Being at its most elusive: The experience of long-term mechanical ventilation in a critical care unit

Submitted by

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This research study explored the meanings former patients attributed to being on long-term mechanical ventilation in a critical care unit (CCU).

An interpretive phenomenological-ontological perspective informed by the philosophical tenets of Heidegger (1927/1962) was used to examine the lived experience of a group of people who had previously been hospitalised in one of three critical care units in southeast Queensland, Australia, during which time they were on a mechanical ventilator for a period of seven days or more. Data were collected using 14 unstructured audio-taped interviews from participants, who had indicated that they were willing and able to recall aspects of their critical care experience. The data were analysed using the method developed by van Manen (1990). A total of nine people participated in the study, of which six were male and three female. Their ages ranged from 21 to 69 years.

Thematic analysis of the data revealed four themes: Being thrown into an uneveryday world; Existing in an uneveryday world; Reclaiming the everyday world; and Reframing the experience. Throughout the description of these themes, excerpts from the interviews with the participants are provided to demonstrate, and bring to light the meaning and interpretations constructed. From this thematic analysis, a phenomenological description drawing on Heidegger’s tenets of Being was constructed. Titled Being at its most elusive, this description showed that participants experienced momentary lapses of: situation, engagement, concern and
care, temporality, and the ability to self-interpret. These findings highlight and affirm the relevance of Heidegger’s ontological tenets to reveal Being.

The findings of this study served as a basis for a number of recommendations relating to nursing practice, education and research. Recommendations relating to practice include: constructing a more patient-friendly critical care environment, increased involvement of patients and their families in decision making and patient care activities; ensuring adequate critical care nursing staff levels; ensuring and maintaining appropriate skill level of critical care nurses; enhancing methods of communication with patients; planning for effective patient discharge and adoption of a designated nurse position for discharge planning; providing opportunities for follow up contact of patients once they are discharged from CCU; and promoting the establishment of follow up services for former CCU patients, and their families.

Recommendations relating to critical care education include: incorporating more in-depth information of the psychological and social aspects of patient and family care into care planning; incorporating communication and counselling education and training to assist nurses caring for mechanically ventilated patients, and their families; further education regarding the role and responsibilities of patient discharge planning from CCU; incorporating more advanced research skills training and utilisation of research findings into practice; and the provision of appropriate and ongoing training and education in areas such as manual handling and communication skills for all health care staff involved in the direct care of CCU patients.
This study also recommended that further research be undertaken to: examine and compare different sedative and analgesic protocols and their effects on the incidence of nightmares and hallucinations reported by CCU patients; replicate this study in a group of patients from different cultural or ethnic backgrounds; evaluate the efficacy of current methods for communicating with intubated and mechanically ventilated patients in the CCU; develop, test and evaluate the efficacy of new methods for communicating with intubated and mechanically ventilated patients in the CCU; examine CCU patients’ perceived level of control and power; explore the extent and type of involvement patients would like to have in their care whilst in the CCU; investigate the extent and type of problems experienced by CCU patients after discharge; explore the usefulness and appropriateness of personal diaries for individual patients as an aid to assist in understanding and resolving their CCU experience; and examine the value of follow up contacts by CCU staff to former patients and their families.

In summary, the findings from this study add substantial knowledge to critical care nurses’ understanding and knowledge about what it means to be on long-term mechanical ventilation in a critical care unit. Findings will help inform future critical care nursing practice and education, and the provision of holistic and evidenced-based care.
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On a final note, I would like to express my sincere appreciation of the continual support and encouragement given unconditionally to me by my husband Bryan, daughter Chloe and son Brett, during the writing of this thesis.
DECLARATION

I certify that the main text of this thesis is entirely my own work. This work has not previously been submitted for a degree or diploma in any university. To the best of my knowledge and belief, the thesis contains no material previously published or written by another person except where due reference is made in the thesis itself.

Signature: .................................................................

Patricia Johnson

Date: .................................................................
August 1997

I remember this as a fairly typical night shift in the ten bed critical care unit where I
had been employed as a clinical nurse for over one year. Prior to this, I had spent
some 15 years working as a registered nurse in a variety of critical care units in New
South Wales and Queensland. I considered myself well experienced in caring for
critically ill patients, including those who were on a mechanical ventilator. It was
4am. The dreaded time in the middle of a night shift where I always started to feel
tired, slightly nauseous from lack of sleep, and wishing morning would arrive, but
hoping it wouldn’t: I had far too many things to do before the morning staff arrived
at 7am. I was caring for a middle-aged woman who had undergone extensive bowel
surgery some days previously to treat a cancerous growth. Due to unexpected
complications resulting in respiratory difficulties, she had been placed on a
mechanical ventilator to support her respiratory efforts. It was now day five of her
mechanical ventilation, and weaning from the ventilator was still some days off. She
was receiving frequent intravenous sedative agents, and appeared to be resting
comfortably.

Throughout the night I chatted quietly to the nurse in the next cubicle. We talked
about our families, work, and other social activities. We kept our voices low so as
not to disturb the other patients in the ward, however, we felt that our respective
patients wouldn’t hear as they were both mechanically ventilated and sedated. I
commented to my colleague: “It must be awful to be stuck on this thing [ventilator] –
if it ever happens to me promise you’ll keep me totally bombed out – I don’t want to
know about it”. “Don’t worry” my colleague replied, “they don’t remember
anything”. As I glanced down at my patient, she opened her eyes at me – they were hazy and very watery, but she did seem to be trying to focus. Afterwards she was very restless. Was something troubling her I wondered? Was she in pain or uncomfortable? I wished I could do more to help her. I knew she won’t hear or remember anything, but I did stroke her forehead and talk gently to her and reassure her. If only I knew what it was like for these patients – then I might be able to ensure that I could meet not only their physical but also their emotional needs.
CHAPTER 1

INTRODUCTION

Introduction to the Study

What does it mean to be on long-term mechanical ventilation in a critical care unit?

This is the question I set out to explore in this research study. As revealed in the prologue to this first chapter, this question arose from my background as a registered nurse and my experience of caring for long-term mechanically ventilated people in critical care units. Although I considered myself an expert critical care nurse in many ways, it was my belief that I did not have sufficient knowledge or understanding of what it was like for patients to be on long-term mechanical ventilation. How then could I plan for and provide the best possible care, when I was unsure of what patients wanted from me? I knew I could manage the technical aspects competently. But was that enough? In order to practise holistically I needed to know more about what it means for critically ill patients to experience this form of medical treatment in the critical care environment. Knowing more would enable me to gain a greater understanding of what it means for people to have experienced this phenomenon, practise from an evidence base, and share this understanding with nurses involved in the care of such patients.

To establish an understanding of the question, it is first necessary to define the term “long-term mechanical ventilation”. Mechanical ventilation is the artificial control of the breathing cycle by means of a machine. In this study, long-term refers to a period of mechanical ventilation lasting seven or more days. Although definitions of what constitutes long-term varies in the literature, this particular time frame was
chosen as appropriate to meet the aim of this study. From my own personal experience of nursing many patients on mechanical ventilators, those who were on this form of treatment for at least seven days were more likely to have experienced periods of time when they were not sedated and could therefore potentially recall events.

Initially ventilator machines were anaesthetic devices driven by a gas flow through which it was impossible to incorporate spontaneous patient breathing. However, in the early 1970s more sophisticated machines were developed that had the capacity to incorporate spontaneous breathing, and also the ability to support the pressure of each breath, thereby help the weaning process\(^1\) and allegedly decreasing patient discomfort (Ashurst, 1997). Modern ventilators of today are extremely complex pieces of machinery that use a variety of sensitive triggers and flow patterns that are able to adapt more closely to patients’ needs.

