatic and if shorter stays reduce the long term impact of being critically ill and having been a patient in ICU.

Many previous studies have examined the experience of critical illness (Granberg, Engberg & Lundberg, 1996, 1998, 1999; Kongsuwan & Locsin, 2011; McKinney & Deeny, 2002; Parker, 1997; Rotondi, Chelluri, Sirio, Mendelsohn, Schulz, et al., 2002; Carroll, 2007; Walters, 1995; Wang, Zhang, Li & Wang, 2008; Li, Wang, Wu, Liang & Tung, 2011). Of concern is that anecdotal evidence suggests that the experiences of patients have been not improved over time (Adamson, Murgo, Boyle, Kerr, Crawford et al., 2004; Ballard, Robley, Barrett, Fraser, & Mendoza, 2006; McKinney & Deeny, 2002; Rundshagen, Schnabel, & Wegner, 2002) despite advances in technology and changes in Intensive Care Unit (ICU) practices such as early tracheostomy and the use of daily sedation interruption (DSI). Overall, advances have been directed at; reducing the time patients are ventilated and their length of stay (LOS) in the ICU (Coyer, Wheeler, Wetzig, Couchman, 2007; Jacobi, Fraser, Coursin, Fontaine, Wittbrodt et al., 2002); promoting comfort, wakefulness and the ability of patients to interact (Wunsch & Kress, 2009); and preventing complications associated with continuous deep sedation (Kress & Hall, 2006; Kress, Pohlmans, O’Connor & Hall, 2000) such as ventilator acquired pneumonia (Combes, Luyt, Nieszkowska, Trouillet, Gilbert et al., 2007). Of importance is that some advances in ICU care and treatment have led to increasing numbers of people who survive ICU (Barie, Bacchetta & Eachempati, 2000; Egerod, Christensen, Schwartz-Nielsen & Agard, 2011; Hall, 2010; Graf, Millar, Feilteau, Coakley & Erickson, 2003; Mendelsohn & Chelluri, 2003). The use of DSI is one such
advancement. The daily interruption of continuous sedation infusions in ICU patients allows for neurological examinations and mental assessments to be performed more frequently than would be achieved otherwise with continuous sedation (Kress et al., 2000). In contemporary ICUs only patients who become agitated undergo continuous sedation. Whilst there are a small number of studies (Kress et al., 2000; Kress & Hall, 2006; Mehta, Burry, Martinez-motta, et al., 2008; Wunsch & Kress, 2009) that have investigated whether or not the use of DSI accelerates recovery the lived experience of patients who have undergone DSI has not been explored during ICU hospitalisation or following discharge from hospital.

The literature shows that many patients who survive ICU treatment have poor quality of life (Desai, Law & Needham., 2011; Elliot, McKinley, Alison, King, Aitken, et al., 2011; Hall, 2010; Hopkins & Jackson, 2006; Needham, Feldman & Kho 2011). For instance, in a study by Elliot et al., (2011) of critical illness survivors, 12 to 43% of patients suffered from anxiety, 28% depression, and 5 to 6.4% reported having post-traumatic stress disorder (PTSD) related symptoms from the distressing experience of critical illness. Of concern is that the sequelae of critical illness place an ever increasing burden on the survivors (Desai et al., 2011; Needham et al., 2011). Evidence suggests that the burden after a critical illness in ICU leads to poor health with some patients needing admission to long-term acute/chronic illness facilities (Mendelsohn & Chelluri, 2003; Elliot et al., 2011). The health care costs associated with caring for ICU survivors are $24 billion each year in the United States of America (USA). The health care costs to the individual in the USA range between $76,000 to $2,000,000 (Wiencek & Wenkelman, 2010). These costs are likely to grow with the changing demography and ageing population (Frost, Davidson, Alexandrou et al., 2010; Seferian & Afessa, 2006).

To date there is no established follow-up care for critical illness ICU survivors in Australia. By conducting qualitative research such as the study reported here, the impact of the ICU hospitalization and critical illness on individuals will contribute to knowledge about the nature of the experiences and how best to support critically ill patients and their families.

**Purpose of the Study**

The purpose of this study was to describe the lived experience of people who experienced critical illness in ICU and following discharge. My goal in undertaking the study was to discover what it was like for people to experience critical illness in the light of the advances in treatment with the use of DSI. This thesis is about the lived experiences of twelve patients who were treated using DSI in contemporary ICU. My interest in studying this topic was
motivated by the need to understand the lived experience of being critically ill in ICU today and surviving critical illness.

The research question for the study asked:

What is the lived experience of critical illness in ICU and how does it affect people’s lives after discharge?

I used the following questions in my inquiry:

- What does it mean to have been critically ill in ICU?
- What is it like to be critically ill and mechanically ventilated with DSI?
- What is it like to emerge from a state of unconsciousness in ICU?
- What is the impact of critical illness in ICU following discharge?

Because I wanted to understand the experience of being critically ill and surviving critical illness in ICU from the individual’s point of view, I used Merleau-Ponty's (1962/2002) Phenomenology of Perception to guide the study inquiry.

Phenomenological research begins in the life world. As a research methodology it aims to gain deeper understanding of the meaning of everyday experiences (van Manen, 1990). Phenomenology asks what a particular experience is like. Unlike other sciences, phenomenology seeks to garner insightful descriptions of the way the world is experienced pre-reflectively without taxonomising, abstracting or classifying it (van Manen, 1990). In this study the findings give insight into how the people who experienced critical illness in ICU lived their lives in the context of ICU and following discharge. The findings show how surviving critical illness remains traumatic despite the advances in treatment approaches such as DSI and how ICU hospitalisation also impacts people following discharge from hospital.

To conduct this study, I sought access to a regional referral ICU where twelve people aged between 20 and 75 years of age who had suffered a critical illness in ICU agreed to tell me about their experiences of critical illness in ICU and their life following discharge.

The study reported here explored the lived experiences of people with critical illness in ICU and following discharge from hospital. Of importance in relation to this study is that the experiences of critically ill patients were explored within the context of the use of DSI. The study was motivated by concerns for patients who were subjected to DSI. Of concern was how critically ill patients experienced the frequent periods of consciousness and
unconsciousness using this treatment regime. A phenomenological approach was considered to be the most appropriate methodology for the study given the research questions focus on understanding lived experiences and meanings within this context. This thesis aims to show the level of distress experienced by the participants in this study throughout their treatment and care in ICU and following discharge from hospital as they continued to re-live their ICU experiences in the form of dreams and nightmares. The findings of this thesis suggest that for the participants in this study the lived experience of critical illness in ICU and following discharge from hospital was a life in limbo characterised by disruption to life generally, and a sense of imprisonment and entrapment in ICU. From the time the participants were admitted to ICU they felt they were suspended between life and death.

The findings highlight the need for alternative models of care to be explored and cast some doubts on the use of DSI as a mechanism for improving health outcomes in the light of the experiences of the people in this study. Recommendations are made for new models of care and support to mitigate the patients’ experiences.

**Structure of the Thesis**

This thesis comprises seven chapters. In the previous introduction to the study I provided a synopsis of the thesis, its purpose, aims and the main research questions. I also provided brief background to the study.

In Chapter One I critically analyse the literature relating to studies that have been conducted on lived experiences of critically ill patients both in ICU and following discharge. I particularly focus on studies that have examined technology in the ICU environment and its impact on the critically ill patient in ICU, the experience of mechanical ventilation, disturbances of consciousness, the transformative nature of critical illness, life after ICU and follow up care for critical illness ICU survivors.

In Chapter Two I discuss phenomenology as the merits of methodology and within the context of this study. I discuss aspects of Merleau-Ponty’s (1962/2002) *Phenomenology of Perception* as they apply to this study and the notion of intentionality, speech and lived time, lived relation, lived space and lived body (Madison, 1981).

In Chapter Three, I discuss the design and methods of the study. I describe how I conducted the study using van Manen’s (1990) six dynamic interplay activities. I also describe my study assumptions, how I dealt with the assumptions, the purpose, aim of the study, and the
research questions. I also outline the research plan, the setting, recruitment processes, inclusion criteria, data collection and analysis and the ethical considerations of the study. Finally, I describe the participants.

In Chapters Four, Five and Six, I describe the findings of the study. In Chapter Four which I named ‘Being Disrupted’, I highlight the participants’ descriptions about their period of regaining consciousness and the meanings they attached to that situation. In Chapter Five, named ‘Being Imprisoned’, I reveal the participants' descriptions of their wakeful experience during their critical illness in ICU. In Chapter Six, ‘Being Trapped’; I disclose the participants experiences following discharge from hospital.

Finally, in Chapter Seven I provide a discussion about the findings of the study including its strengths and limitations. I also outline the implications of the study for clinical practice, education and research.
CHAPTER ONE

LITERATURE REVIEW

In the introduction, I outlined the study problem, introduced the background to the study including ICU and the main reasons for admission to ICU. I also discussed the purpose of the study, aims, the research question and the thesis structure.

In this chapter, I critically examine the body of knowledge relating to the experience of critical illness in ICU. In particular, I examine the literature relating to technology and innovation in ICU treatments, experiences of mechanical ventilation, disturbances of consciousness and critical illness, life after ICU and follow up care and treatments.

Search Strategy

This literature review was guided by the question: What is the experience of being critically ill in ICU? Literature was identified through an electronic search of the databases: Medline, EMBASE, CINAHL, PsychInfo, Ovid, ProQuest, Google, Google scholar and the University of Newcastle’s search engine Super Search. Literature search included full text articles and abstracts published in English between 1988 and 2011 and relevant articles from these articles’ reference lists.

The search was conducted using the search terms; critical illness, mechanical ventilation, and intensive care unit. MeSH terms included: experience, hospitalisation and memories, follow up care, intensive care diaries, and rehabilitation in intensive care units. The literature search was ongoing and cumulative, guided by an inductive research process.

It is evident that there is a growing body of knowledge that examines patients’ experience of critical illness in ICU. Researchers have examined the patients’ responses to the highly technological and invasive ICU environment and medical care they receive, the experience of being mechanically ventilated and the experience of disturbed consciousness (Adamson, Murgo, Boyle, Kerr & Crawford, 2004; Laitinen, 1996; Roberts & Chaboyer, 2004; Roberts, Rickard, Rajbhandari & Reynolds, 2006; Karlsson & Forsberg, 2008; Li et al., 2011). Other authors have examined the longer term effects of critical illness and the ICU experience (Elliot et al., 2011; Kress et al., 2003; Löff, Berggren & Ahlstrom, 2006; Papanatsiopoulos & Patiraki, 2003; Samuelson, 2011; Unroe, Khan, Carson, overt, Martinu et al., 2010). Much of what is reported points to the need for treatments that help to overcome both the short and long-term deleterious effects of critical illness and the ICU on patients.
I critically review the literature with regard to patients’ responses to the highly technological, invasive ICU environment, the experience of being mechanically ventilated through an endotracheal tube (ETT), the experience of being mechanically ventilated through a tracheostomy tube, communication difficulties associated with being mechanically ventilated and the experience of disturbed consciousness. I also discuss the follow-up care strategies that have been implemented to deal with long-term effects of critical illness and finally life after ICU hospitalisation.

**Technology in the ICU Environment**

The technological nature of ICU has been the focus of a number of studies (Almerud, Alapack, Fridlund & Ekebergh, 2007a, Almerud-Österberg, 2010; Fairman, 1992; Granberg, Engberg & Lundberg, 1998; Kongsuwan & Locsin, 2011; McKinney & Deeny, 2002; Parker, 1997; Rotondi et al., 2002; Carroll, 2007; Walters, 1995; Wang, Zhang, Li & Wang, 2008; Li et al., 2011). Although technology is a valuable part of our life, particularly in the Western world, it can be counterproductive, when it replaces virtues such as empathy and touch (Almerud et al., 2007a). Patients’ embodied experiences of technology have been those of being close to, and invaded by technological apparatus, objectification and alienation (Almerud et al., 2007a; Donnelly & Wiechula, 2006; Foster, 2009; Löf et al., 2006, 2008; Rotondi et al., 2002; Samuelson, 2011; Wang et al., 2008).

Recognising and understanding responses to technology are fundamental to appreciation of the lived experience of critically ill patients in ICU. Within the literature, critically ill patients have described the high-technological ICU environment as strange, frightening, restrictive and persecutory in nature (Almerud et al., 2007a; Löf et al., 2008; Parker, 1997). Fear is associated with the strange and noisy nature of the ICU environment (Parker, 1997) and bright lights (McKinney & Deeny, 2002; Honkus, 2003; Eliassen & Hopstock, 2011). In addition, critically ill patients have reported feelings of panic, vulnerability, loss of control, unreal experiences, a heightened sense of death (Almerud et al., 2007a; Granberg et al., 1998; McKinney & Deeny, 2002; Parker, 1997; Rotondi et al., 2002) and disturbed sleep (Fredriksen & Ringsburg, 2007; Li et al., 2011; Parthasarathy & Tobin, 2004; Richardson, Allsop, Coghill, & Turnock, 2007; Tamburri, 2004; Wang et al., 2008; Weinhouse & Watson, 2009). Fear and anxiety, objectification, pain and discomfort, and perceptions of dependency as aspects of experiencing the ICU technological environment are discussed in the following paragraphs.
Fear and Anxiety

Patients’ experience of fear and anxiety evoked from the exposure to the technological environment of ICU (Parker, 1997) and from the physiological changes caused by critical illness (Cypress, 2011) effects critically ill patients’ immediate responses, their ongoing perceptions and their overall state of health. How much of what patients remember in relation to the technological environment is unclear and varies across studies (Egerod et al., 2011; Granberg et al., 1998; Löff et al., 2008; McKinney & Deeny, 2002; Parker, 1997; Ringdal, Plos, Ortenwall, & Bergbom, 2010; Strachan & Brown, 2005). However it is clear technology is related to people’s sense of security and feelings of dependency (Almerud et al., 2007a). Interestingly, the fear they experience is not only a response to being exposed to the technology but later, the separation from a technological environment they perceive as lifesaving (Granberg et al., 1998; McKinney & Deeny, 2002; Parker, 1997; Strachan & Brown, 2005). Although fear has been connected to technology in ICU, it is more likely that it is the physiological changes emanating from the critical illness and the treatments the patients receive that heighten the sense of fear and anxiety (Cypress, 2011).

Parker (1997) conducted a phenomenological study at a referral hospital ICU in regional Australia in which she investigated the lived experience of eleven critically ill patients in the ICU through face to face interviews over a period of twelve months. The author’s participants described perceptions of the highly technological ICU environment as scary, uncomfortable, not nice, noisy, depressing and weird. Patients said they felt like they were on “show”, they felt exposed and watched by the nursing staff a finding that is consistent with Fairman’s (1992) comments. Parker’s (1997) participants described how the technology was restrictive, preventing them from moving or escaping their circumstances. Parker’s participants also described a sense of losing control and being maintained by technology. Some found this a “nuisance” while for others it was a source of safety; the prospect of going back to their rural communities which did not have lifesaving technology and expertise was frightening. McKinney and Deeny (2002) and Straham and Brown (2005) also reported participants who were afraid of going to a ward without ICU technology. Parker’s (1997) study provides insight into what it is like to be critically ill in a high technological environment of ICU and knowledge that can be applied to clinical practice in the provision of psychological care of the critically ill.

Reports about the experience of, and response to, the technological environment vary with individuals ascribing meaning according to their particular experience. For example, while some of the patients in Parker’s study felt objectified and frightened, others became watchful
of the monitors and nursing actions and tried to tap into what could help with their recovery. Some were unable to maintain their vigilance when they could no longer cope with pain and doubt. Losing vigilance was also reported by Almerud et al. (2007a) who argued that surveillance promotes a sense of security. However, being connected to technological apparatus without the human touch evokes feelings of vulnerability and loss of hope. In this way, patients often not only credit their survival to technology but as highlighted above often become dependent on it and dread leaving the technological environment of ICU (Almerud et al., 2007a; McKinney & Deeny, 2002; Parker, 1997). In addition, the experience of technology has a transforming power in so much as it heightens participants’ sense of finitude; they see the world through a different lens. For some it erodes the trust that they had in their body and replaces certainty with uncertainty (Granberg et al., 1998; Parker, 1997).

**Objectification**

Objectification in ICU is a subjective experience of disappearance in which the patient perceives themselves as invisible in the eyes of the ICU practitioner (Almerud et al., 2007a). The experience of objectification in the midst of technology and seemingly uncaring strangers (ICU staff) evokes feelings of loneliness and fear (Almerud et al., 2007; Parker, 1997). Feelings of objectification are associated with loneliness, a sense of threat to patients’ life resulting in panic and a struggle to survive (Parker, 1997). Almerud et al. (2007a) argued that at the objective level, the ICU members of staff are seen to be preoccupied with preserving life by maintaining constant surveillance over technology, often ignoring the patients’ subjective need to be heard and touched. Patients’ perceptions of ‘disappearing’ in the eyes of the ICU staff is in part due to being immobilised by the technology, together with the noise from machines and people in the unit that prevents their attempts to call for attention being noticed.

Objectification also featured strongly in a Heideggerian phenomenological study by Wang et al. (2008) who explored patient’s experience of mechanical ventilation in ICU. Wang et al’s (2008) study involved eleven Chinese patients whom they interviewed three to fourteen days post ICU discharge. The authors’ aim was to explore Chinese patients’ experience of mechanical ventilation in ICU. Participants described the ICU environment as an ‘unfamiliar terrible jail like environment’ (p. 185), or as another world in which one participant likened the experience to ‘throwing a child who cannot swim into a swimming pool’. Patients talked of being confused and disturbed by the alarms which woke them from sleep. The participants in Wang et al.’s study described being ignored as being treated like vegetables or inanimate
objects. Wang et al.'s findings were consistent with those of Granberg et al.'s (1998) that the ICU was a place of suffering in which participants felt helpless, passively received treatment and care, a place where they could not move, talk or breathe on their own. The state of restriction imposed upon patients by technology was described as overwhelming and evoking feelings of vulnerability, dependency and powerlessness. This finding resonates with what Almerud et al. (2007, p. 151) succinctly referred to as forced dependency, which when overlooked can result in patients feeling uncertain about their care. The similarity with Almerud et al’s (2007) and Parker’s (1997) shows the findings are consistent and highlights the global need to address the issue of objectification in ICU.

**Pain and Discomfort**

Besides its therapeutic purposes, technology causes pain (Madjar, 1999; Wang et al., 2008). Reports of pain, suffering and discomfort associated with penetration of technological devices into a person’s body through procedures such as intubation, blood sampling and suctioning are evident within the literature (Granberg et al., 1998; Madjar, 1999; Wang et al., 2008). Suffering also results from experiencing noise and lack of sleep (Granberg et al., 1998). Such suffering is reported to evoke feelings of imprisonment (Zeilani & Seymour, 2010).

Granberg et al. (1998) conducted a hermeneutic phenomenological study in Sweden involving nineteen critically ill patients. They interviewed their patients at one week and at eight weeks after ICU discharge. Their participants reported that being connected to machines triggered concerns and questions about the seriousness of their illness. At the objective level, technology in the form of invasive and non-invasive lines was experienced as therapeutic yet at the subjective level, the participants’ tension and discomfort was associated with the presence and foreignness of lines like nasogastric tubes, intravenous and other lines and cables that rendered them motionless by forcing them to lie still. The authors found that perceptions of ‘forced dependence’ were compounded by noise from technology, particularly when the participants attempted to move, setting off alarms which caused them to feel panicked.

When patients perceive technology as harmful it can cause them to become aggressive (Granberg et al., 1998). A participant in Grandberg et al’s (1998) study described intravenous needles and the central lines as painful fishing hooks that left his hands numb so that he became increasingly afraid, anxious and aggressive. Granberg et al (1998) concluded that feelings of being imprisoned by the ICU technology could cause unpleasant thoughts and bodily sensations that can make people question whether they will survive.
However, some participants in Granberg et al’s (1998) study reported feeling safe and comfortable with technology. For instance one participant reported that seeing tracheal suctioning being done for other patients suctioned made her appreciate the value of it being done for her. being suctioned. Alternatively, Granberg et al’s (1998) study reveals that technology can be therapeutic as well as harmful for the critically ill. The study also gives insight into some of the causes of aggression in the critically ill. The follow up period of one week was short, but it can be argued that this could be a strength providing fresh memories of ICU.

Twelve years later Granberg et al’s (1998) and Parker’s findings were supported by a phenomenological study conducted by Zeilani and Seymour (2010) whose participants also described feelings of forced dependency and imprisonment. Zeilani and Seymour (2010) conducted their study in Jordan where they interviewed sixteen women from two Jordanian ICUs who had been mechanically ventilated for at least 48 hours. The authors used in-depth face to face interviews. Patients were interviewed one to three times post discharge from ICU. Reports of physical, social, spiritual suffering and suffering from the technological experience were elicited. Participants in this study described feeling trapped by technology without any room to escape and the isolating loneliness the technology evoked, along with a sense of closeness to death, which made them liken their survival to ‘being taken out of the tomb’ (p. 180). Zeilani and Seymour (2010) show that the experience of the technological ICU environment has not changed over time. The study also adds a spiritual perspective and emphasises the social suffering associated with being critically ill and connected to technology in the strange environment of ICU. Although the period of six months is rather short compared to Parker’s (1997) 12 month follow-up, the number of interviews conducted in that time added strength to the study.

The ambiguous and multifaceted nature of technology meaning is that patients perceived it as a threat to life and yet at the same time it is associated with preservation of life. Despite improved technology and ICU practices, the distressing experience of the critically ill patients in relation to technology remains unchanged. The varied locations of studies by various authors reveals the nature of critical illness as a shared experience characterized by embodied suffering, and the global significance of the need to address the negative impact technology has on the experience of critical illness in ICU.
The Experience of Mechanical Ventilation

The experience of mechanical ventilation has been examined extensively in the literature. Much of what is reported by patients about their ICU experience relates to the experience of the endotracheal tube (ETT) and being mechanically ventilated. The presence of an ETT in the mouth and throat is consistently perceived by study participants as a threat to their existence. The presence of a life sustaining device like the ETT, transforms an individual’s existence by obliterating the gap between the patient and the technology and making them inseparably one (Anderson, Moyle & McAllister, 2002). The experience of technology heightens emotional chaos (Granberg et al., 1998; Nanthakumar, Dorian, Ham, Lam, Lau et al., 1998) for the recipient and leads to anxiety and fear which in the case of invasive mechanical ventilation invariably results in breathing difficulties (Ballard et al., 2006; Löf et al., 2008; Rotondi et al., 2002). Furthermore, having an ETT and being attached to a ventilator alienates the critically ill person from the primordial social, historical and cultural self (Merleau-Ponty, 1962/2002). This alienation causes loneliness and, coupled with breathing difficulties, evokes and perpetuates feelings of terror, fright, discomfort, bewilderment, panic and dread as the patient senses their mortality and engages in a battle to survive (Löf et al., 2008). In addition, mechanical ventilation is associated with sleeplessness and uncertainty about survival during critical illness (Löf et al., 2008).

Mechanical ventilation, particularly pressure support ventilation\(^2\) (PSV), is associated with sleep deprivation in the critically ill (Parthasarathy & Tobin, 2004; Tembo & Parker, 2009; Weinhouse & Watson, 2009) as it interferes with the quality and quantity of sleep (Parthasarathy and Tobin, 2004). However, critical illness and the medications used to facilitate mechanical ventilation are known to interfere with quality and quantity of sleep in mechanically ventilated critically ill patients.

Reports of pain, thirst and inability to talk in relation to mechanical ventilation have also been documented (Löf et al., 2008). Studies reporting ventilator dependency (Almerud et al., 2007; Granberg et al., 1998; Parker, 1997; Wang et al., 2008; Zeilani and Seymour, 2010; Löf et al., 2008) identified that people often become vigilant in relation to the technology that is supporting them, moving from fear and terror to appreciation of and dependency on the ventilator.

Löf et al. (2008) interviewed nine patients at three months and at twelve months after discharge from a Swedish ICU. Using content analysis, their aim was to identify critically ill patients who have been ventilated.

\(^2\) Partial ventilatory support in which the patient shares the work of breathing with the ventilator to achieve the required respiratory needs.
mechanically ventilated patients' memories of both factual events and unreal experiences. The authors asked their patients to describe their experience of critical illness from the onset of critical illness and arrival at the hospital; and before, during and after mechanical ventilation. Löf et al found that patient’s reports ranged from having no memories to fragmentary and even vivid memories. Patients reported a dramatic and sudden deterioration in their condition, experiences of breathing difficulties, high temperature, body aches and things going ‘fuzzy’. Patients also recalled caring staff and oxygen administration devices. The authors also found that patients experienced horrible and terrifying nightmares even before they were mechanically ventilated. Findings associated with mechanical ventilation included recollections of communication difficulties, noise, feelings of chaos and misperception of place. The experience of mechanical ventilation was further generally described as. ‘horrific and frightening’. In contrast to many other studies, there were no reported memories of the ETT.

Post mechanical ventilation was associated with no memory of mechanical ventilation and misperception of time for some patients, while others felt safer to remain on mechanical ventilation support demonstrating the ambiguity of technology Löf et al. (2008) shows that although mechanical ventilation is associated with negative experiences such as delusional memories like nightmares, severely ill patients are already affected by cognitive disturbances before their arrival at the ICU. Disorientation or cognitive decline may have been present prior to admission to ICU. Hence from their first moments in the ICU patients suffer from unreal experiences, which are then considered as part of the ICU delirium. It can therefore be concluded that memory disturbances and delirium in critically ill patients are multifactorial, possibly arising from environmental, physiological, pharmacological and psychological causes or sleep disturbance. These could have detrimental effects on cognition and may be associated with non-recall or fragmentary memories of factual events during the ICU stay. The study also reveals that critically ill ICU patients need to talk about their experiences and thus emphasises the necessity of follow-up for these patients. The strength of this study lies in longitudinal design tracking the trajectory of critical illness from pre to post mechanical ventilation and ICU discharge.

In a larger and more recent qualitative study by Samuelson (2011) of 250 patients in Sweden, the findings of physical distress associated with mechanical ventilation were similar to those of Almerud et al (2007a); Granberg et al (1998); Löf et al (2008) and Rotondi et al (2002). Samuelson (2011) used interviewed people who had been critically ill in two Swedish adult ICUs for more than 24 hours. The aim of the study was to describe pleasant and unpleasant ICU memories of adults who had been mechanically ventilated.
Samuelson (2011) interviewed the participants five days after discharge from ICU. Patients described the ETT as ‘horrible and distressing’. Not being able to breathe in synchrony with the ventilator and not getting air, ‘choking’ on the secretions, and struggling to communicate both during and after being mechanically ventilated caused them to believe they would die. The participants’ association of their predicament with imminent death evoked feelings of vulnerability, powerlessness, fear, anger, loss of control and frustration. Samuelson’s participants also reported experiencing depressive feelings emanating from dependence, not knowing what was happening and uncertainty and helplessness. The finding of ‘feeling trapped’ and considering or ‘attempting to escape’, loneliness and emptiness was also present among these participants. The finding of being trapped was also described in Almerud et al.’s study of 2007a and Löf et al. (2008). The difference between these studies lies in the participants responses to the forced dependence on machines and health professionals, in that Löf et al.’s participants attempted to escape through struggle while Wang et al’s (2008) and Zeilani & Seymour’s (2010) participants did not. Like the studies above (Almerud, et al., 2007a; Granberg et al., 1998; Löf et al., 2008; Wang et al., 2008; Zeilani & Seymour, 2010) the ambiguity of technology was also described by some participants in Samuelson et al’s study. On the one hand technology was perceived as divisive and harmful. On the other, it was perceived as lifesaving.

The qualitative studies above show that reports of the experience of being mechanically ventilated have not changed over the last decade. Patients have continued to experience discomfort, pain, sleep deprivation and feelings of terror when they are mechanically ventilated despite the innovation in mechanical ventilators and more sensitive modes of ventilation. Furthermore, the strangeness and foreignness of the ETT, along with the associated breathing and communication difficulties, have been highlighted as heightening the sense of being close to death. Findings of loss of control, vulnerability, powerlessness, uncertainty, fear, anger, frustration and feelings of depression associated with being dependent have also been reported. The ambiguous experience of mechanical ventilation among the cohort of critically ill patients has also been highlighted. In addition, the studies above, both earlier and recent have demonstrated that despite the changes in practices and the technological advances in mechanical ventilation the experience of critical illness in relation to mechanical ventilation appears to be unchanged.

While the patient is unaware of the benefits of technology his/her experience and relationship with it is that of body-object and alienation. The body perceived by others and in some ways experienced by participants themselves as an object results in alienation and suffering. Suffering that may go unnoticed. Suffering can negatively transform patients'
perception of the world for the rest of their life as evidenced in some studies (Capuzzo, Bertaccchini, Davanzo, Glovanna, Paparella, & Tadini, 2010; Hofhuis, Spronk, van Stel, Schrijver, Rommes & Bakker, 2008; McKinney & Deeny, 2002; Ringdal et al., 2010).

Technology can, however be appreciated as lifesaving and have a positive effect as described by some of the participants in the studies reviewed. Data on early tracheostomy as another means of mechanically ventilating critically ill patients as opposed to the ETT are emerging (Bouderka, Fakhir, Bouaggad, Hmamouchi, Hamoudi, & Harti, 2004; Holevar, Dunham, Clancy, Como, Ebert et al., 2009; Sugerman, Wolfe, Pasquale, O'Malley, Knudson, DiNardo, et al., 1997; Yaseen, Samir, Nehad, & Abdullah, 2004). However data on the benefits of early tracheostomy remains debatable (Arthur, & Slutsky, 2002) and limited (Golan, & Fan, 2011). Of particular interest is that tracheostomy is now viewed as a better alternative to the ETT (Combes et al., 2007; Freeman, Borecki, Coopersmith, & Buchman, 2005; Zagli, Linden, Spina, Bonizzoli, Cianchi, Anichini, et al., 2010). It is argued that early tracheostomy reduces the number of ventilator and ICU days (Freeman et al., 2005; Sugerman et al., 1997; Zagli et al., 2010), and enables patients to communicate more effectively (Foster, 2009). Hence reducing the suffering experienced by patients. However, like the ETT, having a tracheostomy is also reported as frustrating; like the ETT, it prevents the person from speaking, and its presence causes anxiety as it inhibits free communication (Donelly & Wiechula, 2006).

In an Australian phenomenological study, Donelly and Wiechula (2006) investigated four critically ill patient’s lived experience of having a tracheostomy tube removed and reinserted. The participants reported receiving no psychological preparation before the tube change procedure. Patients reported feeling panicked due to the pain, discomfort and communication difficulties they experienced. The intensity of discomfort, uncertainty, fear and anxiety were associated with waiting and not knowing who was going to conduct the procedure. However, most of the participants in this study described the experience of losing their voice as a means of communication as worse than the discomfort they experienced from the tracheostomy and suctioning3 procedure. Donelly and Wiechula (2006) concluded that the ability to verbally represent one’s self was fundamental to self-concept. Three years later, Foster (2009) conducted a phenomenological study in the U.K. in which he investigated the lived experience of tracheostomy tube change in ICU for three patients. The author’s aim was to describe the experience of the tracheostomy tube as part of a critical illness experience or as a procedure linked to an acute event. Foster (2009) used purposive

3 Artificial way of removing secretions from the respiratory system using a flexible tube attached to a vacuum machine.
sampling and face to face interviews guided by semi structured questions. He found that patients experienced communication difficulties which evoked anger and frustration. Pain and discomfort were associated with the tracheostomy and suctioning. Foster’s patients also reported fear of the unknown, being scared when they learnt about the threat to their life that meant they required a tracheotomy be performed. Foster’s (2009) findings are similar to Donelly and Wiechula's (2006) about the communication difficulties critically ill patients encounter when they are tracheostomised, highlighting that the experience of mechanical ventilation is unpleasant regardless of whether a person has an ETT or tracheostomy. Foster’s participants described not being able to swallow or breathe normally and they spent most of the time coughing. Again these are experiences that are similar to those of patients who are mechanically ventilated using the ETT (Haftondettir, 1996; Laitinen, 1996; Parker, 1997). Foster also confirmed experiences of vivid unreal experiences related to the tracheostomy reported in earlier studies (Granberg et al., 1998, 1999; Hafsteindottir, 1996; Kress et al., 2003; Laitinen, 1996; McKinney & Deeney, 2002; Roberts & Chaboyer, 2004; Rundshagen et al., 2002). Critical illness and technology distances the patient from his/her body and disrupts the patient from the taken for granted way of being in the world (van Manen, 2002) in that the body is fore grounded and experienced as alien and dysfunctional. This was highlighted by one of Foster’s participants who had a permanent tracheostomy who described the experience of being suctioning with mixed feelings: i.e. relief and at the same time disgust in that while he could benefit from the procedure by breathing better, he was at the same time disgusted by the sputum he saw and the idea that it was coming out of him. Foster further reported that the experience of exhaustion from suctioning led to social withdrawal in the participant with a long-term tracheostomy. The author’s findings were similar to those of earlier studies (Hafsteindottir, 1996; Happ, 2001; Laitinen, 1996). Unique to this study is the report that the tracheostomy stoma (wound) was very sore. Participants described experiencing worsening pain especially when they coughed. The ambiguity of technology was again revealed in this study in that previous life threatening experiences from a strong cough led to heightened caution as a strong cough evoked fear of dislodging the tracheostomy tube out of position. In addition, Foster found that some participants who had been mechanically ventilated through a tracheostomy experienced worry and anxiety about the slow healing process of the tracheostomy stoma. Foster’s findings are consistent with other studies in which participants longed to be normal again (Parker, 1997; Zeilani & Seymour, 2010). Foster’s (2009) study demonstrated that the quality of experience of technology was closely linked to attitudes of nursing staff. Participants described both negative and positive feelings about the nurses’, where some nurses did procedures without explaining what they were doing while others were kind. Negative experiences are consistent with other studies in which patients have described being dehumanised (Li et al.,
2011; Wang et al., 2008). Foster (2009) concluded that the tracheostomy was not a singular isolated experience but it was a facet of the whole inter-related experience of critical illness. Although the number of participants was small in this study, the findings demonstrate that despite the changes in ICU practice the experience remains unchanged and as such there is a need for more research into how these experiences can be changed for the better. The insight gained from Foster’s study about the experience of tracheostomy in important to nursing practice and education in the care of tracheostomised patients. The fact that Foster’s U.K. based study findings resonate with those of Donnelly and Wiechula’s (2006) Australian study is reassuring; however both studies had a small number of participants raising concerns about whether or not data saturation was achieved. In addition, interviews were conducted during their ICU hospitalisation. Other issues may have emerged had interviews also been conducted later following discharge revealing a depth of data not evident in single face to face interviews during hospitalization.

reveals the transferability of the studies and thus the need to provide psychological care to tracheostomised patients before, during and after tracheostomy care. In some cases long term counseling particularly about scarring might be required.

The studies above reveal the experience of critical illness and being mechanically ventilated through a tracheostomy is as uncomfortable, painful, and isolating as being mechanically ventilated through the ETT. The importance of communication and being understood by others is paramount. Furthermore, the attitudes and competency of nursing staff were closely linked with the quality of experience of technology. The deeper meaning of these experiences among the critically ill and why the experience has remained unchanged have not been extensively explored. International studies show that this is a worldwide problem that needs to be addressed. Nurses, their behavior and attitudes have been shown to be central to alleviation of patients’ suffering during their critical illness in ICU.

Communication Difficulties.

Studies that have examined the impact of technology and ventilation for patients have demonstrated the distressing nature of being ventilated, either through an ETT or tracheostomy. Part of that distress results from not being able to speak and communicate effectively with staff and family. Communication difficulties are associated with feelings of powerlessness and vulnerability resulting in frustration, anxiety and possibly delirium (Happ 2001). Nurses’ inability to lip read and their busyness, patients’ personality and inability to write contribute to communication difficulties for the critically ill patient (ibid). Granberg et al (1999) conducted a hermeneutic phenomenological study in Sweden. Their study comprised
nineteen participants who had been mechanically ventilated in ICU. The authors interviewed their participants at one week and at eight weeks after discharge from ICU. Their aim was to explore and expose patients’ experiences of acute confusion, disorientation, wakefulness, dreams and nightmares during and after their stay in the ICU. Granberg et al (1999) found that communication difficulties were associated with difficult thought processes that led to patients failing to find the right words to communicate. The authors further reported that nurses were not patient enough to wait for the patients to find the right words to express themselves. Communication difficulties and the nurses’ busyness consequently resulted in patients failing to share horrible delusional experiences with the nurses because the nurses were too busy to listen. However, Happ (2001); Happ, Garrett, DiVirgilio, Thomas, Tate, George, et al. (2011); Happ, Harrington, and Kluger, (2006); Happ, Tuite, Dobbin, DiVirgilio-Thomas and Kitutu (2004) attributed this problem to the absence of staff education systems for communication with mechanically ventilated critically ill patients. The study further revealed that patients became frustrated and angry at their spouse and the nursing staff for not understanding what they were saying. Granberg et al’s (1999) study provides insight that communication difficulties can lead to feelings of loneliness, resentment, feelings of fear, vulnerability, agitation, anger, delirium and violence. Follow-up after ICU to establish ongoing problems and change in initial recall was strength of this study. Granberg al (1999) interviewed participants on the ward and in their homes four – eight weeks later. They did not report on going communication difficulties post discharge.

In an interpretive phenomenological study conducted by Carroll (2007) in the USA, nineteen mechanically ventilated patients⁴ described their experience of being voiceless as being trapped in a silent, slow world. Carroll’s participants were all tracheostomised⁵ for a period of between one and half weeks to nine years and were aged between 43 and 82 years, had had extubations⁶ and reintubations⁷ before and most of them were non-vocal for 24 hours a day. Further they were required to be well enough to maintain oxygen saturation of 92% and above to withstand the interview, to be alert and orientated and able to use communication devices such as the communication board, writing, speaking valves⁸, typing and mouthing words. Carroll conducted the first interview through lip reading (She is a trained and experienced lip reader) and clarified the messages by repeating the patients’ mouthed words back to them verbatim. The second interviews were vocal as some of the patients had regained their voice. The aim of the second interviews was to compare the experience of

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⁴ Patients who are not able to speak.
⁵ Having in tracheostomy in the breathing passage.
⁶ Removal of the breathing tube from a patient’s breathing passage.
⁷ Replacing a breathing tube after removing another one.
⁸ One way devices that are fixed on a deflated tracheostomy tube to allow a patient to speak with the tracheostomy.
communication while being without a voice and being with a voice. The author found that the silent slow world of being without a voice rendered the patients restricted, powerless, frustrated and incomplete. Carroll reported that patients felt like an integral part of their body was cut off. They were not understood when they tried to communicate and failed to connect with others. Some participants felt they were treated inhumanely and nurses were too busy to stop and listen to them as they struggled to be heard. This finding is consistent with Donelly and Wiechula (2006); Foster, 2009; Happ, 2001; Happ et al., 2004; Happ et al., 2006; Happ et al., 2011) whose participants described negative attitudes of nurses. Findings of feelings of isolation, loneliness or imprisonment were also reported by Granberg et al. (1999) who reported that nurses were not patient enough to wait for the participants to find the right words to express themselves. Granberg et al.’s participants also described failing to share horrible delusional experiences with the nurses because the nurses were too busy to listen. Granberg et al.’s participants became angry with both nurses and family as they failed to understand them while they struggled to communicate.

The finding that patients expected consistent nursing care that was reliable was also consistent with Foster’s (2009) and Donelly and Wiechula’s (2006) studies. Despite finding ways to cope, Carroll’s participants felt uncertainty that emanated from their loss of control, dependency on technology and powerlessness. This finding is consistent with Bergbom-Engberg and Haljamae (1988), who found that communication difficulties heightened the experience of uncertainty in mechanically ventilated patients and Lõf et al. (2006) whose participants described having no voice to communicate as being without power to fight for their rights. Carroll’s study shows how fundamental speech and language are to human existence. Mechanical ventilation requires that patients be sedated in order to cope with the discomfort resulting from not being able to breathe for oneself. Being sedated, along with other possible physiological problems may result in disturbances of consciousness. In the following section I explore the literature that examines the nature and impact of these disturbances.

**Disturbances of Consciousness**

Within the literature, the suite of symptoms often experienced by critically ill patients such as disturbances of consciousness occurring in ICU have been described as the ICU syndrome (Granberg et al., 1999; Inouye, 2006: McKeney, 1966). Post-traumatic stress disorder (PTSD) related symptoms such as depression, nightmares and delusional memories have been collectively associated with the ICU syndrome (Capuzzo, Pinamonti, Cingolani, Grassi, Bianconi et al., 2001; Capuzzo et al., 2010; Kapfhammer, Rothenhausler, Krauseneck, Stoll,
& Schelling, 2004; Ringdal et al., 2010; Rundshagen et al., 2002). Disturbances of consciousness in the form of non-recall, delusions, hallucinations and dreams have all been associated with critical illness and ICU hospitalisation (Capuzzo et al., 2001; Capuzzo et al., 2010; Kapfhammer et al., 2004; Ringdal et al., 2010; Rundshagen et al., 2002). I discuss reports of these experiences in the following paragraphs.

**Recollections of Events.**

The experience, and impact on critically ill patients of not being able to recall events that occurred when they were in ICU and the consequent misperceptions have been extensively documented in literature (Adamson et al., 2004; Bergbom-Engberg & Haljamae, 1988; Capuzzo et al., 2010; Granberg et al., 1999b; Granja, Hispano, Coutinho, Dias, Costa-Pereira et al., 2004; Hafsteindottir, 1996; Hupcey & Zimmerman, 2000; Jones, Griffiths, Slater, Benjamin, & Wilson, 2006; Kress et al. 2003; Löf et al., 2008; Parker, 1997; Rotondi et al., 2002; Rundshagen et al., 2002; Samuelson, Lundberg & Fridlund, 2006; Tonner et al., 2003; Weinert & Sprinkle, 2008). Other studies have shown that some patients do remember (Capuzzo et al., 2001; Capuzzo et al., 2010; Kapfhammer et al., 2004; Ringdal et al., 2010; Rundshagen et al., 2002).

Adamson et al. (2004) conducted a qualitative study in which they examined the lived experience and memories of critically ill ICU survivors six months after ICU discharge and found that some participants had no memory recall at all of their critical illness and ICU hospitalisation. Adamson et al. (2004) recruited their participants from a twelve bed tertiary referral ICU in Australia. The participants had been in ICU for at least 48 hours. Adamson et al. (2004) had 40 potential participants but only managed to contact 20 of whom ten declined to be interviewed for various reasons, including poor health which would not allow them to sit and converse over the phone for a long time. Others did not want to go over the traumatic experience. In the end Adamson et al. interviewed six patients. Their finding of non-recall was consistent with Granberg et al. (1999). Adamson et al. attributed this finding to the timing of the interview. They argued that six months was long enough for some patients to have lost memories. Their argument about timing was supported by Jones et al. (2001) who asserted that factual memories faded over time and Walker, Skowronski and Thompson (2003) who argued that depressive and disruptive states lead to fading of both pleasant and unpleasant memories. However, Adamson et al.’s argument is in contrast to Jones et al. (2006) who found that patients had no memory at two weeks and Tonner et al. (2003) whose participants had no recollection at 48 – 72 hours after ICU discharge. Furthermore, other scholars have associated no memory recall with depth of sedation and ICU LOS (Bergbom-Engberg & Haljamae, 1989; Haftondetoi, 1996; Löf et al., 2008; Samuelson et al., 2006).
Rotondi et al. (2002) argued that chronic use of beta blockers had an effect on memory recall particularly of pre ICU events and that planned ICU admission was associated with better memory recall. Jones et al (2006) and Samuelson et al. (2006) argued that no memory recall was associated with high APACHE II\(^9\) scores and old age. Jones, Skirrow, Griffiths, Humphris, Ingleby, et al. (2003) found that participants who had not been on benzodiazepines had better memory recall than those who had and argued that non-recall was associated with the amnesic effects of benzodiazepines.

Adamson et al. further found that participants were curious to know what happened when they were unconscious while Granberg et al.’s (1999) participants associated non-recall with violation of personal space and integrity. The findings of participants being curious about what happened during the period of unconsciousness were also recorded in earlier studies conducted by Granberg et al. (1999) whose participants referred to their period of non-recall as missing days and time standing still and Parker (1997) loss of days, and a relatively later study by Ballard et al. (2006) who also reported descriptions of lost time. Hupcey and Zimmerman (2000) found that participants needed to know what happened to them while they were unconscious. Although some participants expressed the need to know what happened to them during their critical illness in ICU, some authors have reported that some participants do not wish to know (Capuzzo et al., 2010; Granberg et al., 1999; Karlsson & Forsberg, 2008; Rattray, Johnston, & Wildsmith, 2004). The tendency to avoid discussing unpleasant ICU memories has been documented in patients who experienced delusional memories during their critical illness in ICU (Capuzzo et al., 2010; Granberg et al., 2006; Rattray et al., 2004). However, participants across studies have reported various reasons for avoiding talking about their memories or lack of memories of critical illness and ICU hospitalisation. For instance Karlsson and Forsberg (2008) found that some participants avoided reading their ICU diaries including any discussion concerning their critical illness in ICU as a means of self-preservation from trauma. The notion of self-preservation was also cited by Weinert and Sprinkle (2008) who argued that amnesia could protect patients from developing PTSD. Another scholar (Löf et al., 2006, 2008) reported that the avoidance tendency was due to embarrassment particularly in patients with delusional memories. To the contrary, Jones et al. (2001) argued that some memory albeit unpleasant during critical illness could offer protection from anxiety. Nevertheless Granberg et al.’s participants interpreted not knowing what happened to them while they were unconscious as a violation of personal space and integrity.

\(^9\) Indicator of sickness severity in relation to threat to life in ICU patients.
The studies above have highlighted non-recall as a prominent feature of the initial phase of being critically ill in ICU for some patients. Anxiety violation of personal integrity and personal space has been described by participants in relation to non-recall. Paradoxically, both the need to know and the need to avoid knowing what happened have also been reported by patients. Various explanations have been cited as causes of non-recall in ICU but these seem to be anecdotal and inconclusive. In addition, most of these studies did not explore the meaning of non-recall for the participants. This could be attributed to the fact that some of these studies are surveys and randomised controlled trials (Adamson et al., 2004; Capuzzo et al., 2010; Jones et al., 2001; Laitinen, 1996; Rattray, 2004; Weinert and Sprinkle, 2008) without capacity to explore the meaning of not remembering for participants.

Recollections of delusions are reported to evoke feelings of anxiety, fear and discomfort in critically ill patients (Granberg et al., 1999; Ringdal, Johansson, Lundberg, & Bergbom., 2006). Ringdal et al. (2006) conducted a quantitative longitudinal multicentre study to examine 236 mechanically ventilated trauma patients' lived experience of acute confusion, disorientation, wakefulness, dreams and nightmares during and after ICU stay in Sweden. Their aim was to describe trauma patients' memories of their stay in the ICU, factors that could influence delusional memories, problems experienced after discharge from the ICU and the patients' return to work. The participants had been in ICU for at least 36 hours and were interviewed approximately a week post ICU and six to eighteen months later. Ringdal et al. (2006) reported that 26% had delusional memories mostly nightmares. Delusional memories were more common in patients with memories of pain, fear and panic. Age <50 year, ICU stay >or=3 days, temperature >or=38 degrees C, S-Haemaglobin <or=100g/l, renal failure, surgery, ventilator support, sedative drugs, and opioids were significantly associated with delusional memories. The authors further reported that age was the best predictor of delusional memories. Most of the patients with delusional memories reported unexplained feelings of panic after discharge from the ICU and did not return to work 1 year after the trauma. Ringdal et al (2006) purported that younger patients are more likely to suffer from delusional memories and these memories affect them even after discharge from the ICU. Ringdal et al's (2006) findings are similar to Granberg et al's (1999) whose patients experienced unreal experiences that lasted several days and that the chaotic and unsettling busy high tech ICU environment led to delusions and disorientation. Granberg et al (1999) also reported that often these disturbances were triggered by nursing activities, noise and shift change of nurses. The authors also found that patients were afraid to sleep due to the unreal experiences they had when they closed their eyes to sleep. These participants described their unreal experiences in various ways such as illusions, dream like experiences, nightmares, dreams, crazy dreams featured by strong colours and shapes like
triangles, stars and classical music without a tune. Granberg et al's (1999) participants distinguished dreams from nightmares as being pleasant. They described dreams in which they had no struggle or fear while nightmares were associated with fear, fighting and panic. The nightmares involved being submerged in water and which meant that they felt they were drowning, which evoked panic, breathlessness, and fear as they attempted to get to the to the surface of the water. Ringdal et al's (2006) and Granberg et al's (2006) studies show that patients' who have delusional memories of ICU are prone to ongoing feelings of pain, panic and fear. Ringdal et al's (2006) study also sheds insight into the relationship between age and delusional memories. It is also emphasises the importance of ICU nurses informing patients and their family about the possible existence of delusional memories and that they can affect patients for a long time after discharge from the ICU. A limitation of this study is that the ICUM tool was self-administered It is not clear if the participants fully understood the questions.

Dreams involving water were reported by Papathasanosoglou and Patiraki (2003) who conducted an interpretive phenomenological study in Greece. The authors explored the experience of critical illness in ICU survivors and how it impacted on their lives after ICU. Papathasanosoglou and Patiraki (2003) interviewed eight patients at one to two weeks after discharge from ICU, twelve to twenty four months later and four to six years following. The authors found that patients experienced altered and unreal perception of the self, distortion of perception of body and bodily sensations. Unlike other studies (Granberg et al., 2006; Parker, 1997; Zeilani & Seymour, 2010) the researchers reported that their participants were not frightened by a heightened sense of death. Nevertheless the authors' reports of misperception of time and space and feelings of loneliness were similar to other studies (Parker, 1997; Zeilani & Seymour, 2010).Papathasanosoglou and Patiraki's (2003) participants also reported transformation of self. Dreams and nightmares reported in Papathasanosoglou and Patiraki's (2003) study were not associated with Midazolam injections, as was the case in Granberg et al.'s (1999) study. Granberg et al. (1999) reported that the experience of delusions varied both in times of occurrence and in the patients' wakeful states. Participants knew when the delusions started and when they ended. They reported that some delusional experience happened with their eyes open while others occurred at night or early morning hours and stopped in the afternoon. Horrific experiences made critically ill patients feel like they were crazy. The authors further reported that delusional experiences led to patients becoming frustrated, angry and aggressive towards their spouse and nursing staff. These patients continued to experience delusional memories even after they went home. Ringdal et al.'s findings about unreal experiences are similar to

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10 Sedative drug used to induce coma in ICU. It belongs to a group of drugs called benzodiazepines.
those of Laitinen (1996); Parker (1997); Roberts et al (2006) and Roberts and Chaboyer (2004). Although Ringdal et al’s study may have been limited by time lapse between the ICU experience and interviews, there are differing opinions on this matter in that some studies have collected data immediately after discharge from ICU (Capuzzo, Valpondi, Cingolani, De Luca, Gianstefani, et al., 2004; Rotondi et al., 2002; Rundshagen et al., 2002) and others up to eight years (Kapfhammer et al., 2004) and no difference in memory recall had been found. Unreal experiences were documented by Laitinen (1996) who conducted a phenomenological-hermeneutic study in Finland about patients’ confusion in ICU following cardiac surgery. She interviewed ten patients who had undergone coronary artery by-pass surgery and had spent two days in ICU. The participants were interviewed between the fourth and eighth day post operatively. Her aim was to capture the participants’ memories of ICU while the experience was fresh. Laitinen (1996) generated four themes; ‘Being on the border of awareness of space and time’ in which the participants described experiencing anxiety and fear when they were between consciousness and unconsciousness, not knowing and at the same time knowing where they were, confusion of space in which they found themselves such as being in the backyard or garage of the ICU and feeling lonely despite being surrounded by nurses. However this could be attributed to many factors such as the nurses’ attitude as explicated below and confirmed by Foster (2009) above and Li et al. (2011) or misperception of nurses as evidenced in this study where a participant experienced misperception of nurses and thought they were Mafia. Laitinen’s (1996) participants were embarrassed to talk about their confusion even though they had a clear recollection. The findings of participants being embarrassed to talk about their experience are reported elsewhere (Ballard et al., 2006; Rattray et al., 2004; Roberts et al., 2006). Laitinen found the strange ICU environment, narrowed visual field from patient positioning and the noises from both the equipment and ICU staff, contributed to patient misperception of ICU. Laitinen discussed this under the theme ‘the threatening vicious circle’, in which participants described feeling threatened and frightened by the ICU environment’s noises and events resulting in perceptual disturbances. Under the theme ‘the importance of human closeness’, Laitinen found that in the midst of confusion patients often felt lonely, helpless and insecure by being confined to bed. In addition, Laitinen found that confusion was heightened by feelings of vulnerability and the patient’s desire for someone they knew to be at their bedside. Laitinen (1996) captured the participants’ need for security, safety and peacefulness in the midst of “oppression” in the genuine presence of the nurse which was demonstrated by the nurse’s way of touching, speaking, gesturing and unspoken presence under the theme ‘the significance of nursing care for confused patients’. The descriptions of Laitinen’s (1996) participants of waking up in ICU highlight the need to understand the
patients' need for repeated orientation to the ICU environment, minimising noises and importance of family presence in ICU.

**Dreams and Nightmares.**

Dreams as a feature of disturbances of consciousness have been documented in the literature (Roberts et al., 2006). Some scholars have associated dreaming with longer ICU LOS (Roberts et al., 2006). Roberts et al. (2006) conducted a qualitative descriptive cohort study in which they sought to establish the relationship between observed behaviour during ICU admission and the subjective memories of ICU experiences. Their study comprised 41 patients who were followed up after 24 months post ICU discharge. Roberts et al. (2006) collected data from patients from three Australian ICUs involved in a multi-centre study about delirium in six Australian and New Zealand ICUs. Their participants had been in ICU for at least thirty six hours. Roberts et al. (2006) identified 103 potential participants from the previous study who were still alive. They mailed study invitations and consents to which only 41 responded and these people were interviewed over the telephone. In the previous multi-centre study these patients were screened for delirium using the Intensive Care Delirium screening Checklist (ICDSC). The researchers collected demographic and psychoactive drug treatment including the APACHE II and SOFA scores from the ICU databases. The interviews lasted 30 minutes and were conducted by nurses who were trained to ensure standardisation. Open ended questions aimed to capture descriptions of dreams/memories and closed questions aimed at establishing whether or not participants had discussed their ICU experience with anyone, who they discussed it with and if they would normally dream away from ICU. Of the 41 participants, 18 recalled dreams during their ICU admission and most of these 18 patients were delirious during their ICU admission and the other 23 participants were non-delirious and mostly did not recall dreaming during their ICU admission. Most participants had dreams of more than one topic, which were thematically categorised as bodily sensations like walking towards a light, experiencing a void; persecutory experiences like being buried alive or harm and impending death; metaphysical feelings (divine) like seeing Jesus Christ’s face, different colours for various religions or being in a temple.

Roberts et al.’s (2006) participants also described bizarre dreams such as hearing clicking noises similar to horses and rock breaking and seeing glass windows everywhere, people fighting, and gruesome rock faces which made participants feel like they were in a prison

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11 An instrument used to assess critically ill patients for confusion specifically delirium in ICU.
12 A scoring system that indicates the function of organs and extent of organ failure in critically ill patients in ICU.
hospital, a café or a temple. The authors further found that non-delirious patients had indifferent, unpleasant but bizarre dreams while delirious patients experienced scary dreams. Roberts et al. (2006) found that patients experienced dreams in which they experienced inability to move or resisted walking towards a bright light while others described being surrounded by beautiful people or glass windows and others had a mixture of good, changing to frightening dreams such as beautiful bright light and then being in prison. They further reported that there was more dreaming with increased LOS in ICU and less dreaming or recollections of ICU in participants with a shorter LOS in ICU. This is consistent with (Capuzzo et al., 2001; Feeley & Gardner, 2006; Geary, 1994; Inouye, 2006; Magarey & McCutcheon, 2005; McAvay, Van Ness, Bogardus, Zhang, Leslie et al., 2007; Laitenin, 1996; Roberts & Chaboyer, 2004) who purported that longer ICU stay was associated with dreaming. Roberts et al’s (2006) use of multiple data collectors could be viewed as strength of the study as member checking among the researchers added to the credibility of the study.

In spite of the introduction of new sedation practices, to date only Kress et al. (2003) have examined the impact of DSI on patient outcomes and experiences. Kress et al. (2003), in the USA, conducted a comparative follow up study of 19 from the 128 participants from their earlier randomised study of 2000 and 14 participants who were not from the original study in which clinical psychologists interviewed their participants. Kress et al.’s study population comprised of 19 control and 13 intervention participants. Their aims were to establish that DSI was not associated with long term psychological harm and to ascertain that DSI led to improved psychological outcomes such as reduced incidence of PTSD. The clinical psychologists experienced in assessing patients for psychological adjustment of patients hospitalised for acute medical illnesses used the Medical Outcomes Study Short Form-36 (MOS SF-36)\textsuperscript{13} to interview and assess the patients for psychiatric and medical conditions since discharge from ICU and recollection of ICU experiences. Both the assessors and the ICU survivors were blinded to the randomisation of the 2000 study (randomization to DSI and to the usual sedation protocol). Participants were interviewed at least six months after discharge from ICU. Kress et al also conducted psychological testing on their participants using the Mann-Whitney $U$ rank sum test\textsuperscript{14}. The scores were recorded on the State-Trait Anxiety Inventory, Beck Depression Inventory-2, total Impact Events Scale and total PAIS scores which they compared using the student-$t$ test or the Mann-Whitney $u$ Rank Sum Test as deemed appropriate. The authors found that there was no incidence of PTSD in the

\textsuperscript{13} Questionnaire used to assess mental and physical functioning of patients following a medical condition.

\textsuperscript{14} Statistical calculation to compare two variables.
intervention group as opposed to 32% of the participants in the control group. They also found that the patients in the intervention group had a shorter ICU LOS as compared to the control group. However there was no significant difference in the health related quality of life between the two groups. It is interesting to note that none of the interventional group patients recalled waking up from sedation where as five non interventions group participants recalled waking up in ICU. It could also be argued that the small response to participate in the subsequent study could be attributed to the avoidance behaviour of patients with negative/traumatic memories of ICU. Participants who chose not to participate in the 2003 study could have decided not to participate when they received invitation letters to participate. The findings are promising; however the strength of the findings is limited by low participants’ numbers. Hence, further studies are needed to establish whether or not sedation practices are linked to patients’ cognitive impairment and if DSI can minimise the negative effects of critical illness.

Despite changes in approaches to sedation and the medications used in ICU sedation practice, patients continue suffering from disturbances of consciousness such as delusional memories and nightmares. For some participants, giving a spiritual meaning to experienced delusional memories has in some way helped them to cope and to continue their existence without long-term effects. There may be varying reasons for non-recall in the critically ill patients’ ICU experience. However, memories are a fundamental ingredient of continued existence. It is for this reason more needs to be done to help critically ill ICU patients deal with these aspects of their experiences.

The Transformative Nature of Critical Illness

Much of the literature relating to critical illness and ICU has focused on symptoms and experiences of ICU. Phenomenological studies operate on the premise of understanding the lived experience from the actor’s point of view (van Manen, 1999). A number of phenomenological studies described above have highlighted the experience of critical illness and ICU hospitalisation as transformational. Many participants have reported how they see the world differently and have developed a heightened sense of spirituality, acute sensitivity and connectivity to the world, nature and families and others (Almerud et al., 2007a; Carroll, 2007; Donnelley & Weichula., 2005; Foster, 2009; Granberg et al., 1998, 1999; Hafsteindóttir, 1996; Kongsuwan & Locsin , 2011; Laitinen, 1996; McKinney & Deeney, 2002; Papathanassoglou & Patiraki, 2003; Parker,1997; Sheen & Oates, 2005; Strachan & Brown, 2005; Wang et al., 2008; Zeilani & Seymour, 2010). Papathanassoglou and Patiraki (2003), for example described their dreams, and the sense or meaning they made out of
their dreams. They analysed the data using symbolism\textsuperscript{15} and found themes about ‘transformations of perceptions’, ‘lived-body, time and space’; ‘death-rebirth’; ‘aloneness’; and ‘transformations of life’. Under the theme ‘transformation of perception’, Papathanassoglou and Patiraki found that participants experienced peaceful unreal and altered sense of self perception to which they referred as being out of it and being out of myself. They also found that participants experienced an altered relationship between their physical body and their psyche of being somewhere else and giving vivid descriptions of where they had been. Participants described images of hovering in space, floating, flying or finding shelter inwards. The researchers interpreted flying as a symbol of transcendence of spirit from matter. The other frequent description in this study was moving inwards and downwards ‘sinking deeper and deeper into themselves’, is a phenomenon that is said to symbolise incarnation. In the theme transformation of the body participants perceived altered body and bodily sensations in which they were ‘bodiless, a head like an enormous ball and being poked in the arm, feeling pain and wanting to get back into the head to hide’ which symbolised the body. In another narrative, a participant felt ‘swollen, huge and very heavy and having fingers feeling large and stiff like gas pipes’. Papathanassoglou and Patiraki's participants interpreted the pipe as the body through which sound was transmitted. Authors further reported that the participants’ descriptions of losing sense of time and absence of walls in which they could see everyone and hear everything meant transformation of time and space. In the theme ‘aloneness transcendent pause’, participants described being alone during their recuperation. They described hearing people talking about them while they were suspended in an empty space like a desert where everything was dark, black, no light, no sound like being under water. Papathanassoglou and Patiraki interpreted narratives about darkness based on Jung’s theory of rebirth or primordial life which was associated with the colour black. They went on to say that having known where they were going, some participants were not afraid of dying and considered death at some point in and out of ICU. The authors found that participants described dying as peaceful, nothingness in which they dreamt they were sinking underground, being put in a black box and saying good bye. They interpreted these descriptions about death as a symbol of absence of conflict, liberation and rebirth. Descriptions of a river were common with the river interpreted as a symbol of death and birth. Transformations of life were in the aftermath of participants’ critical illness which characterised all aspects of their life by heightened joy in life, family love and other people. Like other phenomenological studies mentioned above, this study offers a more spiritual dimension to the meaning of the participants’ critical illness which is different from the notion of PTSD which has been described in some studies (Capuzzo et al., 2001; Kapfhammer et

\textsuperscript{15} Writing in which words represent a deeper meaning mostly to with religion, culture, arts and history.
al., 2004; Jones, Griffiths, Humphris, & Skirrow, 2001). Papathanassoglou and Patiraki referred to hallucinations and dreams as savage thought in which critically ill patients are perceived to transcend psyche and body and relay tactile and inner facets of experience as described by ethnologists. Papathanassoglou and Patiraki used the term ‘cocooning and spiritual awakening’ in relation to participants’ descriptions of dying and argued that participants’ feelings were in line with Heidegger’s (1976) notion of being towards death as a fulfillment of life. The literature describes the experience of ICU as traumatic. Yet for many research participants it was also transformative in that it raised questions for them about the meaning of their experience and the reason for their survival. Questions remain about the long term nature of the impact of ICU.

**Life after ICU**

Australia has an 86% adult critical illness survival rate (Elliott, Aitken, & Chaboyer, 2011). However most of these survivors have physical and psychological sequelae that continue to afflict them for most of their life U (Elliott, McKinley, Alison, et al., 2011; Needham, Dowdy, Mendez-Tellez, Ciesla, Desai et al (2005); Needham et al., 2011). Despite the growing knowledge and concern about survivorship sequelae there are only a few interventional studies and thus no established models of care that systematically address this issue particularly in Australia (Elliott, Mudaliar & Kim, 2004).

In an Australian study conducted by Skinner, Warrillow and Denehy (2011) into HRQoL of Australian survivors of critical illness, participants (n=67) had no significant differences in the preadmission and post ICU HRQoL score. Skinner et al. (2011) used a survey and asked their participants to complete the SF-36 form while they were in ICU and six months later and found that mental status based on the SF-36 form was unchanged at six months as compared to the initial assessment. Cardiac surgical patients reported improved physical functioning, bodily pain, role-emotional domains and social functioning. Although Skinner et al. (2011) claimed that their findings of medical patients being worse than surgical ones were similar to those from other countries; an earlier study conducted by Capuzzo et al (2010) had different findings.

Capuzzo et al. (2010) conducted a quantitative prospective study across three Italian ICUs which examined 104 patients’ memories over three and six months with regards to health-related quality of life before and after planned ICU. The patients had undergone urologic, general or orthopaedic surgery from October 2007 to July 2008. The researchers’ aim was to compare the baseline HRQoL examined before surgery and admission to ICU with the one
reported at three and six months in patients with elective admission to ICU. Capuzzo et al. (2010) used the Mini Mental Status Examination (MMSE) to assess global cognitive functions for example orientation to space and time, immediate and delayed verbal memory, concentration and attention span and constructive praxis and language. Capuzzo et al. (2010) adjusted the final MMSE score for each patient according to education and age. The EuroQol was used to evaluate mobility, self-care, pain/discomfort, usual activities and anxiety/depression (EQ-5D) to which the patient responded as no problems; some/moderate problems; severe/extreme problems. Patients were asked to quantify their health status on a scale of 100 (best imaginable health status) to 0 (worst imaginable status) using the EQ-VAS. Capuzzo et al. (2010) used the CAM-ICU to rule out delirium by assessing patients for acute onset of mental status changes or a fluctuating course, disorganised thinking, inattention and altered level of consciousness. Capuzzo et al. (2010) assessed patients for PTSD using a two part PTSD 14 questions inventory. Using structured survey questions Capuzzo et al. (2010) asked their patients to indicate if they had any traumatic memories from ICU such as respiratory distress/dyspnoea, severe pain, nightmares or feelings of anxiety/panic. The authors then assessed their patients for 14 PTSD symptoms such as sleep problems, jumpiness, nightmares, depression, frequent mood swings, need for withdrawal, bad conscience, muscular tension, fear of place and situation, upsetting/unwanted thoughts or image of the ICU stay, avoiding places/people or situations that reminded them of ICU and feeling as though future plans or dreams will not come true. The patients answered the questionnaire by using a scale of 1 (never) to 7 (always). The sum score of 14-98 was calculated of which 45 was taken to predict PTSD. Capuzzo et al. also assessed the patients for severity of illness at three months using the Numerical Rating Scale (NRS) of 0 (not serious) to 10 (as serious as possible). On the mobility and self-score, Capuzzo et al. (2010) found that there was a steady increase in the number of patients who reported problems with mobility throughout the study period. Patients who reported having mobility difficulties were 41 pre ICU admission, 44 three months post ICU and 45 six months post ICU admission. Self-care problems were reported by 27 patients before admission, 33 at three months and 34 at six months. There was a fluctuation in the usual activities in that 48 patients reported having problems with their usual activities pre ICU admission, 51 at three months and 49 at six months. The same trend was noted in the pain assessment results where 64 patients reported having pain pre admission, 82 at three months and then 76 at six months. Results in the anxiety assessment showed a variation over time as 66 patients reported anxiety prior to their ICU admission, 64 at three months and then 67 at six months. Capuzzo et al.’s (2010) results showed that pre ICU health status could be perceived to be generally better than post ICU with time. However, Capuzzo et al. (2010) also argues that patients with elective ICU admission have good memory of their health
condition as assessed by the EQ-5D before surgery and ICU admission particularly at three months. A limitation of this study, in the light of the findings reported in this thesis, is that people may have unreliable memory during and following their ICU experience. Furthermore, Capuzzo et al.'s (2010) patients had elective ICU admissions and were all surgical patients. Similarly, Ringdal et al., (2010) conducted a multi-centre longitudinal study among trauma patients and investigated memories and HRQoL from five months to five years and five months after ICU. Their patients had a mean severity injury score of 10.7± 7.1. Using the SF-36 form, Ringdal et al. found there was significant improvement over time. However, patients with delusional memories, depression and anxiety had poorer HRQoL and took longer to return to work. In an earlier study conducted by Elliot et al (2004) of 34 patients, the findings were different. Using the SF-36 and 15D health instrument variables Elliot et al. (2004) found that patients’ HRQoL in relation to mobility, eating, breathing, vitality and common activities was significantly declined even though the patients managed to return to similar kind of life style. This was also documented by Khan, Benson, Appleby, Carson and Iwashyna (2010) who documented a 10-20% admission rate of ICU survivors to long term acute care facilities for persistent organ failure.

The findings in these studies point to the fact that despite increased survival rates from critical illness some patients continue to suffer from the sequelae of critical illness and ICU hospitalisation long after discharge. The fact that the sequelae is mostly related to delusional memories, depression and anxiety means that patients’ experience of critical illness and ICU therapies has not changed. The previous studies show how critical illness and ICU hospitalisation transform people’s perception of the world. In addition studies have shown that increasing survivorship from critical illness places burden on the patients long after hospitalisation. Of concern is that there are very few models of care that address follow-up care for survivors of ICU described in the literature. The following discussion reviews some of those that have been established, largely in the UK.

Follow Up Care

In this section I discuss the two main strategies described in the literature that have been used to reduce the long-term negative effects of critical illness following discharge from ICU. These two strategies are patient diaries kept in ICU and rehabilitation clinics.

Intensive Care Patient Diaries.

The inability to remember the past predisposes critically ill patients to developing PTSD (Egerod et al., 2011). Since the 1990s, patient diaries have been used to help patients
account for the time they were unconscious in ICU. The aim has been to facilitate psychological and social recovery (Bergbom, Svensson, Berggren, & Kamsula, 1999; Egerod et al., 2011; Griffiths & Jones, 2007; Jones, Bäckman, Capuzzo, Egerod, Flaatten, et al., 2010; Karlsson & Forsberg, 2008) and to add coherence to people’s existence by filling the gaps left by loss or absence of memories. Dairies have reportedly been used in Scandinavian countries with good outcomes (Bergbom et al., 1999; Engström, Grip & Hamrén, 2009; Jones et al., 2010; Karlson & Forsberg, 2008).

Jones et al. (2010) conducted a randomised controlled study with in 352 patients from twelve hospitals in six European countries in which they explored the effectiveness of dairies in protecting patients from developing PTSD. One hundred and sixty seven patients were randomly selected to receive a diary which the nurses and relatives completed in layman’s language. Photographs were also taken to accompany the daily diary entries. After the patients were discharged from ICU, nurses explained the diary contents to the patients until they understood the course of events that had occurred during their ICU stay. Jones et al. (2010) found that 5% of the participants who had diaries developed PTSD whilst 13% of the participants who did not have diaries also developed PTSD like symptoms at three months. Their finding was consistent with Engström et al. (2009) who found that ICU diaries were instrumental in giving ICU survivors coherence about their critical illness experience. These findings suggest that the diaries may be helpful in preventing PTSD.

In a Danish grounded theory study conducted across two sites Egerod et al. (2011) investigated how patients and relatives used ICU diaries in the context of their critical illness trajectory. Egerod et al. interviewed 19 patients and 13 relatives six to twelve months after ICU discharge. Of these, six were individual patient participants and 13 were paired (patient and relative participants) interviews. The two centres in Egerod et al.’s study routinely maintained diaries for critically ill patients. Photographs about the patient’s daily events of ICU accompanied the diaries during their critical illness. Egerod et al. read and explained the diary contents to the patients in the intervention group before giving them the diary on discharge, a month after discharge from ICU, and at three months for the patients in the control group. The researchers found that some participants had no memory recall and those who did their memory was fragmented and constituted an array of memories such as nightmares, delusions, dreams and unreal experiences. For both groups of participants the diary was a source of information that helped to fill in the blanks and construct their lived experience of ICU. This finding is consistent with research by Karlsson & Forsberg (2008). The critical element of the diary strategy proved to be the “handover” to the patient (Egerod et al., 2011). Despite the initial confrontational experience of the “handover” it established a
potential relationship for the participant and the diary. However, the timing of the hand over may affect the patient’s reactions to the diary contents. It is difficult to determine the right time to hand over for each individual. Most importantly, the diary is a source of information that serves to prevent long term disturbances of consciousness arising from memory loss (Egerod et al., 2011; Engström et al., 2009; Jones et al., 2010; Karlsson and Forsberg, 2008). The other important finding is that besides telling the patients what they observed in ICU relatives can also access the diary and utilise it to support the patient with their recovery. Whilst the inclusion of photographs may be a strength of Egerod et al’s (2011) study it may also be confronting for some patients and in the light of the findings of the study reported in this thesis.

Research shows that diaries kept in ICU for the critically ill patients can help to address the problem of non-recall during the period of sedation in ICU and alleviate sequelae such as PTSD and PTSD related symptoms particularly depression. Researchers argue that keeping a diary is fundamental to ensuring coherence and continued existence for ICU patients to fill in the blanks for the lost time. Unfortunately, the use of diaries is not widely practiced despite its possible utility for preventing PTSD and PTSD related symptoms. The reasons why this is the case needs to be explored.

Other post ICU follow up care strategies have included rehabilitation clinics for ICU survivors. Rehabilitation clinics have been aimed at addressing both the psychological and physical sequelae of critical illness.

**Rehabilitation Clinics for Critically Ill Patients.**

Rehabilitation clinics for critically ill patients have been established particularly in the United Kingdom. These clinics emerged as a means to manage various physical and psychological sequelae that ICU survivors continued to experience (Jones et al., 2003). Their purpose was to monitor the physical and psychological well-being of ICU survivors and identify and provide continued care where necessary (Jones et al., 2003). Persisting physical disorders identified include muscle weakness, chronic fatigue syndrome and chronic obstructive pulmonary disease which were seen as benefiting from continued physical exercise. Psychological sequelae have predominantly been identified as PTSD and PTSD related symptoms that have traditionally been managed using prescribed medication (Jones et al., 2003).

Jones et al. (2003) conducted a randomised controlled trial of 126 patients whom they visited on the ward after transfer from ICU in the U.K. Their study was based at two district
hospitals and one teaching hospital with patients who had been in ICU for at least 48 hours and had been mechanically ventilated. They interviewed the intervention group of patients after hospital discharge by phoning them three times at home. Participants also received a self-help rehabilitation manual about coping strategies. Participants were then reviewed in the clinic at eight weeks and at six months. The aim of the study was to evaluate the effectiveness of a rehabilitation programme which was designed to help patients recover from psychological and physiological sequelae of critical illness, mechanical ventilation and sedation. Jones et al. (2003) assessed the patients for depression and anxiety levels using the hospital anxiety and depression scale (HADS)\textsuperscript{16} PTSD related symptoms using the Impact of Events scale and the Short-Form Health Survey physical dimension at eight weeks and six months after ICU discharge and the phobic symptoms using the Fear Index Scale. The researchers also assessed patients for memory using the ICU Memory Tool at two weeks following ICU discharge. The control group was not given a self-help rehabilitation manual but was followed up like the intervention group. Jones et al. (2003) found that there was more improvement in the intervention group as compared to the control group both in physical function (\(p=0.006\)) and in the tendency toward depression at eight weeks (12\% vs. 25\%). Jones et al. (2003) also found that because of the self-help manual, the intervention group’s possibility of experiencing depressive symptoms at eight weeks was halved and indicated that the control group patients on antidepressants were likely to remain depressed at the time of follow up.

Jones et al’s (2003) findings further showed that patients who were not on benzodiazepines had better memory recall. Jones et al. (2003) attributed this finding to the fact that the intervention group did not experience the amnesic effects of benzodiazepines. However, the recollection of delusional memories was the same which further supports the need to find more ways to address this problem. It is not clear from the way in which the study was reported whether or not the patients in the intervention group had good memory recall prior to the study. In addition, the researchers did not account for the finding that both groups had delusional memories. Based on their findings, Jones et al. (2003) recommended that the self-help manual could be helpful in prevention of PTSD related symptoms in people who were critically ill and mechanically ventilated and sedated in ICU. In addition, qualitative studies exploring the experience are needed to elucidate the deeper meaning of overcoming a negative ICU experience by going through rehabilitation clinics. However, the benefits of a self-help rehabilitation program need to be recognised and explored further.

\textsuperscript{16} It is self assessment questionnaire used to assess patients for anxiety and depression.
Six years following Jones et al.’s (2003) study, Cuthbertson, Rattray, Campbell, Gager, Roughton et al. (2009) established a nurse led follow up clinic for ICU survivors. They followed up patients at three months and at nine months and evaluated the follow up effectiveness at twelve months. Their study was a pragmatic non-blinded multi-centre randomised controlled trial in which 286 patients older than 18 years were recruited from two teaching hospitals and one district hospital in the UK between 2006 and 2007.

In their study, Cuthbertson et al. (2009) evaluated the effectiveness of nurse led ICU follow-up programs in comparison to standard care. The authors took baseline data of the patients’ quality of life using the short form 36 (SF-36)\(^{17}\) and EuroQol-EQ-5D\(^{18}\) questionnaires, HADS and the intensive care experience (ICE score)\(^{19}\). They used a computerised telephone non-blinded randomisation method based on sex, age, HADS score, severity of disease using the acute physiology and chronic health evaluation score II (APACHE II) and ICE score to enroll patients into their study. The patients in the intervention group went into a manual based self-directed physical rehabilitation program designed by physiotherapists and implemented by the study nurse. The patients commenced the program whilst in hospital and continued for three months post ICU discharge. Patients self-evaluated their compliance and progress using the manual treatments and the study nurses formally evaluated the patients' progress using a standardised assessment and interventional requirement format at three and nine months post discharge at the nurse led clinics.

Cuthbertson et al’s (2009) follow up clinics included discussion of ICU experiences, structured case reviews, assessment for referral to medical specialists and psychological morbidity screening in relation to ICU treatment. Depending on their need, patients were referred to physiotherapists, mental health practitioners, taken to ICU for a visit, their drugs were reviewed and a progress report sent to their general practitioners. They used standard National Health Service (NHS)\(^{20}\) pathways to do referrals and implement interventions with the exception of psychosocial referrals which had no ready suitable pathway. Follow up nurses trained trial nurses as a measure of standardisation. The non-intervention group was followed up by their general practitioner and primary hospital specialty after ICU discharge as indicated by their teams. Cuthbertson et al. sent out SF-36 questionnaires at twelve months to measure the primary health related quality of life (HRQoL)\(^{21}\) of the patients, secondary outcomes at six months by means of the HRQoL, quality adjusted life years.

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\(^{17}\) Short form comprising 36 items used to assess various aspects of wellbeing.

\(^{18}\) Questionnaire used to assess health outcomes.

\(^{19}\) Assessment tool that indicates patients’ emotions and perception of ICU treatment after discharge from ICU.

\(^{20}\) British government health system.

\(^{21}\) Standard of the general wellbeing of an individual or a society.
(QALYs)\textsuperscript{22} at twelve months, incidence and severity of PTSD (Davidson trauma score) and anxiety and depression using the HADS at six and twelve months, cost effectiveness at twelve months, primary and secondary health care costs at one year post discharge, mortality at twelve months post discharge. The measured outcomes were assessed using the postal questionnaires that were sent out to the participants. The researchers who conducted the analysis were blinded to the intervention group. In assessing the prognosis Cuthbertson et al. (2009) found that at one year, 18 patients in the interventional group had died as compared to 14 in the non-interventional group. Thirteen of their patients withdrew from the study following the formal channel and 49 could not be contacted for follow up. The researchers did not find any difference between the interventional and the non-interventional group in the primary and secondary outcomes at six and twelve months.

Cuthbertson et al. (2009) found the SF-36 physical aspect showed that the interventional group had a mean score of 42 compared to the non-interventional group which had a mean score of 40.8. The mental aspect of the SF-36 had a mean score of 47.1 in the interventional group and the non-interventional group had 46.8. Cuthbertson et al. (2009) contended that although ten of the interventional group patients did not attend both nurse led follow up clinics they did not have a significant bearing on the research findings. Also, there was no difference in the number of patients who had returned to work at six and twelve months (16/40 versus 15/41), 92 out of 102 interventional group patients as compared to 98 out 110 non-control group patients had visited their GP at six months after discharge. At twelve months 75 out of 92 interventional group patients and 85 out of 97 non-interventional group patients visited their GP and there were no grave adverse effects in both groups. They also found that there was no significant difference in the QALY between the two groups (0.423 versus 0.426). In the analysis of the cost of care, the mean cost for each interventional group patient was £7126 as compared to £4810 for each non-interventional group patient. Cuthbertson et al.’s (2009) study shows that rehabilitation clinics had no significant contribution to the improvement of ICU survivors’ quality of life post ICU discharge. However, there are limitations that could have impacted on the findings in that the program was designed after one health care system’s guidelines rather than on evidence based practice. This study shows that psychological distress represented a significant level of morbidity in both groups. However, the use of surveys did provide room for the participants to express themselves in detail and seek clarification on things they did not understand. Nevertheless, Cuthbertson et al.’s (2009) study is one of the few nurse led ICU follow up clinics. The findings might inform the implementation of future clinics, however further research in this area is needed.

\textsuperscript{22} Measure of disease burden and the quality and quantity of lived years.
Conclusion

The literature review demonstrates that despite advances in technology and ICU practices the experience of critical illness in ICU remains unchanged. Patients continue to experience ICU as alienating, frightening, restrictive, painful and objectifying. Much of the literature has focused on the experience of ETT as a foreign object in critically ill patients' body. The ambiguity of technology has also been highlighted as evoking a heightened sense of death at the same time perceived as life giving. Communication and breathing difficulties associated with being mechanically ventilated have also been highlighted. Disturbances of consciousness relate to non-memory recall, delusional memories and dreaming. ICU diaries and ICU rehabilitation clinics have been used to address critically ill patients' sequelae of critical illness and ICU hospitalisation and shown to be beneficial. However follow up care practices are not widely used.

The key features of the literature reviewed show the impacts of technology and mechanical ventilation including breathing and communication difficulties, disturbances of consciousness such as memory loss, heightened sense of death and delusional memories, and transformative effects of critical illness in ICU. The research shows how follow up care strategies such as ICU diaries and rehabilitation clinics alleviate patients' suffering following ICU hospitalisation. In the next chapter I describe the research methodology I used to conduct the study.
CHAPTER TWO

METHODOLOGY

The purpose of this chapter is to describe and justify phenomenology as the methodology for this study. In the following, I explicate the ontological, epistemological and axiological tenets of phenomenology by drawing upon various phenomenological texts including *Phenomenology of Perception*, Merleau-Ponty’s (1962/2002); *Signs*, Merleau-Ponty, (1964); *Sense and Non-Sense*, Merleau-Ponty, (1964); *The prose of the world*, Merleau-Ponty (1974); *What is Phenomenology?*, Merleau-Ponty, (1956) and the relevant commentaries about his work (Hamington, 2004; Madison, 1981; Langer,1989; Spurling,1977). I also reviewed other phenomenological texts such as Heidegger (1962/2008) and Sartre (1957/2008) and those relating to nursing (Bogdan & Taylor, 1975, Munhall & Boyd, 1986; Munhall & Boyd, 1993; Munhall, 1994; Munhall, 2007; Paterson & Zderad, 1976; Wilkes, 1991). In addition I explored other phenomenological writers such as Moustakas (1994) and van Manen (1990, 2002).

I begin this chapter by discussing the place of phenomenology in nursing and provide an account of phenomenology and the rationale for its use in this study. I consider the relevance of phenomenology to nursing practice and scholarship and discuss the key attributes of phenomenological inquiry and the phenomenological view of a person with special emphasis on the phenomenology of the body by Merleau–Ponty (1962/2002). By doing so, I provide a discussion of the framework that informed this study and its findings. I describe the research design, methods and procedures used in this investigation and other details of its implementation in Chapter Three.

Phenomenology was first introduced as a method of research in nursing as a human science by Paterson and Zderad (1976) in their book *Humanistic Nursing*. It was in the realisation that using empiricist research methods objectified the subject and thus reduced the subject to having only five senses i.e. seeing, hearing, touching, tasting and smelling, that phenomenology was introduced to nursing research (Gray & Pratt, 1991). Empiricist research left out fundamental aspects of awareness like intuition and feeling (Gray & Pratt, 1991). The cornerstone of nursing philosophy is based on the holistic, individualistic view of man (Munhall & Boyd 1993). This notion purports the idea of not breaking down an individual into pieces but to treat them as a whole person (Wilkes, 1991, p. 230). According to Wilkes (1991), caring and holism are fundamental to nursing with the latter believing that there are different ways of describing the same phenomenon based on the individual, situation and
language. This is in line with phenomenology which seeks to find meaning in lived experiences based not on the causes, but on the perspectives of individuals who may have experienced the phenomenon.