Mechanically ventilated patients are nursed in specially equipped critical care units in acute care hospitals, where specialist critical care staff, including nurses and medical practitioners, manage their care. Allied health care personnel such as physiotherapists also provide treatments where necessary. Nurses caring for mechanically ventilated patients have a unique role, as they provide continuous care at the bedside on a one-to-one basis 24 hours a day, thereby assisting people throughout their illness episode. To function effectively in the critical care environment, many nurses choose to undertake postgraduate studies in this specialty

\[\text{REFERENCE}\]

\(^1\) Please refer to Appendix A for an explanation of critical care terminology used throughout this thesis.
in order to attain the requisite skills needed to provide optimal nursing care in this complex environment (Confederation of Australian Critical Care Nurses [CACCN], 1996a). Optimal care includes not only the technical skills and knowledge required to competently manage critically ill patients, but also knowledge of the psychosocial aspects of critical illness. This present study was undertaken to explore the meaning former patients attributed to being on long-term mechanical ventilation in a critical care unit as a means of extending knowledge and understanding of the experience of this form of critical care treatment from the patients’ perspective.

**Background to the Study**

This research study is both timely and relevant in the current critical care climate for two main reasons. First, a number of reports have indicated a steady increase in the number of people requiring long-term mechanical ventilation, which has been attributed to the increasing number of elderly persons or those with chronic illness being admitted to critical care units (Adams, Shapiro, & Marini, 1998; Burns et al., 1998; Campbell & Pierce, 1998; Chelluri, Pinsky, Donahoe, & Grenvik, 1993; Clochesy, Daly, & Montenegro, 1995; Cohen, & Lambrinos, 1995; Gluck & Corigan, 1996; Goldberg & Frownfelter, 1990; Gracey, Naessens, Krishan, & Marsh, 1992; Kite-Powell, Sabau, Ideno, Hargraves, & Dahlberg, 1996; Luce, 1996; Meinders, van der Hoeven, & Meinders, 1996). Although definitions of what constitutes long-term vary from three days onward, statistics from the Australian Institute of Health and Welfare (AIHW) indicate that between 1996-1997, a total of 17,469 patients were mechanically ventilated in Australian hospitals, with approximately half this number requiring continuous mechanical ventilation for 96 consecutive hours or more (AIHW, 1998). The latest available statistics for the years 2000-2001 show a total of 25,614 patients undergoing continuous ventilatory
support, an increase of nearly 8,000 (AIHW, 2002). Of these, slightly more than 50% required ventilation for 96 consecutive hours or more.

In Australia there are 170 critical care units that are equipped to manage mechanically ventilated patients. Of these, 114 are located in the public sector, with the remaining 56 situated in private hospitals (ANZICS Research Centre for Critical Care Resources Survey [ARCCCR], 2000). The total beds available number 1672, and from these, 1140 or approximately 70% are designated as ventilator beds. That is, these beds are equipped and can be used to treat patients requiring mechanical ventilation as part of their critical care management. For nurses working in this area, caring for a long-term mechanically ventilated patient is often an everyday occurrence. It is well recognised that ventilator-dependent patients present one of the most challenging aspects of critical care practice, as their management and treatment incorporates the utilisation of a complex array of biomedical equipment, and sophisticated diagnostic and therapeutic regimes (Urden, Lough, & Stacy, 2002). It is therefore essential that critical care nurses have access to the best available evidence on managing the care of ventilated patients. This must include evidence derived from studies that examine the effect and meaning of this form of treatment from the viewpoint of the patient.

Second, despite critical care nurses’ interest in understanding the effects of technologies and treatments on patients (McKinley, Nagy, Stein-Parbury, Bramwell, & Hudson, 2002; Parker, 1997) and a call by the peak professional critical care organisation in Australia to adopt a holistic approach and incorporate research to guide practice (CACCN, 1996b), research studies have predominantly focused on the physiological effects and complications of mechanical ventilation (eg. Bishop, 1989;
Estban, Anzueto, Frutos, & Alia, 2002; Glauser, Polatty, & Sessler, 1988; Seneff, Zimmerman, Knaus, Wagner, & Draper, 1996). In contrast, fewer studies have been undertaken that specifically focus on the experience of mechanical ventilation from the patient’s perspective, so there is less evidence on which to base non-physiological, or psychosocial aspects of care. This may be partly due to the widespread belief that most patients do not remember their critical care experience, so little would be gained from interviewing them (Parker, 1997, pp. 14-16). However, a number of studies have found that many people do remember their critical care hospitalisation, and are able to provide vivid and detailed descriptions of their experience (Adler, 1997; Bergbom-Engberg & Haljamae, 1988a; Green, 1996; Heath, 1989; Holland, Cason, & Prater, 1997; Laitinen, 1996; Parker, 1997; Parker, Schubert, Shelhamer, & Parrillo, 1984; Puntillo, 1990; Russell, 1999; Simpson, Armstrong, & Mitchell, 1989).

The following studies have explored the experience of critical care from the patient’s perspective, although not all of the participants had been on a mechanical ventilator (Adler, 1997; Asbury, 1985; Ballard, 1981; Bergbom-Engberg & Haljamae, 1988a; Bradburn & Hewitt, 1980; Chew, 1986; Cochran & Ganong, 1989; DeMeyer, 1967; Easton & McKenzie, 1988; Elpern, Patterson, Gloskey, & Bone, 1992; Granberg Axell, 2001; Gries & Fernsler 1988; Hafsteindottir, 1996; Jablonski, 1994; Johnson & Sexton, 1990; Jones, Hoggart, Withey, Donaghue, & Ellis 1979; Logan & Jenny, 1997; McKinley et al., 2002; Parker, 1997; Riggio, Singer, & Hartman, 1982; Russell, 1999). Findings from the studies undertaken prior to 1990 indicate that patients experienced communication difficulties, insufficient explanation of procedures by nurses, activity restrictions, anxiety and panic, nightmares and hallucinations, feelings of insecurity and helplessness, and discomfort related to
equipment and various nursing procedures. The studies from 1990 onward revealed similar findings, once again highlighting the ongoing problems associated with poor communication, and feelings of dependence and helplessness. In addition, the presence and use of technology was reported as experienced in different ways, with some participants finding it promoted feelings of security and comfort (McKinley et al., 2002; Russell, 1999), whilst others found it frightening (Adler, 1997; Granberg Axell, 2001; Jablonski, 1994; Parker, 1997). Concerns raised were related to nurses’ perceived misuse of power to gain control over patients (Jablonski, 1994; Adler, 1997; Russell, 1999). There were, however, more reports of positive experiences related to the care provided by nurses, particularly regarding the information provided to patients and their families (McKinley et al., 2002; Russell, 1999).

Overall, findings from these studies are difficult to synthesise, as a variety of research approaches including quantitative and qualitative methodologies, or a mixture of both, were used to collect and analyse data, and the focus of research questions and aims changed over time. In addition, the majority of studies had been conducted in North America or Scandinavia, where critical care practices differ markedly from those of Australian critical care nurses. For example, in North America respiratory technicians usually manage the mechanical ventilator and its associated equipment, whereas in Australia the critical care nurse who is responsible for the patient totally manages the mechanical ventilator and all patient care. Thus the findings from these studies may have limited relevance for Australian critical care nursing practice.

Moreover, none of the studies specifically focused on long-term mechanical ventilation, thus the meaning of this experience from the patients’ perspective has
been under-explored. Against a background of increasing numbers of people receiving long-term mechanical ventilation, and a lack of available evidence of the meaning of this for patients, the need for this research study was apparent.

**Purpose of the Study**

This study sought to explore, describe and interpret the meaning patients attributed to their experience of being on long-term mechanical ventilation in a critical care unit in southeast Queensland. To gain a greater understanding of what it means for people to have experienced this phenomenon is to make known what it means for people to exist and live through this particular event in their lives. This is an ontological question. It is from this experience and the event in their lives that the question of meaning arises, and was posed to the study participants. The research question asked: *What does it mean to be on long-term mechanical ventilation in a critical care unit?* To reach an understanding of this question it was essential to turn to those who have lived through such an experience, and utilise an appropriate research approach that can assist in providing an answer to the research question.

**The Research Methodology**

In order to gain a greater understanding and awareness of the experience of being on long-term mechanical ventilation in a critical care unit, it was essential to use formal research methods that could best explore this phenomenon of interest. Qualitative methodology, in particular phenomenology, was seen as the most appropriate approach, as it offered a methodological and philosophical perspective whose purpose is to develop a greater understanding through description, reflection, and awareness of the many meanings of particular phenomenon (van Manen, 1984, p. 12). Phenomenology does not impose structures such as hypotheses, or attempt to
explain, predict and control the world through generation of empirical facts and scientific generalisations. Instead, phenomenology aims at gaining an insightful understanding and description of human meaning by bringing us into closer contact with those experiencing a phenomenon. Thus, phenomenological inquiry takes into account the meanings individuals attribute to a situation. I considered this extremely important, because as nurses we need to understand people’s experiences of illness and illness treatments to allow us to better understand and care for patients throughout their illness episode.

The particular phenomenological approach utilised in this study was ontological-hermeneutic phenomenology informed by the ideas of Heidegger (1927/1962). The decision to use this approach to inquiry was guided by the research question, which is concerned with the meaning people attribute to a particular experience, in this instance being on long-term mechanical ventilation in a critical care unit. Such an approach is valuable as it enables the researcher to explore a phenomenon from the experiencing person’s perspective, and bring to light a greater understanding and awareness of the meaning people attribute to their experience. In this study, meaning was revealed through the reflective conversations between the researcher and the interview texts. Throughout the research process, an authentic and textually rich picture of what it means to experience long-term mechanical ventilation in a critical care unit was revealed. Through the ontological-hermeneutic approach, I was able to reveal how people experience the phenomenon, and generate an understanding of this from an interpretation of the interview texts provided by the study participants.
Significance of the Study

This research is significant for three main reasons. First the study extends the knowledge of what it is like for patients to be on long-term mechanical ventilation in a critical care unit, and builds evidence upon which to base critical care nursing practice. Nurses are urged to utilise reliable evidence upon which to inform and guide decision making in practice (Pearson, Borbasi, Fitzgerald, Kowanko, & Walsh, 1997) as a means of enhancing nursing practice and improving patient outcomes.

The development of evidence-based practice (EBP) has been widely embraced by many health care professions, particularly medicine, with nursing also taking a keen interest. EBP is a concept defined by Sackett, Rosenberg, Gray, Haynes, & Richardson (1996) as the “conscientious, explicit and judicious use of current best evidence in making decisions about the care of individual patients” (p. 71). It is a means of applying the findings from rigorous research studies into clinical practice. This includes findings from qualitative studies, which until recently had not been considered within this framework. Furthermore, as the well known Australian academics Madjar, Taylor and Lawler (2002) argued recently, qualitative research is a valuable approach to exploring human experience and offers a means of both complementing and extending the findings of more objective forms of evidence.

It has been identified that the majority of studies undertaken to examine peoples’ experiences of critical care were conducted overseas. McCarthy and Hegney (1998) urge nurses to be wary of uncritically applying research findings that are derived from a different context. It is therefore important for critical care nurses to utilise evidence from studies that are both rigorous and contextually relevant. This study will therefore provide valuable evidence for critical care nurses working in
Australian critical care units, and may lead to improvements in practice and patient care. In addition, findings from this study can be used to compare and contrast findings from other international studies in order to gain a more complete understanding of patients’ experiences.

Second, findings from this study will increase the awareness and understanding of this experience from the patients’ perspective. This may assist all health care professionals involved in the management of the long-term mechanically ventilated person in the critical care unit, including critical care nurses, to reach a greater appreciation of what it means for patients to live through and endure such an illness experience. This understanding has the potential to change practice.

Last, this study will assist critical care education providers to develop and incorporate content based on contemporary research findings. Health care, particularly in the area of critical care, continues to experience rapid change. The increasing use of sophisticated technology and complex patient treatment regimes requires critical care nurses to be educationally prepared with the appropriate level of skill and knowledge in order to provide quality care to patients and their families. The former Confederation of Australian Critical Care Nurses, now known as the Australian College of Critical Care Nurses (ACCCN) endorses the recommendations of the 1993 Madrid Declaration that outline the desired curricula for critical care nurse educational programs (CACCN, 1996a). This included content dealing specifically with the psychosocial aspects of patient care. Findings from this study will therefore reflect the profession’s educational needs, and be of benefit for critical care educators.
Structure of the Thesis

This is an ontological study of the meaning of a particular human experience. The nine participants in this study all shared their stories with the researcher, and although each story was unique, a number of shared meanings emerged and generated major themes. From these major themes of the lived experience, I was able derive a phenomenological description that revealed the meaning participants attributed to being on long-term mechanical ventilation in a critical care unit in southeast Queensland, Australia.

This thesis is organised into nine chapters. In this first chapter, I have introduced the study and made known my interest in pursuing this topic of research. I described the background of the study and clearly identified the need for this research. Following this, I outlined the purpose of the study, posed the ontological question, and justified using Heideggerian phenomenology as the most appropriate research approach. Finally, the significance of this study to nursing was explained.

Chapter two discusses the management of the mechanically ventilated patient in the critical care unit in order to provide a contextual picture for this study. The chapter commences with an overview and description of the history, purpose and function of critical care units, mainly from an Australian context. A discussion of critical care nursing then follows, focusing on critical care nursing practice and education. Next, a description of mechanical ventilation and the management of the mechanically ventilated patient within a critical care unit are provided to give the reader a background understanding of the context of the study.
Chapter three reviews the literature that is relevant to the research question. Studies that focus on patients’ experiences of critical illness and critical care hospitalisation, including the experience of being on a mechanical ventilator, are discussed and critically analysed. Findings from these studies are grouped in four main themes: alterations in perception, responses to illness and the critical care environment, pain and discomfort, and comforting factors. While these studies have identified, through a variety of research approaches, significant factors relating to patients’ experiences of critical illness, they have failed to adequately explore the meaning of being on long-term mechanical ventilation in a critical care unit. This present research study aims to address this topic, fill the gap in the literature and provide an extra dimension in the research on critical care patients’ perspectives.

Chapter four provides a description of ontological phenomenology, which is the methodological approach chosen for this study. This chapter begins by locating the methodology within the paradigm of inquiry and provides a rationale for using this particular approach. Following this, an overview of the various types of phenomenology and the historical development of this particular methodology are then discussed. The philosophical tents underpinning Heideggerian (1927/1962) phenomenology that are pertinent to this study are described. This demonstrates how Heideggerian philosophy offers a foundation to assist in revealing the meaning of a phenomenon through taking an ontological perspective. In the final part of chapter four, a discussion that addresses the critiques raised by a number of authors concerning nurses’ use of interpretive methodology is provided, and the limitations to this approach are identified, to demonstrate my awareness of the issues involved for nurses in taking this particular perspective.
Chapter five discusses the research process and methods utilised in this study to explore the study’s research question. The issue of rigour in this particular phenomenological approach is described to highlight the importance of ensuring methodological consistency with the chosen approach throughout the entire research process. The procedures for the selection and recruitment of the study participants, collection and analysis of data, and ethical considerations are then outlined. In particular, the way in which van Manen’s (1990) six activities for phenomenological data analysis are congruent with the chosen methodological approach is described and demonstrated. It will be shown that this method was most suited to this study, as it reflected the philosophical underpinnings of the methodology, and enabled me to draw on my experiences whilst closely interacting with the text. Thus, the horizons of the participants and myself came together to find a meaningful account of the phenomenon.

Chapter six is entitled participants’ stories. This chapter provides a brief overview of the stories told by four of the nine people who participated in this study. This chapter ‘sets the scene’ for the following two chapters that present the findings of the study by providing paradigm cases to demonstrate how the research method was utilised for interpretation. Participants needed to set the scene and described their critical illness event in its entirety. From this, a thematic analysis of the lived experience was developed which is presented in the following chapter.

Chapter seven discusses the major theme categories that were revealed from thematic data analysis of the lived experience of participants. Four major themes emerged from the data. Being thrown into an uneveryday world, existing in an uneveryday world, reclaiming the everyday world, and reframing the experience. These major
themes encompass the critical illness episode, including the admission to the critical care unit, being on long-term mechanical ventilation in the critical care unit, the transfer from the critical care unit to the hospital ward, and the discharge from the hospital to home. I chose to present the findings this way as it represents the totality of the experience from the viewpoint of the participants. From these major themes, an ontological description of being on long-term mechanical ventilation in a critical care unit was constructed, and this is presented in chapter eight.