Nurses are human participants who are invariably involved in situations that confront them in their duty of care, they are unique and their flow of consciousness is unique and so their influence is intersubjective (Paterson & Zderad, 1976). By looking at the lived experience of critical illness at a deeper level such as that which phenomenology can provide, nurses can choose their values; give the ICU world meaning based on the shared experience of critical illness and contemporary ICU hospitalisation with their patients. This then I believe will cause them to contribute to the nursing of critically ill patients in a better and more informed way than in the past. While I believe that by virtue of their humanness, nurses’ influences are also determined by the situations and demands that confront them, I believe this thesis will influence my readers to execute their care of critically ill patients in a more meaningful and caring way.

Phenomenology invites the reader to be attentive and thoughtful to body language such as the posture, silence, pauses, hesitation, emotion and the tone of the voice in the story and to garner the meanings hidden behind them with a view to providing a phenomenological picture or perspective on experience that causes us to reflect or “wonder”. As van Manen (2002, p. 5) states:

> From a philosophical perspective, wonder is the central methodological feature of phenomenological inquiry since phenomenology is a philosophical project. Ancient philosophy has proposed that all philosophical thought begins in wonder, but we may also turn around and say that philosophical reflection is the product of wonder. Phenomenology not only finds its starting point in wonder, it must also induce wonder. For phenomenological text to “lead” the way to human understanding it must lead the reader to wonder.

In using phenomenology as the methodology for this study I intend to induce “wonder” in a way that will invoke health care professionals to question their ways of caring for critically ill patients. I seek to bring about “thoughtfulness” and “tact” (van Manen, 2002, p.x) in the way health professionals execute care.
Phenomenological Inquiry

I have chosen phenomenology for this study because of its ability to illuminate the lived experience of being critically ill in a contemporary ICU. Phenomenology gives a perspective on the nature of human reality. It has had a significant influence on qualitative research efforts (Munhall & Boyd, 1993; Wilkes, 1991). Phenomenology’s main concern is to understand human behaviour from the individual’s point of view (Bogdan & Taylor, 1975). Imbedded in this is the meaning that individuals attach to embodied experience, their descriptions of experience of the world, other people and their relationship with others (van Manen, 1990).

Phenomenology is distinguished by its emphasis on describing experience as it is and to describe it directly, without considering various causal explanations that social scientists might give (Merleau-Ponty, 1962/2002 p. 59). In other words, the aim of phenomenological description is to explore the meaning of experience as awareness of the world or rather consciousness or existence itself (Munhall & Boyd, 1993). Central to this purpose are meaning, focused on embodied lived experience, description, human touch and connection and everyday activity in our environment. In reflecting on human experience, phenomenology brings forth a complex account of self, temporal and spatial awareness, attention, and awareness of other people (Munhall & Boyd, 1986) which encompasses linguistic activity with its meaning, communication, being understood and understanding others. In other words it is the social interaction such as collective action in everyday activity in our immediate life-world in a given culture.

Phenomenology is different from history, which deals with historical periods, psychology which deals with mental types, or biography which deals with a person’s personal life history. Phenomenology does not reduce people’s lived experience to a particular event of the world or an aspect of their being nor does it restrict lived experience to phases of their lives, but rather it deals with experience as it is lived in everyday life (van Manen, 1990). Because people are always situated and always individuated (Merleau-Ponty, 1964, p. 51) this study seeks descriptions of people who experienced being critically ill in ICU as they lived through the experience as individuals. The purpose of using phenomenology in this study was to feel and live the experience with the people who were critically ill in ICU. This is what is called intersubjectivity Munhall (2007). It is by existing and sharing experiences and being affected by other people’s experiences that we develop an understanding of what it is like to go through a particular situation.
Phenomenology is the study of the life world which is primarily concerned with the nature and meaning of human experience as it is lived. Its aim is to describe and understand lived experience with insight (van Manen, 1990, p. 9). Only the people who have lived the experience can provide this insight. Unlike natural science which aims at finding explanations, predictions or controls, phenomenology aims at the study of phenomena as they are experienced. Phenomenological inquiry is aimed at gaining a deeper understanding of experience that is rich in meaning whose conceptualization is directly related to the lived world (van Manen, 1990). The use of phenomenology to conduct this study was to gain a deeper understanding of what it is like to be critically ill in ICU and following discharge.

Merleau-Ponty defined phenomenology as a study of essences which means the essential nature of phenomena or, rather that which makes a thing what it is (Merleau-Ponty (1962/2002, p. vii). The word essence is derived from the Greek word ousia which means the inner essential nature of a thing or the true being of a thing. In the Latin language the word essence means essential derived from esse which means to be or that which makes a thing what it is without which it would not be what it is (Merleau-Ponty (1962/2002,). By studying essences, phenomenology systematically brings to light and describes the hidden meaning of the layers of lived experience (van Manen, 1990). It tries to recapture experience as it is lived pre reflectively and as such, it relies on descriptions, stories and observations of the people who had the experience (Hamington, 2004). Phenomenology takes us back to the experience itself, it takes us back to the things themselves as Merleau-Ponty (1962/2002, p. ix) says,

*To return to the things themselves is to return to that world which precedes knowledge, of which knowledge always speaks, and in relation to which every scientific schematization is an abstract derivative sign-language, as is geography in relation to the country-side in which we have learnt beforehand what a forest, a prairie or a river is.*

In this study, the participants’ individual stories and the researcher’s reflective writing and departure from scientific knowledge are means through which the experience was revisited and a new way of understanding has been generated. Phenomenology asks about the way the world is experienced, it seeks to know and understand the world in which we live as human beings and more so, from the individual’s perspective (van Manen, 1990). It is committed to understanding the life world through the eyes of those who experienced the issue in question.
Merleau-Ponty’s Phenomenology

Merleau-Ponty’s philosophy was greatly influenced by Husserl’s work which he based on his fascination with the mystery of consciousness which he called “wonder of all wonders” (Hamington, 2004). Merleau-Ponty was more interested in preconsciousness and this led to inquiry into the body (Hamington, 2004). His own strand of phenomenology was based on his belief that each one of us is a body-subject (Langer, 1989, p. xv) we are all situated at all times in concrete lived experience and that the body is the hub of experience (Langer, 1989). From a phenomenological lens experience is inherently ambiguous and rooted in the corporeal and perceptual world. The uncertainty of experience makes it subjective and concealed from the lived other, so much so that unless the other expresses their feelings their feelings remain their secret. Phenomenology puts its emphasis on the importance and significance of ordinary, everyday situations in the world and the thoughts that have had no influence from other ideas or conceptualisations. It considers the lived experience as the starting point for any philosophy (Langer, 1989). Because the main concern of the existential phenomenologist is the way we exist as individuals, the focus of the phenomenologist is to encourage us to live thoughtfully and attentively, to know about our freedom and independence, and how much we shape and are in turn shaped by the world in which we live (Langer, 1989). Lived experience is a shared phenomenon. By paying attention to other people’s lived experience we share their experience and by so doing, we not only understand them but we also off load their pain and suffering.

Merleau-Ponty (1962/2002) asserts we communicate with the world through our body. It is through the body, that we perceive the world. Perception is the ‘silent conversation’ that our body has with the world around it. It is not an act of the mind that is separate from the body (Hamington, 2004). I discuss the lived body in detail in the following pages under the headings of the perceived world and the lived body.

The Perceived World

The way we are drawn to the world, the way we exist in the world whereby the body and the world are constantly communicating with each other is called intentionality (Langer, 1989; Madison, 1981; Spurling, 1977; van Manen, 1990. The objects that make up the world have meaning for us, not because we give them meaning but, because we perceive an already structured and unified world to which we are inextricably connected and engaged in dialogue (Madison, 1981, p. 22). In turn, the world and its objects have a bearing on how we behave,
act and respond without thinking, to various situations that come our way. Just as Langer (1989, p. 153) purports;

We are primordially related to, and animated by a pre-objective world which solicits our sensibilities and enables us to actualise and develop them.

The space we occupy becomes our world; it is the only place that we communicate with: feel, see and whose sounds or noises we hear. The human being exists in the world as a body that perceives, that is situated in the world. The body therefore is the focal point of existence. In other words, the body is our way of being in the world from which all things turn, communicate with us and through which we are present in the world among other people and objects. Our being in the world as intentionality encompasses consciousness and the body. As Madison (1981, p. 22) states:

I am a subject only by means of the many unbreakable bonds which tie my consciousness and my body together; I am an embodied subject only by being in a direct mutual relation with the world; and I am in the world only by being in a direct mutual relation with the world; I am in the world only through my co-existence with others who, themselves, are also so many beings in the world. Inversely, the other exists for me only because I am directly linked to the world by a body which is inseparable from my existence

The Lived Body

The body itself is essentially an expression of existence in that it is constantly in communion with the world as another pole of existence. The perceived world therefore is not just a collection of objects that surround us on which we impose meaning but that we are connected to the world in an irrevocable manner which Langer (1989, p. 70) calls a living connection. Our perception of the objects of the world is our response to them because they have meaning for us. We do not inhabit our body but we are embodied beings who exist in a world which constantly beckons our very existence in that even before we conceive an object, we experience its connectedness to our body. It is this very connectedness of our body to the world that constitutes our experience of being in the world even before we consider what makes up the world around us. This is why Merleau-Ponty (1962/2002, p. 203) says that the theory of the body is already a theory of perception we perceive through our body. It is through our body that we hear, see, and feel. It is through our body that we communicate with the world and it is through our body that we are aware of the world. The
body is the pivot of our existence and it is this very communion between the world and our body that we and the objects of this world are animated (Merleau-Ponty, 1962/2002)

Phenomenological description is based on what is presented to one’s conscious in its form and not based on intellectual reconstruction of phenomena (Madison, 1981). Hence by using the phenomenological tradition, I sought the meaning of the experience of the critically ill patients as embodied beings in the world of ICU.

We exist in the world with other human beings. The people in our interpersonal space are always part of our existence. Patients present to ICU in a state of critical illness. In this state, the patients are often unconscious or semi-conscious in pain and vulnerable. Their state of awareness is dulled: it is not as clear as it is in their everydayness. Their perceptions and experience of the ICU environment and the presence of staff are influenced by the way they are in the world in this state. Separation from loved ones and the familiar evokes fear and distorts perceptions of the world. A phenomenological inquiry serves to establish how patients experience critical illness in ICU. Being critically ill affects the temporal aspects of being in the world. Temporality is time that is lived as change where the past and the future are experienced as horizons of our living present with the future being towards which my present activities are directed and it is this that helps to make sense of being in the world (Merleau-Ponty, 1962/2002). By the same token, the past is an ever diminishing phase of my present situation which can still be re-interpreted based on my present and future experiences (Spurling, 1977). The anchoring of our existence is embedded in our past and future as intentionality that ground us to our space (Spurling, 1977) which Merleau-Ponty (1962/2002, p. 416) calls ‘lines of intentionality’. Hence we get to know people based on their past, present and future because these are what make up their existence. Our past is our memory that somehow shapes our lives (van Manen, 1990). Thus a person’s history influences the way he/she interprets time in ICU. For instance a patient’s culture and spiritual beliefs can shape their ICU experience. However, our present situations can also change the way we perceive our past experiences (van Manen, 1990). The lived experience of being critically ill in ICU affects the patients’ perception of the future.

Phenomenologically, the dialogue between being and the world, intentionality, is also shaped by language and speech. The participants in this study were often rendered voiceless by virtue of their critical condition, their state of consciousness and sedation, and that they were intubated and ventilated. The phenomenological description of speech renders it possible to apprehend the importance of being unable to speak and what it meant for the 12 people in this study.
Speech

We live in a world where speech is an institution. For all these many commonplace utterances, we possess within ourselves ready-made meanings. They arouse in a second order thoughts; these in turn are translated into other words which demand from us no real effort of expression and will demand from our hearers no effort of comprehension. Thus language and understanding of language apparently raise no problems. The linguistic and intersubjective world no longer surprises us, we no longer distinguish it from the world itself, and it is with a world spoken and speaking that we think. We become unaware of the contingent element in expression and communication, whether it be a child learning to speak or in the writer saying and thinking something for the first time, in short, in all who transform a certain kind of silence into speech. It is, however quite clear that constituted speech, as it operates in daily life, assumes that the decisive step of expression has been taken. Our view of man will remain superficial so long as long as we fail to go back to that origin, so long as we fail to find, beneath the chatter of words, the primordial silence, and as long as we do not describe the action which breaks this silence. The spoken word is a gesture, and its meaning, a world.


Merleau-Ponty (1964, p. 17) argues that language is essential to our being. Language and communication are essential to our being-in-the-world just as the survival of fish is dependent on the availability of their habitation in suitable water. Because we are in the world with others, we are inevitably connected with others and we are compelled to communicate with them. It is through this communication that we encounter others and that we are able to achieve our goals. In other words, language and speech are fundamental aspects of our being-in-the-world. It is that which makes our way of being in-the-world with others and it is that which links us to others. It is an indispensable aspect of our co-existence with others in the world. It is poignant when language and speech are impossible as it was for the participants in this study who discovered themselves in a strange place, not knowing where they had been and what had happened to them and unable to speak. The loss of their voice and speech was a threat to their existence.
Phenomenologists dispute the empiricist and the intellectualist idea that explains language as an external relation to thought. What Phenomenologists believe is that speech and thought is one and the same thing that speech is the body of thought and as such, speech is the bringing to light the thoughts themselves (Merleau-Ponty 1962/2002). Speech is one of the ways in which we are directly linked with the lived other and it is indeed one other way in which the lived other leaves an impression on us and the way in which the lived other influences us in shaping our being in the world with them. Speech is the signifying of intention of bringing to light that thought which is struggling to establish itself - the momentary desire (Merleau-Ponty, 1962/2002, p. 183). It is this act of making our intention known to others that is significant. If then from a phenomenological stance speech/language is another way of sustaining our being in the world, we as health care givers can only but imagine what it must be like to be unable express ourselves whilst critically ill and feeling our existence threatened. Whilst our imaginations cannot give us insight into this experience, the phenomenological approach used in this study provides some insight and understanding. The way we communicate with others using actions and gestures is fundamental to the way ours and other people’s acts impact on the shared meanings and understandings of the world. Critically ill patients try to communicate using gestures. At times they try to mouth words but their efforts to communicate often prove futile as health care staff and loved ones do not comprehend or they misunderstand communications. This points to the fact that language must be coherent; it must be and should be understood. In other words, language should be able to reveal its meaning to those that understand it. (Merleau-Ponty, 1962/2002) As noted in Chapter One, critically ill and mechanically ventilated are known to be unable to express themselves; they are voiceless. Speech and language is denied them with the presence of an endotracheal tube (Happ, 2001, Happ et al., 2004, Happ et al., 2011). This is contrary to the way they exist in their everyday life. Merleau-Ponty highlights the taken-for-grantedness of speech in everyday life. Phenomenology investigates speech from its origin in the primordial silence to its existence in the natural attitude where it is already constituted as an institution (Spurling, 1977). Speech is like perception in that it effaces itself, and it is through speech that we reveal ourselves. Whilst gestures are a form of language they are also socially and culturally mediated and can therefore be misinterpreted or misunderstood. To this end Merleau-Ponty (1962/2002) contrasts speech with painting by saying that we are able to find ourselves in speech and that its resources are readily available and it is possible for us to speak about speech whereas it is impossible to paint about painting. Hence speech is unique in that it moves between sedimentation and innovation (Spurling, 1977). Being intubated and mechanically ventilated takes away the critically ill patient’s ability to speak but not their ability to gesticulate. Speech, however, is a way of interaction of the body with the world (intentionality) itself (Spurling, 1977).
Freedom

Freedom according to Merleau-Ponty (1962/2002) is the way we exist and the way we adjust to various situations as they arise and present themselves to us in the world. We exist in the world with others and our actions consequently affect others with whom we exist and share experiences of similar situations in the world. Freedom is not freedom from external compulsion but the ability to create, innovate and act by working on and shaping our world (Merleau-Ponty, 1962/2002) as we respond to the various solicitations that confront us in the world. It is *appropriating a de facto situation by endowing it with a figurative meaning beyond its real one* (Merleau-Ponty, 1962/2002, p. 172). It is in other words, the ability of a person to transform their circumstances and thus change his existence by altering its impact on his life.

We do not exist in the world as many multiple individuals but rather in an intersubjective way in which we share our experiences. In as much as experiences affect us as individuals they are inadvertently shared with those who are in this world with us as participants in a similar situation. So our lives are interwoven through the shared existence with those who are involved in this world in a similar manner as we do. Likewise, as individuals we are born into a society whose values and culture determine the way we live with others and from which we can either choose to emancipate ourselves or to accept to live as such (Merleau-Ponty, 1962/2002).

Our lives and our past are pregnant with meaning Merleau-Ponty (1962/2002) which determines the way we live in the world. In other words, our background - our past which is our history determines our relationship with the world in which we live and the way we treat other people and the objects that exist in it. In the same manner, the way critically ill people interpret their experience is based on how their previous experience had shaped them. Freedom, according to Merleau-Ponty (1962/2002, p. 438), is *the real choice of the whole character and the manner of our being in the world*.

In other words, freedom, to a certain extent is never complete (Spurling, 1977,) and although sometimes there are no visible boundaries for freedom, there are certain worldly elements that determine our freedom and the nature of freedom that we experience at certain times of our being in the world. It is our way of responding to the worldly solicitations as they appeal to our sensibilities at a given time in specific circumstances. This includes the way we co-exist with others and how we exercise our freedom. The bonds with other people is so strong that it has a bearing on how we see the world and it is from this stance that we exercise our freedom. The presence of others, as in the health professionals whose role it is to provide treatment, care and closely monitor critically ill patients in ICU can be unsettling for some at
the same time it can be reassuring with the promise of safety and security. How people respond to these situations is a demonstration of freedom shaped by past experiences. Freedom is a primordial acquisition; that which we are born with and which Merleau-Ponty (1962/2002, p. 436) calls *our state of nature*. Since freedom belongs to the natural order of things, it is imbedded in time – past, present and future and in the same manner, freedom to make decisions, thrusts itself into the future and is preceded by a past though not necessarily a requirement (Merleau-Ponty, 1962/2002). Even in sickness, our freedom is at play because the way we respond to illness also stems from freedom (Merleau-Ponty, 1962/2002). Freedom is the ability to live to the full in spite of our circumstances, being able to unreservedly move on from one's circumstances (Merleau-Ponty, 1962/2002) such as critical illness. In talking about freedom from a philosophical point of view, my aim is to prepare my readers for the experiences of the participants in this study. The world of ICU has been likened to a prison (Wang et al., 2008) among other things and it is for this reason that I have discussed freedom in a phenomenological.

**Death/Finitude**

As Dasein\(^{23}\), we are intended towards death from the moment we are born (Heidegger, 1962/2008). Death is an existential (van Manen, 1990) that in our passed over state we are unconscious of yet dread and avoid talking about. Death can be considered as both ‘pathetic’ and ‘complacent’ which strikes our finality through perpetuation of violence or as an integration into our self and heightening our sense of life in a dry and resolute manner (Merleau-Ponty, 1964) (Sense and Non-Sense). Similarly it is in fact in death that we find our wholeness (Heidegger, 1962/2008, p.281). In this instance, our being towards death is awakened and heightened by any threat such as illness to our existence (Leder, 1990). Critical illness in the case of this study undoubtedly throws the patient into a pervasive sense of death that only he or she can experience and contend with. Death is an individuated existential that leaves an impression on the lived other (Heidegger, 1962/2008). It is in the lived other that we become conscious of death. As Merleau-Ponty (1964, p. 68) declares that;

*The only experience which brings me to an authentic awareness of death is the contact with another, since under his gaze I am only an object just as he is merely a piece of the world under my own.*

\(^{23}\) German word used by the philosopher Martin Heidegger to refer to personhood or being.
It is in the awareness of death that we discover awareness of life (Merleau-Ponty, 1964). Death marks the end of being in the world (Heidegger, 1962/2008). It is the fear of ceasing to be that evokes anxiety when faced with the possibility of death particularly in an illness state.

So phenomenology as applied to this study of the lived experiences of critically ill patients in ICU, the question at hand was; what was it like for the twelve participants in this study to be critically ill in ICU and following discharge? By exploring this question, the experience of being critically ill in a contemporary ICU is described to reveal its true nature and existential meanings. This is what separates phenomenology from other methodologies such as ethnography which seeks to investigate culture and meanings specific to social groups.

**Conclusion**

In this chapter, I discussed the methodology for this study. I discussed the notion of being-in-the-world and why I have drawn on the philosophy of Merleau-Ponty. My study draws upon my readings of phenomenology works but most of all, the Phenomenology of Perception (Merleau-Ponty, 1962/2002). I have argued why phenomenology is an appropriate methodology for understanding the human nature of critical illness in ICU (Munhall & Boyd, 1993).

Phenomenology is a methodology that is different from traditional scientific research such as empiricism and intellectualism in that instead of dealing with measurement, generalisations, objectivity, replication and knowledge that must be uniformly true for all, phenomenology seeks to uncover the uniqueness, quality and significance of human experience as it is lived and perceived by individuals. Essentially, it seeks to understand what it is to be human. Phenomenological research aims at transcending scientific understanding, conceptualisations and abstractions about the world by describing lived experience. In keeping with the notion of science, the phenomenological method is a ‘systematic, explicit, self-critical and an intersubjective study of its matter; ...lived experience’ (van Manen, 1990, p. 11). Phenomenological inquiry’s method, techniques, procedures and processes demand attentiveness, openness, thoughtfulness and insight (van Manen, 1990, p. 12) which are the guiding principles of this study’s method.

In the next chapter, I discuss the study design, plan and methods which detail the processes I used to conduct the study.
CHAPTER THREE

STUDY DESIGN AND METHOD

Introduction

In Chapter Two, I showed that phenomenology as a research methodology values the way people experience the world. The phenomenological method described in the following text aimed at re-awakening the participants’ lived experience of critical illness in an ICU in the context of DSI. The approaches used were designed to enhance understanding experiences based on the descriptions of the participants. In this chapter, I described the processes and procedures I used in conducting this study and investigating the lived experience of being critically ill in ICU. I provided a description of the setting for the study, an introduction to the participants and I outlined the relevant ethical considerations.

I chose phenomenology to conduct this study because of the nature of my concern. Phenomenology aims to highlight the meaning that an individual attaches to their lived experience. The research question with its focus on understanding human experience determined the methodology that was selected. Furthermore, I am a nurse whose personal beliefs and values and approach to human beings and care is holistic. I am committed to caring, helping and understanding people as individuals and this made phenomenology the most appropriate modality of conducting this research.

The phenomenological researcher is concerned with understanding human experience from the individual’s own frame of reference (Munhall & Boyd, 1993; van Manen, 1990; Wilkes, 1991). The phenomenological researcher examines how the world is experienced; for them, the important reality is what the people perceive it to be (Munhall & Boyd, 1993; van Manen, 1990). The only true experience of being critically ill in the world of ICU lies with the people who were critically ill. The use of phenomenology in this study to answer the question; “What is the experience of critical illness in the context of ICU hospitalisation and how does it affect people’s lives after discharge?” reveals the perceptions and experiences of the participants in this study.

Most of the research on health care outcomes of ICU treatment is mechanistic in nature. As such this kind of research tends to be concerned with the physical outcomes rather than the lived meaning of health care outcomes (Leder, 1990). As an ICU nurse and a researcher using phenomenological methods, the experience of a critically ill person in ICU is
inaccessible through mere observation of the patient. The meanings attached to their experience of being critically ill are hidden from this perspective. My scientific knowledge and understanding of being critically ill in the ICU does not help me understand their lived experience of critical illness. Because phenomenological methods seek to understand lived experience (van Manen, 1990), it allowed me to reveal the depth and the meaning of the experience from the perspectives of the participants in this study.

Phenomenological inquiry allows researchers to explore the depths of experience and the associated meanings. One can only appreciate the experiences of others by acknowledging my preconceptions, assumptions and previous knowledge about experience as a backdrop of their research. Indeed, gaining a deep understanding of the experience of critically ill patients is like entering a new world. As van Manen (1999, p. 19) says;

\[
\text{To understand people’s experience we … need to get really close to them so that their hopes become our hopes, their pain becomes our pain – we … need to listen and speak, read and write in a manner that is attentive to the things of the world that are ultimately unnamable. Our words … have to be “as slow, as new, as single, and as tentative” as if we were going down a path away from the familiar toward a world we had never navigated before.}
\]

Doing phenomenology is the attentive practice of “thoughtfulness” (van Manen, 1990, p. 12). Being absorbed in the experience of being critically ill through in-depth interviews with the participants in this study and analysis of the transcripts allowed me to achieve understanding of the meanings it had for the participants in this study. As health care workers we give care, not only in a knowledgeable manner but also, in an empathetic manner. We are concerned about the people we are caring for from the perspective of their humanness. By using a phenomenological stance in this study I was able to understand the experiences of the participants in this study from their perspective as opposed to the scientific conceptualisations previously learned.

The major purpose of conducting phenomenological research in nursing is to pay attention to the lived experiences of people during illness and health. Through attentive listening to the stories of those who were critically ill in ICU, my aim was to bring to speech the aspects of their lived experience that were ineffable and elusive. Phenomenological inquiry invokes reflection which in turn, brings about better understanding of past experiences (van Manen, 2002). By conducting this study using phenomenology, I sought to bring to light what it was like to be critically ill in a clear (explicit) manner that would invoke a relationship between my
readers and the text so that they identify with the experience and make it their own. My aim in conducting this study was to cause the ICU staff to reflect on their practice and change practice based on these insights. By using phenomenology, pathic knowledge is revealed. Health care professionals need pathic knowledge in order to be able to discharge their duties with compassion, understanding and empathy. Without phenomenological research, we cannot be as sensitive to the pathic nature of our practice as ICU staff. As van Manen (1999, p. 34) states:

If we want to be sensitive to the pathic nature of nursing and medical practice then we need to pursue forms of research that use pathic language. Pathic questions cannot be answered by texts that primarily communicate cognitive meaning. And gnostic insights cannot produce pathic experience.

As health care workers, we have the naturalistic knowledge about critical illness in ICU but we lack the pathic knowledge about people’s experience of critical illness and it is only the people with the experience who can provide insight into the nature of the experience of being critically ill. Phenomenological research also challenges us as health care workers to be thoughtful not only about what we can hear as spoken word but also about the things that cannot be talked about that is both in the presence and the absence of language. For even in silence, there is a hidden meaning. Phenomenology is a human science that 'explicates phenomena as they present themselves to consciousness... whether it is real or imagined, empirically measurable or subjectively felt' van Manen (1990, p. 9). By explicating phenomena, we make things that are unclear coherent and understandable.

**Doing Phenomenology**

Phenomenological methods use procedures and techniques with special consideration of the philosophical tenets of phenomenology and direct how a study is carried out (van Manen, 1990). Phenomenological research suspends the notion of constructing hypotheses or predetermined procedures, techniques and concepts that would govern the research project. However, the methods or way of doing phenomenology is by reflecting and clearing so as to clarify, show, reveal or uncover that which could have been hidden in its essential nature (van Manen, 1990). For this reason, the phenomenological method cannot be prefixed; it can only be created or discovered as determined by the question at hand. Hence phenomenological research is a scholarship whose scholar must be a sensitive observer of the everyday life subtleties and can only conduct research by immersing him or herself in the
world of human experience. The research must be characterised by sensitivity to language, reflecting, writing and rewriting (van Manen, 1990).

In the following section I outline the relevance of van Manen’s (1990) method to this study.

**Van Manen’s Approach to phenomenology**

In this study, I used van Manen’s (1990) hermeneutic phenomenological method to describe the critically ill patients’ experiences of ICU. Van Manen’s method is pertinent to this study because it has close relation to nursing and holism. This method allowed the study to capture the interpretive essence of the experience of being critically ill patients during their ICU admission, and to understand the meaning of these experiences and thereby, reveal that which was ‘hidden’ from the health care professionals.

In this study I adopted van Manen’s (1990) six dynamic interplay activities as a guide to my method of this study as follows:

1) Turning to the phenomenon which interests and commits us to the world.
2) Investigating experience as we live it rather than as we conceptualise it.
3) Reflecting on the essential themes which characterise the phenomenon.
4) Describing the phenomenon through the art of writing and rewriting.
5) Maintaining a strong and oriented pedagogical relation to the phenomenon.
6) Balancing the research context by considering parts and whole.

**Turning to the Phenomenon**

Turning to the phenomenon as it interests and commits us to the world, means that as a researcher, I focused on the phenomenon that captured my attention and put aside the scientific conceptualisations and understandings. I oriented myself to the phenomenon of being critically ill and experiencing ICU by committing myself to understand the experience of critical illness. By orienting myself to the lived experience of critical illness, I began to understand what it might be like to be critically ill in ICU. By investigating experience as it was lived, I sought to establish contact with the original experience afresh. I asked the participants to describe their lived experience of critical illness in ICU. In doing this I reflected upon my assumptions, scientific knowledge and pre conceptualisations about the experience of critical illness. By doing this I attempted to keep them in check so they did not interfere with the research process. Defining my assumptions helped me to focus on the participants
as individuals and their experience in order to be able to gain new insights about their experiences.

**Investigating Experience**

To truly investigate the experience as it was lived by the participants, I had to understand the question at hand and open myself to the meaning of the lived experience of critical illness in ICU. As mentioned earlier, I declared my knowledge and preconceptions concerning the notion of being critically ill and the contemporary ICU experience and then focused on gaining a deeper understanding of being critically ill in ICU and beyond. In order to gain a deep understanding of the lived experience, I explored the hidden meanings of etymological origins of the words and idiomatic phrases and most importantly, I collected stories of the participants’ experience through in-depth face to face interviews. In doing so I was investigating the experience as it was lived. By investigating the experience as it was lived, I was reviving the participants’ basic experience of critical illness and ICU. This meant that during the face-to-face in-depth interviews, I situated myself in the midst of the lived experience of the patients who had been critically ill in ICU by listening attentively to their experience and I explored all the aspects and modalities of their lived experience (Van Manen, 1990)

**Reflecting on the Essential Themes which Characterise the Phenomenon**

To understand the essential meaning of being critically ill in ICU I reflected on the structure of the lived experience during the analysis phase of the research. My reflections were centered on the essential themes – things that made critical illness in ICU the kind of experience it was. This process involved deep, thoughtful and reflective understanding of the participants’ lived experience of being critically ill in ICU all the while considering that which made it important and special. It was a process of drawing near to and exposing that which seemed to hide itself from my everyday intelligible understanding (van Manen, 1990) of being critically ill in ICU from day to day. I began the analysis process by reading and re-reading the transcripts and records of observations from my field journal and conversing with the data. I read and reflected on each transcript as a whole and as a part of each participants’ experience and as a relation to other transcripts' transcripts and experience. Through this process I identified common themes from the participants’ narratives that which made the experience of being a critically ill in ICU what it is. The themes that emerged represent the structure of the lived experience in this study. They do however, only point to a single facet of the lived experience. To this end, this work is in part personal as I did not
capture the essence the lived experience once and for all. Another person at a different time could have portrayed a different aspect of the lived experience. ‘A thematic phrase only serves to point at, to allude to, or hint at, an aspect of a phenomenon’ (van Manen, 1980, p.92).

**Describing the Phenomenon through the Art of Writing and Rewriting**

The art of writing and rewriting is a thoughtful ‘bringing to speech’ (van Manen, 1990, p. 32) that lived experience which is at hand in this case the experience of being critically ill in the context of ICU. Hence, the writing and rewriting process of phenomenological inquiry into the lived experience of the people who were critically ill in ICU was the *logos* – the thoughtful full representation of the aspects of the participants’ experience (van Manen, 1990). The process of writing, reflecting and rewriting was used as the process for the analysis of the data in this study and thematic descriptions. As I read and reread, wrote and rewrote, and reflected on the transcripts and my writing, patterns and themes emerged depicting the meaning of critical illness in ICU. The aim of the writing and rewriting was to craft deep, multiple layers of meaning that laid bare the essential elements of the experience. To this end, van Manen (1990) states;

*To be able to do justice to the fullness and ambiguity of the experience of the life world, writing may turn into a complex process of rewriting (rethinking, reflecting, recognizing ...//... writing and rewriting aims at creating depth: constructing successive or multiple layers of meaning, thus laying bare certain truths while retaining an essential essence of ambiguity. This depthful writing cannot be accomplished in one straightforward session. Rather, the process of writing and rewriting (including revising or editing) is more reminiscent of the artistic activity of creating an art object that has to be approached again and again, going back and forth between the parts and the whole in order to arrive at a finely crafted story that often reflects the ‘personal’ signature of the author.*

(pp. 131-132).
Writing and rewriting was a fundamental aspect of reflecting on and analysing the data in this study. The thematic descriptions in this study were a result of the painstaking process of working the data by moving back and forth between the data and the text, reflecting, and writing, rewriting, carefully interpreting and seeking meanings of the lived experience.

**Maintaining a Strong and Oriented Pedagogical Relation to the Phenomenon**

The qualitative nature of phenomenological research makes it extraordinarily demanding. It involves maintaining a strong and oriented relation that is, focusing on the question and not getting sidetracked by existing theories, abstractions and conceptualisations. I focused my interest on the lived experiences of the people who experienced critically illness in the ICU. Because I started my research as a nurse, I declared my pre-existing knowledge and assumptions about the experience of critical illness.

**Balancing the Research Context by Considering Parts and Whole**

There are no formulae for writing phenomenological text, however, the structure arose as the writing advanced. It is what van Manen (1990, p. 167) calls 'working the text'. Hence the writing only advanced through conceptualising and developing the text bearing in mind the part-whole relation. In the research process, I was guided by van Manen (1990) and elements of Merleau-Ponty, (1962/2002).

In the following section, I outline my study assumptions, define the aim of the study and explain the procedures I used.

**Study Assumptions**

I began my study out of curiosity and wonder about the meaning the people who were critically ill in ICU attached to their experience in the light of the innovations in ICU practice that have taken place over the past decade. As I worked every day in ICU, I provided DSI previously described in the introduction, for patients who were critically ill and mechanically ventilated. I cared for patients who were ventilated with ventilators that were very different from the ones that were used a decade ago. The most striking thing for me was the use of DSI: I wondered how patients experienced being in and out consciousness. I sought to explore the practice of DSI but I discovered that much had been written about it previously (Combes et al., 2007; Kress et al., 2000; Kress et al., 2003; Kress & Hall, 2006; Mehta, et
al., 2008). Randomised controlled trials (Combes et al., 2007; Kress et al., 2000; Kress et al., 2003; Kress & Hall, 2006; Mehta et al., 2008) showed that DSI was associated with good physical outcomes (Kress et al., 2000; Kress & Hall, 2006) such as short ventilator days, ICU and hospital stay (Kress et al., 2000; Kress & Hall, 2006). My concern was consistent with phenomenology where inquiry begins and ends in wonder (van Manen, 1990). My study was motivated by my concerns about patients’ welfare and assumptions that I had from my theoretical knowledge as an ICU nurse and as a person. The presuppositions were based on my observations of clinical practice and the research literature, noted previously in the introduction, relating to the successes of innovations in ICU. Patients got better faster in ICU; they stayed ventilated for a shorter period of time as compared to the previous decade (Kress & Hall, 2006; Kress et al., 2000). I concluded that the patients’ would report their experiences of critical illness as less traumatic, more comfortable and having less long term impact for them. Because patients appeared to be awake with the use of DSI, I assumed that they should have been able to remember their experience in ICU more so than patients who had been in ICU in previous years.

In spite of my knowledge and respect for the science that underpins ICU practice, my key assumption is that the impact of these practices can only be understood through the meaning they have for the people who experience them.

My assumptions acted as a guide to my study as I reflected on what I was hearing, thinking and feeling. My assumptions were the basis upon which I began this study and they were my taken for granted views about the impact of the innovations in ICU practices on the lived experience of the people who were critically ill. These are the things that Merleau-Ponty (1962/2002) refers to as assumptions arising from the natural attitudes that should be put in abeyance so as to understand the phenomenon at hand. He states;

*Phenomenology is a transcendental philosophy which places in abeyance the assertions arising out of the natural attitude, the better to understand them; but it is also a philosophy for which the world is always ‘already there’ before reflection begins - as an inalienable presence: and all its efforts are concentrated upon re-achieving a direct and primitive contact with the world, and endowing that contact with a philosophical status.*

By using the word abeyance, Merleau-Ponty was urging us to suspend our thoughts, knowledge and conceptualisations and get into the field ready and receptive to the stories and observations that we get from our participants without any judgment. In the same way, Merleau-Ponty (1962/2002, p. xxi) further described philosophy as ‘revealing how to look at the work ..//.. with attentiveness and wonder..//.. never knowing where it is going.’ However, it was by acknowledging my personal and professional beliefs and attentively surrendering myself to the possibilities and new understandings offered to me through patients’ stories that I could see in a new way what meaning people who were going through critical illness attached to their experience. By putting aside my views, I opened myself to the experience and cleared the path to genuine inquiry.

**Aim of the Study**

The aim of the study was to describe the lived experience of critical illness in ICU in the context of DSI and how it impacted the participants’ continued existence. Every phenomenological project is driven by commitment to the question at hand (van Manen). From a phenomenological point of view, the aim of the study was to transform the participants’ lived experience of being critically ill in ICU, into a phenomenological text of its essence.

**Purpose of the Study**

The purpose of this study was to describe the lived experience of people who experienced critical illness in ICU and following discharge in the context of DSI. My goal in undertaking the study was to discover what it was like for people to experience critical illness in the light of the advances in treatment with the use of DSI. This thesis is about the lived experiences of twelve patients who were treated using DSI in contemporary ICU. My interest in studying this topic was motivated by the need to increase clinicians’ awareness of people’s experience of being critically ill in ICU and surviving critical illness in the context of DSI.

**The Research Question:**

What is the experience of critical illness in ICU and how does it affect people’s lives after discharge?

The following questions helped me to achieve my aim:

- What does it mean to have been critically ill in ICU?
What is it like to be critically ill and mechanically ventilated with DSI?
What is it like to emerge from a state of unconsciousness in ICU?
What is the impact of critical illness in ICU following discharge?

Research Plan and Methods
In this section I outline the setting in which I conducted the research. I also describe the selection criteria for recruitment of participants. In addition, I outline the data collection process, ethical considerations I took during the research process and I describe the participants to orientate the reader. I also discuss matters pertaining to how I conducted data collection and analysis, how I maintained the credibility of the study and the conclusion.

Setting Description.

The study site was a modern 22 bed well equipped ICU at a tertiary referral teaching hospital\textsuperscript{24} in NSW in Australia. The unit treats a variety of patients ranging from infants to the elderly. It is a multidisciplinary unit that treats all types of injuries and illnesses, and provides post-operative care to patients following major surgery including head and neurosurgery. It has a helicopter retrieval service that transports critically ill patients from smaller hospitals within the 500Km radius from it and also transports patients to specialist treatment in the metropolitan hospitals of Sydney. Mechanically ventilated patients are nursed on a ratio of one to one basis and other patients are on a one to two ratio. Bed occupancy was about 99% with 24 hour nursing and medical cover (John Hunter ICU Bed occupancy annual report, 2008).

Criteria for participants’ study inclusion

The criteria for this study were that the participants had to have been critically ill in ICU and mechanically ventilated for at least 24 hours. The potential participants’ prognosis needed to be good, in other words there needed to be a prognosis of survival from the critical illness. They had to understand and speak English and they had to be 18 years old and over. The criteria are discussed in further detail below under the heading “informed consent” on page 64.

Recruitment of Participants.

Although there are no set prior considerations for locating and selecting participants for phenomenological inquiry, there are general and essential considerations for locating and

\textsuperscript{24} A major hospital catering for paediatrics including various branches of medicine and surgery at consultancy level.
selecting participants for qualitative research such as age, gender, and race, ethnic and cultural factors (Moustakas (1994). Religion, political and economic factors and essential considerations are that the research participants must have experienced the issue at hand, have an interest in understanding and knowing the meaning of the experience, willingness to engage in long interviews, granting the researcher the right to tape or video record the interview, transcribe and publish the data in various publications including the thesis (Moustakas (1994, p. 107). The study of critical illness is complex and so are the participants. Critical illness impacts people from all walks of life and the treatment can be frightening and life changing. Each experience is individual and that is what makes phenomenological research unique. The participant must be able to give an account of the particular experience in question (Gerrish & Lacey, 2010). Participants may fulfill the criteria for recruitment into the study but the nature of their health and prognosis may not allow them to participate in the study. Therefore all these elements were taken into consideration when recruiting participants for this study.

Because I was aware that critically ill patients are vulnerable, I asked the ICU Nurse Educator (NE), the Clinical Nurse Consultant (CNC) for Research and the Clinical Nurse Consultant in Quality Improvement to assist me with recruitment. I also asked the Nursing Unit Managers (NUMs) to ask the ward staff to assist with the recruitment. The NUM, CNC and NE approached potential participants whom they deemed capable of reading the information letter and understanding the scope of the research and what was going to be required of them if they agreed to participate in the research. Potential participants' needed a prognosis of survival to ensure the continuity of the study as the plan for data collection extended over a period of six months for each participant. Because all the participants had undergone DSI and some had experienced hallucinations, the NUMs, CNC and NE staff only approached potential participants once they were alert and orientated and there was no sign of confusion or effects of sedation. The NUM, CNC and NE staff only approached the potential participants once they had been lucid for a day or more and they were transferred or just before they were transferred to the ward. Potential participants with cognitive impairment were not approached. Once the NUM, CNC, NE had made the initial contact and explained the nature of the study and the rights and implications of the potential participants in the study, the potential participants were asked if they were interested and invited to sign the consent form where they indicated their preferred way to be contacted by the researcher. The consent forms, enclosed within a sealed envelope addressed to the researcher, were placed in a designated mail box in the ICU or ward for retrieval by the researcher. Upon receipt of the consent letter I made initial contact with the participants a day or two later. I introduced myself, and thanked the participants for agreeing to participate in the study. I
further explained what the study was about and the responsibilities and rights of the participants particularly that they were participating at their free will and that they had the right to withdraw from the study at any time without fear of being denied treatment or being mistreated. I then made an appointment to interview the participants within a week after they were discharged to their home or before they went home for those who lived out of town (Alex & Moira) and those who stayed in hospital for a longer time like Erick, Monica and Maggie. Twelve participants who fulfilled the recruitment criteria were selected to participate in the study.