The final chapter, chapter nine, summarises and discusses the overall findings, and compares and contrasts these with the extant literature. From this, an affirmation of the chosen methodology, in particular Heidegger’s tenets of Being for deriving human meaning, and the unique contribution of this study to an ontological understanding of Being and nursing’s knowledge base are made explicit. A number of recommendations for changes in clinical practice and education are outlined, and areas for further research are suggested. The limitations of the study are then discussed, issues of rigour are examined, and a conclusion to the study is provided.
CHAPTER 2
THE MANAGEMENT OF THE MECHANICALLY VENTILATED PATIENT IN THE CRITICAL CARE UNIT

Introduction
The first chapter of this thesis outlined that the focus of this research was the meaning people attributed to being on long-term mechanical ventilation in a critical care unit. This second chapter provides an overview of the context of critical care, and describes the management of mechanically ventilated patients in the critical care unit. This overview is essential to this study, as it provides the reader with the necessary background knowledge of the study setting. This includes a discussion of how management of mechanically ventilated persons came to be located in critical care units, and the central role of critical care nurses in patient care.

In order to structure the discussion in a way that has meaning and provides relevance and background to the study, it was necessary to divide the discussion into a number of sections. Therefore, the chapter commences with a description of critical care units, including the history, purpose and current function of these units, particularly within the Australian context. Because registered nurses provide the vast majority of care to mechanically ventilated persons in critical care units, the ways in which they practice may have a significant impact on patient’s perspectives of their critical illness experience. Thus, it is necessary in this chapter to also provide a review of critical care nursing, including nursing practice and education to establish an understanding of the knowledge nurses bring to the care of critically ill patients.
Following this, the discussion turns to the management of the mechanically ventilated patient within a critical care unit.

**Critical Care Units**

A critical care unit (CCU) is an area within a hospital specifically staffed and equipped for the continuous care of critically ill, injured or post-operative patients who have a condition compatible with recovery (CACCN, 1996a). For the purpose of this study I have used the term critical care unit (CCU), although critical care units include intensive care and coronary care units, or a combination of both (ICU/CCU) as well as high dependency units. The main purpose of any critical care unit is to provide quality care for critically ill patients. The Australian College of Critical Care Nurses (ACCCN), described the critically ill person as follows:

The critically patient is characterised by the presence of actual and or potential life-threatening health problems. The needs of these patients include the requirement for continuous observation and intervention to prevent complications and restore health where possible. The preservation of the rights and dignity of the critically ill patient are also paramount needs, including the right to refuse treatment and right to die with dignity where the restoration of health is not possible. As man (sic) is a biopsychosocial being, the concept of the critically ill patient includes the family and or significant others. (ACCCN, 2002a, p. vi)

Critical care medicine developed in the early 1950s due to several factors. First, it was shown that mortality from acute respiratory failure associated with poliomyelitis, which was epidemic at the time, could be reduced if patients were ventilated using negative pressure ventilators, known as “iron lungs” and that better results could be obtained if all patients were grouped together in one ward. The use of this particular management regime for poliomyelitis patients with paralysed respiratory muscles first developed in Scandinavia, where at Blegham Hospital in Copenhagen, up to 75
patients were mechanically ventilated at one time (Bryan-Brown, 1988). As a direct result of this epidemic and the need for ventilatory support for many patients suffering from poliomyelitis, clinical testing of positive-pressure ventilation was undertaken, and modern respiratory supports began to be incorporated into hospitals on a world-wide basis.

Development of critical care units was also helped by the rapid advances made in surgery and anaesthesia that resulted in the introduction of specialist post-operative recovery rooms. Finally, advances in cardiology such as cardioversion and electrocardiograph (ECG) monitoring also played a major role as patients requiring these technologies need monitoring and observation that could more effectively be performed by qualified staff in a discrete area. Critical care units proliferated rapidly in the 1970s and early 1980s, as the benefits of centralising specialist staff, equipment and technologies became recognised (Oh, 1990).

The origins of critical care units in Australia have been similar to other Western countries. Within Australia there is a range of critical care units, where the type and scope of patient management regimes provided is often a reflection of the size of the unit, and the human and technological resources available. Depending on the size of the hospital and the patient casemix, critical care units may also be organised into one or more specialties. For example, units may be separated into surgical units or medical units, or organ systems (spinal, cardiothoracic), or be age-dependent (neonatal, paediatric, adult). Regardless of the type of critical care unit, it is imperative that the health practitioners employed within these units have the appropriate level of skill and education to enable them to practise competently. Critical care nurses are the largest group of health practitioners working in critical
care units, and provide continuous care to patients over 24 hours. On this basis, the significant impact critical care nurses have on patient care cannot be over-estimated. Thus, to provide a full contextual picture of the critical care unit, it is also important to include a discussion and review of critical care nursing.

**Critical Care Nursing**

With the introduction of critical care units within Australia in the early to mid 1960s, a demand arose for nurses with specialist skills in managing the care of critically ill patients within these units. As a specialty group, critical care nurses have always been professionally active, by the early 1970s critical care nursing special interest groups formed in most Australian states (Williams & Leslie, 2001). The Australian Society of Critical Care Nurses (ASCCN) was formed a decade later. This group went on to become the Confederation of Australian Critical Care Nurses (CACCN), and finally in 1999 the Australian College of Critical Care Nurses (ACCCN) was formed as a single national body. ACCCN is recognised as the peak clinical professional organisation for critical care nurses in the country (Williams & Leslie, 2001).

It has been estimated that there are approximately 20,000 critical care nurses in Australia (AIHW, 1998). Of these, around 50 percent work in critical care units, and the other half in critical care related areas such as coronary care, high dependency and emergency services. In common with the overall nursing workforce in Australia, critical care nurses are predominantly female with the majority of them working within capital cities or other major metropolitan centres (Williams & Leslie, 2001). Although periodic shortages of critical care nurses occur due to factors including: insufficient recruitment practices; a lack of perceived available education programs;
and a myriad of industry based issues, the profession has been able to establish a standard clinical staffing arrangement of 1:1 nurse-intensive care patient ratio and a 1:2 nurse-high dependency patient ratio across Australia (Williams & Leslie, 2001).

Management of the critically ill patient involves a multi-disciplinary health care team including nurses, physicians and allied health workers. As nurses are in constant attendance at the bedside, they are an integral part of patient care. Critical care nursing is a key element in patient care delivery within critical care units, and nursing practices can have a significant impact on patients and their families. With this in mind, findings from this study will provide a valuable resource for critical care nursing practice and education, particularly from an Australian perspective.

In Australia, critical care units are almost exclusively staffed by registered nurses. To function effectively in the critical care environment, critical care nurses must possess a variety of advanced nursing skills. Such skills encompass a comprehensive knowledge of advanced physiology and pathophysiology, advanced clinical assessment skills, problem solving and communication skills, research skills and a sound knowledge of legal, ethical and professional issues (CACCN, 1996a). In line with the adoption of the Madrid Declaration on the preparation of critical care nurses, it is also essential that comprehensive psychosocial assessment and support for both the patient and family is provided (CACCN, 1996a).

The Australian College of Critical Care Nurses provides the following definition of a critical care nurse:
A critical care nurse is a registered nurse who provides competent and holistic care for the critically ill patient through the integration of advanced level knowledge, skills and humanistic values. He or she demonstrates advanced problem-solving and communication skills and utilises these effectively in managing complex patient care situations and coordinating health care activities within the critical care environment. The critical care nurse specialist delivers care within a sound ethical and legal framework, fulfilling the role of patient advocate when appropriate, and demonstrates accountability for his or her actions. The critical care nurse specialist promotes a team approach to care in the critical care environment through effective collaboration with other members of the health care team, and by encouragement and support for his or her colleagues as a leader and role model. The critical care nurse specialist contributes to the advancement of critical care nursing practice through involvement in professional activities, including the development of self and colleagues, and through promotion of research based practice. (ACCCN, 2002a, p. vi)

Many nurses working in the critical care area undertake postgraduate studies in this specialty in order to attain these skills and provide optimal nursing care in this complex environment (CACCN, 1996a). Postgraduate study may be at the level of Graduate Certificate, Graduate Diploma or Masters level. These qualifications are usually undertaken on a part-time basis, as students are required to be working within a critical care unit where learning and knowledge can be applied in the clinical setting (Williams, Chaboyer, & Patterson, 2000).

ACCCN has been pro-active in areas such as the development of advanced specialty competencies, processes for credentialling, and publishing position statements on critical care nurse education (CACCN, 1996a; Kendrick et al., 2000; Underwood et al., 1999). Currently, a study into the desired educational outcomes of critical care nurse education programs is being undertaken as part of a project for the ACCCN Education Advisory Panel (Aitken, Curry, & Daly, 2001). Critical care nursing in Australia is therefore a well-established specialty group that is active in establishing standards for education, professional recognition and clinical excellence. Critical care nurses are also research-oriented, as evidenced by the growing body of research
publications and development of collaborative research projects between industry and the tertiary sector (Chaboyer, Dunn, & Najman, 2000). Findings from this present study will extend the knowledge base relating to critical care patients’ experiences, and contribute to evidence-based critical care nursing practice.

Critical care nurses from all over the world are increasingly networking through their professional organisations and conference gatherings, thus the need for a worldwide forum for the advancement of critical care nursing practice became evident. As a result, the World Federation of Critical Care Nursing (WFCCN) was formed in October 2001 and launched at the 8th World Congress of Intensive and Critical Care Medicine in Sydney, Australia. The purpose of the WFCCN is to link critical care nursing associations and nurses throughout the world, with the overall objective of improving the standard of care provided to critically ill patients and their families (Williams et al., 2001). Currently, countries associated with the WFCCN include Australia, Canada, Denmark, United Kingdom, Hong Kong, Korea, New Zealand and the Philippines. The number of countries associated with this organisation is expected to increase through publication and networking.

Thus critical care nursing is a dynamic specialty with a common goal of improving the quality and effectiveness of care for critically ill patients and their families. This includes care of the patient requiring mechanical ventilation. As this study explores the meaning people attribute to being on long-term mechanical ventilation in a critical care unit, it is appropriate to review the management and care of the mechanically ventilated patient.
Care of the Mechanically Ventilated Patient in the Critical Care Unit

The clinical profiles of critically ill people admitted to a critical care unit are diverse, but in general most will require some form of respiratory support, usually as a result of hypoxaemia or respiratory failure, or both. Support may range from oxygen therapy by face-mask to non-invasive techniques such as continuous positive airways pressure (CPAP) to full mechanical ventilatory support with endotracheal intubation (Shelley & Nightingale, 1999). As defined in the previous chapter, mechanical ventilation is the artificial control of the breathing cycle by means of a machine. Prior to discussing the management of the mechanically ventilated patient, it is necessary to briefly review the physiological effects of normal respiration in order to understand the effects of mechanical ventilation.

Physiology of Respiration

As a comparison of how respiration is altered when a mechanical ventilator is used, review of the mechanics of normal, spontaneous respiration is important. Oxygen is required for the catabolism of chemicals that occurs in the production of energy at the cellular level. Although some energy can be stored, cells differ in the amount of energy they can store. Catabolic energy-producing reactions produce carbon dioxide, and high levels of this waste product can seriously impair cell function. Therefore, there is a need for providing oxygen to body cells and at the same time removing carbon dioxide from the body. Respiration can be defined as the exchange and transport of oxygen and carbon dioxide between cells of the body and the external environment, and occurs both in the lungs (external respiration) and in the tissues (internal respiration) (Kidd & Wagner, 1992).
The physiology of spontaneous respiration requires that energy be expended to contract the muscles of respiration. The contraction of the respiratory muscles enlarges the thoracic cavity, which creates negative pressure within the chest and results in the flow of air, at atmospheric pressure, into the lungs. Adequate respiration is dependent on adequate functioning of the lung tissues and pulmonary capillaries (Kidd & Wagner, 1992). If a patient presents to a critical care unit experiencing inadequate or decreased respiratory capacity then it may be necessary to instigate mechanical ventilation as a form of respiratory support in order to achieve adequate respiration.

**Indications for Mechanical Ventilation**

The classic indication for ventilatory support is reversible acute respiratory failure (ARF). ARF is the inability of the lungs to maintain adequate alveolar ventilation, and is diagnosed on the basis of the acid-base imbalance it creates. In ARF, acute respiratory acidosis occurs, indicated by arterial blood gas analysis showing $\text{PaCO}_2 > 50\text{mmHg}$, and pH $< 7.30$. A variety of problems can cause ARF such as head trauma, apnoea of any aetiology, neuromuscular dysfunction, and drug-induced central nervous system (CNS) depression (Kidd & Wagner, 1992). According to Oh (1990), guidelines for instituting ventilation may be based on respiratory mechanics, oxygenation, and ventilation (Oh, 1990). However, each respiratory variable must always be evaluated in the clinical context and determined by looking at the individual’s history and current clinical picture. Table 2.1 demonstrates indications for endotracheal intubation and mechanical ventilation (Shelley & Nightingale, 1999).
Table 2.1  Indications for Endotracheal Intubation and Mechanical Ventilation

<table>
<thead>
<tr>
<th>INDICATION</th>
<th>EXAMPLES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reversible acute respiratory failure</td>
<td>Patients with head trauma, apneoa of any aetiology, neuromuscular dysfunction, or drug-induced central nervous system depression</td>
</tr>
<tr>
<td>(ARF).</td>
<td></td>
</tr>
<tr>
<td>To treat profound hypoxaemia</td>
<td>Patients with pneumonia, cardiogenic pulmonary oedema or acute respiratory distress syndrome</td>
</tr>
<tr>
<td>To protect the airway</td>
<td>Patients with facial trauma or burns, or who are unconscious</td>
</tr>
<tr>
<td>For post-operative care</td>
<td>Patients who have had cardiothoracic surgery and other major complicated or prolonged surgery</td>
</tr>
<tr>
<td>To allow removal of secretions</td>
<td>Patients with myasthenia gravis or Guillain-Barre syndrome</td>
</tr>
<tr>
<td>To rest exhausted patients</td>
<td>Patients with severe asthma</td>
</tr>
<tr>
<td>To avoid or control hypercapnia</td>
<td>Patients with acute brain injury, hepatic coma, or chronic obstructive pulmonary disease</td>
</tr>
</tbody>
</table>

**Physiology of Mechanical Ventilation**

There are a number of physiological effects associated with this form of respiratory treatment. As mechanical ventilation is achieved by applying positive pressure ventilation through an endotracheal tube, compared with spontaneous ventilation created by negative pressure, there is a reversal of pressure gradients with large pressures being applied. There is an increase in the mean intrathoracic pressure, with a resultant reduced venous return and fall in cardiac output. Left ventricular output is also decreased (Oh, 1990). If normal vascular reflexes are intact, peripheral venous tone usually increases, which overcomes these effects and restores the venous gradient for return to the heart. However, this method of compensation fails when hypovolaemia exists, or when sympathetic responses are impaired (Oh, 1990).
Mechanical ventilation is a complex intervention that requires a protocol of procedures and equipment. It requires the choice of a particular mode of ventilation that is determined by the patient’s respiratory condition, and the use of special artificial airways, placed in the trachea.

**Modes of Mechanical Ventilation**

It would be ideal if mechanical ventilators could mimic the mechanics and physiology of spontaneous respiration while achieving the goals of adequate oxygenation and ventilation. This would serve to overcome many of the physiological effects associated with its application. Indeed, negative pressure ventilators attempt to do this, and are used to augment the normal physiological pattern by producing a negative pressure outside the chest wall so that air is automatically inhaled when the patient opens his or her airway. Known as the iron lung, these ventilators were commonly used during the poliomyelitis epidemic of the 1950s, and became a familiar sight in many hospitals. However, due to the unwieldy nature of the machine, and the patient discomfort associated with their use, negative pressure ventilators are now rarely used (Ashurst, 1997).