**Data Collection.**

I conducted data collection by conducting in depth face to face interviews with the participants. All participants were interviewed on several occasions during and following their ICU hospitalization for up to one year following discharge. All interviews were audio recorded and later transcribed for analysis. During interviews I also took notes of the participants’ body language including gestures and emotional expressions. As noted previously data collection took longer than I had anticipated. Because the aim of phenomenological research is to establish the meaning of lived experience, I conducted in-depth interviews using van Manen’s (1990) processes as a guide. Qualitative researchers use depth interviews to gain a deeper understanding of meanings of central themes of an individual’s life world through their own words and language (Kvale, 1996; Minichiello et al., 1995; Patton, 1980, 2002; Seidman, 1991). Because ICU survivors have no established follow up program of care, narratives about their critical illness and experiences of ICU often go unheard. It is for this reason that face to face interviews were suitable for this investigation. I also felt that by conducting face to face interviews I was providing the participants with a forum to recount their experiences. It is through speech, or giving voice to experience, that one discovers what people wish to say (Merleau-Ponty, 1974) in relation to their lived experiences. Furthermore, the power of in-depth interviews is that they are means through which ones identity is revealed because it is through creating, telling, revising and retelling that one discovers, knows and reveals themselves (Valeras, 2010). In addition, our identities are made up of our stories (Porkinghorne, 1991). In-depth interviews were conducted in participants’ homes or place of preference where both the participants and the researcher were safe and comfortable. I set out to conduct interviews at two weeks post ICU discharge and at six months following the first interview. That was to capture the experience as raw and as fresh as possible at two weeks and to discover how critical illness and ICU hospitalisation had impacted on the continued existence of the participants. However, some of the second interviews were not done until up to eleven months later due to various
circumstances described below in the introduction of participants in this thesis (pp. 67-72). Before starting each interview, once again I introduced myself again to the participants; thanked them for agreeing to take part in the study; confirmed their consent to have the interview audio taped; explained to them what the research was all about, what was required of them during the study. During the interview, I let the participants describe their experiences to the full and I did not hurry them. I listened in an understanding, attentive and empathetic manner (van Manen, 2002). I also took notes on body language and other things that were going on that could not have been picked up on the tape recorder at the same time. For example, I noted that Kate’s eyes filled up with tears when she finished telling me about how she had been packed in ice; Moira looked sad when she talked about at the same time her memory loss before she broke down into tears. I also noted how Maggie’s demeanor changed from sadness to a twinge of joy when she talked about her family’s presence in ICU.

Furthermore, I kept a field diary in which I recorded the events of the day during data collection. Events of the day included how my mood was affected by the participants’ narratives and how I dealt with my feelings.

**In-depth Face to Face Interviewing**

By using face to face interviews I was able to explore the depths and meanings of lived experience. The close interactions with the participants allowed me to listen intently and elicit their body language. It allowed me to explore the silences in a way that the structured interview or survey could not. The participants in this study were interviewed on several occasions with each interview lasting thirty minutes to one hour or more for some. Because some participants came from a radius of 500km from the hospital, I conducted some of the first interviews before the participants were discharged from the hospital. I arranged for private rooms for the conduct of these interviews so that privacy and comfort were ensured and so that we were not disrupted by other patients, staff and visitors. Most participants were interviewed on two occasions throughout the study at two weeks after discharge from ICU and up to eleven months after the first interview. Two participants declined to be interviewed a second time. One participant could not be interviewed a second time because he was too sick to be interviewed and underwent frequent readmissions to the hospital. The other participant could not be contacted for the second interview.

For the purpose of this study, I asked the participants the following questions:

- What does it mean to have been critically ill in ICU?
• What is it like to be critically ill and mechanically ventilated with DSI?
• What is it like to emerge from a state of unconsciousness in ICU?
• What is the impact of critical illness and ICU hospitalisation?

In order to encourage the participants to give a rich, detailed story I asked probing questions such as:

• What was it like to breathe with the respirator/breathing machine (ventilator)?
• Can you tell me more about what it was like for you to be in ICU?

Ethical Considerations

I sought ethics approval from the Hunter New England Health Research Committee and the University of Newcastle's Human Research and Ethics Committee before I commenced the study. Ethics approval was granted in December, 2007.

Informed Consent.

My ethical responsibility as a researcher was to ensure that participants were informed and free to give their consent. To ensure participants’ were informed about the study; I developed an information letter where I explained what my research was about and how the findings were to be disseminated (Gerrish & Lacey, 2010). I also outlined that confidentiality was ensured by erasing the participants’ names and using pseudonyms. Data was stored in a locked filing cabinet at the university to which only the researcher and my supervisors had access. In the information letter I also explained to the participants that they had right to refuse to participate or withdraw from the study at any time without fear of being mistreated (Gerrish & Lacey, 2010).

In order to ensure freedom to consent and an autonomous decision to participate in a study (Gerrish & Lacey, 2010), I asked five senior clinicians in ICU to approach the potential participants with a view to determining their interest in the study. Once interest was established they were provided with an information letter with details about the study and a letter of consent. The senior clinicians went through the information letter with the potential participants and answered any questions the participants had.

The participants were only approached by the researcher about consenting to the study if they had read the information letter. Upon receipt of the letter of consent I explained the study again in order to ensure they were fully aware of what the study was about, the
implications of participating in the study and their rights to withdraw from the study without any fear of being denied future treatment. To achieve this, I checked for understanding by asking questions of the potential participants. Participants were reminded of their right to withdraw from the study at any time. This statement was also verbally repeated to the participants when I re-enforced the information about the participants’ rights when I contacted them to make an appointment for the interviews and also before I started the interviews including obtaining the consent to tape record the interviews. Informed written consent to participate in the study was sought from the participants once they were discharged from ICU. The informed written consent was returned to me in a sealed pre paid reply envelop.

**Potential for Harm.**

Conducting research with ICU survivors can be emotionally distressing for the participants (Preller, Matta, Martinelli, Dagleish, Hails et al., 2010). Any research that can be potentially distressing for participants charges the researcher to be sensitive to the participants’ need should they arise (Kaler & Beres, 2010). Because the study involved recollection of experiences that were potentially stressful, I was sensitive to the participants’ emotional needs and provided them support as needed. I placed the importance of their wellbeing before the need for data collection. I was prepared to refer any participants who needed psychological or social work help for emotional needs that would have arisen from the study.

The place of interviews was based on the participants’ choice taking into consideration their comfort and safety. This was in line with safety for the participants and the researcher, I further put the following measures in place:

1. In the event that participants and their families became distressed due to talking about their past experiences in ICU during the interview, a referral to the counseling service of Hunter New England Health was to be offered to them. This was to be achieved through the ICU social worker.

2. If a participant became distressed during the interview, the interview was going to be terminated and measures to ensure the person’s physical and psychological wellbeing will be taken. During transcription of interviews, pseudonyms were used to protect the participants’ identities.

3. No potential harm to the researcher was anticipated. However, if the need arose the supervisors and other relevant resources such as the University of Newcastle counselors were going to be called upon. The supervisors helped in dealing with the sad stories of the participants.
4. The University of Newcastle Home Visiting Policy was adhered to at all times such as the participants' homes were only be accessed with their permission and using the entrance preferred by them. My clock in and out was observed by leaving the details of home visits to be done on a particular day with the supervisors and informing them of the movements of the day.

One participant became distressed and cried during the second interview; I stopped the interview and sat silently whilst holding her hand and until she asked me to continue the interview. I advised her that it was okay to terminate the interview at that stage but she insisted on continuing saying that “in a way she was going to get some of it off her chest” as she had no one to talk to in the same manner as she did with me. I offered Moira counseling referral in accordance with the information letter; however, she advised me that her family doctor had already done so. Nevertheless, she wondered if there were other people who had similar experiences and whom she could talk to. Unfortunately I could not disclose other participants' to her as this would have violated the confidentiality.

**Confidentiality and Ownership of Data.**

In the information letter, the participants were assured anonymity which is consistent with research ethics requirements and in keeping with qualitative research tradition of assuring participants confidentiality (Gerrish & Lacy, 2010). For this reason, at the end of the interviews, I erased the participants' real names used in the voice recording. In the transcripts, I replaced the names of participants with pseudonyms (Burgess, 1988; Minichiello et al, 1995; Seidman, 1991) and I locked all the data in a filing cabinet at the School of Nursing which was only accessible to me and my supervisors. I will destroy the data five years after the completion of the study as per University of Newcastle Human Research Ethics Committee's policy.

I also advised the participants that should they desire to read the transcripts, they would be made available to them. Participants were free to edit their comments if they deemed it necessary (Burgess, 1988; Kvale, 1996). I further advised them that they would be notified about the completion of the study and a summary of the findings would be sent to them if they requested a copy. Only one participant (Jason) edited his transcript.
Table 1 - Summary of Demographic and Other Relevant Data

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age</th>
<th>Reason for Admission</th>
<th>LOS in ICU (days)</th>
<th>Period of Mechanical Ventilation (Days)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Keith</td>
<td>76</td>
<td>Cardiac event</td>
<td>36</td>
<td>27</td>
</tr>
<tr>
<td>Jason</td>
<td>69</td>
<td>Haemothorax</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>George</td>
<td>58</td>
<td>Chest infection</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Rosie</td>
<td>34</td>
<td>severe metabolic acidosis</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Ian</td>
<td>56</td>
<td>Metabolic diabetic keto acidosis</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td>Moira</td>
<td>76</td>
<td>Triple Vessel CABG</td>
<td>10</td>
<td>8</td>
</tr>
<tr>
<td>Alex</td>
<td>65</td>
<td>Aortic bifemoral bypass</td>
<td>9</td>
<td>5</td>
</tr>
<tr>
<td>Kate</td>
<td>60</td>
<td>Cardiac arrest. Aspiration pneumonitis</td>
<td>13</td>
<td>11</td>
</tr>
<tr>
<td>Eric</td>
<td>20</td>
<td>Traumatic chest injury</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td>Maggie</td>
<td>23</td>
<td>Status epilepticus</td>
<td>6</td>
<td>4</td>
</tr>
<tr>
<td>Liam</td>
<td>71</td>
<td>Major abdominal surgery</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Monika</td>
<td>41</td>
<td>Motor vehicle accident</td>
<td>6</td>
<td>4</td>
</tr>
</tbody>
</table>

Description of the Participants

In this section, I introduce my study participants in order for the readers to identify them and with their stories as they meet them later in the thesis. The participants in this study came from all walks of life and from all age groups starting from the age of 18 years of age. All participants, with an exception of one were Caucasian. For the purpose of confidentiality and anonymity, the names of the participants have been replaced with pseudonyms.

Participant 1 – Keith.

Keith was a 76 year old man who found himself in ICU following a cardiac event. Keith had a delayed presentation to ICU because he did not take the initial symptoms seriously until his wife noticed deterioration in his condition. He was treated with interventions Keith then suffered a range of complications including pulmonary oedema (APO)\(^{25}\), atrial fibrillation (AF)\(^{26}\) and renal failure. On day three of his ICU stay, Keith developed respiratory failure was intubated. He further developed a pleural effusion on the right side which was treated with pigtail catheter\(^{27}\) drainage. Keith remained intubated\(^{28}\) for 27 days after which he had a

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\(^{25}\) Extravassation of fluid into lungs due to increased pulmonary capillary pressure mostly due to fluid overload in heart failure.  
\(^{26}\) Irregular heart rhythm often felt and described as palpitations.  
\(^{27}\) Small flexible tube inserted into the chest wall to drain fluid from the pleural space.  
\(^{28}\) Had a flexible breathing tube inserted in the trachea.
percutaneous tracheostomy\textsuperscript{29} performed on him with which he was discharged to the ward. Keith was in ICU for a total of thirty six days. Keith had no significant medical/surgical history prior to this admission. During Keith’s illness, the medical team considered and discussed with Keith’s family the possibility of withdrawal of treatment as Keith’s prognosis was poor with complications meaning a bleak future for Keith. Keith returned home in a satisfactory physical condition (he was self-caring but had a hoarse voice) after spending a week and half on the ward and I conducted the first interview in his home a week after that. Keith declined to participate in the second interview because he was frustrated about his voice which was still hoarse and his failure to sleep at night six months after ICU discharge. However, he allowed me to use the data from the first interview. During the first interview Keith asked a lot of questions, and his wife talked about what happened. Since I was after his story and not his wife’s and following my supervisor’s advice, I repeated the first interview a week later with the emphasis on Keith telling his story.

**Participant 2 – Jason.**

Jason was a 69 year old man who was admitted to ICU following a right haemothorax\textsuperscript{30} due to a leaking aortic aneurysm. Jason was married and lived with his wife in a small country town. Jason was in ICU for four days. He was ventilated for three days. His ICU stay was uneventful. Jason had an extensive cardiac history. He spent five days in the ward and went home in a good physical condition. However, Jason reported having difficulties in concentration and having bad dreams when he went home. I conducted the first interview in his home a week later. He asked a lot of questions about critical illness and ICU treatment including his experience after ICU discharge in the initial first interview. His wife did more talking and I spent time answering questions. Again following my supervisor’s advice, I repeated the first interview a week later. I conducted his second interview eight months later because that was only time that suited him.

**Participant 3 – George.**

George was a 58 year old man who was admitted to ICU with pneumonia associated with sepsis and acute renal failure. He was retrieved from a small nearby hospital where he was intubated and remained ventilated and sedated for three days. DSI commenced on day two. George was in ICU for four days. George lived with his wife. His children were grown up, married and lived away from home within the city. He was discharged home in a good physical condition with full functional capacity. He had continued coughing as that was part

\textsuperscript{29} Airway access surgically made in the trachea.

\textsuperscript{30} Accumulation of blood in the pleural space.
of his chronic condition (bronchiectasis). His voice was hoarse from time to time. I interviewed George in his home a week after discharge from hospital. This fell within the intended two week period after ICU discharge. When I went to conduct the second interview at six months, George's wife informed me that he was back in hospital and that she would contact me when he was discharged. After waiting for a month, I tried to make contact, but I was unsuccessful. George was not contactable thereafter. Even when I sent the transcripts for verification, they were returned to me with a Return to Sender label.

Participant 4 – Rosie.

Rosie was a young woman in her 30s who lived with her partner. Rosie was admitted to ICU following a caesarian section\(^{31}\) for foetal distress\(^{32,33}\). It was Rosie’s first pregnancy. Rosie was in ICU for three days of which two days were mechanical ventilation and sedation days. DSI was commenced on day two. She spent four days on the ward and went home in a good general condition. I conducted the first interview in her home two weeks after that. At the time I conducted the first interview, Rosie was traumatised by nightmares concerning her ICU experience and she felt that things were going to improve after her son was discharged from hospital. Rosie declined to have the second interview. She gave me permission to use data from the first interview.

Participant 5 – Ian.

Ian was a 56 year old male admitted to ICU for metabolic diabetic ketoacidosis\(^{34}\) which was complicated with bilateral pneumonia. Ian was intubated and ventilated for five days. DSI was commenced on day one. He was discharged from ICU after six days and was on the ward for a further five days and went home in a satisfactory physical and mental condition. However he complained of having pain in the left wrist where the arterial line had been inserted. Ian lived on a property with his wife in a nearby rural town. I conducted the first interview at his property two weeks after discharge from hospital. I conducted the second interview seven months later because he was busy with Christmas commitments at six months.

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\(^{31}\) Incision of the abdomen and uterus to deliver a baby.

\(^{32}\) It is a life threatening physical stress suffered by a foetus during pregnancy or labour due to lack of oxygen supply. It is characterised by an abnormal heart rhythm.

\(^{33}\) Excessive vomiting during pregnancy.

\(^{34}\) Build up of ketone bodies due to excessive breakdown of fats as result of abnormal metabolism of carbohydrates in diabetes.
Participant 6 – Moira.

Moira, a 76 year old lady was admitted to ICU after a coronary artery bypass graft (CABG). During her ICU stay, Moira was intubated and sedated. She was ventilated and sedated for eight days. She was heavily sedated for five days and changed to propofol and Fentanyl from day five to day eight where DSI was used. She remained in ICU for ten days. She stayed on the coronary care unit for four days and spent two weeks on the general ward as she lived 400 km away from the hospital. It was during the second week of her ward stay that I conducted the first interview. The interview was conducted at two weeks in the interview room where there was privacy from other patients, visitors and hospital staff. Moira went home with full physical functional capacity but was troubled by memory loss and a hoarse voice. Moira was married with four adult children who are married and live away from home. The second interview was conducted eleven months later because at six months Moira was busy with Christmas and her family and at seven months, Moira lost her husband.

Participant 7 – Alex.

Alex was a 65 year old man who was admitted to ICU following an aorta bifemoral bypass which was complicated by graft thrombosis. Alex had an extensive cardiac history. He was ventilated and sedated with Midazolum and Fentanyl for five days and DSI was practiced for four days. He was awake for four days before he was transferred to the ward. He spent two and half weeks on the ward and I conducted the first interview on the ward in his room as he had a single bed room to himself because of the MRSA infection he had acquired in hospital in the second week of his ward stay. At the time of the interview, Alex was in a satisfactory condition. He could not be contacted by phone for the second interview. He was divorced and lived on a property with his son in a country town 350 km away from the referral hospital.

Participant 8 – Kate.

Kate, was a 60 year old lady who was admitted to ICU following a cardiac arrest. Kate vomited during resuscitation and suffered aspiration pneumonitis. She also suffered cardiac complications. She was ventilated for eleven days and sedated with Midazolum and Fentanyl for ten days and was subjected to DSI for seven days. Kate was transferred to the

35 Surgery creating new routes of blood flow around blocked arteries to supply blood flow and oxygen to areas of the heart beyond the blocked artery. This involved three coronary arteries.

36 Surgical rerouting of blood vessels from the lower abdominal aorta to the two femoral (groin) arteries. around a blocked artery to supply blood to legs and feet.

37 Irritation and swelling of the lungs due to inhaling of fluid.
ward after thirteen days in ICU. She spent two weeks in the coronary care unit where I conducted first interview in the second week of her stay there. She was discharged home in a good physical functional capacity but her voice was hoarse. She lived on a farm. She preferred to have her second interview at the hospital so the interview was conducted at the hospital in a private area following her visit to the cardiologist.

**Participant 9 – Eric.**

Eric was a 20 year old man who was admitted to ICU with chest and abdominal trauma. He was intubated, ventilated and sedated with Midazolam and Fentanyl infusions for five days. DSI was conducted from day two Eric developed post-surgical complications. He remained in ICU for six days. Eric had no significant medical or surgical history. He stayed on the surgical ward for 15 days and went home in a good physical and mental functional condition. I interviewed him on the 14th day on the ward as he preferred to be interviewed there. I conducted the second interview at six months in a restaurant in a corner which was secluded as that was his place of choice. In the second interview, Erick revealed that he had nightmares about ICU. I suggested counseling but this was already arranged by his general practitioner.

**Participant 10 – Maggie.**

Maggie was 23 year old lady who was admitted to ICU for status epilepticus. Maggie was intubated and mechanically ventilated, sedated with Midazolam infusion with a Morphine infusion for pain and other anti-epileptic treatments. DSI was practiced from day two in ICU once it was deemed safe to do so. Maggie eventually improved with some right upper limb myoclonic jerks. Maggie was in ICU for six days of which four days were mechanical ventilation and DSI days. She spent three weeks on the medical ward where I conducted the first interview in the second week of her stay there. She went home in a good general condition. Maggie lived nearby the hospital. She also had a supportive mother who lived in the same town not far from where she lived. At the time I conducted the second interview Maggie was living with her parents.

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38 Seizures that last for 30 minutes or longer or two or more seizures that occur in succession of each other without regaining of consciousness.
39 Brief shock-like jerks of a muscle or groups of muscles.
Participant 11 – Liam.

Liam was a 71 year old man who was admitted to ICU post operatively following laparatomy for a hernia\(^{40}\). Liam was in ICU for three days and was ventilated and lightly sedated with Midazolam and Fentanyl infusions for two days and DSI was conducted from day one in ICU. He was transferred to the high dependency unit and was treated for hypernatremia\(^{41}\) for two days. He spent two days on the surgical ward and went home in a good general condition. Liam had no significant medical or surgical history and that was his first hospital admission. I interviewed Liam in the first week of his stay at home. Liam lived alone in a nearby town. He had a son who worked with him in a family business. I conducted the second interview at eight months in his home.

Participant 12 – Monika.

Monika was a 41 year old woman admitted to ICU following a motor vehicle accident. She sustained multiple injuries. Monika remained intubated and sedated with Midazolam and Morphine infusions for four days. DSI was practiced from day two. She was transferred to the ward on day six. She stayed on the surgical ward for a month and half and I conducted the first interview in the second week of her ward stay. Monika had no significant medical or surgical history. She worked locally, lived with her partner in town and her parents. The second interview took place in the ward seven months later as Monika had been readmitted for more orthopedic surgery.

Data Analysis

As a phenomenological researcher I engaged in a dialogue with the data I collected, the literature that was available and the participants' body language I observed in the field all the while looking and sensing for the most common meaning of the experience that the participants were conveying. It is here that I declare the dialogic activities that I was engaged in during the analysis. The dialogue involved reading and reflecting on the individual transcripts, recollecting the participants' demeanor during data collection, formulating themes by highlighting significant aspects of text from the transcriptions, clustering and categorizing the highlighted text, comparing parts of the transcripts with whole transcripts and writing and rewriting - working and crafting the text (van Manen, 1990).

\(^{40}\) Condition in which bowels are blocked due to a loop of the bowel abnormally twists on itself and causes an abnormal protrusion in the membrane that covers abdominal organs. Strangulated means there was constriction of blood vessels leading to loss of blood supply around the neck of the hernia.

\(^{41}\) High content of sodium in the blood.
In order to clear my ‘vision’ of the data I conducted a selective highlighting approach (van Manen, 1990). By using this approach I looked for phrases that stood out and the sentences that were exemplars of the lived experience of critical illness in ICU. I began data analysis as soon as I started collecting data. The process of looking at individual transcripts helped me to guide the subsequent interviews all the while keeping in mind the original research question. Having conducted the interviews and the preliminary data analysis of each transcript, I then looked at the parts and the whole by considering all the transcripts and identifying the recurrent ideas and themes from individual transcripts (comparing commonalities and differences between each participants’ narratives) that culminated into one major theme. Themes are structures of experience (van Manen, 1990, p. 79) which add control and order to data analysis. Recurrent themes emerged which comprised subthemes. Emergent themes allowed me to demonstrate and bring to light the various differences, contradictions and tensions that characterise the participants’ experiences.

The next step I took was to transform linguistic data into phenomenological sensitive text. Constructing linguistic transformation is a challenging creative hermeneutic process (van Manen, 1990) that involved writing generating text and forming paragraphs from the data and my field observations of the participants. To help me construct phenomenological sensitive text, I paid particular attention to chapters about the body, the world as perceived, being-for-itself and being-in-the-world by Merleau-Ponty (1964). I was also guided by van Manen’s (1990) explication of the existentials. I reread van Manen (1990) not only for existentials but also for guidance in the analysis and process.

**Credibility of the Study**

Considerable debate exists between quantitative and qualitative researchers about how qualitative researchers attend to matters of validity (Freeman, deMarrais, Preissle et al., 2006; Trochim, 2000). However, qualitative researchers judge their research based on guidelines pertaining to theory which encompasses the philosophical and theoretical traditions of different communities from which they are developed and practiced (Freeman et al, 2006; Mishler, 1990; Moss, 1996; Scheurich, 1993). These guidelines encompass the formulation of a question, research design, accessing and entering settings, selection, collection and analysis of data and building of a conclusion. To this end Lincoln and Guba (1985) formulated measures to address rigor in qualitative research credibility, transferability, confirmability and dependability. In other words, rigor is a continuous process to which the researcher attends throughout the study and it should be considered in relation to the nature of the study at hand (Freeman et al., 2006; Wolcott, 1994).
Phenomenology has its own way of attending to matters of credibility and understanding such as describing the study population, selection of participants and accurate representation of the participants’ experiences, opinions and perspectives (Gerrish & Lacey, 2010; Moustakas, 1994). Most importantly phenomenological research is judged by the evocativeness and transferability of the experience. Phenomenological research is judged by its accuracy of representation of a facet of the life world (van Manen, 1990). This act of evocativeness and transferability of experience is what is called a ‘phenomenological nod’ or ‘validating circle of inquiry’ (van Manen, 1990, p. 27) or verisimilitude (Holliday, 2002). It is data that evokes feelings of identity to the experience at hand or the possibility of experiencing the phenomenon in question (van Manen, 1990). Hence credibility in phenomenological research is a process of gathering and regathering lived experience which is validated by lived experience and in turn validates lived experience (van Manen, 1990). It is also known as transferability and can also be attended to through thick description of the experience that can match other similar experiences (Gerrish & Lacey, 2010; Munhall, 2007).

Phenomenological researchers attend to rigor by approaching research from a presuppositionless position without fixed or predetermined procedures (van Manen, 1990) and engaging themselves in constant reflection. Identifying research assumptions from the outset of the study and checking and expanding on these throughout the data collection and data analysis also assists with reflection. Reflexivity is also used.

**Reflexivity**

Reflexivity is a process in which the researcher continually reflects on possible nuances such as preconceptions, intuitions, own beliefs, and motives that might cloud their interpretation of the research (Munhall, 2007). I have provided an account of how I dealt with my own assumptions by declaring and acknowledging them earlier in this chapter. To this end, from the time I started my research, I documented my preconceptions, intuitions, beliefs and motives. By documenting these I attempted to ensure that they did not influence the way I conducted the research; particularly during the data collection and analysis process. During data collection, I ensured that I did not ask leading questions to the participants. I ensured that the participants told me their stories from their own perspective by asking them broad questions and instructing them to tell the story in their own words. I clarified the participants’ statements by asking them to repeat or expand on what they said. During data analysis, I frequently moved between the data and the writing to ensure that my own perceptions, theories and ICU knowledge did not affect the way I interpreted the data. I ensured that I
read and reread the transcripts individually and in relation to the others to identify how each one contributed to the whole story and the whole story related to each transcript. I shared the participants’ experiences in such a way that I constantly to engage in the ‘validating circle of inquiry’ (van Manen, 1990) by checking that I did not write what I felt but what the participants felt. I also took breaks from writing whenever I felt I was being overtaken by emotions.

**Member Checking.**

Member checking, confirming and disconfirming is fundamental to qualitative research which is achieved by confirming with the participants that what is written represents what they meant and experienced (Munhall, 2007) is a way of attending to credibility. For this reason I sent transcripts of the interviews and data analysis to the participants so that they could confirm and or disconfirm what they said. Only one participant changed some sections of his transcript which he corrected. Because I was mindful of the possible trauma member checking would cause for the participants, I did not follow-up to establish why the majority of the participants did not comment on their transcripts.

**Dependability of the Study.**

Dependability of the study was attended to by describing and elucidating the research process as clearly and as transparent as possible through the decision trail (Gerrish & Lacey, 2010). The audit trail of how I made decisions and arrived at actions in the research process also serves as confirmations of the study. Confirmability of the study was revealed in the link between the data, findings and interpretation of the study (Gerrish & Lacey, 2010).

**Conclusion**

In this chapter, I have provided a description and rationale for the study design, described the research setting and introduced the participants. I explained the methods I used to collect and analyse data. By describing the decisions and actions I outline how each facet of the research process was influenced by and consistent with phenomenological inquiry. I also provided an audit trail for the reader’s judgment of the study's integrity and adequacy by outlining the procedures, processes and ethical considerations made.

I also highlighted how I dealt with my assumptions by discussing my experience as phenomenological researcher and the importance of phenomenology to the lived experience of critical illness in ICU. In addition I have given a general account of my reflections on my
research journey. In the next three chapters, I reveal the data analysis in its fullness. I provide a prologue to the data analysis pointing to the overarching theme of ‘Being in limbo.’ I entitled the first of the three analysis chapters ‘Being Disrupted’ which depicts the sense of life in limbo where the participants felt that life was suspended between life and death as they lay unconscious in ICU. I have called the second chapter ‘Being Imprisoned’ as a continuation of the sense of living in limbo when the participants were awake and discovered themselves in the ICU unable to move, talk or breath for themselves not knowing what happened and what was going to happen to them next. In the third chapter, which I have called ‘Being Trapped’, portrays the state of limbo the participants' experience of living in a changed body. By providing exemplars I have grounded the study and have textually animated the descriptions of the participants in a way that is hoped “speaks” to the readersand prompts them to act with thoughtfulness.
BEING IN LIMBO

PROLOGUE

In the previous chapters I justified phenomenology as the methodology for conducting this study and described the study methods. I described the meaning of phenomenology as a methodology for the study of lived experience and why it was significant to this study of the experience of critical illness in ICU and following discharge. I also described the relevance of phenomenology to nursing practice and scholarship and discussed the key attributes of phenomenological inquiry and the phenomenological view of a person according to Merleau–Ponty (1962/2002). By doing so, I provided a discussion of the framework that informs this study, the phenomenological research methods and procedures used in this investigation and other details of its implementation.

In chapters 4, 5 and 6, I present my interpretations drawn from thematic analysis and grounded in exemplars from the participants’ interview transcripts. The overarching theme that captures the nature of the experience is ‘Being in Limbo’.

‘Being in limbo’, the central theme of this thesis is characterised by the notion of disruption, imprisonment, and entrapment and is represented by these themes and subthemes in Figure 1 below.

From the time the participants were admitted to ICU they felt they were suspended between life and death. When the participants were unconscious and oblivious to what was happening to them, their family members lived with the possibility of their death. On learning about their family members’ perceptions of events, participants realised their proximity to death. Being critically ill in ICU left the participants in a state of limbo where nothing was certain. Not knowing what had happened to them left them surprised, confused and unsure about where they had been, what it had meant and why they had survived and what was going to happen next. Floating as a state of being between consciousness and unconsciousness also marked the participants’ sense of being in limbo. ‘Being in limbo’ was further characterised by the participants’ hallucinations and losing their hold on the world.

‘Being in limbo’ robbed the participants of control over the affairs of their life. They reported being unable to sleep in the same way they used to sleep before their critical illness and ICU hospitalisation. Their new voice was changed and unreliable. Forgetting the traumatic and horrific experience of critical illness and ICU hospitalisation was a struggle for many of the participants. The participants’ lost their sense of self identity and past memories. That they
were often forgetful, along with the lack of sleep and voice, left them feeling in a state of limbo. The impact of their experience and a slow return to health was disruptive. For some, comprehending what they had been through impeded their ability to move forward with their lives and kept them in limbo.

Being admitted to ICU with a critical illness disconnected participants from their everyday world and the time related trajectory that metered and chronicled their life. In the early hours of their ICU experience they ceased to be in the temporal world. They could not perceive time, past, present or future. For them the world was “black”, “blank” and “silent”. Participants were aware that they had, albeit momentarily, a life devoid of experience whilst they were unconscious and, as such, their life as they knew it had ceased. “Time stood still” for them while the rest of the world carried on. This temporal disruption was marked by not knowing what happened to them and not having a bridge between life before they became critically ill and their awareness of ICU. Temporal disruption also disconnected the participants from their family and their sense of bodily existence. This sense of loss left them in limbo; not only unsure about their past but also uncertain about their future. Some of them tried “to figure out” what had happened to them but soon realised that some of their time during ICU would never really be known to them.

Being in limbo denied participants the certainty of a future: being in limbo meant they could only hope for the best possible outcome for themselves. For the participants in this study being in limbo was disruptive and alienating. Their experiences left them feeling vulnerable and fearful of death. As one participant, Moira said:

*It’s frustrating not being sure what will happen next [pause] being in limbo [pause] don’t know when all this will end.*

(Moira 2nd Int.)

‘Being disrupted’ is a state of limbo in which the participants’ lives were suspended between life and death while they were unconscious. I describe the participants’ perceptions of the world while they lay unconscious in ICU through to the time they regained full consciousness in the sub themes ‘being blacked out’, ‘being adrift’, ‘under the shadow of death’, ‘trying to figure it out’ and ‘losing time’. As the participants regained their consciousness some of them described their wakeful experience as that of ‘being imprisoned’.

‘Being imprisoned’ is the major theme presented in Chapter Five, which portrays their sense of death as a possibility and being unable to control their fate. It captures their inability to free
themselves from the physical constraints of being restrained and tethered by drips, tubes and machines. Participants were kept under close surveillance with every activity monitored and controlled by the ICU staff. This chapter also shows how, as with prisoners, the participants found comfort in the presence of their family members in ICU. This chapter also examines how participants perceived themselves as imprisoned by critical illness, the ICU environment and its staff. In chapter five, I explore the sub themes; ‘bound and drowning’, ‘fighting for life/fighting to breathe’, ‘being voiceless’, ‘encountering strangers/being with family’, ‘being at the mercy of others’, ‘being watched’ and ‘being in the dungeon’.

Chapter Six, ‘Being trapped’ is a major theme that shows how life following discharge from ICU continues to be a life in limbo as participants live with the sense of being trapped in time, unable to recall events of their illness, unable to sleep, and seemingly unable to move forward with their lives. Being in limbo in this sense is illuminated by the uncertainty and expectation of the return of normalcy and the existential struggle to regain control and coherence in their lives. Being trapped in time is about; ‘losing memories’, ‘being forgetful’, ‘longing for restorative sleep’, ‘and waiting for the familiar and reliable voice’. ‘The subtheme ‘trying to forget all about it’, captures the participants’ sense of helplessness and being in limbo waiting for the usual self to return while either making the most of their changed circumstances.
Figure 1. Study Themes
CHAPTER FOUR

BEING DISRUPTED

Introduction

In the prologue, I outlined the main themes that emerged from the data analysis and what will be discussed in the following chapters. I also described the overarching theme: ‘Being in limbo’ and how each of the major themes, that are the foci of this and the next two chapters constitute this overarching theme.

In this chapter, I examine the participants' descriptions of regaining consciousness and becoming aware of their surroundings and their situation in the ICU; of the disruption in their life. The participants experienced existential disruption from their everyday life which was caused by their critical illness and ICU hospitalisation. The theme ‘being disrupted’ captures the temporal disruption the participants experience from the time they were rendered unconscious to when they emerged from this state. It also uncovers the social and physical disruption the participants experienced by being removed from their everyday life and family whilst confined to ICU environment and staff. The essential elements of being unconscious, being in and out of consciousness and what that meant for the twelve participants in this study are described.

*Being disrupted* is depicted in the subthemes; ‘Being blacked out’, ‘Being adrift’, ‘Under the shadow of death’, ‘Trying to figure it out’ and ‘Losing time’. These subthemes reveal both the nature of the disruption they experience whilst critically ill and the elements of life in limbo for the participants in this study. The sense of disruption was experienced as periods of being “blacked out” when participants were unconscious. These episodes of unconsciousness and being blacked out created a sense of disorder to the lives of the participants so that they were unsure of where they were, whether they were dead or alive or between the living and the world of the dead. Disruption meant they were suspended in limbo regarding their survival. Perceptions of the world were distorted as participants hovered between states of consciousness and unconsciousness. They were distracted by sights, sounds and events that did not make sense to them. There was an overwhelming sense that things were not right for them. They tried to make sense of the situation they were in by reasoning and ‘Trying to figure things out’ knowing that something in their lives had been disrupted, they had lost a sense of time and events past, they had lost the
everydayness and continuity of their existence. Heightening the sense of disruption, of things not right, was that the environment was devastatingly unfamiliar. As George said:

*I thought, where...//.. am I?..//.. like I say, everything’s clean and quiet it is ‘where am I? It was all foreign to me.*

(George 1st Int.)

**Being Blacked Out**

‘Being blacked out’ captures the participants’ reflections on being unconscious and having no awareness of the world. “Blank”, “black” and “silent” was how they described their experience. They described the absence of sound, time and feeling. There was “nothing”. The world, its objects and others were not known to them: they had lost the ability to commune with the world. The ability to see, to sense themselves and thus see and sense others was taken away from them. Participants described what it was like to lose time (life) as they reflected on their failure to know or remember what happened to them when they were unconscious. ‘Being blacked out’, was how some participants described having been unconscious. It was essentially being ‘absent’ from the world.

*I was blacked out, I don’t remember anything. ..//.. I only thought I was ventilated for four hours for some reason, I don’t know where that figure came from, that I thought I was only asleep for four hours – ventilated for four hours but I was asleep for three days ..//.. I didn’t know what was going on and I didn’t know how long I’d been there and I didn’t know what was happening.*

(Rosie 1st Int.)

Rosie and other participants could not recall their immediate past. Nor could they remember how or why they were in ICU. Rosie described her inability to account for time and what happened to her when she was ‘blacked out’. She expressed her inability to make sense of the disconnected events that led to the situation in which she found herself; it was perplexing that she could have slept for three days.

‘Being blacked out’ was marked by nothingness in that there was nothing known and as such nothing remembered. In this situation there was no dreaming, there were no supernatural encounters and there was no sense of time. For most of the participants, there was only
“silence, darkness and blankness” (Keith 1st Int.). Many participants believed they should have had memories of their critical illness situation, or at the very least dreams or supernatural encounters such as “seeing bright lights or going to heaven” (Keith 1st Int.) or other near death experiences. In the following exemplar, Moira describes the strangeness of not having her ideas realised while she hovered between life and death.

I’ve heard people say they know when they’re unconscious, but I didn’t.../... ‘I thought I would have an experience where I would go to heaven.../... but I didn’t.../... It was strange.

(Moira 1st Int.)

Some participants were “mystified” (Keith 1st Int.) by not having dreams during that time as they realised how far removed from the world they had been. They described how the experience of “visions” (Keith 1st Int.) would have created memories of the time they were unconscious and how that would have facilitated a continuous existence for them. Coming out of the black out without dreams or visions was strange and puzzling. Moira likened her experience to being in limbo without any dreams or visions as she contrasted her previous experience before being operated on for cancer of the ribs with her awakening in the ICU.

[There were] No dreams, no going to heaven that’s strange, because long time ago I had cancer and I was pregnant with my daughter and they’d found it and it was spreading up under my ribs and they said you’ll have to wait until after the birth. So, just before I went into the theatre my grandmother had passed away and she was a lovely little old lady and she came towards me at the end of the bed and said, ‘You’re going to be right, you’ll be alright you’ll see - you’ll be alright and it’s not your time to come. And I got over that and that was - I often think of that, I can remember that. So having had no supernatural experience, it was just as if you were floating all of the time, lifeless, but no experience, no.

(Moira 1st Int.)
Keith was awestruck by being unaware that he was critically ill while he was unconscious;

It's all just went blank .//. I was out to it: absolute blank .//. It was like black - blank. No dreaming, no nothing. No thoughts, no nothing, no vision, no, not a thing. You'd think you would have, but not in my case, nothing .//. you've got no recollection .//. it was all just a mystifying blank. Until I was back in the land-of-the-living you might say .//. From what the wife has told me .//. (cough) .//. I was surprised about it. I was puzzled by it all.

(Keith 1st Int.)

Being blacked out was “puzzling” for some of the participants: in particular while unconscious they did not feel pain and yet pain was inflicted on them, and they should have felt pain from their illness or injury. They did not feel the touch of their loved ones, yet they were touched. They could not hear yet people spoke to and over them. They did not know nor could they remember what happened to them. Their communication with the world was broken. They had existed as unknowing bodies - as ‘inanimate objects’ that were between the world and nothingness.

Once awake, but not alert, they described seeing obscure figures as if they were in a dreamlike state. They were neither fully awake nor were they unconscious; it is in this way that they were in limbo. Some participants talked of “being out to it”, others felt like they were “floating” while others described having had “hallucinations” – living in an unreal world while being in the real world. They were in a transitional state where they were between wakefulness and unconsciousness, which could be likened to the theological definition of the word limbo as a ‘place between heaven and earth where good souls go to rest before finally entering heaven’ (Word Power Dictionary, 2006, p. 560).

All the participants were so perplexed by their failure to sense the world that some of them concluded that they had experienced a kind of death. Kate said, “my mind must have been dead for a fortnight”. Some described having been “out to it” – out of their bodies and thus out of the world. Realising that death was a possibility that was close for them meant they lived under the shadow of death. Coming out of the “black out” where they felt they underwent a sort of death revealed how close to dying the participants had been and how close to dying they still were. They saw others dying and they sensed their own death too.
Being Adrift

‘Being adrift’ describes participants’ experiences of semi consciousness or hallucinating and not having a complete hold on the world. Some participants emerged from their unconscious state and were immediately aware of what was going on around them. Others experienced a sense of drifting between sleep and wakefulness or being blacked out and being in the world. Most of them had no clear appreciation of the world when they were in this state of semi consciousness. They were juxtaposed between nothingness and the world, aware that their lives had been disrupted in some way.

Some participants described their state of semi consciousness as being in and out of the world or floating. Most of them could vaguely see what was going on around them as in a mirror or a dream. Their surroundings and people (family, medical and nursing staff) were distorted figures. George described being suspended between reality and unreality as follows:

You know like ../.. you see those mirrors that are rounded and people look at them and your face distorts, I remember Chantelle [daughter] coming to me and she got really close ../.. And then she did that a couple of times. Like it was strange [sic].

(George 1st Int.)

At that stage of their ICU stay, some participants could not hear or feel anything but they could see. They saw people floating around in the rooms they occupied and they felt themselves floating off. For them, not being able to clearly perceive the world was an experience of being partly blacked out and partly being-in-the-world. Most of the participants found the state of being semi-conscious “weird” (George 1st. Int.).

Some participants did not know whether seeing people doing procedures on them and not being able to feel their touch during the process made them wonder if it meant that something was terribly wrong. Some of them were confused by seeing people talking to and around them and not being able to hear what they were saying. They described having brief encounters with awareness and of their surroundings as being in a dreamlike state. Jason described his state of hovering between consciousness and unconsciousness as follows:
It is just a thing that you go in and you get a little or big conscious and you think, 'oh yes.' You are not actually aware of the whole surroundings [sic], you’re only aware of whoever, or you don’t even know whoever or whatever, but they’re doing something for you and you’re just a little bit aware of that and then you float off a bit, you know .//.. And then you’re not really aware of a lot of things, some would say I don’t know if that is the norm or if you’re supposed to be that way or you feel so completely and utterly out of it, was I in too much of a coma? I’ve got no idea, but I sort of, like I said, I didn’t feel any pain, I didn’t feel anything very much, you know, I was aware of people floating around doing things.

(Jason 1st Int.)

For Jason, the brief encounters he had of being aware of his surroundings helped him to feel safe and cared for. In particular, he remembered a woman brushing his teeth.

when I was in the dream-like state or the state that I was in sort of thing, but not knowing anything every now and then I have memories of a nice lady who brushed my teeth for me. Every now and then there must have been someone there that did something for me when I came out and I thought, that’s nice, but I felt so taken care of and safe.

(Jason 1st Int.)

Unlike Jason, being between the black out and the world was bewildering for other participants. Some participants remembered hearing and seeing things that were not real. In contrast to Jason, they did not feel safe and cared for.

Some of them could see things and hear sounds. Their hallucinations evoked feelings of uncertainty, doubt and ambiguity. The participants who had visual hallucinations described their experience as being in a world where everything was predominantly red. Some spoke of having been frightened, finding it unbearable. Moira thought the doctor and the nurse had sewed her lips with red cotton. She was frightened. She said:
I thought my lips were – that’s what it felt like, that my lips were sewn up - they weren’t, but I thought it was with red cotton and why red, I don’t know, but that’s what I thought. And I had seen the nurse that was on and the doctor that I had seen when I was coming to and they frightened me because I thought, ‘they’re the ones that have done this to me’. I must have been in a daze.

(Moira 1st Int.)

Monika’s transitional state of between reality and unreality was marked by unbearable hallucinations:

And everything was red! I had red Zulus dancing for me in the (pause) – you know with their rings and their spears. They were dancing for me in the room. [Laughs timidly] Ha! ha!– spiders and people peering in the glass and I couldn’t stop mopping the floor but the floor just wasn’t vinyl, it was pavers with chip-bark and I was mopping all the chip-bark off the red pavers and sticking the red mop in the corner with the other mops I had a collection of about half a dozen mops in there and vacuum cleaners over here, (but I didn’t use the vacuum cleaners) and I’m thinking, what am I doing, I’m not cleaning, I’m in my bed. So, yes and then I was seeing spiders and things and but everything, all the visions were red, everything was bathed in red and I thought – I can’t have this stuff no more.

(Monika 1st Int.)

Other participants experienced misperception of things and sounds. Ian was convinced that the red lights he saw were red Christmas trees or fairy lights. He also thought he heard a baby goat crying and that somebody was slaughtering it for a bloody ritual. Ian was most especially distressed about the baby goat’s death so much that (sensing his powerlessness to save it) he asked the doctor to intervene on his behalf. Here is how Ian described his experience:
All the red lights looked like Christmas trees or fairy lights. So I actually went back to thank the staff there a few weeks ago and I asked them to look at this thing so that I could see what it was and it was just red lights. Another thing I remember is, looking down the corridor, I kept hearing this what I thought was a baby goat (because I had a baby goat, so I know what they sound like) and I thought that they were slaughtering it and all these people kept going into the room and I’m thinking, oh no, they’re going to kill the goat for some sort of bloody ritual. And I got the doctor and I said to her, ‘tell them not to kill that goat.’ And she said to me, ‘there are no animals in this hospital.’ I said, ‘there’s a baby goat in here.’ It was a baby alright, but not a goat – a newborn child. But that’s what was going through my mind.

(Ian 2nd Int.)

As the participants regained consciousness, they were overcome by the pervasive presence of death. They sensed their own death, felt they had just escaped death and they were bewildered by witnessing other people dying. They lived under the cloud of death.

**Under the Shadow of Death**

*There was one night a doctor’s husband died. He had a heart attack, they rushed him in. The whole place was erratic, you know and I hardly slept at all that night ..//.. I should have been dead too, but they brought me back and they looked after me.*

(Kate 1st Int.)

Here the state of being in limbo was marked by being at the edge of life where the participants’ sense of death was heightened. The participants described being blacked out as having been ‘dead’ and they recounted how they felt the nearness of their own death when they saw others around them dying. Not only did they feel the pervasiveness of death, but they also described being “saved” from dying by the ICU staff. In the following exemplar George demonstrates his surprise at how much his life lay in limbo between living and dying;
Learning about his resuscitation, made George, realise how he lived at the edge of life with his survival uncertain in the ICU. Not knowing the events about the time the ICU staff resuscitated him was unimaginable for him. He could not imagine or understand how he could not have felt the ETT being passed down his throat. The only explanation he could attach to his experience was that he was ‘dead’ at that time. Having concluded that he had “miraculously” escaped death, George realised that for him, death was a situation that could not be felt or known.

In contrast to George, Keith expected that a near-death experience would lead to a transition from living in the world to the supernatural realm. Surviving, living under the spectre of death without supernatural encounters was a mystery that bewildered him. Although they were mystified, participants responded differently to the stories about the time their lives lay in limbo when they nearly died.

I know I come close to passing away, but I didn’t see any white lights or anything like that – there was nothing. I didn’t even know that had occurred – no idea at all. So if it happened, I wouldn’t have even known ..../.. Which is a bit annoying in some respects. I can’t add much to it at all - no recollection at all and yet I recovered from it ha! ha!. I was sort of mystified.

(Living under the shadow of death evoked a sense of uncertainty about survival; it kept participants in limbo, between life and death. They were surprised to find that they had plastic tubes of all shapes and sizes that emerged from various parts of their own body. The presence of intrusive objects like tubes, coupled with not knowing what had happened to him, left Erick in limbo when he thought he was going to die:
I woke up with that tubing down my throat, ..//.. must have just woke up out of it and with this thing stuck down my throat, the tube, I just freaked right out, 'cause I didn't know how it got there ..//.. I could feel that I was going to die ..//.. Couldn't breathe. I don't know. I felt like I was going to die ..//.. I couldn't handle it, ..//.. it really freaked me out. ..//.. the tube down my throat ..//.. the hell what happened to me. What was I doing for six days you know, what was going on, what was happening for six days while I was asleep. That's all ..//.. Like I was dead you know what I mean?

(Erick 1st Int.)

The unnatural presence of things such as an ETT invoked fear as George said: “I didn’t like that thing in my throat. Well it was foreign. Like you know it shouldn’t be there. So I was afraid I was going to die.” He and Kate were mystified in that although death was pervasive and they felt and sensed death, they did not die, instead they survived.

I was shocked to find all sorts of tubes coming out of my face, my arms, chest [pause] and down below ..//.. gave me a fright thought I was going to die because I didn’t know when all that happened ..//.. My mind must have been sort of dead ..//.. Apparently they packed me in ice and all sorts of stuff. I don’t know any of that ..//.. must have been dead ..//.. but it was strange they [tubes] made me feel like I was dying because I didn’t even know when they went in.

(Kate 1st Int.)

For Kate, being alive meant knowing, being able to sense the world and all that was in it. Being alive meant having thoughts, possessing an active mind that could comprehend the world.

Without hearing, seeing or feeling, some participants were unable to relate to those they loved and who loved them. Some participants recounted how mystified they were when they learned that while they were “blackened out” their families reached out to them. George said: ‘Chrissie [pseudonym of wife] was told I’d be able to hear if they spoke to me ..//.. but no, that is not true ..//.. It's like I was dead.” They described their inability to hear their family
talking to them or at least sense their presence as a kind of death. For them, being unable to relate to their loved ones meant ‘being dead’. Living under the shadow of death cut George off from his family: he could not sense or relate to them. Neither could he sense or relate to the medical and nursing staff in ICU. Similarly, Moira described her disconnection from the world and getting into the ‘twilight zone’ of between life and death as follows: “the doctors and nurses I did not hear them and I was not aware of them working on me when I nearly died.”

**Trying to Figure it Out**

> Trying to figure out how long I was there for and who, who was coming in and out of the room and which, you know, where was I and things like that, trying to figure out what happened in that time when I was blacked out. I didn’t like not knowing what was going on.

(Rosie 1st Int.)

An essential part of most of the participants’ experience of being in limbo while they were critically ill was that of trying to understand what had happened to them while they were unconscious. They did not know and they could not remember what happened to them during that time. They expressed a need to remember how they got to ICU, to know how long they had been in ICU, where they had been before and what they were doing in ICU. They needed to know when and who inserted the tubes in their body. They found the whole situation strange and overwhelming. Not knowing what happened to them left them in limbo, uncertain of what the next day was going to bring. In trying to figure out what happened to them, the participants wanted to re-establish control of their everyday life.

George described waking up and being astonished at the situation he found himself in. He said:

> … what actually happened to me how did I get here? I didn’t remember being in hospital I don’t remember, I can’t remember intensive care. I opened my eyes. Why? What? What happened to me? Why and when did I get here? Like when I came to in ICU, I had a tube in my throat. The actual getting in there, I don’t remember a thing. I honestly couldn’t remember it and I was going why is this thing in my throat? Like I said, catheter, I didn’t realise
that was even in there until I felt like I wanted to go to the toilet and when the girl came back and I realised I had the tube down and I said to her then, ‘when did that get put in?’ I had another one here on my neck. I had tubes running out of me everywhere, My daughter was saying, when I was in intensive care there was a woman in there and she had a tube down there sucking the phlegm out of me, but again, I don’t know anything about that. I didn’t even know I was in a coma. Well actually I don’t remember being in a coma ..../.. Just weird.

(George 1st Int.)

Most of the participants were unsettled by not knowing and not remembering what had gone on or how things had happened to them. For some of them the need to know was paramount as knowing meant living, being in control and remembering. Most of the participants did not like not knowing and not remembering what happened to them: it interrupted their existence and disconnected them from their past and future. Others preferred not to know about their critical illness and their treatment. Those who needed to know struggled as they tried to find out what happened to them. Not knowing was distressing and disempowering. They needed to make sense of their experience. In trying to figure out what happened to them, they were puzzled, not only about their inability to know and remember but also the disbelief that such things had happened to them. They called their experience “a mystery” (Keith, 1st. Int.) and their recovery “a miracle” (George, 1st. Int.). As George said; “I came close to passing away but they brought me back. It is a miracle that I am alive.”

In reflecting on his inability to remember, George concluded that he had been vulnerable to being abused during that time. He said: “I felt pretty vulnerable and I thought ..../.. like somebody could have belted me or done anything to me, like I wouldn’t have known.” The fact that George had undergone procedures that would normally be painful without his knowing was difficult for him to comprehend. He said: “I don’t have any recollection of pain or anything and that was the thing that really had me [pain] when I did come to.”

Rosie tried to understand who was with her and what was happening to her when she was blacked out. Not knowing, for Rosie, was more about losing control over her relationships with others, such as not being able to know and choose who went in and out of her room. She regarded her inability to see, hear, feel and know what was happening as unusual. She said living, by definition, means making decisions, knowing what is happening and making memories:
…but the central line, I didn’t know was there. I woke up and didn’t know how it got there and I woke up with the things in my face and I didn’t know how they had got there. So I’ve asked John [pseudonym of partner], when did that happen? I don’t remember.

(Rosie 1st Int.)

As was the case with other participants, not knowing meant that Rosie felt vulnerable and that she had missed out on important events in her life. Not remembering meant she could not connect being blacked out with being in the world. She tried to bridge the gap between being blacked out and the world by using her partner’s recollections.

Kate could not imagine a tube being passed down her “throat” (trachea) to suck secretions out of her lungs. She did not want to know such details concerning her critical illness and treatment. Kate preferred to dwell on the fact she was alive as she said:

According to little bits and pieces, my sisters and my daughter have told me, it wasn’t very pleasant so I don’t want to know about it. [Pause, hesitation and then eyes welling up with tears] They were using that tube apparently all the time down my throat and one of my sisters said to me, ‘there were big bottles full of gunk that came out of me – out of my lungs ..../.. I’d rather not know anything about it ..../.. they packed me in ice and all sorts of stuff ..../.. Well there’s nothing to tell I just don’t want to know… but I am still alive so that’s the main thing.

(Kate 1st Int.)

However, while others did not want to know and remember what happened to them, Moira had mixed feelings about this for different reasons. On one hand, she did not want to know what happened to her during her time of ‘absence’ (own word) from the world – the extent to which she was sick and how the ICU staff ‘kept her alive’, yet on the other hand, she wanted to know that her family had been present with her. She did not want to abandon them. To Moira, it was a special time to know that she belonged:
No, don’t think I want to remember, because I was so sick they said, and no, that’s a strange question. In a way, I would like to know, in a way I wouldn’t because they had to work so hard on me that I wouldn’t have wanted to know that. But then, I would’ve had liked to have known that the family were there and caring and loving and they’re always caring and loving, but this was extra special.

(Moira 1st Int.)

Nevertheless, a few participants whose ICU experience eluded them wanted to know what happened to them. Maggie was intrigued by the stories others told her about what happened to her when she was in ICU. She regretted that her family had not taken photos of her when she was critically ill. She thought the photos would bridge the gap between her life before and after her ICU experience:

Yeah I’m actually, I think that everything about intensive care, I haven’t had any problems. I’m quite intrigued by what happened in intensive care. I would like to know more about what happened when I was in intensive care. I think I’d like to know more about what happened in my stay in intensive care. I know it probably seems a bit morbid but I’d like to have had photos taken so I could see to prove I actually looked like that because people would tell you stories about what you looked like or you had those breathing tubes down your throat, but you can’t believe it until you actually see it for yourself, so it would be interesting to know.

(Maggie 2nd Int.)

Keith did not want to remember either. What he was told and what he experienced when he was awake was enough to make him choose not to know. For him not knowing was better than knowing everything that he perceived as so unpleasant:

Why rack my mind about it? From what I have been told, if I’d been conscious in any way at all, I wouldn’t have been too happy about it, but being oblivious to it all, all the better. What happened after that was bad enough. Can remember almost every day taking blood and things like that and sticking needles in you and ah. And
the tracky [with reference to the tracheostomy tube]... changing that and doing that...Those little things that annoy you. When you’re conscious, you’re thinking I don’t know what they done when I was unconscious, but I’m pleased I was. Sticking tubes in you in one hand and in the other and things like that. So, I’m glad I wasn’t aware of it.

(Keith 1st Int.)

Losing Time

Losing time depicts the continued sense of existential disruption the participants suffered long after their critical illness and ICU hospitalisation. It differs from the initial experience of being blacked out in that it relates to the biographical disruption that continued to be an absence in the participants’ lives long after they had physically recovered. The ambiguity that went with the period of unconsciousness perpetuated the experience of being in limbo for these participants. Eleven months after reflecting on their inability to know or remember what happened to them when they were unconscious, some participants, particularly the older ones, felt a part of their life had been lost. Some participants described the period they were “blacked out” as “lost time”. Because time is part of how participants live and know themselves in the world, losing time created a sense of discontinuous existence for them. As Keith said:

> It is time stood still: don’t remember the time I went in – time I woke up just seemed like five minutes, but it was weeks. And then the time...no recollection or knowledge of what happened, what transpired, nothing at all. It is all just a mystery. It was all just a mystifying blank..//.. it is time lost.

(Keith 1st Int.)

His life was halted by being blacked out. None of the participants remembered the time they went into ICU nor did they know how long they had been there. Some thought they were in ICU for a few minutes and yet they had been in there for days or even weeks. They were puzzled that they did not know what happened to them during that time. They were surprised to wake up in ICU and find their loved ones by their bedsides, some of whom had travelled long distances to be with them. Ian, for example, was amazed to find his wife and daughter at his bedside when he regained consciousness. He said:
Then when I came to, um just saw my wife’s face and my daughter’s face. I wondered how did they get there because I knew my wife didn’t know where the place was from here even and she wasn’t well herself, so that amazed me.

(Ian 1st Int.)

Most of the participants in this study were acutely aware of losing time - knowing that time had passed without them having any memory of what had occurred during that time. Moira’s loss of time affected her relationships with her loved ones and with others. Losing time meant losing a part of history and hence herself. She could not relate to her family’s stories because she did not share the same experiences and hence memories as others, even though they were about her. She was troubled by not having memories from the ‘black-out’ to share with her family. She could not remember her family talking to her nor could she remember them staying with her by her bedside. Worst of all, she could not remember her grandson cuddling and kissing her. It was the pain of not knowing about, and not experiencing, the care that her family demonstrated to her while she was unconscious that caused her the worst grief.

At the second interview, Moira was still upset when she recalled that she was not aware of the love and care she received from her family while she was unconscious. Most upsetting was the emotional pain she believed she had put her family through when she was unconscious.

I still feel the pain now that they were going through so much and you’re not aware of it, because I know what it’s like to love and then you don’t want that person to be hurt… it’s hard to explain. You know they love you and they want the best for you, but you’re putting them emotionally through pain and you don’t want that, so that’s how I used to … and I still feel sad about that now, that he’s seen me like that and was cuddling me and talking to me and yet I didn’t respond. And I think to myself, maybe it will affect him in later life, so I hope it doesn’t affect him in any way …/... it is strange to lose so much time.

(Moira 2nd Int.)
Conclusion

This chapter highlighted the nature of disruption experienced by the participants in this study. Critical illness and ICU hospitalisation disrupts the continuity of existence. It captures the temporal disruption the participants experience from the time they were rendered unconscious to when they emerged from this state. It also uncovers the social and physical disruption the participants experienced by being removed from their everyday life and family whilst confined to ICU environment and staff. The essential elements of being unconscious, being in and out of consciousness and what that meant for the twelve participants in this study were described.

The major theme ‘being disrupted’ depicted the physical and psychosocial disruption the participants suffered while they were unconscious and in a state of limbo. The participants’ descriptions of disruption revealed the sense of dislocation, disorientation and confinement to ICU. The chapter has also revealed the vulnerability and uncertainty the participants experienced. ‘Being adrift’ describes the isolation and disconnection participants experienced when they could not fully comprehend and participate in relationships and the events that occurred around them. This chapter also highlighted the participants’ perceptions of death. Critical illness brought death near to participants whereby they felt suspended between life and death. The chapter has portrayed how the pervasive presence of death magnified the uncertainty of the participants’ survival. The subtheme ‘Trying to figure it out’ highlighted the participants’ desire to bridge the gap in their knowledge of events that led to them discovering themselves in ICU. The subtheme also highlighted the uncertainty the participants faced about their future. Essentially, being disrupted captures the discontinuity and incoherence associated with the participants’ experiences.

In the next chapter I describe what it was like for the participants to awaken from a state of unconsciousness in the strange world of the ICU, finding they were tethered in many ways, unable to move or speak. I have called this chapter ‘being imprisoned’.
CHAPTER FIVE

BEING IMPRISONED

Introduction

In the previous chapter I highlighted the participants’ the major theme of ‘Being Disrupted’. In this chapter I turn to the participants’ descriptions of their wakeful experience of critical illness and ICU hospitalisation.

*Being Imprisoned* also an element of *being in limbo* highlights the participants’ dislocation and isolation from their familiar environment and their inability to move or express themselves during their wakeful period of critical illness in ICU. The restrictive nature of the treatment and care given to them in ICU and the ICU environment was likened by participants to “Being imprisoned”. Participants described being unable to speak or move; they were ‘imprisoned’ by critical illness; the presence of the ETT tube which meant they could not vocalize or talk; they were often tethered to the bed with restraints and the effects of the medications meant they could not mobilise themselves. Reinforcing this sense of imprisonment was that the ICU staff kept them under constant surveillance.


Bound and drowning as a subtheme, shows the participants’ sense of being imprisoned and being in limbo, in which they were unable to move and unable to breathe as they discovered themselves in ICU. Being bound and drowning evoked a sense of threat to the participants’ life and caused them to ‘fight for survival as evidenced in their struggle to breathe and free themselves from the restraints that bound them to their ICU bed. ‘Encountering strangers/family’ highlight the imprisoning nature of the strange ICU staff to the participants and the liberating nature of family presence to them during their critical illness in ICU. In addition being voiceless highlights a ‘verbal imprisonment’ imposed upon them by the presence of the ETT in the oropharynx. ‘Being at the mercy of others’ reveals the sense of imprisonment the participants’ experience through the loss of control over their life and being maintained and controlled by mechanical ventilators and staff. Their sense of imprisonment was reinforced by the watchful gaze of ICU staff. Being watched left the participants feeling exposed and vulnerable in a dungeon like situation where there were walls with no windows
to the outside world, where time was not accounted for and where uncertainty abounded with strange and disturbing sounds. These elements of imprisonment marked a sense of life in limbo; participants did not know when and if their ordeal would end. As Alex said;

*I call it a dungeon...//.. When I sort of half woke up and looked out, all I still could see was walls, I didn’t even have a window...//.. it would be nice to come out of somewhere and look out the window and think, ah gees it looks like it is raining or a nice day, you know what I mean and then drop back off to sleep ..//.. You’re sort of stuck for a while and you haven’t got anything around you that can indicate to you what day it is...//..and you don’t know what is going to happen next.*

(Alex 1st Int.)

**Bound and Drowning**

*I just can’t stand being tied down. Just not, you know, I like to be free you know. Just waking out of a coma or whatever it is and to be tied down, feels like you’re in prison. No, can’t stand that going on. No, I can’t stand that. Yes. ..//.. Because you’re being tied down...I’m not free, I’m not moving, I don’t feel free, my hands are tied down, I can’t move or – sure anyone don’t like to be tied down ..//.. And that tubing stuck in my throat and I couldn’t talk...//.. just freaked me out.*

(Erick 1st Int.)

Most of the participants emerged from their state of unconsciousness to find themselves in ICU with their arms tied to their bed unable to move. They described gagging violently and wanting to vomit with a tube in their throat that prevented them from drawing their own breath. With the tube in their throat they were voiceless and could not call for help. They felt like they were being ‘suffocated, strangled and drowned’ (Rosie 1st Int.). Sometimes this feeling of imprisonment evoked in them a powerful instinctive response to fight against the restraints on their arms in order to free themselves and save their own life. They couldn’t move to pull out the ETT. Scared, they felt helpless and uncertain about their survival: they thought they were going to die. Monika expressed her state as follows:
I wanted to get out and get up and I wasn’t going anywhere. I thought what am I doing tied down? How come they’ve tied me down?..//.. Just helpless..//.. I felt like a log and I just was scared, I thought I was going to die. I didn’t know if I was going to live, pull through or die, because I thought I can’t move ..//.. I just didn’t know whether I’d pull through or not.

(Monika 1st Int.)

The subtheme ‘Bound and drowning’ reveals the participants’ struggle to breathe with the ETT tube “stuck down their throat” (Kate, 1st Int.). Their experience of ‘being tubed’ was firstly about the intense fear and struggle associated with not being able to pull out the ETT from their throat and secondly about how having the tube meant that they were imprisoned. They were physically, verbally and emotionally bound.

Here the state of limbo is depicted in the participants’ existential struggle to survive as they lived at the verge of death. For most of them, the struggle to extricate the ETT from their throat, which made them gag and feel like they were suffocating, was an overwhelming and frightening departure from the taken-for-granted life in which moving ‘just happened’. The following exemplar highlights how the participants were engaged in a struggle to hold on to life while at the same time sensing death. This was intensely shared by Kate who said:

I was tied down in the bed…It was hard for me to get that gunk out of my belly and I wanted to be sick. I kept… well ..//.. I started to fight it. It was worse than having a finger at the back of your throat and trying to get it out. It was a horrible feeling to have something stuffed down your neck.

(Kate 1st Int.)

Rosie described being ‘Bound and drowning’ as being stuck out on the water. Being drowned was being without air and feeling like being strangled, suffocated and gasping for air to breathe. For Rosie and others, drowning was being strangled by the tube that was in their throat. Being stuck [out] on water, “they were left abandoned in a dangerous place beyond reach, beyond help” (Rosie 1st Int.). The experience of being bound and drowning was scary for Rosie and other participants. For Rosie the drowning experience was not only the suffocation but also the unnatural presence of vomitus in her hair, face and down her neck, and the burning sensation that she experienced in her nose while she was lying flat on
her back. She felt threatened and scared. Rosie described being alive and sensing death beckoning and struggling to evade it, she said:

The first thing I remember was the tube in my throat. I was vomiting: I was flat on my back and vomiting and I've got a face covered in vomit, my hair's covered in vomit, I had vomit going up my nose and down the back of my throat and it was burning and I couldn't breathe... felt like I couldn't breathe, so I was very panicked there was things in my mouth and laying on my back and vomiting and that was really scary...I couldn't see, I couldn't move... there's something in my throat that's stopping me from getting air and then there's something tying my hand down so I can't pull out whatever is in my throat. So, it just adds up to this whole panic cycle, where I can't move, I can't pull it out.

(Rosie 1st Int.)

For a few participants, the tube did not make them gag neither did they recall being suctioned. Nevertheless, they were frightened by its strange and obtrusive presence in their throat. The tube's strange, unexpectedly disfiguring, uncomfortable and disabling occupation of their body evoked a sense of insecurity and fear of the unknown. George best described that experience when he said:

It was pretty frightening... there was this thing in my throat – I had not expected to see a tube hanging out of my throat. And then when you realise you've got this thing stuck in your throat and you think, why is this thing in my throat? I could feel it at the back of my tongue, it was a plastic thing and very uncomfortable... Didn't stop me from breathing or anything like that. It sort of had my tongue pushed forward, I think the tongue was swollen, I couldn't swallow, it was false, like you knew you had something that shouldn't have been there, it was really foreign... It's just very strange... it was all foreign to me. I didn't remember going in and I've come to and I've got this thing in my throat. And I'm shaking my head... because of this thing in my throat and it is pretty frightening, I thought I was going to die.

(George 1st Int.)
The foreignness of the tube, together with some participants’ total incapacity and inability to do anything to overcome their terrible predicament made them think they would die. While most of the participants in this study were frightened by being invaded and maintained by machines, others were not frightened but they were frustrated. Being frustrated emanated from being deprived of control and power to maintain their own lives and to relate to the world in the way they had always done. The presence of the ETT and tracheostomy tube in their throat had turned their world upside down. The unusual and uncomfortable presence of the tube drove some of the participants to desperation as was the case with Keith:

The only thing I wanted to get out was the tracky – I was desperate to get that out... the thing stuck under the neck there was annoying. You’ve got to persevere with it. ‘oh, ok.’ You’re stuck with it. And it stays. That’s it. I was stuck with it and just had to contend with it. I wasn’t frightened or anything like that, not in the least. Knew it must be some medical reason.

(Keith 1st Int.)

Keith was very annoyed by the tube – the tracheostomy tube that was stuck in his neck. He was desperate to have it out of his throat but the ICU staff would not remove it for him. He was powerless and he had lost control. Even though he knew that the tube was there to save his life, the disability, desolation and the discomfort it caused drove him to desperation.

Although most of the participants felt imprisoned and frightened by the tube, two participants did not remember having the tube in their throat. Both its presence and its disabling consequences eluded them. For instance Ian said:

I was unconscious ../.. and when I came out, the things in my throat were gone ../.. Everything was gone.

(Ian 1st Int.)

Whether they were intubated or not, the participants felt confined by the ICU staff and the technology. They were removed from their everyday world and confined to the ICU room. There was only lying on a bed and staring at the ceiling with the occasional interruption of people leaning over and talking to them. For some, that experience was frightening. Their world had constricted to the ICU bed from which they could not separate themselves. That kind of existence was different from the way they knew their everyday life:
I was laying flat on a bed. I don’t think I even had a pillow there. And I knew I was in trouble by the ward I was in and the guy was sort of leaning over and talking to me and then when I went to talk ..//.. I just couldn’t talk ..//.. I say it was pretty frightening I thought I was going to die.

(George 1st Int.)

In their predicament, they had lost control and were helpless. Rosie explained it as being submerged under water without any help at hand. The fact she was bound meant that she could not “swim to safety, could not wave her hand or scream for help nor could she stand on solid ground to catch a breath” (Rosie 1st Int.). They were fighting for life – for breath.

**Fighting for Life/Fighting to Breathe**

‘Fighting for Life’ elucidates the descriptions and the meaning the participants attached to the experience of trying to save themselves from the life-threatening events that they faced in ICU.

_The tube was a big thing ..//.. I couldn’t breathe with it. I wanted to pull it out ..//.. And I kept trying to pull the tube out of my mouth I felt like I just couldn’t breathe with it in there it was gagging me and I just wanted it out. I just wanted to pull it out. I can remember feeling that I wasn’t getting enough breath I thought I was going to suffocate. My fighting spirit kicked in I tried to pull it out._

(Monika 1st Int.)

Fighting for life meant responding with immediacy to an imminent threat of death. For some participants, it meant struggling to get their breath and struggling to get help to stay alive. It meant summoning all their resources to stay alive and not die at that time. The fear of dying sent them into a panic and the more they struggled to stay alive and the more helpless and powerless they felt the more they feared and the more they panicked and thus the cycle went on.

With the tube choking her, Rosie felt vulnerable when she realised that she was lying flat on her back, the tube felt like it was pinning her throat down to the bed and it was strangling her. From that position she could not sit up and cough the tube out or pull it out of her throat.
and she found it hard to breathe. Being breathless and bound was a frightening experience that posed a menacing threat to her life. This was a common experience described by most of the participants. It meant, for them, being trapped by the tube, which was the reason they were tied down. This brought the immediacy of dying to the fore for some of the participants so much so that they instinctively panicked. Panic-ridden, gasping for air, with their arms tied to a bed, some participants were unable to remove the tube that was strangling them … killing them. By sucking away the air they were supposed to be breathing, the tube was taking their life away, compelling them to fight to stay alive.

\[ I \text{ couldn't breathe.} ..\text{//. It just makes you feel like there's something strangling you and that you can't get air in.} ..\text{//. The only thing I can equate it to is drowning, like being stuck out on the water and not being able to get your breath and getting that real panicked.} \]

(Rosie 1\textsuperscript{st} Int.)

Some participants did not attribute their difficulty with breathing to being connected to or being reliant on a machine, rather, it was the unnatural, obstructive presence of the tube that was unbearable for them. The tube brought upon them a crisis that cut them off from the rest of the world, a crisis that they sensed was fast dragging them towards their death:

\[ \text{They had the machine on me that didn't stop me from breathing} \text{.} ..\text{//. But that thing in my throat [the tube], that was full-on – a shocker, that thing. I could feel it at the back of my tongue} \text{. I even though its out now, I could still feel it there, but even just the thought of it was – but no it was ah very uncomfortable, but it was really like a, like it was false, like you knew you had something that shouldn't have been there, it was really foreign, like it was not – this thing was jammed in there, in the back of my throat. I couldn't relate to anybody I really started to get a like not a panic, but an anxious feeling and I thought something bad is wrong. And I thought,} \text{'}\text{what's happened to my throat.} \text{And I knew I was in trouble, I thought I'm in deep trouble here it was pretty frightening I didn't feel real good actually, I thought I was going to die. That's the thing that panicked me a bit. I thought well whatever it is, it's going to come out, this things got to come out, got to get it out.} \]

(George 1\textsuperscript{st} Int.)
For most of the participants, the fight to live was a primordial act that was intensified by the realisation that not only were they deprived of air, but that they were bound and they could not call out for help. They were voiceless.

**Being Voiceless**

‘Being Voiceless’ describes what it was like for the participants to be unable to speak. Speech was a means through which the participants would have been able to raise their fears and anxieties and it is the means through which they could have asked questions about their presence and their predicament in ICU. The notion of being in limbo is also brought to light in the descriptions of not knowing what was happening and the inability to ask questions. Again, the meaning of the experience of being verbally imprisoned for some participants is emphasised. It is also linked to the participants’ descriptions of ‘Being under the shadow of death’ in the previous chapter. Here they described the loss of voice as having fore grounded death for them. In this instance, I seek to clarify what it was like for the participants to find themselves trapped in a body that could not speak.

*When I went to talk ..//.. I just couldn’t talk. And I thought, ‘what’s happened to my throat, like it is – someone’s taken your voice off you. I had a lot of questions to ask, but I couldn’t ask ..//.. You can’t ask a question because you’ve got this thing jammed in your throat and you want to ask, but you can’t ask and no-one’s telling you the answers that you want to know.*

(George 1st Int.)

Being unable to call out or scream intensified the participants’ fears. Without their voice, they could not defend themselves. They were frightened. Without their voice, they could not call out to people to save them. The possibility of not being noticed frightened them. They needed answers but without their voice, they could not ask questions. They could not find out where they had been, what was happening to them, what was yet to happen to them and why they had the tube down their throat. They were afraid that their questions were not going to be answered. Without their voice, they had no means of expressing their distress. Struggling to scream compounded their fear about not knowing what was happening to them and why their voice was not there for them when they needed it most:
Everyone’s saying, you’re going to be alright but I’m thinking to myself, why am I here? And that was the frightening part because I couldn’t relate to anybody. When I went to write, I couldn’t my hands were too weak I could only scribble…pretty frightening, because the questions you want to ask: what happened? What happened to me? What am I doing here? How did I get here?

(George 1st Int.)

Attempting to voice his feelings, thoughts and questions through writing proved futile for George. His arms were too weak to write. The futility of his efforts to communicate and relate to others frightened him, hence death was fore grounded for him. He was terrified at the possibility of dying. He panicked. Other participants described being annoyed and frustrated by their inability to communicate. Some felt isolated. They felt trapped in their dysfunctional body. Keith described losing control and being powerless:

I couldn’t talk, which was unfortunate, I had no voice and was just you know, what I wanted, trying to get my feelings across, but it was difficult. I knew what they were saying, but I couldn’t respond, Body movements and gestures… It was difficult. Knew what the daughter was saying: knew what the wife was saying, but it didn’t mean a great deal to me because I couldn’t respond in any way ..//.. I was very frustrated.

(Keith 1st Int.)

Keith could not voice his emotional distress. The voice was a means of maintaining his relationships with others in the world. As a social being that belonged to and with his family, Keith felt alienated from them. He was very frustrated by the emotional isolation he suffered:

I couldn’t get my feelings across, my emotions, what I wanted to say, I couldn’t get it out and if I mumbled something out, they couldn’t understand it and I couldn’t get the knowledge because they couldn’t understand it and thought, I know what I wanted to say, but she just can’t understand. It was very irritating and frustrating in that respect.

(Keith 1st Int.)
Being unable to express themselves, some participants were unsure and unsettled by the presence of the strangers they encountered in ICU. They were gripped with the fear of the unknown. They struggled to understand why they did not have their voice. Being voiceless, was as George put it, frightening because “it felt like someone had taken his voice off him” and Moira suspected the strangers she encountered. She said:

…and I had seen the nurse that was on and the doctor that I had seen when I was coming to and they frightened me because I thought, they’re the ones that have done this to me.

(Moira 1st Int.)

Other participants shared this experience. They suspected the strangers of having taken away their freedom of expression and disconnected them from their usual world. Being imprisoned meant they were at the mercy of the people around them, those they perceived as having control over them. Some recounted how they felt they had no choice but to endure their suffering and fear for the unknown to happen, others realised that being plugged into the various form of ICU equipment was required to save their life, and as such, they knew it was in their best interests to trust the ICU staff and endure their imprisonment.

I guess you’re at their mercy because they’ve got you plugged into all their equipment and they’ve just saved your life so you’ve got to do as you’re told. So if they don’t want you to turn over, then you don’t turn over because they’re obviously not doing it just to be spiteful, so um you just put up with it.

(Ian 1st Int.)

Without their voice the participants were robbed of their control over their ability to express their intentions. Bodily gestures also betrayed them in that they set off the ventilator and monitoring alarms that attracted the attention of the ICU staff. They felt they were at the mercy of the strangers they had encountered in ICU.
Encountering Strangers/family

‘Encountering Strangers/family’ explains what it was like for the participants to wake up and to find themselves in the company of ICU staff who were total strangers to them and, who were controlling them and their life. Through this subtheme, I share the descriptions of how some participants perceived the ICU staff, their sense of helplessness and imprisonment as strangers took over the maintenance of their life and constantly watched them as if they were a spectacle. I also reveal the participants’ descriptions of how safe and reassured they felt in the presence of their family. A number of participants perceived the ICU staff as strangers whose presence and voices were frightening. This experience was best described by Rosie who said:

Oh, it is a horrible feeling and because none of the voices are familiar. You don’t know who the people are, you don’t know who’s talking to you, why they’re talking to you. It makes it scarier because they’re people you don’t know. I didn’t trust that. It didn’t matter who it was, it was because it was strangers. I like taking control.

(Rosie 1st Int.)

Although Rosie recalled hearing strangers talking to her, she did not remember them ever telling her that she was in ICU and that she was ventilated, or what that meant. They had tied her hands to prevent her from removing the ETT that she desperately wanted to pull out of her mouth. Distressed and terrified, she panicked:

I didn’t understand why no-one around me would help me do that [remove the ETT] and it made me feel very, oh, not lonely but (that’s not the right word) isolated. It is like people stand around and watch but won’t help, that was, you know I couldn’t understand why they weren’t helping me and I couldn’t understand why they wouldn’t stop doing things and wouldn’t let me go and it just made me.. Yeah, all I can remember is just being completely panicked and feeling terrified. It was only when I heard John’s voice that I calmed down.

(Rosie 1st Int.)
Participants described being tied up and unable to move, unable to call out, being unable to breathe and being forcibly moved into positions they did not like. They felt lonely and lost. In their state of distress and lostness there was no one to orient them and reconnect them to their world. They needed the strangers to help them remove the tube from their throat, untie them and set them free. Rosie was terrified by the strangers’ unhelpful behavior, which was baffling to her. She felt isolated, abandoned and helpless. The fear was intensified for Rosie by being unable to see and hear the strangers. She said:

I couldn’t see very well ‘because my face was all swollen ..//.. I couldn’t open my eyes very well, they were sort of quite swollen shut and I couldn’t see who was talking to me and none of the voices were familiar ..//.. It is very scary because I was tied up and I couldn’t breathe and there were things in my mouth and lying on my back and vomiting and that was really scary. ..//.. I didn’t like being there, at all ..//.. and not being able to call out and… why anyone wouldn’t do anything; they’re all just pushing my head down and going, ‘lay still’ instead of helping because it yeah, really horrible.

(Rosie 1st Int.)

Some participants contrasted how they felt in the presence of strangers to how they felt in the presence of their families. They said that family was important and that family provided relief and comfort while the strangers only constantly watched them and did not help them at all.

Maggie was perplexed and worried by the strangers’ social gestures towards her. She did not trust them. She could not understand why they were talking to her. As described in Chapter Four, most of the participants were trying to understand and figure out what had happened to them and were uncertain about their future. The presence of strangers emphasised disconnection from the familiar world. Maggie found it hard to accept them as part of her life in that strange place. She was reassured by her family’s presence. She particularly emphasised the importance of her boyfriend’s presence to her and how distressing and stressful it would have been for her if he had not been allowed to stay with her. She said that without her family’s presence, she would have been very distressed:
So yes, you really worry, you don’t understand and then you see people you don’t know who they are: it is a really worrying problem. And people come in and say, ‘hi’ and you don’t know who they are, whereas if you know the person that’s sitting next to you, they can explain it to you: it is a lot easier.

(Maggie 1st Int.)

Like Maggie, all the participants perceived their family members as symbols of the familiar—a link to their everydayness and thus sources of security and safety.

My sisters were there all the time for me and my daughter. They just stayed with me, kept talking to me apparently. I think that might have been something that kept me going, either that or—I don’t remember listening to them or hearing them but that must have been something there that kept me going and I appreciate it—that’s about all—I’ve started to lose my voice.

(Kate 1st Int.)

Family nullified the impact of the strangers in ICU. As Maggie said:

... It is a lot easier at least to have a couple of people there that you know, kind of permanent, because otherwise it is too distressing ... Yes, family and partner, I know that boyfriends are played down a lot because it is just a boyfriend, but it is not just a boyfriend to a lot of people. Like, we’ve been together for five years but for us, if he hadn’t been allowed in, I wouldn’t have known what to do. I would have really freaked out because we spend 24/7 together and like if he hadn’t have been allowed in, I would have really freaked out ... I would have really, really been stressed out. The situation would have been a lot worse, yes for sure.

(Maggie 1st Int.)

Having awakened in a strange place where they did not know how and when they got there, who took them there and why they were there created mistrust and uncertainty about the future for most of the participants. They found it easier to relate to their families, who were
the only familiar aspect of their experience, symbols of their identity and their freedom. Their families connected them to world in which they belonged; their presence was a sign of continuity of their world in a place where they felt they could not trust anyone. They needed to feel safe and reassured, to have explanations about their critical illness and their treatment. They became anxious in the presence of the ICU staff and they feared for their lives.

Erik became defiant towards the nurse who tried to stop him from biting the ET tube. Without his family he felt the nurse who was stopping him from saving himself could not be entrusted with his life. Like other participants in this study, the circumstances under which he encountered strangers were unusual and frightening. He described his mother’s calming presence:

When I woke up must have just come out of it...//..And I couldn’t see no-one that was scary. I didn’t know where everyone (his family) was. There was a lady there who tried to tell me to stop biting it [the tube] and I freaked out going, ‘No, who are you, I don’t even know you. What are you doing there?’..//.. Because I didn’t know her and I thought, ‘what’s she doing?’ I just wanted to get the tube out ..//.. And then my mum came. I remember seeing her face and it calmed me down a bit. But, still with the tube there I was still freaking out. Yeah, well it was, because if I didn’t see my mum there I don’t know what would have happened...

(Eric 1st Int.)

Although some participants initially felt imprisoned by, and frightened and suspicious of the ICU staff, they later found their presence very calming. For instance, Moira was initially frightened when she emerged from her state of unconsciousness, thinking her lips were sewn together. But her anxiety was soon alleviated by the reassuring conversation of nurses and doctors who comforted and calmed her:

[I was] very frightened, when I came out of it and felt my throat, because I thought my lips were stitched and didn’t know why! But it wasn’t it was the tube..//.. And I was a little bit frightened because I thought I’d never walk and never talk again. I thought, ‘this is not going to be any good.’ And then the doctor started to
talk to me with one of the nurses and told me that I would be alright and gave me a little cuddle and I felt calmer.

(Moira 1st Int.)

Despite their varying perceptions of the ICU staff, most of the participants longed for the freedom to do things as and when they wanted to. They felt disempowered and ‘at the mercy of others’.

Being at the Mercy of Others

‘Being at the mercy of others’ portrays the restriction some participants experienced the presence of other people during their time in ICU. After the ET tube was removed, the participants’ continued to fight for their lives. The need to quench their thirst was paramount for most of the participants in this study. Moira was thirsty after the tube was removed from her throat but she was not allowed to drink water at that time. She was not told why she could not have the water when she asked for it. She was shocked that she could be denied a basic need such as water when her throat felt so dry. Others now controlled her life and she had to do as she was told. The denial of a life-sustaining need such as water at a time when her throat was parched also emphasised her imprisonment, hopelessness, helplessness and powerlessness:

*I felt my throat and I felt the [pause] I wanted a drink of water.
And the staff said, ‘no, you wouldn’t be able to have a drink of water yet. It was horrible.*

(Moira 1st Int.)