The vast majority of mechanical ventilators used in clinical settings today are positive pressure ventilators. A variety of modes of positive pressure ventilation can be used, for example intermittent mandatory ventilation (IMV), synchronized intermittent mandatory ventilation (SIMV) and pressure-cycled ventilation. Currently, no consensus exists on the best mode of ventilation, and studies continue to be undertaken to determine the most effective mode, based on patient outcomes (Establan et al., 2002). As each new mode emerges, so too do arguments surrounding
its use and the associated advantages and disadvantages. Generally, there is no one best mode for patient management, rather the mode used depends on the patient’s medical condition, availability of equipment, and the skill and experience of staff (Ashurst, 1997).

*Intermittent positive pressure ventilation (IPPV)*

Intermittent positive pressure ventilation is the method used to mechanically ventilate most critically ill patients (Ashurst, 1997). It is based on the simple principle whereby oxygen-enriched air is forced via a machine into the patient’s lungs and allowed to drain out passively. The patient may exhale to atmospheric pressure or to a set level of positive end-expiratory pressure (PEEP). Methods of ventilation that also allow the patient to breathe spontaneously are thought to be advantageous. Modern ventilators have sensitive triggers and flow patterns that can adapt to the patient’s needs, thus reducing the ‘work’ of breathing. Synchronised intermittent mandatory ventilation (SIMV) is designed to deliver a set number of breaths by the ventilator and allows the patient to breathe between these breaths. This method is frequently used during weaning, often with a pressure support, by which the ventilator enhances the volume of each spontaneous breath up to a predetermined positive pressure (Shelley & Nightingale, 1999).

*New ventilatory strategies*

New management options for patients with acute respiratory failure are continually being developed and tested with the aim of reducing or avoiding ventilator-induced lung injury, while maintaining adequate gas exchange. In addition, as being on a mechanical ventilator is often an uncomfortable experience, methods that can potentially reduce the duration of mechanical ventilation, and or reduce the
discomfort associated with it are also considerations. Methods are aimed at either
augmenting carbon dioxide elimination via tracheal gas insufflation, veno-venous
extracorporeal carbon dioxide removal, and or intra-vascular oxygenation.
Improving oxygenation can occur through the judicial use of positive-end expiratory
pressure (PEEP), venoarterial extracorporeal membrane oxygenation, and
pharmacological intervention with inhaled nitric oxide. However, although some of
these strategies have demonstrated improved mortality rates and a reduction of side
effects, more clinical trails are considered necessary before any are adopted on a
widespread basis (Gowski & Miro, 1996; Urden et al., 2002). Nursing patients in the
prone (face-down) position is another strategy that has also been utilized with the
aim of increasing oxygenation as well as patient comfort; however, outcomes have
also been inconclusive (Gibson & Rutherford, 1999).

Endotracheal Intubation

Although patients with respiratory failure may be treated with IPPV delivered non-
invasively via a nasal mask, many patients in critical care units cannot comply with
this therapy or maintain an effective airway and will require IPPV to be delivered via
a sealed airway. This is achieved by intubating the patient’s airway with a specially
designed tube. For adults, this may be a nasal cuffed endotracheal tube (ETT), an
oral cuffed ETT, or a tracheostomy tube.

The nasal cuffed ETT has several advantages as it is held rigidly in place in the nasal
cavity, does not impair oral function or induce the gag reflex as often, and may be
more comfortable than the oral route. However, there are also a number of
limitations to its use, including a high incidence of nasal trauma and external
ulceration. In addition, the need for a long, small bore, cuffed ETT increases the
dead space (space where gas exchange does not occur), which serves to decrease gas exchange and oxygenation, and make suctioning of the trachea to clear the airway of secretions more difficult (Ashurst, 1997).

Oral cuffed ETTs are commonly employed due to their relative ease of insertion and because a tube with a larger diameter can be used which helps to overcome resistance to airflow and facilitate tracheal suctioning. However, oral cuffed ETTs are quite uncomfortable for patients, and may cause a number of unpleasant side effects including oral irritation, ulceration and infection, and increased salivation. In addition, this type of tube is more mobile than a nasal tube, and is more likely to cause gagging. Patients can also bite these tubes. Therefore there is a possibility of restriction or obstruction to the airway, particularly in patients who may be confused, anxious, and or agitated (Ashurst, 1997).

Inserting an airway via a tracheostomy, which is an incision into the trachea percutaneously, is an approach that is used when the need for an artificial airway is likely to be prolonged. A tracheostomy may also be done to increase patients’ comfort and to facilitate weaning from the ventilator. Complications of this form of endotracheal intubation include misplacement or displacement of the tube, bleeding, infection, failure of the stoma to heal, and tracheal stenosis (thickening). However, because patients generally tolerate a tracheostomy better than the other forms of endotracheal intubation, sedation can usually be reduced, weaning may more rapid, and the length of time a patient spends on the mechanical ventilator in the critical care unit may also be decreased (Shelley & Nightingale, 1999).
Sedation of the Patient

Mechanically ventilated patients generally require some type of sedation to enable them to tolerate the effects of the ventilator and the presence of an endotracheal tube. Sedatives, muscle relaxants, and analgesic drugs may be used to improve patient comfort during ventilation, improve gas exchange, and reduce anxiety (Shelly & Nightingale, 1999). However, sedatives have a number of adverse effects. For example, the action of a sedative may be prolonged and active metabolites may accumulate if the patient has renal failure. Other side effects include hypotension, alterations in sleep patterns, decreased motility and paralytic ileus formation, and some patients may develop withdrawal symptoms when the medication is ceased (Shelly & Nightingale, 1999).

In the past, mechanical ventilation could be controlled only if a patient was heavily sedated or even paralysed. Modern ventilators that allow for patients to breathe spontaneously have reduced the need for heavy sedation. However, critical care nurses are still required to assess each individual patient’s need for sedation and analgesia on a regular basis. Because critically ill people cannot always effectively communicate to the nurse whether or not they are comfortable, accurate assessment of anxiety, depression and discomfort may be difficult. Therefore, it is important that critical care nurses be aware of the effects of mechanical ventilation, utilise effective assessment skills to observe the patient closely for any indication of discomfort, and then treat accordingly.

Monitoring Patients on Mechanical Ventilators

Critical care nurses need to understand the various modes of ventilation and how to assess patients’ responses to ventilation (Bolton & Kline, 1994). There are a number
of measures and observations that need to be closely monitored. Pulse oximetry and
measurement of end tidal carbon dioxide concentration allow continuous monitoring
of oxygenation and ventilation whilst the patient is on a mechanical ventilator. End
tidal carbon dioxide concentration is roughly equal to arterial carbon dioxide partial
pressure in healthy individuals, but may differ widely in critically ill patients with
ventilation-perfusion (V/Q) mismatch. Adequacy of ventilation should be confirmed
regularly by arterial blood gas analysis (Shelley, & Nightingale, 1999).

Albarran and Price (1998) outline the nursing priorities for care of the mechanically
ventilated patient in the critical care unit. These are summarised in Table 2.2.
### Table 2.2 Priorities of Care for a Mechanically Ventilated Patient

<table>
<thead>
<tr>
<th>NURSING PRIORITIES</th>
<th>INTERVENTION/MANAGEMENT See 2.1</th>
</tr>
</thead>
<tbody>
<tr>
<td>Airway maintenance and security</td>
<td>Provide adequate humidification</td>
</tr>
<tr>
<td></td>
<td>Effective and regular ETT suctioning</td>
</tr>
<tr>
<td></td>
<td>Secure ETT in place</td>
</tr>
<tr>
<td>Promoting oxygenation</td>
<td>Ensuring delivery of required oxygen</td>
</tr>
<tr>
<td></td>
<td>Correct use of PEEP</td>
</tr>
<tr>
<td></td>
<td>Effective patient positioning and posture</td>
</tr>
<tr>
<td>Monitoring respiratory progress</td>
<td>Ensure ventilatory parameters are maintained</td>
</tr>
<tr>
<td></td>
<td>Arterial blood gases monitored</td>
</tr>
<tr>
<td></td>
<td>Sedation level adequate and appropriate</td>
</tr>
<tr>
<td></td>
<td>Monitoring for complications of IPPV</td>
</tr>
<tr>
<td>Safe and uncomplicated weaning from mechanical ventilation</td>
<td>Optimising clinical status</td>
</tr>
<tr>
<td></td>
<td>Providing physical and emotional support</td>
</tr>
</tbody>
</table>


**Weaning from the Mechanical Ventilator**

Critical care nurses play an important role in planning for the safe and uncomplicated weaning, or removal, of patients from the ventilator. There are a number of techniques that can be used for weaning, but these will only be effective if the patient is well prepared. Weaning techniques allow the patient to breathe spontaneously for increasing periods of time or to gradually reduce the level of ventilatory support. Planning and preparation for successful weaning involves the use of thorough clinical assessment, patient education and reassurance about the procedure. Recently weaned patients require close monitoring by nurses to detect any signs of deterioration (Shelly, & Nightingale, 1999).
In summary, mechanical ventilation is a mechanical means by which the patient receives ventilatory support in order to achieve and maintain adequate alveolar ventilation. Mechanical ventilators cannot cause diffusion of gases in the lungs rather they facilitate the ventilatory process. In turn, improved ventilatory status enhances the ability of the gases to diffuse across the alveolar-capillary membrane (Kidd & Wagner, 1992, 55). It is important to acknowledge that mechanical ventilation is a supportive intervention only. It is meant to support the patient’s ventilatory status while curative interventions are initiated.

**Complications associated with Mechanical Ventilation**

Due to the improvements in mechanical ventilators and patient care, patients who would previously have died from respiratory failure now survive (Gowski, & Miro, 1996). The goal of all forms of mechanical ventilation is to maintain adequate oxygenation while avoiding ventilator-associated complications (Gowski & Miro, 1996). However, it is acknowledged that positive pressure mechanical ventilation is an extremely complex intervention that creates a number of physiological effects that are counter to the normal physiology and mechanics of respiration (Bishop, 1989; Estban et al., 2002; Glauser et al., 1988; Johnson & Sexton, 1990; Seneff et al., 1996). Patients needing this form of treatment are usually critically ill and or severely compromised, thus the possibility of developing one or more complications associated with the use of positive pressure ventilation is ever present.

Albarran and Price (1998) provide an outline of the numerous potential complications associated with mechanical ventilation. These are summarised in Table 2.3
Table 2.3 Complications associated with Mechanical Ventilation

<table>
<thead>
<tr>
<th>Compartment</th>
<th>Complications</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cardiovascular</td>
<td>Decreased cardiac output</td>
</tr>
<tr>
<td></td>
<td>Decreased venous return</td>
</tr>
<tr>
<td></td>
<td>Dysrhythmias</td>
</tr>
<tr>
<td>Respiratory</td>
<td>Barotrauma</td>
</tr>
<tr>
<td></td>
<td>Pulmonary oedema</td>
</tr>
<tr>
<td></td>
<td>Tension pneumothorax</td>
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Critical care nurses are generally aware of the physiological effects and complications of mechanical ventilation, as these are discussed in all critical care medical and nursing textbooks, and are an essential component of critical care nurse educational programs. An understanding of the complications associated with mechanical ventilation provide useful information concerning this form of
respiratory support, enabling health professionals involved in managing ventilated patients to plan and deliver care and treatments aimed at preventing or minimising the side-effects of this treatment.

Nursing Priorities for the Mechanically Ventilated Patient

Over the last three decades, there has been a rapid proliferation of technology used in the management of the critically ill, giving rise to the not uncommon perception that critical care units epitomise the ultimate in “high tech low touch” environments. In such an environment, the focus of attention in the care of the critically ill person may centre on curing the physiological symptoms of disease and trauma, and the management of the associated technology. It is interesting to note that the textbook by Albarran and Price (1998) titled “Managing the Nursing Priorities in Intensive Care” contains the following statement in its introduction:

The premise of this text is that the effective management of patient care begins with the accurate assessment and interpretation of patient data, in order that the nursing plan of interventions reflects the uniqueness of patients’ priorities as well as the distinctiveness of the nurses’ contribution to the delivery of holistic care. (Albarran & Price, 1998, p. ix)

However, this particular nursing focused textbook merely lists and describes the nursing management, physiological effects and technological complications associated with the use of mechanical ventilation on patients. The effects of this form of treatment as experienced by patients are not discussed. A quick browse through nursing critical care textbooks shows that this is not uncommon as most tend to use a biophysical approach to describing patient management. For example, the well-known textbook by Urden et al., (2002) discusses patients’ perspectives of critical care within a framework of psychosocial alterations and the effects of stress on mind/body interactions. Similarly, Hudak and Gallo (1998) describe patients’
experiences using a nursing diagnosis framework and the concepts of stress, adaptation and coping behaviours. There is a small section dedicated to discussing the meaning of critical care to the patient, which urges nurses to ensure that patients and families have a positive experience of critical care, regardless of the outcome. However, the discussion in this section does not refer to findings from any research studies, so the relevance and usefulness of this information is questionable. Furthermore, although the texts by Urden et al. (2002) and Hudak and Gallo (1998) attempt to incorporate aspects of patients’ perspectives on critical care, they do so within a rather narrow framework that is not research-based and the material presented inadequately reflects the individual human experience.

The main focus of critical care nursing textbooks is, therefore, on the technical aspects of care, with insufficient attention given to patients’ perspectives of critical care hospitalisation, treatments and nursing care. Critical care nurses provide nursing care for mechanically ventilated patients on a regular basis, and aim to provide competent and holistic care (CACCN, 1996b, p. viii). The ability of critical care nurses to be a distinctive part of the patient’s care and contribute to holistic care will be limited if patients’ perspectives are not central to that care. Increasingly nurses, including critical care nurses, are seeking to explore patients’ experiences and impressions of their illness episode in order to gain a greater understanding and knowledge on which to base individualised and evidenced-based patient care. Research studies that have taken this focus are reviewed in the next chapter.

**Conclusion**

This chapter commenced with an overview and description of the history, purpose and function of critical care units, mainly from an Australian context. A discussion
of critical care nursing then followed, focusing on critical care nursing practice and education. Next, a description of mechanical ventilation and the management of the mechanically ventilated patient within a critical care unit were detailed. A critical analysis of critical care nursing textbooks revealed that nursing priorities focus on the biophysical and technical aspects of caring for the mechanically ventilated patient. This highlights an urgent need for research into human aspects of critical care, which is the focus of this present study, to overcome this gap in the literature.

The next chapter is a literature review that examines the research studies of peoples’ experience of critical illness and critical care hospitalisation.
CHAPTER 3

LITERATURE REVIEW:
PEOPLES’ EXPERIENCE OF CRITICAL ILLNESS AND CRITICAL CARE HOSPITALISATION

Introduction

This chapter reviews the growing body of literature directed towards understanding patients’ experiences of illness and critical care hospitalisation, including mechanical ventilation. This increasing interest in exploring aspects of critical care from the experiencing persons’ perspective may reflect nurses’ and other health care professionals’ desire for a more complete understanding of the meaning and effects of health care delivery and practices on patients.

The chapter commences with a discussion of why nurses are interested in exploring patients’ experiences. Following this, the importance for critical care nurses of including patients’ perspectives into their practice is highlighted through identification of previous studies that examine peoples’ recall of their critical care experience. An overview of the relevant studies cited in this chapter is then presented, organising the findings into four main themes: alterations in perception, responses to illness and the critical care environment, pain and discomfort and comforting factors. The chapter concludes with a discussion and summary of the research literature pertaining to the research question. It is demonstrated that while previous studies have identified a number of significant factors related to patient’s experience of critical illness, these studies have not fully explored in any real depth what it means for people to be on mechanical ventilation, especially long-term mechanical ventilation, in a critical care unit.
Nurses’ Interest in Human Experience

The impact of hospitalisation and illness on patients is of interest to nurses who are concerned with understanding human responses. It is important to recognise that a distinction between illness and disease needs to be made. Health is not the absence of illness, and illness is not synonymous with disease. Rather, illness is the human experience of loss or dysfunction, whereas disease is the manifestation of aberration at the tissue, cellular, or organ levels (Benner & Wrubel, 1989). Since illness and disease do not always reflect each other, illness cannot be reduced to a non-scientific account of a particular disease. Each disease has its own social definition, and its own threats and constraints, and these aspects, in conjunction with the individual person's history and context, serve to define the person's illness experience.