Unlike Moira, some of the participants understood why they could not have water at that time as their nurses had explained to them the effects of having had the tube in their throat. So they knew what was going to happen to them. Nevertheless, that did not take away the desire. For instance, Liam was told by his nurse that his throat was going to be sore and dry but the anguish he suffered without water made sucking ice cubes a very delightful life giving experience for him:

*The greatest thing was to get a mouth full of ice cubes down your throat. They had already explained to me that my throat would be probably sore and dry because there’d been nothing down there*
for a while. That was the least of my worries – a sore throat. They took the thing out on the Saturday morning, they took the tube out and I asked the lass could I have something like ice cubes to suck on, you know and she said she would ask the doctor and he said ‘yes’. That was the highlight of my stay – to suck on some ice cubes. But after a while, that becomes a bit of a, I don't know, when you sit there and you think, this is all you’re getting: And oh, you're not eating anything you can't see the light at the end of the tunnel, when you can't see you're getting anything else so I started to imagine that one bucket of ice cubes were orange mango and the other ones were pineapple. You just had to imagine they were something different but at least they were better than having the tube down your throat.

(Liam 1st Int.)

Although sucking ice was a relief for some participants, they still missed their usual way of tending to their life. They missed drinking the water and other usual beverages. They missed the independence of choosing what, how and when they were going to drink. Water was not the only life-sustaining thing the participants were denied in ICU, they were also denied food. Denied the right to enjoy the food they also liked and missed. They were distressed when they saw and smelt food when they were not allowed to eat. Ian was starving when he saw the night duty staff eating. When he asked if he could have a cracker from the food trolley, he was told that he could not. He said:

I was hungry. I was very hungry, very thirsty. I didn't have a sore throat or anything, on night shift they bring a trolley and it has got full of food, chips and crackers and chocolate and they put it right next to where I was laying and I was starving. And I'm thinking, and watching these people just feeding their face – so I said to the doctor ‘do you think I could have a cracker?’ She said, ‘I don't think so.’ And I went, ‘Well, move the trolley, so I can’t see it’. The food trolley got me.../... Right in front of me and they were just – some of them weren't even eating and I'm thinking, well give it to me because I'm so hungry ../... I lost ten kilos. Ah. Gee.

(Ian 1st Int.)
Not only were the participants denied food and water, but also they were not allowed to do anything without the ICU staff’s permission. For instance, they could not move or change their position in bed unless the nurses allowed them to do so. Ian described being uncomfortable, tired and sore from being in the same position. He had been lying on his back for a long time. His back had started to hurt and they could not turn him to relieve the pressure that was causing all the discomfort and pain he was experiencing. When he tried to move, the nurse stopped him. The loss of control made him feel powerless and dependent on the ICU staff. He felt restricted. This experience was shared across some participants. Not only had their world been constricted to ICU but also they felt constricted in the narrow beds that they found themselves in. Those beds, unlike the wide beds they had at home did not give them freedom to move. Ian gave the best description of that phenomenon:

I had to lie like this the whole time and if I lifted my arms, it sent the machine off, so the nurse came in and said, ‘keep your arms down.’ And I’m going, ‘ok.’ And this bloody things as well. And I was – my backside was really starting to hurt. I wanted to – I did want to move onto my side, but every time you did, they stopped me doing it, you had to stay on your back ..../.. But you really did get sick and tired of laying on your back…um… you would like to move over a bit and – but those beds don’t lend themselves to that, I mean they’re only this wide: they’re only narrow and I sleep in a queen-size bed normally.

(Ian 1st Int.)

The powerlessness, restriction and objectification the participants suffered in ICU was intensified by the watchful gaze of the nurses.

**Being Watched**

Where I was, I felt like a fish in a fish bowl, because I was right in front of the main desk there ../.. I thought they were talking about me at the front desk../.. But I felt like a real gold fish in a bowl because I was in the room right in front of the main desk ../... Because you can’t escape the main gaze of the people at the desk, you’re the first one they see all the time when they look up, ‘cause you’re right in front of them. You feel like you’ve got no privacy. Yeah, I didn’t like being in that situation right in the front
desk there..//..Yeah ..//.. You’re under watch ..//.. They’re watching your every move ..//.. I found that a bit freaky.

(Monika 1st Int.)

Some described feeling “imprisoned” (Erick 1st Int.) by the constant watchful eye of the ICU staff. In ICU the participants felt deprived of their privacy and had nowhere to hide to escape the constant gaze of the nurses and others. The participants who particularly suffered were those whose rooms faced the main nurses’ desk in the ICU. Their rooms were only separated from the main corridor of the unit by a glass wall. That meant that they could see whatever was going on outside their room and likewise, they could also be seen by the people outside their room including those who were just passing by. Monika was so profoundly troubled by the spatial-temporal constriction and her very public exposure to others that she described her experience as that of a gold fish in a goldfish bowl. Monika could see that the nurses were talking and laughing among themselves. Because she could not hear what the nurses were talking about, she thought they were talking about her. She felt like a spectacle and dehumanised. Instead of trusting the nurses, she became suspicious and uncomfortable. Other participants shared this experience, like Liam, who said:

*It was a bit strange..//.. Sometimes it might be in the middle of the night and the girl would be at the end of the bed on her own. Other times I’d wake up and she’d be there talking with the one at the desk beside her.*

(Liam 1st Int.)

Being watched was frightening for some of the participants especially when they realised they were restricted to a narrow bed with no room and freedom to move.

*Here you are hemmed into a bed with bits hanging out of you everywhere and a girl monitoring there what’s going on 24 hours a day you’re not yourself, you’re not in charge of yourself, somebody else is looking after you. At different times I pinched some of those tubes, the little alarms would go off and things like that. I felt a bit restrictive, it was frightening ..//.. Just lay there and put up with it.*

(Liam 1st Int.)
Being hemmed into a bed was a frightening experience for most of the participants. They felt caged in that space with tubes protruding from their body. Whatever movement they made set the alarms off thus intensifying their fear and drawing the attention of others who were constantly watching them. The alarms served as reminders that their life was not their own. They were not in control. They felt trapped in and by their beds and monitors and they felt trapped by the constant gaze of others. They were captured and they had no power to escape.

Liam described how he felt vulnerable and upset by being constantly watched. He stifled his feelings and kept quiet because he feared staff might knock him out, perceiving him as obnoxious. Liam said:

*When you’re hemmed in the bed there with pipes and tubes and everything and you can’t move, there’s not much you can do about it. The people that have got you tied up in that bed, you’re in their care. It is most upsetting but I suppose you’ve just got to sit there and say, ’well, it can’t last forever.’ That’s all, just sit there and put up with it. I thought I was a nuisance anyway being there, had I offered any resistance or opposition to what they were doing, I would fully understand why, if they had a patient being obnoxious, for lack of a better word, they would probably knock them out, getting them out of the way so they wouldn’t hinder anything.*

(Liam 1st Int.)

Not only did being captured in the ICU mean that some participants were subjected to the uncomfortable and constant watchful eye of others, but it also held them in a contracted place which disconnected them from the outside world. Having been *blackened out* and discovering themselves in strange place where they were cut off from their usual world was *unsettling*. Others felt *caged in* while others felt threatened. They could no longer differentiate day from night, one participant likened his isolation to being in a dungeon. The world of ICU was a strange and foreboding place.

**Being in the Dungeon**

‘Being In the Dungeon’ tells of how the participants experienced being in the space of the ICU life world. In this section the descriptions and the meaning of what it was like for the participants who experienced imprisonment through physical and social isolation by being
confined to the ICU room are revealed. ‘Being in the dungeon’ invoked feelings of uncertainty and fear for some participants. They were not sure about their future and when and if they were going to leave the dungeon.

I'm out of the dungeon, that's what I used to call it – the dungeon. [Pause] You know what a dungeon is like? You see it in the pictures, down the bottom of everything the last place on earth. I couldn’t get up and I couldn’t see any sky, I felt like I was cloistered... I’d never noticed myself having been claustrophobic before but this time I really did, you know, and not knowing if you are going to leave or be moved to another place makes it awful if someone said ‘how long do you think you were down there?’... I really couldn’t say how long I’d been there, I could have been there a day, I could have been there two days, I could have been there two weeks. You don’t know. That’s the way I felt any way... To me, like when I sort of half woke up and looked out, all I still could see was walls, I didn’t even have a window... it would be nice to come out of somewhere and look out the window and think, ah gees it looks like it is raining or a nice day, you know what I mean and then drop back off to sleep... You’re sort of stuck for a while and you haven’t got anything around you that can indicate to you what day it is... And that does unsettle you, yes... It did unsettle me, it sort of throws you out of whack a bit.

(Alex 1st Int.)

Alex felt that the social and physical isolation along with the geographical location of the room evoked feelings of being trapped. He was unsettled by the sameness of the colour of his room and the lack of social interaction;

When you look at the whole four walls, the roof the whole bloody lot is the same colour... And that does unsettle you... You feel trapped and when you don’t know when someone you know will come to visit the waiting combined with walls starts to get to you.

(Alex 1st Int.)
For some participants being in the dungeon emphasised their disconnection from their family and familiar noises that characterised their everyday world. The silence they experienced in the dungeon evoked feelings of terror and heightened their imprisonment. George was frightened by the strangeness, silence and the ‘sterility’ of his ICU room. He lived with his wife and always had small grandchildren making noise in his home. He said:

> When I woke up, and as soon as I opened my eyes I thought, where am I? It was all foreign to me. It was pretty frightening. Like it’s just very strange. At home I am used to my grandchildren running around and making noise.

(George 1st Int.)

Unlike George, the dungeon was experienced as a plethora of strange equipment and noises for Liam. Liam had never been in hospital before. The unfamiliar room was a confronting experience for him. He said:

> I had never seen anything like it before so ah, bells and whistles and alarms and instruments everywhere. I think it was quite an experience. And I couldn’t move. The machines and their bells made strange noises every time I tried to move. There was no freedom to move. I just had to lie still. couldn’t wait to get out of there.

(Liam 1st Int.)

The dungeon was the last place here on earth, as Alex described it; a place in which the participants dwelt in ICU before they made it back into their world of freedom where they had power and control over their lives. In ICU, they had felt imprisoned, they were bound and felt as if they were drowning. They had been cut off from the rest of the world, they had fought for their lives, their voice and speech, mobility and control over their life as a whole. They had encountered strangers who had imprisoned them. They were robbed of their privacy and were watched constantly. In ICU they had come close to dying. They felt enormous relief that they had evaded death.
Conclusion

The participants in this study described their experience of imprisonment broadly in relation to technology and the watchfulness of the ICU staff. Being Imprisoned an element of being in limbo highlighted the participants’ dislocation and isolation from their familiar environment and their inability to move or express themselves during their wakeful period of critical illness in ICU. The restrictive nature of the treatment and care given to them in ICU and the ICU environment was likened by participants’ imprisonment within a dungeon like place. Participants described being unable to speak or move; they were ‘imprisoned’ by critical illness and their situation. The presence of the ETT tube meant they could not vocalize or talk; they were often tethered to the bed with restraints and the effects of the medications meant they could not mobilise themselves. Reinforcing this sense of imprisonment was that the ICU staff kept them under constant surveillance.

This chapter emphasises the frightening nature of technology, that it is experienced as exposure, vulnerability and life being threatened. The chapter also highlights the importance of family presence as helping of nullify the fears associated with their experience. The dungeon highlights the profound sense of imprisonment. The participants’ sense of helplessness and powerlessness has also been highlighted. Some of these experiences were confined to ICU while others, such as the ability to speak, continued to plague participants eleven months after their ICU discharge.

‘Being trapped’, discussed in the next chapter, is where the participants describe what it was like for them to feel trapped in a strange and dysfunctional body, and where they long to be free from the sequelae of illness, to be able to move on from being limbo; to regain their former sense of self and equanimity before critical illness and ICU hospitalisation.
CHAPTER SIX

BEING TRAPPED

Introduction

In the previous chapter, I described the participants’ wakeful experiences in ICU in the theme ‘being imprisoned’. In this chapter I share the participants’ descriptions of ‘being trapped’ in a dysfunctional body that was in many ways unfamiliar to them. The participants continued life in limbo as they struggled to regain a sense of their previous and familiar life and identity. The changes they experienced as a result of their critical illness in ICU are highlighted in this chapter. The participants describe their distress and frustration at their inability to remember their past. They describe being forgetful, being unable to have restorative sleep and living with an unfamiliar and unreliable voice. Some participants describe how they move on with life despite their acquired deficits.

**Being trapped** is a major theme that shows the continued existential imprisonment the participants suffered up to eleven months after their critical illness in ICU. This theme shows how the loss of memories past and the loss of memories about their recent hospitalisation suspend them in time as they struggle to make sense of what has happened to them. That they cannot sleep and experience nightmares that depict scenes of their ICU experiences disallows their ability to move on with their lives. The strangeness of their voice following extubation also reminds them of their illness experience and hospitalisation. Unable to recall events and unable to move forward leaves them suspended. All that was familiar is lost however, the way forward is also not yet clear hence the sense of entrapment.

The subthemes; ‘Being without memories’, ‘Being forgetful’, ‘Longing for normal sleep’ and ‘Waiting for the familiar and reliable voice’ depict the elements of ‘being trapped’. Being without memories, being ‘Being forgetful’, ‘Longing for normal sleep’ and ‘Waiting for the familiar and reliable voice’, are subthemes that shed light on the participants’ struggle and their desire and expectation for regaining a sense of their pre-ICU identity.

‘Being without memories’ captures what it was like for the participants to be trapped in a body that was unable to recall their past after leaving ICU. ‘Being forgetful’ highlights being trapped through the difficulties associated with getting on with life when they remained forgetful and had difficulty planning and carrying out tasks. ‘Longing for normal sleep’ portrays being trapped as the participants continued to endure sleeplessness and the
meaning it held for them. ‘Waiting for the familiar and reliable voice’ describes the being trapped through the participants’ experience of having to live with a different sounding voice and one that cannot be relied on when needed to speak. On the other hand, the loss of voice was associated with the loss of memories through which they could represent themselves. Without a voice they were disempowered and, left with an unreliable body as the means by which to represent their identity.

**Being Without Memories**

Most of the older and the two youngest participants had trouble remembering events of their past before their ICU admission. They described how they could not remember who they were and the people they knew from their past. Jason described being vague and able to focus:

> I lost; it seems a big part of my memory. I was very, very vague, you know.//.. I was like that, apart from that, I could not keep my mind on anything. I could not read a book and I'm a great reader, I could not even watch TV or anything because I could not keep my mind on anything, my mind seemed to be, like I was behind the eight-ball all of the time.

*(Jason 1st Int.)*

Lost memories meant that participants were unable to pick up life from where the critical illness and their ICU admission had interrupted them. Most of the older participants and one younger participant anticipated reconnecting with their past when they recovered from their critical illness. Maggie thought her memories were going to be triggered by virtue of being back in a familiar world.

> I've lost memories, so it is frustrating but once I leave the hospital memories are going to be triggered and I'm going to continue living and I'm going to create new memories so, that's what is going to be important from what happens when I leave this hospital ...

*(Maggie 1st Int.)*
Maggie hoped that the creation of new memories was going to overcome the frustration that she felt; that perhaps the fact that life goes on meant that the gaps were going to be diminished over time as new memories were created, in part from the experiences that were not had as well as those new experiences encountered along the way. But it was strange for Moira to have lost her memory especially the happy times that she had once enjoyed with her family. She could not share and enjoy fond memories with her children whom she loved so dearly. The photos that were supposed to bridge the gap between her past and her present at that time could not help. For her, losing memories from the past meant she had lost some fundamental aspects of her being. Moira’s memories of the past experiences that helped to define her, such as raising her children and her continuous existence were at stake. Without her past she was lost both to herself and to the world. She could only move on from the present to the future with reference to her past. The past is what contained the fabric of her being in the world. The events of her past were important because they were what had shaped her. The sense of being alone that she suffered despite being in the midst of her loved ones frustrated and devastated her so much that she broke down during the interview:

*It frustrates me - because I’ve had four children, sometimes I can look at their photos and think, I should remember them going to school, because we had a - we were on a farm, we had a good relationship, we had three children on the farm my husband and I. The other day my daughter was down and she said to me, ‘Oh the pony clubs are going. Did you remember when we went to the pony club and I beat my brothers and got ribbons?’ I said, ‘I didn’t know you were all in a pony club. I didn’t even know you had ponies’. So she sat down and told me the names of their ponies and I could not - could not remember! And it makes me so sad that [emotional moment - sobbing] - that they can remember the things and I can’t. But then they say to me, ‘Mum, we’re lucky you’re alive. Don’t worry about silly things like that.*

(Moira 1st Int.)

Moira could not remember her children’s childhood and her courtship experience with her husband, the happy times she shared with him when they were dating. Again, her family’s efforts to help her remember were in vain as she would forget the following day.
I look at photos (this may sound strange) and I think sometimes I should be remembering that, that was a happy occasion - and I can’t. And the children say (well, they’re adult) say to me, ‘We’ll tell you about it’ and my husband used to sit and say, ‘What do you want to know today?’ And I’d say, ‘I want to know about what we did when we were going together’, so we’d sit for hours and he’d tell me and I’d ask him and I would still not remember the next day, what he had told me. It’s sort of short term and yet other times I can remember, as I say about that little boy, just strange things. The brain is a strange thing they tell me.

(Moira 2nd Int.)

The need to remember and reconnect with friends was important for most of the participants in this study. They needed their friends for support to continue living a social life as demonstrated by Erick:

My mates, they haven't changed since I've been in there. Like, they've all been pretty nice, they're all pretty helpful, which is pretty good actually with all my mates to help me. They're sort of like the only ones I look to, my mates, because they were there through, when I was in intensive care and when I was out of intensive care as well, they were there every day, so I look to them, my family all the time.

(Erick 2nd Int.)

Longing for the past was fundamental to the participants for various reasons but most of all for the purpose of interacting with others and for maintenance of their old self.

Being Forgetful

I can go from here to the shed and forget when I've got down there what I've gone down there for. Long term’s fine, but short term memory is not! I know I'm getting older but it is not like that.[chuckle] Yeah it does bother me, because if I didn't have my own business but if I was working for someone that would not be
very good. [Chuckle] You know they say, ‘Could you do so and so? And you go, ‘do you want to run that by me again?’

(Ian 1st Int.)

Ian’s comment is typical of participants’ descriptions of short term memory loss. Being able to hold on to information was important to them as it was synonymous with being in the world. Ian was concerned that it also would seriously impact on his ability to earn a living, had he not been self-employed. He alludes to the difficulty and possible embarrassment of having to continually ask people to repeat their instructions.

Erick, who was the youngest participant in this study, previously had a well-structured life, always kept his appointments and remembered to do things according to his plans before he went into ICU. He described how he began to forget things after his ICU hospitalisation:

I used to keep appointments but I forget a lot of things now. I forget meetings I’ve got to go to. I just forget all about things I’ve got to do

(Erick 2nd Int.)

As mentioned earlier in Chapter Three Moira was a 76 year old lady who was admitted to ICU after a triple coronary artery bypass graft (CABG) for crescendo angina. She had severe bradycardia and resistant hypotension (low blood pressure) post operatively which necessitated temporary cardiac pacing. Moira also suffered a ventricular fibrillation arrest which was treated by mechanical defibrillation. Moira remained in ICU for ten days. Her past medical history did not reveal that she had underlying cognitive decline. However, after her ICU hospitalisation Moira could not remember a lot of things including her name. She was astounded that she could forget her own name and feared the worst about the possibility of being in public with other people and not being able to remember her name. She had lost her identity – that which made her special. She was horrified by the possibility that she could fail to identify herself on the street. Moira’s account was intriguing:

I had to stop and think what my name was and I thought, you silly old woman, been married 58 years, you should know ..../.. So it’s just strange what does happen ..../.. Well you’re born and you’re given a name aren’t you? And you’ve had that all your life ..../.. Some days, if someone knocked on the door and said to me,
Moira regarded her name as a means through which she related with others in the world. It was also the means through which others related to and differentiated her from others. The name was her identity that was synonymous with her existence – her being in the world. She was, therefore shocked to find that sometimes she could not remember her name on occasions when it really mattered most that she should have remembered her name/herself such as when getting her medications from the pharmacy. She found it strange that at other times she could remember.

Losing memories was not the only deficit that some participants took with them from ICU into their everyday world. They described not being able to sleep and having nightmares that kept them awake through the night. They longed for a day when they were able to wake up feeling they had slept. They were frustrated by the lack of sleep they suffered during and after the world of ICU.

**Longing for Normal Sleep**

You just doze on and off if you’re lucky. And back then ah I’d sleep for a couple of hours and wake up. Once I woke up, I knew that was the end of the night’s sleep. It might be 11 o’clock, 12 o’clock or whatever, I knew I wasn’t going to get anymore sleep that night. And you just lay there all night – for the rest of the night. You knew what was going on around you all the time and think ‘oh 1 o’clock, 2 o’clock, 3 o’clock, 4 o’clock all awake, all the time I just couldn’t sleep of a night time. I lay awake all night – hour after hour. Ah, it was – oh, I was getting desperate to get a night’s sleep. I don’t know why. I’m still the same here. I wake up at 11 or 12 o’clock, that’s it. That’s the end of the Sleep for the night. No more sleep .//.. Just waiting for normal sleep to return

(Moira 1st Int.)

(Keith 1st Int.)
Most of the participants were desperate to sleep. So desperate were they that some took sleeping tablets even though they were told not to. The sleeping tablets proved to be futile in achieving a good night's sleep. Most of the participants attributed their inability to sleep to the medication they had received in ICU and the ongoing medication they were using at home. That was most upsetting for them especially for Keith. He expressed his anguish as follows:

No reason why whether it was the medication or the surroundings or what it was, just couldn't get back to sleep. I just couldn't ..//.. Like last night I think I woke up about half past 12 or something like that ..//.. Same thing I had even when I took sleeping tablets. You take one and I’m lying awake at the same time the rest of the night – no sleep, so no point taking them. I was told I shouldn’t be taking them anyway ..//.. I so desperately want to sleep. Becomes annoying. And you don’t know why. You can’t understand it. ..//.. One day I’ll get back to a normal nice sleep.

(Keith 1st Int.)

In intensive care, most of the older participants could not sleep. Some could not sleep because the people around them were dying. They were frightened to go to sleep in a place where death was pervasive, as Ian said I couldn’t sleep because the people around me were basically dying. For Ian sleeping would have meant going back into the black out described in Chapter Four where death may have caught up with him. Seeing others dying made him sense his own death more profoundly. Yet when he thought he had left death behind and he could now escape the cares of the world and renew himself at night in the security and comfort of his home and bed, he found that he still could not sleep.

Kate attributed her sleeplessness to her inactivity:

I think I’ll sleep better, or I hope I do anyway. And I should be more tired then, as I said, I’m not as active now as I used to be. When I get more confidence in myself and I start doing things that I want to do ..//.. Because I’m not as active now as what I used to be.

(Kate 1st Int.)
Others, such as Moira could not sleep because they experienced nightmares. Yes it has been a while but I still can’t sleep because I still have bad nightmares after all this time and I don’t think I should.

Most of the participants were dismayed to find they could not sleep even after they left the hospital. They spent most of the time waiting for their normal sleep to return. The nightmares stopped them from extricating themselves from the ICU environment:

I can’t sleep. I don’t know why I just can’t go to sleep. I want to but I don’t know whether it is that I did close my eyes and I had my eyes closed for five days. Ha! No, no, I don’t…but I hope I will be able to sleep like I used to again.

(George 1st Int.)

Surviving ICU and going home for majority of the participants meant moving on from the world of ICU and resuming their lives before ICU. However night after night they were reminded of the ICU through the nightmares about their ICU stay that continued to torment them every night.

Rosie’s sleep times were filled with nightmares about her ICU experience and often she would wake up with beads of perspiration and not sure where she was. She would ask her partner to clarify the nightmares as to whether or not they really happened in real life. Rosie’s world changed when she was awake and when she was asleep. The nightmares often took her back to the dark horrific world of ICU at night when she was asleep. Daytime kept her in her normal world of home which was characterised by being awake and being with her partner along with others whom she knew. Daytime was being herself as she knew herself - having control and a hold on the world and doing things that mattered to her, like thinking about her son. She had no power to change the situation and all she could do was wait for things to change and for her usual self to return. The commitment to her sick son was the only thing that kept her going. In the meantime, Rosie continued being distressed by her nightmares that left her stuck in the world of ICU. Rosie narrated her turmoil as follows:

I wake up distressed in the middle of the night and a lot of that’s got to do with, I don’t know what’s real and what isn’t. So I have to ask Peter, did that really happen? Did they really do those things to me or am I imagining it? And he’ll either confirm or deny what
Six months after ICU, Erick was still traumatised by the ICU experience which he relived every night when he went to bed. The nightmares were so profound that Erick lived a life of disorientation to place and of fear and despair. He used to get frightened by the nightmares. Erick, like Rosie, hovered between the frightening world of ICU and the familiar world of his home and his wife. He woke up frightened with beads of perspiration not knowing where he was because the nightmares took him back to ICU and being with strangers. Erick also depended on his wife to put things in perspective – regaining his orientation to the real world of that time. The silence of the night was relentlessly frightening for Erick. It took him back to the sounds of the monitors he endured when he was in ICU. For Erick there may be no moving on from ICU:

_They come in the dreams and I’m waking up with the tubes and being tied to the bed. That’s lack of sleep, like I don’t sleep much, I keep waking up, tossing and turning and getting up through the night../.. I’ll feel like I’m tied down and they’ve got tubes in my mouth and just could be waking up out of a dream and it just freaks me out. I still remember hearing noises. Like I’ll be asleep and when it’s real quiet I can hear like the sounds of the monitors going off, like beep and beep beep. That sort of starts to freak me out a bit, ‘because I had the feeling of back in hospital../.. My Mrs. being next to me, she’s had to calm me down saying, ‘You’re right. You’re at home. You’re not in hospital.’ I just freak right out../.. I don’t know when all this will end._

(Eric 2nd Int.)

The terror of having nightmares was so profound that Erick’s life was significantly changed. Erick was so troubled by the nightmares that he tried to get rid of them by using narcotics and benzodiazepines. But his efforts were futile - the nightmares kept oppressing him. He felt powerless and hopeless. The Erick that survived ICU was totally different from the Erick that went into ICU. From the Erick that was active, outgoing and hard working. Erick spent his time at home doing nothing. He lost interest in his work because he was too tired from not having enough sleep. Erick was so anguished that he could not express himself
coherently. There were pauses mid sentences; the silences were filled with profound sadness. Here is how Eric narrated his story:

I can't get rid of them, they just come. I try and sleep sometimes at night and then it won't -- and that's when I start thinking of it and that's when I can't sleep and its sort of stuffed me up for work, I can't sort of work. I get up in the morning and I couldn't be bothered going to work 'cause too tired, haven't had any sleep from nightmares I've had, so it's sort of -- yeah, everything's sort of... like I hated sitting at home and I hated doing nothing and now I hate going to work, I hate going out. Just changed me completely.

(Eric 2nd Int.)

The younger participants and most of the older participants were plagued with nightmares. Moira for instance, she was suffering from and imprisoned by the nightmares about her ICU experience so much so that she despaired because that was unnatural for her. It was contrary to what she expected when she was leaving the ICU:

Yes it's taken a while but I still have bad nightmares after all this time and I don't think I should. The experience of having to - I woke up crying and feeling and - but my local GP says that that could go on for a while. I don't know - do you?

(Moira 2nd Int.)

Although most of the participants were plagued by sleep deprivation, a few of them were able to sleep. They were able to shut the world out at night and renew themselves and heal from the ICU experience and as such they moved on and freed themselves from the shackles of the ICU treatment and its technology. Ian could not sleep while he was in ICU because people around him were dying but he described being able to sleep once he went home. He said:

I do sleep very well, yeah and I've just recently (well, in the past six months) I sleep in 'till about eight, whereas before I used to get up at six or something and try and keep the work ethic going, but I
thought, I'm tired I want to sleep so, and sleep is what heals the body -- so bugger it, I'm going to sleep.

(Ian 2nd Int.)

Sleep, for participants was seen to some extent as both a means to and a symbol of their recovery. Without sleep they were unable to resume their lives. Some were afraid to sleep because of recurring nightmares. Consequently, they were constantly tired, often depressed and unable to feel safe in the world.

Sleeplessness for some participants is captured in the following poem I composed based on the stories participants narrated about their inability to sleep.

I finally fall asleep

Sleep so sweet and so longed for

My sleep is plagued and stolen by dreams

I go to a place where I am lost

My sleep is lost in nightmares

I cannot talk, move or breathe

I am afraid and I am sweating

I am dying

I do not like it here

I go back to wakefulness

I am wet and lost

I do not know where I am

Tell me I am where I belong

Tell me I am safe.

(Own poem)

For the participants in this study some could sleep, others could not understand why sleep eluded them while others experienced disrupted sleep with nightmares. The participants
shared a longing for the return of their old self. In the absence of sleep they were in limbo. Their sense of safety and certainty in the world after ICU was also compromised by the loss of the usual characteristics of one’s voice; another important symbol of their loss of self and the impact of their ordeal.

**Waiting for the Familiar and Reliable Voice**

So there we are - in limbo. Oh, it is annoying. You know, you’re talking softly and people can’t understand or hear you. You’ve got to sort of repeat yourself and you know that it’s not your normal voice and I’ll get that one day. They say its three to four months (oh God!) but it is so annoying for yourself because you haven’t got your normal voice; you can’t talk normal to people and they can’t understand you a lot of the times; you’re talking too softly. That makes you become frustrated. The wife said, ‘can’t understand what I’m saying or hear.’ Give me time. I’ll talk properly, one day ..//. Hopefully, one day too. I’ll be free.

(Keith 1st Int.)

Most of the older participants in this study had a different voice or no voice at all. They spent a large amount of their post hospital time at least up to the time they were interviewed, waiting for their voice to become normal and reliable again. For most of them, their voices were hoarse and at times were reduced to just a whisper. They felt strange and that they had lost their identity:

Now and then my voice goes and I get very hoarse. ..//. I can go alright but if I talk too much, my voice starts to go very croaky ..//.

But my voice has never really come back really clear. That’s really hoarse type thing ..//. It is strange.

(George 1st Int.)

For the participants in this study, as with everyone, their ability to express themselves through speech in their everyday life is a taken-for-granted attribute which helps to define them. In this study some of the participants were unable to respond to the solicitations that demanded a verbal response as they did in the past. Their pre ICU voice was the means through which they communicated to others their intentions and their feelings through their
tone, their language and their choice of words which they lost as a result of their ICU experience. Following, ICU speech was a challenge and was no longer reliable. Even though they had survived ICU they had a dysfunctional body, a body which was damaged as a result of their experience in ICU. They had to learn to redefine their existence while they waited for normality return:

You can’t talk normal to people and they can’t understand you a lot of the times; you’re talking too softly .//... You just can’t achieve what you want to do. You know you can do it but under the circumstances you just can’t. So, there we are – in limbo. You make an effort and you’re achieving nothing and the more you try, the more annoyed you get with yourself. So it is not like me to be able to try something and not be able to do it. That makes you become frustrated .//... In a couple of months’ time I’ll get my voice back properly – hopefully anyway.

(Keith 1\textsuperscript{st} Int.)

Participants in this study waited to regain their usual voice. They had expected to have their normal voices back by the time they left ICU and the hospital. Some participants were frustrated because they could not easily communicate with others. They found that the desire and the hope they had to be understood, to belong and be themselves again in the world they had always known was shattered.

Keith was ventilated for five weeks in ICU. He had a tracheostomy tube for a considerable length of the time that he was awake in ICU and in the ward before he went home. He had trouble communicating with his family, the nursing staff and other medical staff so much so that he could not wait to have the tracheostomy tube out of his throat. When the tracheostomy tube was removed, Keith found that his voice was different – it was hoarse and at times it was barely audible. He had difficulties communicating with his wife and other people. That made him frustrated and annoyed with himself and with his family. He felt imprisoned. He was stuck in a body that was a body that could not effectively represent him in the world:

I just feel frustrated I couldn’t talk. I felt annoyed with myself that I couldn’t, even though I could make the effort, I Just couldn’t – nothing there. It was just no voice, just a croaking sound. Lips were moving and nothing was coming out. And I get annoyed with
myself. Anytime I try to do something and can’t achieve it, I get annoyed with myself, very much so. Anything I want to do, I like to achieve it and succeed – not be stuck in not being able to do it.

(Keith 1st Int.)

The participants gave up on regaining their pre ICU sense of self as they felt powerless to do so. Among their deficits was the different and unreliable voice which robbed them of their normal voice. The voice was fundamental to their identity. By not having their usual voice, some participants felt trapped by the critical illness and the ICU experience. They resigned themselves to living each day as it came. They were exasperated by the uncertainty about when the strange self was going to be replaced by the old familiar self. The voice was what constituted their being and their identity. It was what connected them to others in their usual world and it was what defined them. The voice was part of their past and their way of being in the world. They felt dislocated and disconnected from their familiar self and others. Sounding distraught with eyes filled with tears, Kate put it this way:

I’ve still got a croaky voice, apparently that’s from the tubes and I don’t know how long that’s going to be before I get my voice back. Well some of them the people that were looking after me in intensive care, they said I’m lucky to be alive, but it might take six months or more for my voice to come back. I just got to go with the flow. That’s all you can do, isn’t it?

(Kate 1st Int.)

Kate’s exemplar represents the powerlessness of the participants over their changed way of existence. At the same time it highlights the uncertainty and state of being in limbo not knowing when they would reunite with their old self.

Most of the participants were frustrated to find that they continued to experience some of the unwanted deficits they experienced due to their critical illness and hospitalisation in ICU. The deficits made them feel different from how they were before they fell critically ill and went into ICU. They had expected to feel better and resume living as they did before they went into ICU as Maggie said, once I leave the hospital people are going to help me ..../.. And I’m going to continue living as I did before.
Surviving ICU was an experience which left most of the survivors in limbo. Most of all, for the participants that had no chance to forget for one reason or the other, such as nightmares, it was something they wished and hoped to forget because remembering stopped them from moving on from the world of ICU. They were waiting for the day when all that was going to be a thing of the past. Remembering meant being shackled to their ICU experience.

Most of the participants in the present study continued being in limbo after leaving the hospital. In reflecting on their experience, most of them decided to move on and make the most out of what they perceived as their second chance at life. They had to resume their self-reliability and ownership in one way or the other.

**Forgetting All About It**

In reflecting on the distressing experience the participants had in ICU during their critical illness, some participants were so overwhelmed they did not want to relive it either in thought or physically. The participants did not want to talk about it. They found that the only way to survive the effects of the ICU was to deny and forget the experience and live as if it never happened. In doing so they found the courage to make sense of their new self and reduce the horrific impact the critical illness and ICU experience had left on them. As mentioned earlier, some participants were shocked by the stories they heard about what happened to them while they were unconscious and when they were conscious in ICU that they maintained they did not want to remember. For instance Keith resolved to take charge of his new life and concentrate on important things in his life such as accepting his new self and being true to himself by resolving to dismiss the traumatic memories of his critical illness and intensive care and get on with life. Here is how he described his resoluteness to self-ownership.

*I've been trying to forget most of it, not trying to think about it. Put it at the back of my mind just get on with things, you know. So, I put it down to a bad experience because I'd rather forget all about it. I don't want to go through that again, in thought or otherwise. No I've been tending to forget all about it.*

(Keith 1st Int.)

Although Keith had resolved to forget about his critical illness and ICU, it was still the past that had become part of his life and as such, he struggled to really forget about it. For instance as mentioned previously, his failure to sleep at night, being sleepy during the day
and having a different voice that could not even be reliable remained a constant reminder of
his critical illness and ICU hospitalisation. Indeed some participants did not have the latitude
to forget their memories of being critically ill and being in ICU. They were plagued by the
physiological and anatomical alterations of their being-in-the-world that were a result of their
critical illness and ICU treatment and this was more profound for the participants who
continued to have nightmares and dreams about their critical illness and ICU hospitalisation.
The transformation left them powerless to change their situation and regain their old self.

That was part of the keeping me alive so you’ve just got to put up
with the consequences. Can’t do much about it. /../ I still feel a little
bit apprehensive about going out by myself in case something goes
wrong, otherwise you’ve just got to go along with the flow haven’t
you. Everybody else is getting used to it so, (chuckle). . I’d rather
forget about it.

(Kate 1\textsuperscript{st} Int.)

Conclusion

In this chapter the ongoing negative effects of critical illness and ICU hospitalisation have
been highlighted. This theme shows how the loss of memories past and the loss of
memories about their recent hospitalisation suspend them in time as they struggle to make
sense of what has happened to them. That they cannot sleep and experience nightmares
that depict scenes of their ICU experiences disallows their ability to move on with their lives.
The strangeness of their voice following extubation also reminds them of their illness
experience and hospitalisation. Unable to recall events and unable to move forward leaves
them suspended. All that was familiar is lost however, the way forward is also not yet clear
hence the sense of entrapment.

The sense of life in limbo is revealed by the nature of ongoing struggle the participants faced
after their critical illness and ICU hospitalisation. The participants were trapped in a body
from which past memories have been erased, a body that could not remember recent
events. It had become a forgetful and unreliable body. Through the participants’ descriptions
the uncertainty and frustration associated with the aftermath of critical illness and ICU
hospitalisation have also been revealed. The participants’ description of not having normal
sleep have revealed the negative effects of critical illness and ICU hospitalisation and the
struggle the participants engage in to regain restorative sleep and the nightmares that
assailed them. How these findings relate to other studies will be discussed in the next chapter.
CHAPTER SEVEN
DISCUSSION AND CONCLUSION

Introduction

The purpose of this study was to describe and understand the nature of critical illness in and following discharge from hospital. It was guided by the question; what is the experience of critical illness in ICU and how does it affect people’s lives after discharge?

In the previous three chapters, I described what it was like for the twelve men and women to have been critically ill in ICU and what their lives were like after discharge from ICU. In Chapter Four – ‘Being Disrupted’ I revealed what it was like for the participants to discover themselves in ICU after awakening from unconsciousness, not knowing what had happened to them.’ Being disrupted’ captures what it was like for the participants from the time they were admitted to the ICU and became unconscious through to the time they awoke to discover themselves in the ICU. In Chapter Five, ‘Being Imprisoned’, depicts the participants’ uncertainty and the struggle to live, their need to be free from threats to their existence and their uncertainty about their survival. Chapter Six concludes the findings section, highlighting the notion of life in limbo for the participants after critical illness. It also explores the participants’ experiences of feeling changed or different following critically illness and their desire for “normality”.

In this chapter I focus my discussion on the notions of ‘disruption’, ‘imprisonment’ and ‘finitude’ or death. The key findings of disruption, the perception of imprisonment along with a heightened sense of death are central to this thesis and depict a life in ‘Limbo’. The discussion of these critical elements is presented here in relation to prior studies and phenomenological concepts such as consciousness, freedom and finitude that help make sense of the experience. The findings of this study show that the experience of critical illness is not only an acute life threatening experience but also an experience that affects everyday life beyond intensive care hospitalisation. Chapters four, five and six, show that the experience of being critically ill in ICU, is complex, confronting, and life changing. It affects the critically ill patients’ fundamental sense of self leaving them in a state of “limbo”. The sequelae of critical illness and ICU hospitalisation highlighted in this study show that surviving critical illness may result in unwelcome changes to an individual’s personal identity or sense of self. Explanation of what happened and why, together with legitimation of their
new self are necessary for participants to understand their experience and to move forward with their life.

The impact of being critically ill in a contemporary ICU imbued with technologically was revealed by the participants in this study. On the one hand technology provides lifesaving measures while on the other it has deprived participants of their volition and humanness. Humanness is replaced with objectification and loss of meaningful contact with others, including their loved ones and the ICU staff. Along with critical illness, technology creates uncertainty, which continued to haunt the participants long after their ICU stay. The objectifying and terrifying nature of the experiences expressed by the participants of this study is consistent with reports from previous studies (Almerud et al., 2007; Granberg et al., 1998, 1999; Li et al., 2011; McKinney & Deeny, 2002; Parker, 1997; Rotondi et al., 2002; Wang et al., 2008; Zeilani & Seymour, 2010). What is new in relation to this study is that

Whilst technology has changed approaches to treatment of critically ill patients in ICU based on improved physiological measures and outcomes, the lived experiences of critically ill patients has not improved according to the findings of this study. While the physiological effects of technology are acknowledged, the negative impact on the lived experiences for survivors of critical illness needs to be addressed with attention given to developing ways to mitigate the impact. There needs to be greater appreciation of the use of new technological approaches for treatment and the impact these might have on the lived experiences of the treatment for survivors.

The verbal and emotional imprisonment that was experienced by the participants who were mechanically ventilated portrays existential suffering resulting from the treatment measures used to save lives and prevent death. Communication difficulties associated with the presence of the ETT highlights the importance of speech for critically ill patients. The social isolation resulting from struggling to make themselves heard and understood by both the ICU staff and their family was devastating for participants. Although, others scholars have described communication difficulties in critically mechanically ventilated patients (Almerud et al., 2007a; Almerud-Osterberg, 2010; Donnelly & Wiechula., 2006; Foster, 2009; Haftondettir, 1996; Happ, 2001, Happ et al., 2004; Happ et al., 2006; Laitinen, 1996; Lof et al., 2008; Rotondi et al., 2002; Samuelson, 2011; Zeilani & Seymour, 2010), in this study some participants, particularly the older participants (George, Kate, Keith and Moira) continued to experience communication difficulties months after their discharge from ICU.

Continued reports of trauma and ongoing psychological and cognitive challenges (Adamson et al., 2004; Ballard et al., 2006; Cappuzzo et al., 2010; Granberg et al., 1999; Laitinen, 1996;
Löf et al., 2006, 2008; Sheen & Oates, 2005; Papathanosoglou & Patiraki., 2003; Roberts et al., 2006; Rotondi et al., 2002; Rundishagen et al., 2002) are of concern because it implies that innovations in ICU practice improve only physical outcomes.

**Disruption**

In Chapter Four, participants referred to the period of their critical illness when they were unconscious as having been *blacked out* and their interpretation of that time as ‘lost time’. I have referred to this finding as existential disruption. The notion of disruption is an existential explication of the theme ‘being disrupted’ which is described in the subthemes of ‘being blacked out’ and ‘losing time’. The disruption suffered by the participants is temporal, spatial and relational.

Being admitted to the ICU with a critical illness disconnected participants from their everyday world and the time-related trajectory that metered and chronicled their life. In the early hours of their ICU experience they ceased to be in the temporal world. They could not perceive time: past, present or future because of their fluctuating state of consciousness/unconsciousness associated with the treatment approach used. For them the world was “black, blank and silent.” Participants became aware that they had, albeit for a short time only, a life devoid of experience whilst they were unconscious and, as such, their life as they knew it had ceased. “Time stood still” for them while the rest of the world carried on without them. This temporal disruption was marked by participants not knowing what happened to them and not having a bridge between life before they became critically ill and their later awareness of the ICU. Temporal disruption also disconnected the participants from their family and their sense of bodily existence. This sense of loss left them in limbo; not only unsure about their past but also uncertain about their future. Some of them tried “to figure out” what had happened to them but soon realised that some of their time during ICU would never really be known to them.

The participants' reports of little or no recollection of their experiences in ICU evoke a sense existential incoherence. The poignant stories of the men and women in this study of momentary and enduring existential disruption raise questions about whether or not innovations in ICU practices are harmful. Improved physical outcomes can only be deemed truly successful if patients not only survive, but are left without emotional scars resulting from traumatic memories of their experience.

Given the strong and consistent reports of harm, ICU practitioners need to find ways of alleviating or reducing the deleterious impact of the experiences on ICU on patients.
That the participants expressed the need to know what happened to them while they were “blacked out” suggests their need for continuity and coherence.

Existential disruption can be debilitating for the rest of the person’s life (Ballard et al., 2006; Jones et al., 2001; Hupcey & Zimmermann, 2000). It is therefore imperative that ICU practitioners provide continued reassurance and reorientation to critically ill patients, through the use of ICU diaries for example. Use of diaries has been shown to prevent the occurrence of PTSD (Bergbom et al., 1999; Egerod et al., 2011; Karlsson & Forsberg, 2008). It would seem, however that listening to the people and garnering the meaning they attach to the disruption is equally important as it may also provide consolation, understanding (Munhall & Boyd, 1993; van Manen, 2002) and healing (Löf et al., 2006, 2008). Although understanding is important, health professionals need to provide care that moves beyond understanding, to acting upon the findings and to search for ways to holistically improve patient outcomes.

The participants in this study had “good physical outcomes” from ICU; however, their experiences suggest that the periods of wakefulness using DSI were distressing. That the participants in this study suffered major negative consequences resulting from their experiences raises questions about the impact of DSI. The participants’ descriptions of “being blacked out” and “losing time” contradict the assertions that DSI provides opportunities for periods of wakefulness in ICU that allow patients to interact (Kress et al., 2000) and prevents complications such as delirium associated with prolonged ICU stay (Ely et al., 2001; Kollef, Levy, Ahrens, Schaiff, Prentice et al., 1998).

Critical illness affects one’s grounding in the world. It threatens one’s historicity and identity. Losing a sense of time past and memories about the critical elements of their illness left the participants in this study uncertain about their existence and their future; they felt vulnerable and disempowered. Their need to know about what had happened to them was an attempt to make sense of their situation and re-establish their confidence and control of their lives. These findings are similar to those of Adamson et al. (2004); Ballard et al (2006); Granberg et al (1999); Hupcey and Zimmerman (2003); Karlsson and Forsberg (2008); Laitinen (1996) and Parker (1997) Roberts and Chaboyer (2004) and Roberts et al. (2006). The concern is that DSI left some participants confused about their ICU experience thus making their outcomes no better than the patients in other studies, such as Karlsson and Forsberg’s (2008), where DSI was not used.

Other participants in this study did not want to know what had happened to them. The variability in the recollection of events and memories questions the uniform approaches used to care for and treat those who have been critically ill. For some participants in this study as
in others (Capuzzo et al., 2010; Granberg et al., 1999; Karlsson & Forsberg, 2008; Rattray et al., 2004; Weinert & Sprinkle, 2008), the denial of the ICU experience may be a form of self-preservation. The use of DSI does not appear to mitigate this. The differences in the responses of the participants in this study is also consistent with other studies (Capuzzo et al., 2010; Granberg et al., 1999; Karlsson & Forsberg, 2008; Rattray et al., 2004; Weinert & Sprinkle 2008), and emphasises the different ways people cope. In addition, the study findings point to the need to recognise that critical illness and ICU hospitalization requires ongoing support and follow up care in the light of these responses.

The notion of disruption does not only pertain to unconsciousness during the critical illness and ICU survivors. It also encompasses a myriad of sequelae such as losing memories of the person’s experiences that they had before critical illness and ICU hospitalisation, and being unable to remember recent thoughts and intentions as described in Chapter Six of this thesis. Whether viewed as positive or negative, existential disruption remains problematic (Needham et al., 2011). It is robs people of their coherence and identity in the world as Bunuel states;

> You have to begin to lose your memory, if not in bits and pieces, to realise that memory are what make our lives. Life without memory is no life at all… Our memory is our coherence, our reason, our feeling, even our action. Without it, we are nothing…

Bunuel in *The man who mistook his wife for a hat* Sacks (2007, p. 25)

Bunuel’s excerpt suggests that memories constitute our being in the world. They are our focal point from which we exist. Our past is the fundamental aspect of grounding our existence; it is the foundation upon which our interpretation of the world is based. It is also the cornerstone of our emotional and physical security in the world (Sacks, 2007, p. 25).

The participants’ struggle to reclaim their identity and the uncertainty they faced about their future resonated with Bunuel’s concern of waiting to lose his entire life, as did his mother. I wondered how it must have felt for his mother when she noticed that she was losing her memories. When I realised that the excerpt was not far removed from some participants in this study, I was gripped with sadness as I read and wrote about the struggle the participants’ experienced and described as they suffered and realised that they had, and were still losing, their memories. It was as if they were approaching the ‘final amnesia’ that was would wipe away their whole life (Sacks, 2007, p. 25). The participants in this study
were aware of what was happening to them and so there is every possibility that even by just listening to them, we could provide some relief which they would otherwise not have had. This is more so because the finding of losing memories after critical illness in ICU in this study is similar to other recent studies (Iwashyna et al., 2011, Needham et al., 2011) even though these studies are more specific to older people aged 65 years and over. In this study both older and younger participants had difficulties with memory and remembering intentions and plans while others had difficulties concentrating (Jason, Ian & Erick). Older participants (Jason & Moira) and one young participant (Maggie) forgot most of their past. For the older participants age related changes and pathology may have been responsible for the poor recollection of events but there was no documented history of cognitive decline for any of these participants.

Although memory loss is extensively documented, there is limited understanding of why it happens (Milbrandt et al., 2010). In this study which was conducted in the context of DSI, two young participants reported cognitive difficulties. The fact that both young and older participants experienced cognitive impairment in the DSI setting means that it is more than just dementia but a greater problem that must be investigated. Furthermore, the increasing data about this problem of cognitive impairment (Ballard et al., 2006; Ehlenbach, Hough, Crane, Haneuse, Carson et al., 2011; Karlsson & Forsberg 2008; Milbrandt et al., 2010; Löf et al. 2008; Parker, 1997; Roberts et al., 2006; Roberts & Chaboyer, 2004; Samuelson et al., 2006; Zeilani & Seymour, 2010) underscores the futility of DSI in this area and urgency with which it should be addressed. It is thus imperative that although older people are more susceptible to cognitive impairment because of their physiological status, younger people (people aged less than 65 years) should also be assessed (Ehlenbach et al., 2011). It could be argued that the cognitive impairment reported by participants could have been associated with physiological events that occurred during their ICU hospitalization, for example Moira’s cardiac arrest which shows that DSI may not improve the critically ill patients’ experience in ICU and following discharge. The participants in this study feared uncertainty and that they did not remember things that troubled them most. They were no longer sure if their dreams and plans for the future. They were tentative, no longer able to live in a taken-for-granted manner.

As mentioned in Chapter Two of this thesis, the future is not founded on daydreams or guesswork (Merleau-Ponty, 1962/2002, p. 416) but it is the horizon of our present which itself is a succession of our past. Here, I refer to the notion of intentionality as the subject matter for these participants. Intentionality itself is founded on the succession of the past by the present, which is also succeeded by the future (Merleau-Ponty, 1962/2002). But one
cannot have a future unless the present recedes into the past and becomes a point from which they roughly behold the future, a phenomenon which Merleau-Ponty (1962/2002) refers to as lines of intentionality that carry our world forward. In this vein, the participants in this study, and many others with critical or chronic illness mentioned in this thesis, had distorted (uncertain) lines of intentionality.

Participants lived in uncertainty as they were no longer sure of their tomorrow. They had lost their sense of security and faith in their body to take them into the future. They were left with a feeling that at any time something could happen just as the critical illness struck suddenly and unexpectedly, they felt they could have no control over the future. The loss, uncertainty and vulnerability that the change imposed on participants placed them in limbo, imprisoned in a body that could not be sure. Being in limbo, they were at the mercy of what the moment or day would bring.

**Imprisonment**

Being imprisoned was associated with confinement in the environment of ICU where the patients found themselves bound and restricted and being trapped in a body that is strange and dysfunctional after ICU discharge. The watchful gaze of the ICU staff exemplified their sense of imprisonment: their privacy and dignity were violated, and they were mere objects or spectacles in the eyes of the ICU staff. The distress associated with being watched highlighted in this study supports the findings of Parker (1997) where participants described themselves as “on show”. Being watched was dehumanizing and objectifying, and evoked fear and anxiety. While most of the participants in this and Parker’s (1997) study felt like a spectacle in the watchful gaze of the nurses, other studies (Laitinen, 1996; Löf et al., 2008) reported patients feeling safe and cared for by merely having a nurse at their bedside. Again this highlights the situatedness and ambiguity of existence. What was distressing for one person was perceived as safety for another. On the other hand, the participants in this study found security and reassurance in the presence of family members. This is consistent with Zeilani and Seymour’s study (2010) in which the participants were composed in the presence of their family, underscoring the importance of family presence in ICU.

The participants’ prison-like experiences raise questions about the appropriateness of DSI. In this study, many participants described their imprisonment in various ways such as “being bound to a bed” (Rosie), “being watched like a gold fish without any privacy with nowhere to escape to” (Monika), “being unable to speak” (George), and not being able to attend to their life as, and when, they wanted. If the use of DSI means that patients must be restrained and that they recount feelings of imprisonment and entrapment then it is failing to deliver on the
improved outcomes it promises. These experiences suggest that constant reassurance including explanations of procedures to patients is essential. In addition, the findings of this study are similar to other studies (Parker, 1997; Zeilani & Seymour, 2010) further highlighting the limitations of DSI.

Being bound and drowning’ in this study is supported by other studies (Granberg et al., 1999; Löf et al., 2008; Parker, 1997) whose participants described being unable to move (Löf et al., 2008), being tied down (Parker, 1997), and trying to free themselves from restraints and fighting the ICU staff (Granberg et al., 1999). The participants’ response of fighting for their freedom is consistent with the above mentioned studies. For the participants in the present study, being bound evoked feelings of fear and the presence of death. Likewise Löf et al.’s (2008) participants talked about feeling like they were going to die. Fear and a heightened sense of dying in relation to being bound is also a finding of Granberg et al.’s (1999) and Parker’s (1997) studies. The participants’ attempts to free themselves from restraints are not surprising as the equipment and technologies used in treatments, such as mechanical ventilation, remain unchanged in contemporary ICUs. It continues to be experienced as strange, exclusionary and restrictive (Parker, 1997). It is not known whether it is the technology, or its mode of application that evokes a sense of imprisonment. However, the technology, often perceived as a foreign appendage (Parker, 1997; Zeilani & Seymour, 2010) is distressing to many. For instance the participants in this study described “strange things that made a noise” with reference to equipment used. With every move they set off alarms that alerted nursing staff who then suggested that they refrain from moving. Alarms or movement evoked unwanted treatments for some. As Liam said “I just had put up with it and lie still because I was afraid that if I became obnoxious I would be knocked out again.” This finding is in contrast with Zeilani and Seymour’s (2010) study whose participants found security in the technology and the ICU staff and Löf et al. (2008) whose participants felt safe in the presence of the ICU staff. With time, the participants in this study realised their powerlessness over their imprisonment and surrendered themselves to the control of the ICU staff and its equipment. They described “being at the mercy of others”, “being watched” also found in Almerud et al.’s (2007); Fairman (1992) and Parker’s (1997) studies. ‘Being in the dungeon’ is a subtheme that describes the participants’ experiences of being isolated from the rest of the world. ‘Being at the mercy' of the ICU staff meant the ICU equipment and its staff controlled their existence, providing sustenance they could not procure for themselves. The participants called upon their survival instincts to carry them through their ordeal. They endured their imprisonment in the hope that it would not last forever. At the same time, the participants in this study realised that things could change depending on the circumstances.
For the participants in this study, speech and voice was a fundamental aspect of their being-in-the-world. Their ability to speak and voice themselves was the means through which they sustained relationships with others. The importance of speech and language is that the participants’ family and friends could not understand them. All the participants in this study were rendered voiceless at some time. They could not talk or express themselves because the ETT interrupted their vocal chords. Participants felt they were held captive by the ETT for this reason. The finding of ‘being voiceless’ is supported by others (Foster, 2009; Donnelly & Wiechula, 2006; Granberg et al., 1998, 1999; Haffsteindóttir, 1996; Happ, 2001; Happ et al., 2004; Happ et al., 2006; Happ et al., 2011; Laitinen, 1996; Parker, 1997; Carroll, 2007; Zeilani & Seymour, 2010). The description of being held captive by the ETT is also supported by Moore (1991, p. 114) who described waking up to loud music from the nurses’ desk and being unable to ask the nurses to turn it down. In this study the participants described “having no voice to call out with” (Rosie 1st Int.) and feeling as if “someone had taken their voice off them” (George 1st Int.).

Speech and language are fundamental to human existence in that it is one’s identity in the world and it is the medium through which people make their intentions known and relate to others. The participants in this study and those of Donnelly and Wiechula (2006); Foster (2009); Parker (1997); Carroll (2007); Zeilani & Seymour (2010) shared feelings of fear and anxiety because they perceived technology as a threat to their life which had taken away their ability to communicate with others. The difference between this study and those of Parker’s (1997) and Zeilani & Seymour’s (2010) studies is that while most of the participants in this study perceived being at the ‘mercy’ of the technology, most of Parker’s and Zeilani & Seymour’s study participants eventually found safety in technology despite the suffering they experienced as a result of being imprisoned by technology. On the other hand, this current study’s participants’ descriptions that the voice was the means through which they could inquire about their condition are consistent with the participants in Löf et al’s (2006) study who described having no voice to communicate as being without “power to fight for their rights”.

Participants in this study described how their inability to express themselves quickly and clearly led to some people, mainly staff, having no patience for them. This left them feeling abandoned and isolated. This is consistent with Granberg et al. (1999) who said that difficulties in expressing oneself in the world could result in feelings of isolation, loneliness or imprisonment. One of Granberg et al’s (1999) participants said that the nurses were not patient enough to wait for him to find the right words to ask questions. When critically ill patients feel imprisoned, particularly in a place like ICU where they are confined to a strange
room with strange machinery, fear takes hold of them and strips them of their ability to maintain their hold on reality. In this study, the participants continued experiencing communication difficulties. This finding is different from other studies (Granberg et al., 1999; Happ, 2001; Happ et al., 2011; Löf et al’s, 2006) in that despite having interviewed patients after discharge from hospital, they did not indicate whether or not participants continued experiencing communication difficulties long after their discharge and what that meant for them as highlighted in this study. Granberg et al. (1999) only reported communication difficulties within the ward, even though they conducted follow up interviews in participants’ homes at four to six weeks after discharge.

In this study, the participants’ voices had changed as a result of the treatment they had received in ICU. They were either reduced to a whisper (Keith), hoarse (George and Kate) or to a voice that was hoarse and intermittently absent (Moira) and they anxiously awaited the return of their signature voice. Their signature voice was part of their defense and their unique identity was lost after their critical illness and ICU experience. The participants in this study were frustrated and annoyed with themselves and their families for not being able to communicate meaningfully in a way they could be understood. Granberg et al. (1999) also reported patients having difficulties with finding the right words when the patients were transferred to the ward. One male participant (Keith) in this study not only became frustrated but also angry when he had communication difficulties both in ICU and at home and stopped communicating and going to social gatherings. This finding is similar to Granberg et al (1999) who reported that male participants expressed anger at their wives when they visited them and withdrew when they could not be understood. This poses a social problem because lack of understanding by others can lead to loneliness as people, and especially family members, begin to withdraw from the person. Having no voice or having an abnormal voice is restrictive. It prevents the person from expressing himself or herself, which can be difficult for them to accept.

**Finitude**

Being in limbo in this study is constituted by a sense of uncertainty about life and death. Many of the participants’ descriptions of their critical illness characterise a heightened sense of death highlighted in the subtheme ‘Under the Shadow of Death’. Here participants described witnessing the death of others and sensing their own death as fore grounded. Chapter Four, highlighted the pervasiveness of death. These findings are consistent with other studies (Almerud et al., 2007a; Ballard et al., 2006; Granberg et al., 1999; Löf et al., 2006, 2008; Parker, 1997; Zeilani & Seymour, 2010).
Some participants in this study found it difficult to discuss their near death experiences. This finding is similar to those of Ballard et al. (2006); Capuzzo et al. (2010); Granberg et al. (1999); Rattray et al. (2004) and Weinert and Sprinkle (2008). Ballard et al. (2006) applied Levine’s concept of self-preservation and argued that failing to remember the whole experience and discussing it was a means of self-preservation for the participants. In this study the sense of death resonates with the notion of self-preservation. Dreams and a sense of death or dying have been known to appropriate meaning. However in this study none of the participants attached spiritual meaning to their near death experiences as compared to other studies (Ballard et al., 2006; Papathanasoglou & Patiraki, 2003 & Zeilani and Seymour, 2010).

Not only did participants realise how close to dying they had come, they also realised that death was an experience that could not be shared (Park, 2006). This resonates with Heiddegger’s (1996, p. 223) notion that ‘death is always essentially my own’. The pervasiveness of death and the near death experience for the participants in this study also marked and highlighted their isolation from others.

**Being In Limbo - Consciousness, Freedom and Finitude**

In this section, I discuss the major elements of being in limbo in this study; consciousness, freedom and finitude from a phenomenological lens.

**Consciousness**

From a phenomenological stance, perception is existence. For one to perceive, he/she must be conscious and because our existence is wrapped up in time, the very act of being conscious highlights temporality as an existential that was impacted by being unconscious (Heidegger, 1962/2008). The participants’ sense of lost time meant that their being in the world was violated and that their hold on the world had become shaky. The need to know for the participants was crucial to their personal identity, integrity and safety in the world and assurance about the future. Phenomenological researchers and other writers (Benner & Wrubel, 1989; Leder, 1992; Stein, 2007; Morse & Johnson, 1991) have attested to the existential disruption that illness causes. Temporal-spatial disruption results in a sense of sudden removal from a familiar place and suspension of plans, chores/work and circle of friends. Despite periods of wakefulness with DSI, the participants in the study reported here had lost a sense of both subjective and objective time. Some expressed their experience as a ‘blank’ event between their pre and post critical illness and ICU experience. This is contrary to what would be expected with DSI (Kress et al, 2000). The subtheme ‘trying to
figure it' out highlighted how the participants tried to bridge the pre and post critical illness and ICU hospitalisation by seeking understanding about what happened to them.

As discussed in Chapter Three, being in dialogue with the world is the expression of intentionality and as Merleau-Ponty (1962/2002) points out, in illness the 'intentional arc' is broken (p. 136). The participants' body, the pivot of their existence, the means through which consciousness was located in their world of ICU and following discharge, had betrayed them and they could not apprehend their world. Critical illness in ICU disrupts existence by the failure of the body to respond to the worldly solicitations. Keeping patients unconscious in ICU essentially cuts them off from the world. Their senses, the means through which the body communicates with the world, could not perceive the objects of the world during their unconscious state. Not only were participants unable to see but they could not hear or speak. Their hands, which act as a medium through which their body engages with the world, could not reach out to communicate to others. Upon wakening from a state of unconsciousness, many of the participants were restrained with their hands tied to the bed.

Temporality changes depending on the way we experience the world (van Manen, 1990). In the early phase of ICU hospitalisation when the participants were unconscious, they were in an unknowing state which Merleau-Ponty (1962/2002, p. 347) refers to as a 'prenatal like' state in which they experienced nothing and therefore they had nothing to recall. Their world had collapsed. Being unconscious, experienced as "black", "blank" and "silent" (Keith, Rosie) was consistent with what they later called "being dead" (George, Kate) in that they were essentially dead to the world; they were not intended towards the world. Their state of unconsciousness had disconnected them from time and space. The world can only be a world if it is apprehended or experienced. For the participants in this study, during their unconscious state there was no world from which to apprehend or recall experience. Time suspended and they had been blocked from the world.

However, the sense of disruption continued even when participants were conscious. In their conscious state, the participants' disrupted existence was characterised by being restricted, restrained and controlled; by being bound and imprisoned. As mentioned above, these findings are consistent with previous studies (Ballard et al., 2006; Granberg et al., 1999; Hupcey & Zimmerman, 2000; Parker 1997).
**Freedom**

For the participants in this study their initial response upon awakening from their state of unconsciousness was to fight in order to free and save themselves from the restraints and they struggled to breathe through the ETT.

The notion of freedom is inherent in us, it is embodied. The situation in which the men and women in this study found themselves called upon their existential freedom, whereby they were compelled to respond. Biting on the endotracheal tube and attempting to tear themselves from the restraints and other technological appliances that restrained them was a natural impulsive and embodied response. Their ability to fight to save themselves was a natural pre-reflective action to preserve their existence. This is in line with what Merleau-Ponty calls the ‘inborn complex’ (Merleau-Ponty, 1962/2002, p. 442) where the drive to save oneself overtakes the natural strength and enables one to fight or run away from danger. Because freedom is limited to our 'knowledge', 'situation' and 'abilities' (Spurling, 1977, p. 120), the participants' ability to fight to live waned and they resigned themselves to their imprisonment, hoping for it to end. They had to surrender some of their spontaneity and involve themselves in the world of ICU in order for them to appreciate the real circumstances of their situation and succumb to their predicament as a demonstration of the limitation of their freedom. The men and women in this study spent most of their wakeful period in ICU in limbo waiting for freedom. On discharge, however, to their dismay, they remained imprisoned in a body that was no longer sure of itself. They had changed and they now had a pervasive sense of vulnerability in the world.

**Finitude**

For the participants in this study their critical illness highlighted their sense of mortality. In everyday life, we prefer not to talk or think about death. When others die, we think of it as another’s finitude. We keep the thought of our own finitude at a distance. It is only in times of anxiety or sickness that we realise that death is pervasive. This is consistent with Harman (2007, p. 71) who argues that in our everyday life, death is a remote phenomenon that we usually associate with those who are sick or dying. But not only is death associated with sickness but also any incapacitation or severance from the normal way of being in the world such as the participants in this study experienced. Anything that threatens our existence evokes feelings of anxiety. Death evokes anxiety because it threatens our very own being in the world. Heidegger (1962/2008) notes that death is not only the absence of the soul, but also a cessation of being who we are in the world. In this study the critically ill participants also suffer an existential death as unwanted deviation from their pre ICU self. The existential
death leaves them overwhelmed and powerless to reclaim their previous self-identity. Whilst ever the participants’ lives were in limbo they continued to experience uncertainty about their future mortality.

**Being in Limbo and Chronic Illness**

Being in limbo, accepting and learning to live with a changed body is not a new phenomenon (Bury, 1991; Charmaz, 1983; Kralik et al., 2001; Kralick, 2002). For example, Kralik et al. (2001) explored women’s experiences of being diagnosed with chronic illness. The women in Kralik et al.’s (2001) study felt lost and alone as they tried to make meaning out of their new diagnosis and their changed circumstances. In this study many participants felt lost and lonely. They struggled to understand what the future held for them, they felt vulnerable, powerless and out of control as they described life as “going with the flow” (Kate 1\textsuperscript{st} Int.). These descriptions show how critical illness disrupts existence in ICU and following discharge from hospital.

Being different from pre critical illness and ICU self is consistent with Kralik’s (2002) notion of transitioning in illness from ‘being ordinary’ to ‘being extraordinary’. She advocates that health professionals provide open and honest communication and that they should be willing to listen and understand; this notion could be extended to critical illness patients in order to help ICU survivors overcome the distress they suffer. Practice needs to shift from that of being techno-biological oriented to that of being holistically oriented and extending into the post ICU period. In Australia, there are no support groups or models of care tailored for the specific needs of ICU survivors. A model of care that extends beyond ICU and provides follow up care and support like those of the U.K. (Keynes, 2010) would be beneficial.

The participants descriptions of “going with the flow” (Kate) and “trying to forget all about it” (Keith) suggest they struggled to accept their new self. Valeras (2010) studied six patients with chronic illnesses and explored how they felt about their disabilities in relation to themselves and others in the community. The struggle was not so much about the illness but about its effects on their identity. Identity is shaped by self-perceptions. It is about who, where, when, what and how we are and who we associate with (Valeras, 2010). Illness determines how people relate with others. In Valeras’ (2010) study, one participant highlighted the struggle with her disease as being bothered by not being able to eat whatever she wanted. The disease had imposed limitations on her requiring constant vigilance. Disease determined her social concept depending on the situation and company she found herself in. Valeras’ (2010) participants’ narratives about their struggle with their
chronic illness revealed how they lived a double, yet juxtaposed, existence where they traversed both the disabled and the non-disabled world depending on their circumstances. In the study reported here the participants had not yet learnt to traverse their two worlds or to accept their changed self. Although the strange and dysfunctional body of critical illness and ICU hospitalisation impacted participants in different ways their struggle to cope with their changed self was determined by encounters of their everyday life such by being socially ostracised, disregarded, and feeling like a burden to others.

As mentioned in the introductory chapter, advanced technology and improved practices in ICU have led to people living longer and surviving critical illness and ICU hospitalisation. However, survivorship can be problematic (Desai et al., 2011; Needham et al., 2011). It has now been recognised that survivors of critical illness and ICU hospitalisation continue to suffer from the sequelae of critical illness and the ICU therapy they received during their hospitalisation. This is more so in the older population who may develop functional and cognitive disabilities following their critical illness and ICU hospitalisation (Desai et al., 2011; Needham et al., 2011; Iwashyna et al., 2011).

**Summary**

The findings of this study show that ‘being in limbo’ is integral to the critical illness experience in ICU and following discharge from hospital. Being in limbo, shows the essential elements of this experience as, being disrupted, being imprisoned and being trapped.

Understanding critical illness requires knowledge and understanding of this experience as it is lived through. Although the problems associated with surviving critical illness in ICU have long been recognised, there are no models of care to guide practice that provide care and support following discharge from hospital like the models used in the context of chronic illness (Gordon, Gulanick, Costa et al., 2004) and cancer survival (Osborn, Demoncada & Feuerstein, 2006). As highlighted in Chapter One of this thesis, the few strategies that are used for patients in ICU such as ICU diaries and rehabilitation clinics are not widely implemented. Perhaps this is because the notion of survivorship sequelae is under recognised as an integral aspect of critical illness (Needham et al., 2011). The findings of this study highlight the need for such programs.

Survivorship, characterised by the sequelae of critical illness and ICU hospitalisation, necessitates the development of models of care resembling those of stroke and cancer patients (Needham et al., 2011). Models of care that will ensure the treatment and support of critical illness survivors across their critical illness trajectory are critical to ensure the best
possible outcomes for patients, their family, community and the health care system. This study shows that critical illness has consequences beyond the initial ICU.

The experiences of the participants in this study highlight their individual and personal way of viewing the world. The current model of care of critical illness is largely directed at disease management and overlooks the patient’s experience of critical illness and its long-lasting effects on their continued existence. Future models of care for critical illness survivors need to focus both on the physiological disease process and the psychological and individual aspects of the patient throughout the trajectory of critical illness.

The experiences of the participants in this study highlight a life in limbo. Participants were transformed by the experience of critical illness and they all remained in a state of limbo as they continued to struggle with their new circumstances and disrupted sense of self. Their certainty and hold on the world had been eroded leaving them with a heightened awareness of death as real and possible. It is clear that survival after critical illness, which is deemed as a physical success, imposes limitations on the survivor that leave them imprisoned in a strange dysfunctional body with which they are in a never-ending struggle to reclaim their identity prior to illness.

The thesis of this study is that critical illness is essentially about ‘being in limbo’, being at odds with the world and constantly trying to reclaim one’s freedom; initially the freedom to live and subsequently the freedom to be and to know oneself in the world.

Although other studies have described the effects of critical illness and ICU hospitalisation for patients, these descriptions have been interpreted largely as PTSD arising from the trauma associated with being ventilated and receiving sedation. Accounts of nightmares and sleepless nights after ICU have been described since the early days of ICU (Blachly & Starr, 1964; Kornfeld, Maxwell, & Momrow, 1969). Indeed, this study attests to the nature of critical illness in ICU as essentially traumatic and life changing for patients. However, it adds a deeper understanding of the embodied impact of the experience for survivors highlighting uncertainty and vulnerability experienced by survivors after discharge. The notion of being in limbo offers a new way of understanding the critical illness experience that appreciates the hiatus and associated changes it creates in people’s lives and the need for recognition, affirmation and reconnection.
Implications for Practice

Although this research set out to investigate the lived experience of critical illness and ICU hospitalisation with the aim of understanding the nature of the experience within a contemporary ICU, the findings point to the fact that the participants in this study continue to suffer months after the critical illness and ICU hospitalisation. This research has highlighted the critical illness and ICU experience as one that is physically and emotionally traumatic for patients and their families.

The need to focus on person-centred care that uses qualitative as well as quantitative evidence to inform practice has been well documented (Parker, 1997). Phenomenological studies have drawn greater attention to lived experience. This study has shown that critical illness and ICU hospitalisation impact the long term experiences of patients. What is lacking are effective systematic models of care that can provide continued care and support for critical illness ICU survivors.

The need to develop models of care with guidelines that incorporate follow-up care and ongoing support is urgent. Explanation and legitimation of critical illness survivorship needs to be included in routine care, beginning in ICU and following through to services such as ICU follow-up clinics and outreach models of care. Health professionals need to consider the impact of various practices and procedures on the well-being of patients, not just in the short term but also in the long term. Hence, whilst many ICU treatment options are limited by current technological understandings and advancements, the findings of this study point to every effort being made to mitigate the likelihood of critical illness sequelae that continue to haunt people about their critical illness and ICU experience.

Coherence is fundamental to our existence hence promotion of patient diaries at a larger scale as a means of dealing with disruption will help provide continuity in critically ill survivors. Similarly every effort to reduce the distress that results from using restraints that bind and imprison a critically ill patient in ICU needs to be made to promote a more humane experience in ICU.

The finding that the ETT tube is experienced as a life-threatening distressing foreign object is consistent with many other studies as highlighted in Chapters Four, Five and Six. The distress identified by participants in this study arose from the perceived threat to life as evidenced by their reports of finding it difficult to breathe and the unnaturalness of the ETT in their trachea. In order to address this problem, more attention needs to be paid to understanding the emotional needs of ventilated patients and the threatening nature of the
high-tech ICU environment. This could be achieved through constant reassurance, explanation and gaining trust from the patients. For those patients requiring invasive mechanical ventilation, reassurance must be given and early extubation wherever possible. Constant reassurance, information, orientation and reorientation are imperative as this study has shown that often patients’ ability to comprehend and remember what they have been told is impaired. Hence the distressing impact of therapies such as endotracheal intubation and tracheotomy needs to be averted in every possible way.

The failure of advanced technology and innovation in ICU practices lies in the increasing number of critical illness ICU survivors with negative sequelae that places a burden on the survivors, families and the health care system. Hence models of care across the critical illness trajectory, that include follow-up pathways including physical therapies, particularly speech therapy as evidenced in this study, cognitive and mental support, sleep clinics and rehabilitation centres need to be established. Additionally community programs such as support groups for critical illness survivors that may help them to actualise their new identity and to deal with issues relating to mortality are urgently needed.

To date, models of care that extend beyond ICU are almost nonexistent in Australia. It is therefore imperative that Australian ICUs follow the few examples of post ICU services that provide ongoing care, and assessment for the need to refer ICU survivors to services such as counseling, sleep clinics or physiotherapy. This has been recommended elsewhere (Hopkins, 2010; Ringdal et al., 2010; Ringdal, Plos, Lundberg, et al., 2008; Beraldo, 2009). Strategies include telephone follow-up and/or post ICU clinics (Capuzzo et al., 2010; Jones et al., 2001). Although some programs of this nature have failed elsewhere (Cuthbertson et al., 2009), their revision could yield better results. Inclusion of family members could improve outcomes. Each ICU needs to examine its own context and work towards a sustainable model of follow up care. More emphasis on comprehensive physical therapy and rehabilitation programmes commencing early in the awakening phase of critical illness and ICU hospitalisation that incorporate psychological, mental health services need to be implemented in the continuum of care within and beyond ICU (Needham et al., 2011) along with speech pathology. An important finding of this study is that communication difficulties continued eleven months after critical illness and ICU hospitalisation. The findings in this study about communication difficulties in ICU are not new (Ashworth, 1980; Granberg et al., 1999; Happ, 2001; Hofhuis et al. 2008; Ringdal et al., 2008; Urden et al., 2006; Zeilani & Seymour, 2010). More needs to be done to find effective ways of communicating with critically ill mechanically ventilated patients. It is important to establish effective methods of communication for the ICU patients because it is the way of relating with others and being-
in-the-world. This resonates with the findings in this study where the patients felt like they were going to die because they could not talk. Although the importance of, and the need for more models of communication have been extensively recommended elsewhere (Happ, 2001; Hofhuis et al., 2008), more use of communication aids such as charts, communication boards and writing pads could improve communication (Happ et al., 2010). Routine assessment by a speech therapist of individual patients’ communication capability and consequent needs before leaving ICU and following discharge from hospital would also help inform treatment such as restorative functional activities and the provision of appropriate communication aids. Nurses’ communication skills could be improved through ongoing education and practice development activities. This would be especially useful for new graduates who may be inexperienced in communicating with intubated patients (Parker, 1997). Technological solutions such as computer generated voice devices (LifeVoice™) are needed as they have proved beneficial elsewhere (Capuzzo et al., 2004).

Loss of the ability to speak resulted in participants feeling isolated, frustrated and, in some instances, betrayed by what had previously been a reliable voice. There is a need for health professionals caring for patients in ICU to understand that speech is not the only way of communicating. They should look out for cues such as physiological and body language. ICU staff members need to be aware that communication difficulties extend beyond the time when the patients are intubated. If the aim is to successfully restore patients to their old self and reunite them with their families and communities, then every care needs to be taken to ensure they are able to communicate what is important to them.

The social isolation the critical illness survivors in this study suffered is a form of existential disruption that needs to be acknowledged and addressed. This can only be done with support from the health care workers including speech pathologists. Family members need to be included in the follow-up care pathways. This is crucial in that the burden of caring often weighs heavily on families and thus disrupts their lives too.

The descriptions about sensing death and seeing other patients dying imply that nurses should try by all means to protect patients from the negative emotional effects of such experiences. The fact that these recommendations have been made elsewhere (Parker, 1997) implies that more emphasis is needed and reasons for why changes have not been made need to be investigated.

Technological advancement has in some way perpetuated the objectification of patients. This sense of objectification seems to have been heightened by the watchful eye of the nurses in this study and other studies (Almerud et al., 2007a; Parker, 1997; Wang et al.,
While constant surveillance of critically ill patients may be necessary, reassurance and explanation to patients of the need for such practices is required. Nurses should not take it for granted that their constant surveillance is perceived as beneficial by their patients. Because family presence was reported as a calming factor, ways to ensure the presence and participation of family members would help to reduce the isolation and sense of vulnerability experienced by patients. This has been recommended before (Parker, 1997; Zeilani & Seymour, 2010). Family members need to be educated about the importance of their presence to their critically ill relative and encouraged to prolong their visits if possible, particularly when their relative is awake.

As highlighted in Chapter One, many studies have established that sleep deprivation is a problem and strategies to alleviate the problem have been explored. The findings in this study support the research literature that indicates that patients experience sleep deprivation while they were in ICU. This study also shows that sleep deprivation associated with nightmares is a problem following discharge from ICU. Bearing in mind that there are many causes of sleep deprivation in ICU (Tembo & Parker, 2009), an individualised approach might include review of medications, psychological assessment and selecting drugs that do not interfere with sleep. Patients also need to be educated about the side effects of some drugs that may cause sleep deprivation. Following discharge and for ICU survivors psychological counseling may be helpful for those people suffering from nightmares. Reassessment for, and treatment of, PTSD disorder may also be beneficial.

DSI has been associated with better physical health care outcomes such as short ventilator and ICU stay, but the experience and perceptions of critical illness survivors have not been extensively explored. The risks associated with DSI have also not been explored. However, this study has established that the experiences of some critically ill patients appear not to have improved at all.

Implications for Education

Based on the findings of this study education and awareness of post critical illness and ICU-sequelae, and their management those involved in caring for this patient population is needed. Nurses, medical practitioners and other allied health professionals including family and other care givers in the community often have very limited knowledge of the ongoing impact of critical illness. Hence this knowledge and awareness will empower all stakeholders to transition critical illness and ICU survivors from the acute settings of the ICU to the community, humanising the quality of life for survivors.
The findings of this study are instructive for educators and nursing, medical and mental health curricula in a number of ways. Like many other studies, this study has highlighted the need to incorporate subjects that deal with the emotional needs of critically ill patients. Undergraduate, post graduate and critical care course syllabi tend to focus on the technical and practical aspects of knowing without attention to pathic ways of knowing and being with patients and their families. Education needs to focus on helping health practitioners understand and appreciate illness experiences to ensure a balance between science of health and the notion of care. This approach may help to reduce the traumatic impact of the high technological environment and trauma experienced by patients long after their discharge from hospital. Universities and hospitals need to formulate curricula that are sensitive to the lived experience of critically ill ICU patients. Students need be sensitised to the needs by exposing and encouraging them to read qualitative literature that deals with the lived experience of these patients. These recommendations have been made before (Parker, 1997) and yet there appears to be little evidence of change. There needs to be examination of why educators are reluctant to pursue curriculum reform that would position patients and their experiences at the centre of learning experiences.

Undergraduate, post graduate and in-service education that helps students and experienced nurses’, medical staff’s and other health care practitioners’ understanding of the meaning of existential disruption is needed. Education about sleep, its importance and implications of sleeplessness would also be beneficial. Because many of the treatment decisions made in ICU are made by doctors, or in collaboration with a multidisiplinary approach, the multifaceted nature of critical illness sequelae makes it important for education to involve not just nurses but all health care disciplines.

The psychological complications of critical illness and ICU hospitalisation have been highlighted for over four decades. The existential change that arises from complications of critical illness and ICU hospitalisation warrant the incorporation of mental health strategies into critical care courses. This will equip nurses with the expertise to assess patients for risks and early signs of mental health breakdown and disorders such as PTSD. Early recognition of such disorders will promote early treatment and prevention of further complications.

Implications for Research

Because phenomenological research aims at understanding people’s lived experience from their own point of view, it provides important findings that can provide impetus and direction for further studies. The knowledge gained from such studies is pathic and as such it is
transformational, and brings about thoughtfulness that can help ICU health care workers reunite their patients with their body, and their life world. The aim to conduct studies such as this is to describe experiences of critically ill patients from their own perspective and provide understanding that can guide future treatment.

The studies reported in this thesis, along with the findings of this study, show that technology still has an “objectifying” character that frightens and alienates the patient both from him/herself and the ICU staff. ICU staff members are perceived to be preoccupied with fixing physiological and anatomical problems guided by technology at the expense of patient experiences. It is for this reason that I feel that more research to do with the experience of critically ill patients in the context of DSI and other ICU practices, including technological advancement, is needed so that the future of ICU care can be guided by both the gnostic and pathic approaches that aim at not only improving physiological responses and outcomes but also at healing the patient. The ambiguous and contradictory impact of technology needs to be better appreciated. What is helpful is often also harmful. Research that examines this understanding from both the patients and health professional perspective would inform critical debate about ways to provide care that places the person at the centre of care with technology as instrument rather than the primary focus.

Researchers need to turn their attention to strategies that examine methods and processes that can reduce the impact, particularly the longer term impact of the experience. Most importantly research and funding is needed to increase awareness of critical illness and ICU survivorship sequelae and facilitate a better survivorship experience of critical illness beyond ICU.

Because of the multifaceted nature of the sequelae of critical illness and ICU treatment, specific focused research on methods for critical illness survivorship measurements is needed to design and evaluate comprehensive interventions aimed at improving long term outcomes. Of particular interest are the physical, cognitive and mental sequelae of surviving critical illness and ICU hospitalisation. These recommendations have been made before (Needham et al., 2011). The fact that some nurse led rehabilitation clinics have not made a difference to patient outcomes (Cuthbertson et al., 2009) also implies that more research in this area is needed.

While phenomenological research helps us to understand the lived experience of critical illness and ICU hospitalisation, some of the problems arising from the technological aspect of ICU hospitalisation cannot be solved by removing technology. For instance, all the participants in this study described the ETT as a very uncomfortable and life threatening
intrusion in their body. Participants asked if any alternative could be found. Research needs to address this question. Can modification of such devices as the ETT be improved for comfort for example?

Furthermore, balancing the need to respect the individual’s rights to anonymity and confidentiality are important ethical considerations as is the stance of the phenomenological researcher. When faced with requests from participants to make contact with other participants in this study I was obliged to decline this request ethically. Assuming the stance a phenomenological researcher also means valuing and respecting the situations of people during the research process and beyond the study. In order to ensure due care of research participants in these types of studies researchers need to be cognisant of the likely issues to be confronted during the research interview process. Information needs to be provided about the range of support services that might be needed and that are available. For example, participants in this study could have been given information regarding the PTSD, illness, sleep disorder support groups and or forums.

**Strengths and limitations of the Study**

The strength of the study lies in the philosophical and methodological lens that I employed to conduct it. Phenomenology’s major strength is that it enables the researcher to reveal the meaning of important human experience (Gerrish & Lacey, 2010). The understanding garnered from phenomenological studies may underpin ethical practice. The narratives of the men and women of this study gives rise to knowledge that may cause readers to identify with the participants in a way that will change the way critically ill patients are cares for in ICU.

By using phenomenology, I believe the lived experience of the men and women in this study has been revealed in a way that bears witness to their experiences. I have shown what it was like for the participants to be critically ill in ICU. Phenomenological research has a transformative effect on the researcher and the readers because it stimulates deep thinking and learning which results in a change of consciousness, increased perceptiveness, thoughtfulness and tact (van Manen, 1990). It is hoped that the findings of this study will stimulate deep thinking in health professionals in ICU and that this will bring about changes in their practice. Through the process of conducting the study I have been transformed.

Transformation may be at a personal level and an organisational level. Furthermore, it is hoped that the findings of this study will inform the development of new models of care for ICU patients that provide support and follow-up care beyond ICU and hospitalisation.
Because the focus of phenomenological research is on the subjective nature of lived experience, the researcher becomes integral part of the research through the data collection and analysis. The findings, therefore, represent the researcher’s account and interpretation of the raw data. There may be other interpretations that are equally valid. The themes identified are my interpretation of the participants’ experiences and guided by my understanding of phenomenology. Throughout the study, I endeavoured to maintain trustworthiness of the findings by emphasising the individuality of the participants’ situation through which I revealed the varied experiences of each one of them. Emphasising the individuality and situations resonate with Merleau-Ponty’s argument that man is ‘always situated and individuated’ (1964, p. 51). It is also a limitation in that what is understood is based only on the individual’s perception at that particular time. Whatever follows is not known.

Higgs, Horsfall and Grace (2009) wrote that successful phenomenological writing requires the researcher to put aside their assumptions about the phenomenon in question, spend long hours observing and interviewing participants and asking them to tell stories or give images, and spend extensive time engaged with data to bring out deeper meaning of data as confirmations of phenomenological research. I attended to the trustworthiness of the study by spending time with the participants and engaging in in-depth interviews with them at two weeks and up to eleven months after their discharge from ICU. In addition I spent long hours immersed in the data, writing and rewriting, reading and rereading, reflecting and rewriting (O’Leary, 2009/2010; van Manen, 1990). Confirmability of qualitative research lies in the clear connections between data set up, findings and interpretation (Gerrish & Lacey, 2010). However, there is a possibility that my situated context may have influenced the manner in which I conducted the analysis of the data. I have, therefore, provided an audit trail and I declared my assumptions in the Chapter three. The fact the findings of this study are different from my assumptions serve as confirmations of the study. To help me put my assumptions aside, I kept a field journal, memos of my thoughts, concerns and feelings in the course of the study. The documented audit trail of the decisions, insights and choices I made in the research process also serve as confirmations of the study. Most importantly the exemplars used in the analysis and discussion chapters also serve as objects of confirmations of both the data and the study.

**Conclusion**

The purpose of this study was to address the question: What is the lived experience of critical illness in ICU and how does it affect people’s lives after discharge? The study was
motivated by my concerns for ICU patients who were undergoing a new form of treatment; namely the use of DSI. Of concern to me was how critically ill patients experienced the periods of wakefulness using this treatment regime. A phenomenological approach was considered to be the most appropriate methodology for the study in order to achieve an understanding of the experiences and the meanings that the participants in this study attribute.

The findings of this thesis suggest that for the participants in this study the lived experience of critical illness in ICU and following discharge from hospital is about being in limbo. ‘Being in limbo’, is characterised by disruption, imprisonment, and entrapment. From the time the participants were admitted to ICU they felt they were suspended between life and death.

The findings of this study have the potential to increase understanding of the experiences of critical illness by nurses and other health care professionals. The experiences of the participants in this study suggest the use of DSI, considered an innovation in the treatment of critically ill patients with improved physiological outcomes, may not improve lived experiences of critical illness in ICU and beyond. Recommendations are made for new models of care and support to mitigate the patients’ experiences.
REFERENCES


Hopkins, R. O. (2010). Haunted by Delusions: Trauma, delusional memories, and intensive care unit morbidity. Critical Care Medicine, 38 (1), 300-301.


<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Abdominal Aortic Aneurysm:</strong></td>
<td>Abdominal aortic aneurysm is an abnormal stretching and bulging of the large blood vessel (aorta) that supplies blood to the abdomen, pelvis and legs (Harris, Nagy &amp; Vardaxis, 2009).</td>
</tr>
<tr>
<td><strong>Absence Seizures:</strong></td>
<td>Absence seizures are brief generalised seizures accompanied by unconsciousness. They could also be accompanied by twitching and fluttering of eye lids. They are not remembered by the patient. They are usually of sudden onset and termination. They usually last about 20 seconds (Harris et al., 2009).</td>
</tr>
<tr>
<td><strong>Acute Pulmonary Oedema (APO):</strong></td>
<td>APO is the extravassation of fluid into lungs due to increased pulmonary capillary pressure mostly due to fluid overload in heart failure (Harris et al., 2009).</td>
</tr>
<tr>
<td><strong>Antibiotic:</strong></td>
<td>An antibiotic is a drug that works against bacteria either by killing (bactericidal) or by inhibiting their growth (bacteriostatic) (Tiziani, 2010).</td>
</tr>
<tr>
<td><strong>Aortofemoral bypass:</strong></td>
<td>Aortofemoral bypass is surgical rerouting of blood vessels from the lower abdominal aorta to the two femoral (groin) arteries around a blocked artery to supply blood to legs and feet (Harris et al., 2009).</td>
</tr>
<tr>
<td><strong>Apache Score:</strong></td>
<td>Indicator of sickness severity in relation to threat to life in ICU patients (Harris et al., 2009).</td>
</tr>
<tr>
<td><strong>Aspiration:</strong></td>
<td>Aspiration pneumonitis is irritation and swelling of the lungs</td>
</tr>
</tbody>
</table>
Pneumonitis: due to inhaling of fluid or food particles (Harris et al., 2009).

Atrial Fibrillation (AF): AF is an irregular heart rhythm often felt and described as palpitations. It is caused by abnormal electrical activity of the heart leading to abnormal contractions of the upper chambers of the heart (Harris et al., 2009).

Benzyl Penicillin: Benzyl penicillin is a drug that acts against a wide range of infection causing microorganisms particularly bacteria like staphylococcus and streptococcus. Benzypenicillin has both bactericidal and bacteriostatic properties (Tiziani, 2010).

Bilateral Pneumonia: Bilateral pneumonia is an infection affecting parts of both lungs (Harris et al., 2009).

Biliary Leak: A biliary leak is a medical condition in which bile seeps from the bile duct into the abdominal cavity through a broken point in an accessory bile duct (Harris et al., 2009).

Bradycardia: Bradycardia is low pulse rate (less than 60 beats per minute) (Urden, Stacy and Lough, 2006)

Bronchiectasis: Bronchiectasis condition in which large air passages (bronchi) become damaged and dilated leading to collection of mucus and repeated infections (Harris et al., 2009).
Cardiac Catheterisation: Cardiac catheterisation is a medical diagnostic procedure in which a catheter is passed under the skin through the blood vessels of either the arm or groin through the circulatory system to the heart. It is used to examine the arteries of the heart, collect blood samples from the heart, measure pressure and blood flow in the heart's chambers and in the large arteries around the heart, measure the oxygen in different parts of the heart and collect a biopsy on the heart muscle. The procedure takes approximately one to three hours (Harris et al., 2009).

Cardiogenic Shock: Cardiogenic shock is a condition in which is the decreased pumping function of the heart with low oxygen distribution to the tissues in the presence of adequate circulatory fluid. It mostly happens in myocardial infarction (Harris et al., 2009).

Cardiopulmonary Resuscitation: Cardiopulmonary resuscitation is the restoration of life in a person who is suspected to be dead (Harris et al., 2009).

Cardioversion: Cardioversion is a procedure used to convert fast abnormal heart rhythms to normal rhythm. It can be chemical (using drugs) or mechanical (using an electric current from a machine with paddles attached to the external chest wall) (Harris et al., 2009).

Cardioversion: Cardioversion is a medical procedure used to restore normal heart rhythm from an abnormal heart rhythm called atrial fibrillation. It can be mechanical (using electricity) or chemical (using drugs) (Harris et al., 2009).

Cartesian Dualism: Rene Descartes' view of mind and body split of a person.
This paradigm purports that the mind is separate from the physical aspects of existence. In medicine it is viewed as the basis upon technological advancement is founded with a view of improving physical outcomes of patients (Harris et al., 2009).

Central Venous Line: Fluid lines inserted in the large veins to end up at the tip of right atrium and the superior vena cava - used for haemodynamic monitoring, fluid and medicine administration, blood sampling (Harris et al., 2009).

Clonazepam: Clonazepam is a benzodiazepine with anti epileptic, sedative and anxiolytic properties. It is used to treat both localised and generalised seizures. It is also used in the treatment of status epilepticus (seizures lasting more than 30 minutes or two or more seizures succeeding each other without full recovery of consciousness) (Tiziani, 2010).

Computed Tomography Scan (CT scan): A CT scan is an electronic X Ray method of obtaining 2D (dimensional) or 3D pictures of cross sections of body slices. It is a 100 times more sensitive than a conventional X ray. It used to shows densities, abnormal fluid accumulation, tumour growths, bone fractures and infarcts (Harris et al., 2009).
Coronary Angiography: Coronary angiography is a diagnostic procedure in which a radio opaque substance is used to visualise blood vessels in this case to show blockages in the coronary arteries. The procedure includes insertion of a special flexible tube under x ray guidance into a blood vessel usually the big vein in arm or the groin to examine the function of the heart and blood vessels (Harris et al., 2009).

Coronary Artery Bypass Graft: Coronary artery bypass graft is a surgical procedure of creating new routes of blood flow around blocked arteries to supply blood flow and oxygen to areas of the heart beyond the blocked artery. This involved three coronary arteries (Harris et al., 2009).

Coronary Artery Bypass Grafting (CABG): CABG is a surgical procedure of diverting blood flow from a blocked artery of the heart to establish blood supply to the area that is deprived of blood supply by getting vein from another area of the body and connecting it to arteries that are not blocked and bypassing the blocked area (Harris et al., 2009).

Daily sedation interruption (DSI): DSI is an ICU practice of intermittently stopping sedatives and pain control drugs where deemed appropriate to allow the critically ill patient wake to up for the purpose of neurological examination and prevention of complications associated with continuous sedation practices (Kress et al., 2000).
Diabetic Keto Acidosis (DKA): DKA is metabolic acidosis resulting from the build up of ketone bodies due to excessive breakdown of fats as result of abnormal metabolism of carbohydrates in diabetes mellitus (Harris et al., 2009).

Defibrillation: Defibrillation is restoration of normal heart function by delivering an electric shock through the heart using paddles attached to the external chest wall (Urden, Stacy & Lough, 2006).

Degloving Injury: A degloving injury is an injury in which a large part of skin is completely removed and the underlying tissue is exposed (Harris et al., 2009).

Delirium: Delirium is an acute mental disorder manifested by confusion, restlessness, disorientation, incoherence, clouding of consciousness, anxiety, fear, hallucinations, excitement, illusions, and delusions mostly visual. It is caused by disturbances in the brain that could be due to metabolic disorders, infections or drugs, postoperative stress, physical, mental shock or exhaustion. The symptoms of delirium are of short duration and can be corrected by treating the underlying cause (Harris et al., 2009).
Electroencephalogram (EEG):

An EEG is a medical procedure used to record electrical activity of the brain. The electrodes are placed on the scalp of the patient and a machine produces a graphic chart representing the electrical activity of the brain cells. It is used for many functions such as determining the type of epilepsy, the depth and length of sleep, levels of consciousness and relaxation (Harris et al., 2009).

Electromechanical Dissociation (EMD):

EMD is also known as pulseless electrical activity (PEA). It is electrical activity in the absence of mechanical activity of the heart (Urden et al., 2006: Harris et al., 2009).

Emphysema:

Emphysema is a chronic lung condition characterised by stretching and enlargement of air passages resulting in accumulation of secretions (Harris et al., 2009).

Endotrachael Tube (ETT):

A flexible tube that is inserted into a patient’s trachea through the nose or the mouth as an artificial airway for breathing. It is used to maintaining breathing in critically ill patients during mechanical ventilation in ICU (Harris et al., 2009).

Epilepsy:

Epilepsy is a neurological disorder characterised due to uncontrolled electrical activity of the cerebral cortex. It is characterised by recurrent convulsions, sensory disturbances, and loss of consciousness. It can be generalised or localised (Harris et al., 2009)

EuroQol-EQ-5D EuroQol-EQ-5D questionnaire is a form used to assess health care outcomes. It is used to assess a variety of conditions (Harris et al., 2009).

Extubation: Extubation means removing the breathing tube from a patient’s breathing passage. Usually happens when the patient is ready to breathe on their own without mechanical ventilation assistance (Harris et al., 2009).

Fractures: Fractures are breakages in a bone sustained from motor vehicle accidents, falls or any other trauma. They can also be pathological where bones break in the absence of a force but because of the weakness in the bone due to infection (Harris et al., 2009).

Fentanyl: Fentanyl is a shorter acting opioid than morphine. Its uses and actions are the same as those of morphine described above (Tiziani, 2010).

Fibula And Tibia: Fibula and tibia are names of bones of the lower leg (Harris et al., 2009).
Flail Chest: Flail chest is a condition in a number of ribs are broken resulting in injury to the underlying area of the lung. That area of the lung then contracts and relaxes abnormally during breathing (contracts on breathing in and relaxes when breathing out (Harris et al., 2009).

Fluid Resuscitation: Fluid resuscitation is rapid administration of fluids to correct fluid disturbances (volume deficit) in the body (Harris et al., 2009).

Foetal Distress: Foetal distress is a life threatening physical stress suffered by a foetus during pregnancy or labour due to lack of oxygen supply. It is characterised by an abnormal heart rhythm (Harris et al., 2009).

Fractures: Fractures are breakages in a bone sustained from motor vehicle accidents, falls or any other trauma. They can also be pathological where bones break in the absence of a force but because of the weakness in the bone due to infection (Harris et al., 2009).

Frusemide (Lasix): Lasix is a loop diuretic –used to treat fluid overload states by removing excess fluid through the urinary system (Tiziani, 2010).

Gnostic: Gnostic means to know. It is a framework of thinking that based on intellectualism (van Manen, 2000).
Haemothorax: Haemothorax is the accumulation of blood in the pleural space often due to chest injuries but it can also be caused by rupture of small blood vessels due to chest infections or tumours (Harris et al., 2009).

Haemopneumothorax: Haemopneumothorax is a medical condition in which air and blood collect in the pleural space. It is usually caused by injuries to the chest particularly when ribs are broken (Harris et al., 2009).

Health Related Quality of Life (HRQoL): HRQoL is a measure of the general wellbeing of an individual or a society (Harris et al., 2009).

Hospital Anxiety and Depression Scale (HADS): The hospital HADS is a standardised questionnaire used to assess patients for anxiety and depression. It has four possible answers for each question and patients are required to choose the answer that best describes their feelings. Questions about anxiety are marked “A” and the ones about depression are marked “D” (Harris et al., 2009).

Hypernatremia: Hypernatremia is a medical condition in which there is a very high concentration of sodium in the blood. It is usually caused by dehydration particularly in conditions that cause fluid loss from the body (Harris et al., 2009).

Hyperemesis Gravidarum: Hyperemesis gravidarum is excessive vomiting during pregnancy (Harris et al., 2009).
Hypothyroidism: Hypothyroidism is a medical condition characterised by low production of the thyroid hormone. It is usually caused by iodine deficiency (Harris et al., 2009).

Induction: Process of inducing unconsciousness before a surgical procedure of inserting an endotracheal tube (Breathing tube into the trachea) for invasive mechanical ventilation in ICU (Harris et al., 2009).

Inotropes: Inotropes are drugs that either increase (positive inotropes) or reduce (negative inotropes) the contractility of the heart (Harris et al., 2009).

Intensive Care Delirium Screening Checklist (ICDSC): Intensive Care Delirium screening Checklist is an instrument used to assess critically ill patients for confusion specifically delirium in ICU (Harris et al., 2009).

Intensive Care Experience (ICE score): The ICE score is an assessment tool that indicates patients' emotions and perception of ICU treatment after discharge from ICU (Harris et al., 2009).

Intensive Care Unit (ICU): Section of the hospital where patients with life threatening conditions, illnesses and or injuries requiring life support and or continuous monitoring are admitted (Harris et al., 2009).

Inter Coastal Catheter (ICC): Flexible catheter used to drain air or fluid from the pleural cavity (Harris et al., 2009).

Intra Aortic Balloon Pump: An intra aortic balloon pump is a mechanical device (catheter with a balloon) that sits in the aorta and counter
pulsates and it increases blood flow to the coronary arteries and thus increases myocardial oxygen perfusion (Harris et al., 2009).

**Intubated:** Intubated means having a flexible breathing tube inserted in the trachea through the mouth or the nose (Harris et al., 2009).

**Intubation:** Insertion of a breathing tube into the trachea (windpipe) through the mouth or the nose (Harris et al., 2009).

**Ischaemia:** Ischaemia is reduced blood and oxygen supply to the heart muscle (Harris et al., 2009).

**Ischaemic:** Ischaemic is lack of blood and oxygen supply to a body part or tissue due to a blockage in an artery (Harris et al., 2009).

**LAD:** LAD is an abbreviation for left anterior descending artery (Urden et al., 2006).

**Laparatomy:** Laparatomy is a surgical procedure of making a large opening in the wall of the abdomen to perform a procedure in the abdominal cavity (Harris et al., 2009).
<table>
<thead>
<tr>
<th>Left Bundle Branch Block:</th>
<th>Left bundle branch block is delayed conduction of heart impulse through the left ventricle pathway (Harris et al., 2009).</th>
</tr>
</thead>
<tbody>
<tr>
<td>Left Sacroiliac Nail And Anterior External Fixateur Inserted:</td>
<td>Left sacroiliac nail and anterior external fixateur inserted operation in which broken pelvic bones are fixed together using a special, nail and an outside frame (Harris et al., 2009).</td>
</tr>
<tr>
<td>Left Ventricular Failure (LVF):</td>
<td>Left ventricular failure is the failure of the left lower chamber of the heart to pump blood to the body at the required capacity (Urden et al., 2006)</td>
</tr>
<tr>
<td>Length of Stay (LOS):</td>
<td>The number of days a critically ill patient stays in ICU.</td>
</tr>
<tr>
<td>Levitiracetam:</td>
<td>Levitiracetam is anticonvulsant (anti epileptic/seizure) drug that works by establishing normal electrical activity between the neurons in the brain. It is used in conjunction with other anticonvulsant drugs where one drug has not been effective. It can also be used on its own in patients older than twelve years of age) (Tiziani, 2010).</td>
</tr>
<tr>
<td>Levosimendan:</td>
<td>Drug that sensitises calcium in severely decompensated congestive heart failure to improve heart contractility (Harris et al., 2009).</td>
</tr>
<tr>
<td>Term / Abbreviation</td>
<td>Definition</td>
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</tr>
<tr>
<td>Liver Packing:</td>
<td>Liver packing is a surgical procedure to stop bleeding from the liver in traumatic injuries. It involves application of procoagulant adhesives, fibrin sealants and firm application of laparatomy sponges (Harris et al., 2009).</td>
</tr>
<tr>
<td>LMA:</td>
<td>LMA is an abbreviation for left marginal artery (Urden et al., 2006).</td>
</tr>
<tr>
<td>Lower Segment Caesarian Section:</td>
<td>Lower segment caesarean section: is an incision of the abdomen and uterus to deliver a baby (Harris et al., 2009).</td>
</tr>
<tr>
<td>Lumber Puncture (LP):</td>
<td>A lumber puncture is a medical procedure in which a needle is introduced into the spinal canal to obtain cerebral spinal fluid. It is mostly used to diagnose infections of the brain (Harris et al., 2009).</td>
</tr>
<tr>
<td>Magnetic Resonance Imaging (MRI):</td>
<td>Magnetic resonance imaging is an X ray procedure in which a magnetic ultrasound is used to obtain detailed images of internal organs of the body (Harris et al., 2009).</td>
</tr>
<tr>
<td>Mechanically Ventilated:</td>
<td>Mechanically ventilated means natural breathing has been replaced or assisted by a machine called a ventilator (Harris et al., 2009).</td>
</tr>
</tbody>
</table>
Meningitis: Meningitis is a life threatening infection characterised by irritation of the membranes that cover the brain and the spinal cord. It can be caused by a virus, bacteria or fungus. It is characterised by headache, irritability, neck stiffness, photophobia (sensitivity to light), vomiting, lethargy (severe fatigue) and a red rash (Harris et al., 2009).

Metabolic Acidosis: Metabolic acidosis is the abnormal pH altering condition resulting from accumulation of acids or loss of bases leading to an increase in hydrogen ions usually due to loss of fluid in conditions like diarrhoea or vomiting (Harris et al., 2009).

Methicillin-resistant streptococcus aureas (MRSA): MRSA is a gram negative staphylococcus (bacteria) resistant to commonly used antibiotics to treat bacterial infections. It is commonly acquired from the health care environment (Harris et al., 2009).

Micro Organisms: Microscopic organisms are substances that invade the body and show disease presence. They can be a bacteria, fungi or virus (Harris et al., 2009).

Midazolum: Midazolum is a sedative belonging to a group of drugs called benzodiazepines. In ICU, Midazolum is commonly used to keep patients unconscious (coma) to facilitate treatment such as mechanical ventilation. It has amnesic properties as well as anxiolytic (anti anxiety) properties (Tiziani, 2010).
Morphine: Morphine belongs to a group of drugs called opioids. Opioids are strong pain relieving drugs that act on the central nervous system by binding to specific opioid receptors in the brain. They have an agonistic action on opioid receptors in the brain. They can be used in injection, liquid or tablet form to treat both acute and chronic pain. In ICU they are commonly used in injection form in unconscious patients suspected to have pain (Tiziani, 2010).

Multi trauma: Multi trauma is a medical term used to describe a traumatic condition in which injuries are acquired in different parts of the body at the same time (Harris et al., 2009).

Multiple Spinal Fractures: Multiple spinal fractures are injuries characterised by a number of broken places in the spine (Harris et al., 2009).

Myoclonic Jerks (myoclonus): Myoclonic jerks are brief shock-like jerks/involuntary movements of a muscle or groups of muscles. It can occur in a person falling asleep or in a person with a neurological disorder (Harris et al., 2009).

National Health Service (NHS): The HNS is the British government health system.

Non-insulin dependent diabetes mellitus (NIDDM): NIDDM is diabetes mellitus not requiring insulin to control blood sugar levels. It is sometimes referred to as type two diabetes mellitus (Harris et al., 2009).
Non-invasive mechanical ventilation (NIV): Non-invasive mechanical ventilation is mechanical ventilation with a mask instead of inserting a tube in the trachea in which the patient remains awake and does most of the breathing (Urden, Stacy & Lough, 2006).

Oxygen saturation: Oxygen saturation is the amount of oxygen in the blood often measured by placing an oxymeter (oxygen measuring machine) on the finger or toe, earlobe or the forehead of the patient (Harris et al., 2009).

Pathic: Pathic is derived from the word “pathos” which means suffering or disease that causes sorrow or sadness. Pathic caring means feeling and sensing the other person’s suffering and caring with understanding and feeling (van Manen, 2000).

Partial arterial oxygen pressure (Pao₂): Partial arterial oxygen pressure is the level of oxygen bound to the haemoglobin (haemoglobin - oxygen carrying component of the red blood cell) (Urden, Stacy & Lough, 2006).

Patient controlled Analgesia (PCA): A PCA is a method of controlling or relieving pain in which a patient uses a pump loaded with the pain relief medicine by pressing a button that prompts the machine to release medicine into the patient’s blood stream (Harris et al., 2009).
Phenytoin: Phenytoin is an anti epileptic (anti seizure) drug used to control seizures. It acts by preventing the spread of abnormal electrical activity across the motor cortex by promoting the influx of sodium ions into the neurons (Tiziani, 2010).

Pleural Space: Pleural space is the space between the internal chest wall and the membrane that lines the lungs (Harris et al., 2009).

Post Traumatic Stress Disorder (PTSD): Post traumatic stress disorder is a severe anxiety disorder caused by exposure to a very frightening or life threatening situation, an injury or illness (Harris et al., 2009).

Pressure Support Ventilation (PSV) Partial ventilatory support in which the patient shares the work of breathing with the ventilator to achieve the required respiratory needs. (Pierce, 1995, 2007).

Primary Coronary intervention (PCI): PCI is a minor surgical procedure to unblock narrowed coronary arteries to restore blood flow by inserting a guide wire with a balloon with the aid of X ray guidance to locate the blocked artery and inflating the balloon at the blocked site and dilating the blocked area. The balloon is deflated and removed immediately after dilating the blocked area (Harris et al., 2009).

Pulmonary Artery Catheter: A pulmonary artery catheter is a flexible that is placed in the pulmonary artery of the heart used for monitoring, administration of drugs and making diagnoses including blood sampling (Urden, Stacy & Lough, 2006).

Pulse Contour PiCCO is a less invasive advanced more specific
Cardiac Output (PiCCO): haemodynamic monitoring system used to treat low blood pressure (Urden, Stacy & Lough, 2006).

Quality-adjusted lived years (QALYs): QALYs is the measure of disease burden including the quality and quantity of a life lived. It is used to assess the monetary cost of medical intervention (Harris et al., 2009).

RCA: RCA is an abbreviation for right coronary artery (Urden, Stacy & Lough, 2006).

Reintubation: Reintubation is the act of reinserting a breathing tube into the trachea through the nose or the mouth after the removal of another one (Harris et al., 2009).

Renal failure: Renal failure is the failure of the kidneys to remove toxins from the body can be sudden or slow onset and it can be with or without formation of urine (Harris et al., 2009).

Renal perfusion: Renal perfusion is the supply of blood and oxygen to the kidney tissues (Harris et al., 2009).
Resistant hypotension: Resistant hypotension is low blood pressure despite administration of multiple drugs (Harris et al., 2009)

Rheumatoid Arthritis: Rheumatoid arthritis is an autoimmune chronic inflammatory condition that affects tissues and joints. It mainly attacks synovial joints but can affect lungs, eyes and the heart including other internal organs (Harris et al., 2009)

Sedation Scale: A sedation scale is a method used to establish and the level of unconsciousness due to the level of sedatives given to the patient. It is used to regulate the amount of sedatives given to the patient in ICU (Harris et al., 2009)

Sepsis: Sepsis is a serious infection in the blood and or parts of the body leading to life threatening drop in the blood pressure (Harris et al., 2009)

Septic Shock: Septic shock is decreased oxygen delivery to the tissues due to severe systemic or local infection characterised by a drop in the blood pressure (Harris et al., 2009)

Sequential Organ Failure Assessment Score (SOFA): SOFA score is a scoring system that indicates the function of organs and extent of organ failure in critically ill patients in ICU. It has six components each representing the neurological, cardiovascular, coagulation, respiratory, hepatic and renal systems (Harris et al., 2009)
Short form 36 (SF-36): SF-36 is a health survey comprised of 36 items to assess a person's wellbeing. It has an eight point scale assessment of physical and psychological domains of wellbeing (Harris et al., 2009).

Speaking Valve: Speaking valve is a one way device that is fixed on a deflated tracheostomy tube to allow a patient to speak with the tracheostomy. It allows natural voicing, uninterrupted phonation, increased length of utterance, louder vocal intensity, and normal speech patterns. It is used in patients off the ventilator who can sustain their breathing without help from the ventilator (Harris et al., 2009).

Status Epilepticus: Status epilepticus is a life threatening condition characterised by persistent seizures lasting 30 minutes or longer or two or more seizures succeeding each other without recovery of consciousness (Harris et al., 2009).

STEMI: Myocardial infarction (heart attack) that affects the full thickness of the heart muscle (Harris et al., 2009).

Suctioning: Suctioning is an artificial way of removing secretions from the respiratory system using a flexible tube attached to a vacuum machine (Harris et al., 2009).

SWAN GANZ Catheter: Catheter inserted into the pulmonary artery for haemodynamic monitoring. It measures the function of both the left and the right side of the heart (Harris et al., 2009).

Temporary Pacing: Temporary pacing is the temporary mechanical generation of the heart rate when the natural heart rate is too low to
maintain life (Urden, Stacy & Lough, 2006; Harris et al., 2009).

**Thiopentone:** Thiopentone is a short acting barbiturate with a duration of action of 10 – 30 minutes. Barbiturates are drugs that are made from barbituric acid. They depress the central nervous system and can cause unconsciousness. Thiopentone is used to as muscle relaxant at the beginning of anaesthesia. In ICU it is mostly used in intubation procedures. It is also to control seizures (Tiziani, 2010)

**Thrombectomy:** Thrombectomy is a surgical emergency procedure of removing a thrombus (clot) from a blood vessel to restore circulation/blood flow to the affected area (Harris et al., 2009).

**Tonic clonic seizures:** A tonic clonic is a seizure consisting two phases – tonic phase (stiffness of the body) followed by clonic phase (generalised jerking movements of the body) (Harris et al., 2009).

**Tracheomised:** Tracheomised is a medical term referring to the presence of a tracheostomy tube in a patient’s trachea (breathing passage) (Harris et al., 2009).

**Tracheostomy:** Tracheostomy is an airway access that is surgically made in the trachea (Harris et al., 2009).

**Trans Oesophageal Examination (TOE):** TOE is an ultrasound of the heart done from the oesophagus (placing an ultrasound probe in the oesophagus to visualise the function of the heart) (Harris et...
Transient Ischaemic Attacks (TIAs):

TIAs are mini strokes resulting from temporary disruption of blood to the brain due to a clot in an artery supplying blood to the brain (Urden, Stacy & Lough, 2006).

Troponin:

Troponin is a specific protein found in the heart muscle which leaks out into the blood stream during a heart attack and is used as a biochemical indicator to diagnose a heart attack (Urden, Stacy & Lough, 2006; Harris et al., 2009).

Type Two Respiratory Failure

Type two respiratory failure is respiratory failure with increased partial arterial carbon dioxide due to fatigue or reduced lung surface for gas exchange e.g. in emphysema (Harris et al., 2009).

Vac Dressing:

A vac dressing is a medical procedure of applying foam with a vacuum pump to a wound to encourage healing (Harris et al., 2009).

Ventricular Fibrillation (VF):

VF is a life threatening condition characterised by very rapid chaotic contractions of the ventricles (lower chambers of the heart) resulting in the heart’s failure to pump (Urden, Stacy & Lough, 2006).
Volvulus (strangulated hernia):

Volvulus is a condition in which a section of the bowel twists upon itself causing an obstruction in the bowels and an abnormal protrusion in the membrane that covers abdominal organs. Strangulated means there was constriction of blood vessels leading to loss of blood supply around the neck of the hernia. It is characterised by nausea and vomiting, abdominal distension, tenderness, and tension, severe gripping abdominal pain and absence of bowel sounds. If untreated the volvulus can ruptures and cause serious abdominal cavity infection called peritonitis (Harris et al., 2009).
GLOSSARY REFERENCES


A STUDY OF LIVED EXPERIENCES OF MECHANICALLY VENTILATED PATIENTS IN INTENSIVE CARE

AN INVITATION TO PARTICIPATE IN RESEARCH.

Dear Sir/Madam,

You are invited to participate in a research project on lived experiences of mechanically ventilated patients in intensive care conducted by Agness C Tembo as part of PhD studies being undertaken at the University of Newcastle under the supervision of Dr Vicki Parker.

NATURE AND PURPOSE OF THE STUDY.

As part of my studies, I am conducting an inquiry into the experiences of mechanically ventilated patients. This study will explore what it is like to be a ventilated patient in intensive care. This knowledge will help nurses and doctors to understand the impact of current treatment and care of patients in intensive care so that we can know what improvements need to be made. I am especially exploring the aspects of mental well-being for ventilated patients in intensive care.
WHAT DOES THE RESEARCH INVOLVE?

Should you agree to participate in this study;

- You will be asked to talk to me, at least twice, about your experience in ICU. My interest is in your thoughts and feelings about the ICU environment, the technology (machines), being away from your family and the care you received from the healthcare professionals.

- The talks will take about 60 – 90 minutes and they will be conducted in your home to ensure privacy and comfort if this is acceptable to you.

- With your permission I will record our conversation. You may ask for the tape to be stopped and sections of it edited or erased at any time.

- I will transcribe (type word for word) our discussions and if you wish to have a copy of the transcripts to make comments and ask me to remove or add to a section of the transcripts you can do so. This is to ensure that all the stories and meanings are as you intended them to be.

- Your true identity will not be revealed and all the information you will give me will be confidential in the reports of the study.

- To ensure confidentiality in the process of the study, all information collected will be kept in a locked filing cabinet in the office at the University and it will only be used for the purpose of this study.

- My supervisors are the only other people who will have access to the information. The results of the study will be published without revealing your identity.

- A summary of the publication will be provided to you at your request by contacting me or my supervisors using the above contact details.

- Results of the project will be made available to you in a clear and timely manner should this be required.
YOUR RIGHTS

Your participation in this study will not affect the way the nurses and doctors will treat you. You are also free to decline this invitation now or at any stage of the study without giving a reason. This, too, will not make a difference in your care.

If you accept this invitation to participate in this study, you have the following rights:

- You can ask for further information from me at any time
- You can terminate your participation at anytime without fear of any changes in your subsequent care
- You can choose not to answer any question if you do not wish to without giving an explanation
- If you decide to withdraw from the project, you have the right to withdraw any information pertaining to your participation in the project that you may have given.

COMPLAINTS

This research has been approved by the Hunter New England Human Research Ethics Committee of Hunter New England Health, reference…..

Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, to Dr Nicole Gerrand, Professional Officer (Research Governance and Ethics), Hunter New England Human Research Ethics Committee, Hunter New England Health, Locked Bag 1, New Lambton NSW 2305, telephone (02) 4921 4950, email HNEHREC@hnehealth.nsw.gov.au.

Yours sincerely,

Agness Tembo
Faculty of nursing
University of Newcastle.
APPENDIX C – CONSENT FORM

Agness Tembo
Faculty of Nursing and Midwifery
University of Newcastle
Callaghan Campus
NSW 2308
29th November, 2007

A STUDY OF THE LIVED EXPERIENCES OF MECHANICALLY VENTILATED INTENSIVE CARE PATIENTS

CONSENT TO PARTICIPATE IN THE STUDY

I have received and read the information letter about the study of the Lived Experiences of Mechanically Ventilated Patients to be conducted by Agness Tembo from the University of Newcastle and all my questions have been answered to my satisfaction.

I hereby freely give consent to participate in the study. I am aware of and I understand the details of the manner in which the study will be conducted. I have kept a copy of the information and I realise that I have the right to choose not to participate in or to withdraw from the study at anytime without giving any reason and my treatment in hospital will not be affected now and in future.

If I decide to withdraw from the study I have the option of withdrawing all information I have provided.
Signature:

Date:

If you agree to participate in the study, please tick the box below and provide your contact details.

Name:

Address:

Phone Number:
APPENDIX D – Hunter New England Ethics Committee’s Ethics approval Letter

21 December 2007

Dr V Parker
Clinical Nurse Consultant – Research & Practice Development
Education Block
John Hunter Hospital

Dear Dr Parker,

RE: Innovation Practices in Intensive Care Over the Past Decade: How Have They Impacted on the Lived Experiences of Mechanically Ventilated Patients? A Phenomenological Inquiry. (07/12/12/5.07)
SSA reference number: 07/HNE/130

Thank you for submitting an application for authorisation of this project. I am pleased to inform you that authorisation has been granted for this study to take place at the following sites:

John Hunter Hospital

The following conditions apply to this research project. These are additional to those conditions imposed by the Human Research Ethics Committee that granted ethical approval:

1. Proposed amendments to the research protocol or conduct of the research which may affect the ethical acceptability of the project, and which are submitted to the lead HREC for review, are copied to the research governance officer;
2. Proposed amendments to the research protocol or conduct of the research which may affect the ongoing site acceptability of the project, are to be submitted to the research governance officer.

Yours faithfully

Research Governance Officer
Hunter New England Health
APPENDIX E – Hunter New England Ethics Committee’s Final Ethics approval Letter

10 December 2007

Dr V Parker
Clinical Nurse Consultant – Research & Practice Development
Education Block
John Hunter Hospital

Dear Dr Parker,

RE: Innovation Practices in Intensive Care Over the Past Decade: How Have They Impacted on the Lived Experiences of Mechanically Ventilated Patients? A Phenomenological Inquiry. (07/12/12/5.07)

Thank you for submitting the above protocol which was first considered by the Hunter New England Human Research Ethics Committee at its meetings held on 12 December 2007. This Human Research Ethics Committee is constituted and operates in accordance with the National Health and Medical Research Council’s National Statement on Ethical Conduct in Human Research (2007) (National Statement) and the CPMP/ICH Note for Guidance on Good Clinical Practice.

I am pleased to advise that following receipt and acceptance of the requested clarifications and changes to the information statement by the Professional Officer under delegated authority from the Hunter New England Human Research Ethics Committee, the Hunter New England Human Research Ethics Committee has granted ethical approval of the above project.

The following documentation has been reviewed and approved by the Hunter New England Human Research Ethics Committee:

- The Participant Information Sheet (version 2 dated November 2007); and
- The Consent form (version 1 dated November 2007)

For the protocol Innovation Practices in Intensive Care Over the Past Decade: How Have They Impacted on the Lived Experiences of Mechanically Ventilated Patients? A Phenomenological Inquiry

Approval from the Hunter New England Human Research Ethics Committee for the above protocol is given for a maximum of 5 years from the date of this letter, after which a renewal application will be required if the protocol has not been completed.

The National Statement on Ethical Conduct in Human Research (2007) which the Committee is obliged to adhere to, include the requirement that the committee monitors the research protocol it has approved. In order for the Committee to fulfill this function, it requires:

- a report of the progress of the above protocol be submitted at 12 monthly intervals. Your review date is December 2008. A proforma for the annual report will be sent two weeks prior to the due date.

Hunter New England Human Research Ethics Committee

(Locked Bag No 1)
(New Lambton NSW 2305)
Telephone (02) 49014 950 Facsimile (02) 49014 818
Email: hnehe@hne.health.nsw.gov.au
Nicole.gerard@hne.health.nsw.gov.au
Michelle.lane@hne.health.nsw.gov.au
8 April 2008

Dr V Parker
Clinical Nurse Consultant – Research & Practice Development
Education Block
John Hunter Hospital

Dear Dr Parker,

RE: Innovation Practices in Intensive Care Over the Past Decade: How Have They Impacted on the Lived Experiences of Mechanically Ventilated Patients? A Phenomenological Inquiry. (07/12/12/5.07)

Thank you for submitting a request for an amendment to the above project. This amendment was reviewed by the Chair of the Hunter New England Human Research Ethics Committee under the provisions of expedited review. This Human Research Ethics Committee is constituted and operates in accordance with the National Health and Medical Research Council’s National Statement on Ethical Conduct in Human Research (2007) (National Statement) and the CPMP/ICH E8 Note for Guidance on Good Clinical Practice.

I am pleased to advise that the Hunter New England Human Research Ethics Committee has granted ethical approval for the following amendment request:

- The inclusion of Dr Isabel Higgins as a co-investigator;
- To modify the inclusion criteria to the following:
  - Patients must have been ventilated for greater than 24 hours;
  - Patients must be 18 years or older; and
  - Patients must have been in ICU greater than 24 hours.


Approval from the Hunter New England Human Research Ethics Committee for the above protocol is given for a maximum of 3 years from the date of the approval letter of your initial application, after which a renewal application will be required if the protocol has not been completed. The above protocol is approved until December 2010.

The National Statement on Ethical Conduct in Human Research (2007) which the Committee is obliged to adhere to, include the requirement that the committee monitors the research protocols it has approved. In order for the Committee to fulfill this function, it requires:

- a report of the progress of the above protocol be submitted at 12 monthly intervals. Your review date is December 2008. A proforma for the annual report will be sent two weeks prior to the due date.
APPENDIX G – The University of Newcastle’s Human research Ethics Committee’s Ethics approval Letter

HUMAN RESEARCH ETHICS COMMITTEE

Acknowledgement of Registration of External HREC Approval

To Chief Investigator or Project Supervisor: Dr Vicki Parker
Cc Co-Investigators / Research Students: Dr Isabel Higgins
Dr Deborah Sundin-Huard
Mrs Agness Tembo

Re Protocol: Innovation practices in intensive care over the past decade: How have they impacted on the lived experiences of mechanically ventilated patients? A phenomenological inquiry

Date: 30-Jun-2008
Reference No.: H-2008-0237

Thank you for your Registration of External HREC Approval submission to the Human Research Ethics Committee (HREC) seeking approval of an Initial and Variation application in relation to the above protocol.

Your submission will be considered under HREC Review of External Approval review by the Committee at the earliest opportunity and you will be advised of the outcome. Meanwhile you may proceed with the research.

Your protocol reference number is H-2008-0237. Please use this in any correspondence with the HREC in relation to this protocol.

Professor Val Robertson
Chair, Human Research Ethics Committee

For communications and enquiries:
Ms Genevieve Farrell
Human Research Ethics Officer

Research Services
Research Office
The University of Newcastle
Callaghan NSW 2308
T +61 2 492 10333
F +61 2 492 17164
Genevieve.Farrell@newcastle.edu.au
APPENDIX H – BROAD QUESTIONS ASKED

Agness Tembo
Faculty of Nursing and Midwifery
University of Newcastle
Callaghan Campus
NSW 2308

ISSUES TO BE COVERED IN INTERVIEWS WITH PARTICIPANTS

In keeping with the qualitative research particularly the phenomenological tradition, all interviews will be broad based, open-ended and will be conducted in a conversation approach (van Manen, 1990). The depth and length of questions will be determined by the individual participant’s ability to openly and comfortably describe their experience, fears, feelings and concerns. The need to probe and clarify statements will also play a major role in determining the course of the interviews. The interviews will begin with questions aimed at providing a background data about each participant. As mentioned before the main items covered will depend on the participants’ responses to the broad, open-ended questions or the need for comments or clarification. Examples of questions to be asked are as follows:

BACKGROUND QUESTIONS

Because demographic data was collected from the clinical notes, I already knew most of it by the time I interviewed the participants.

BROAD OPEN-ENDED QUESTIONS

- In your own words can you tell me what it was like to be critically ill in intensive care?
- What is it like to be critically ill and ventilated?
- What is it like to wake up from unconsciousness?
- What is the impact of the experiences of people who have been critically ill?
- What does it mean to have been critically ill in ICU?
APPENDIX I – PUBLICATIONS FROM THIS THESIS

PUBLICATIONS FROM THIS THESIS

FULL ARTICLES


ABSTRACTS