Traditionally, nursing education was structured upon the body systems approach and reflected the biomedical model. This model evolved from the doctrine of Rene Descartes (1596-1650), a French Philosopher, who stated that there is a division of reality between the mind and body (Black & Matassarin-Jacobs, 1993). The dividing of the body into a number of parts has been enormously beneficial for science, and has allowed the body to be studied objectively for purposes of disease recognition. However, the biomedical model, through its focus on the physiological response to disease, fails to acknowledge the interrelatedness of mind, body and spirit that is essential to holistic care. Nurses, in recognising the inadequacies of the biomedical model, have sought to provide nursing care that embraces not only the body but also the mind and spirit as well. The widespread introduction of nursing care plans using a problem-solving framework, such as the nursing process, were indicative of the beginning move toward a commitment to total, or holistic patient care. Although this
approach to constructing and organising patient care is no longer widely embraced, it encouraged nurses to think about patients on an individual basis.

**Patients’ Recall of their Experience**

In the context of the critical care environment, it is often difficult for nurses to comprehend how patients experience their stay in the critical care unit. This is because the usual means of reaching a shared understanding through oral communication is lost when the patient is intubated with an endotracheal tube, sedated and or experiencing fluctuating levels of consciousness (Stein-Parbury & McKinley, 2000). Indeed, because many patients in critical care units are often sedated and, therefore, appear unresponsive, health care professionals may assume that they are not experiencing anything memorable under this sedation. This assumption has been challenged in a number of studies which have found that many people do remember their critical care hospitalisation, and are able to provide vivid and detailed descriptions of nursing care during this time (Adler, 1997; Berggom Engberg & Haljamae, 1988a; Green, 1996; Heath, 1989; Holland et al., 1997; Laitinen, 1996; Parker, 1997; Parker et al., 1984; Puntillo, 1990; Russell, 1999; Simpson et al., 1989). A case study reported nearly two decades ago by Parker et al. (1984) provided an insight into one woman’s experience of being artificially paralysed with the anaesthetic drug pancuronium whilst on mechanical ventilation in an CCU. At that time it was common practice to combine sedation with muscle paralysing agents as a means to increase compliance and facilitate adequate ventilation for mechanically ventilated patients. In this particular case study, the patient was a 38 year old nurse who was in CCU on a mechanical ventilator for over two months. On recovery, she recalled her experience during that time, and was able to describe in detail many aspects of her CCU stay. Feelings of powerlessness,
disorientation, physical discomfort from nursing procedures, desperation due to the seriousness of her illness, frightening hallucinations and delusions, and fear and anxiety all featured in her story. Parker et al. (1984) concluded by urging nurses caring for mechanically ventilated patients to not assume that sedated and paralysed patients are unable to remember their CCU experience.

In these studies described above, the degree of participant recall was reported to be from 50 percent (Bergbom-Engberg & Haljamae, 1988a) to over 90 percent (Green, 1996; Holland et al., 1997). For example, Bergbom-Engberg and Haljamae (1988a) interviewed 303 former patients about their experience of mechanical ventilation in a large critical care unit in Sweden, and their recollection of nursing and medical care. The time that elapsed from the period of mechanical ventilation to interview varied from two months to four years. This study found that 158 (52%) participants were able to recall their ventilator experience. In another study by Green (1996) of 26 former patients of a surgical ICU, over 90 percent of participants were reported to have been able to recall their experience. Such variations in recall have been attributed to a multitude of factors including different patient populations and characteristics, different patient management regimes within the CCU, and the timing and type of participant interview. It is therefore neither useful nor realistic to attempt to quantify the number and ability of patients who are able to remember their CCU experience. What is of importance is that some patients are able to remember and recall their time in CCU, and as such provide an invaluable source of data from which understanding can be derived. Findings from these studies assist critical care nurses to develop evidence and knowledge on which to base care of critically ill patients. For example, overcoming an assumption that patients are unable to recall
their experiences may lead to improvements in the way that nurses interact with patients.

**Overview of Studies**

To date, a number of studies have been undertaken to explore patients’ experiences of critical care hospitalisation, although it is not always possible to determine how many participants were on mechanical ventilation. The aim of studies conducted prior to 1990 was mainly to examine aspects that nurses and physicians thought were negative for CCU patients, for example sleep deprivation and an unpleasant CCU environment (Asbury, 1985; Ballard, 1981; Bradburn & Hewitt 1980; Chew, 1986; DeMeyer, 1967; Easton & McKenzie, 1988; Gries & Fernsler, 1988; Jones et al., 1979; Riggio, et al. 1982). Stein-Parbury and McKinley (2000) attribute this program of research to the perception that the critical care environment and critical care practices were seen at that time to be major factors in the development of adverse patient events such as sleep deprivation, and the Intensive Care Unit (ICU) syndrome. Research was therefore aimed at the identification, prevalence and impact of stressors for CCU patients, as it was believed that findings would increase knowledge about patients’ experience of stressors within the CCU environment. Although these studies focused mainly on negative aspects of patients’ experiences, they provided valuable insights and a basis on which further research could build. However, as these studies used mainly structured or semi-structured questionnaires, participant responses were organised into a predetermined framework. Therefore, the opportunity for both in-depth and unique individual responses, and development of understanding of the complexity of the experience, was extremely limited.
The majority of studies undertaken since 1990 (Adler, 1997; Granberg Axell 2001; Hafsteindottir, 1996; Jablonski, 1994; Laitinen, 1996; Logan & Jenny, 1997; McKinley et al., 2002; Parker, 1997; Russell, 1999) have used predominantly qualitative approaches to allow for a fuller exploration of patients’ experiences and further extend understanding of the experience of critical illness within the critical care environment.

Findings from the above studies can be grouped under four main themes: alterations in perception, responses to critical illness and the critical care environment, discomforts and pain, and comforting factors.

**Alterations in Perception**

*ICU Syndrome*

Perception has been defined as “the continuous recognition of and interpretation of sensory stimulation through unconscious associations, especially memory, that serve as a basis for understanding, learning, knowing, or for the motivation of a particular action or reaction” (Anderson, Anderson, & Glanze, 1998, p.1233). Research studies that have examined the experience of critical illness and critical care hospitalisation have found that many participants report disturbances or alterations in perceptual, sensory and affective functioning. These alterations are most often grouped within a clinical framework known as the Intensive Care Unit (ICU) syndrome, a term first used by McKegney in 1966. He defined the ICU syndrome as a delirium involving impaired intellectual functioning, which occur in patients who are being treated in a critical care unit. The prevalence of the ICU syndrome reported in the literature varies, ranging from 32 percent to 70 percent of patients who stay in a critical care unit for more than two days (Granberg Axell, 2001). It is manifested in a variety of
psychological reactions, and can produce problems ranging from a mild confusion to acute psychosis, with one author going so far as to liken CCU patients’ experiences to torture (Dyer, 1996).

In an attempt to describe and define the ICU syndrome, Granberg, Bergbom-Enberg and Lundberg (1996) reviewed 20 studies published between the years 1954 to 1990 relating to this condition. They found that the signs and symptoms of the syndrome described in these studies included depression, fear, anxiety, loss of memory (amnesia), disorientation, paranoia, hallucinations, insomnia, alteration of perception, labile emotions and mental exhaustion. A multitude of factors were thought to contribute to the onset of the syndrome, including environmental conditions, sensory overload, sleep deprivation, disturbance in the neurotransmitters dopamine and serotonin, and alterations in levels of adrenal and other hormones due to stressors such as pain and surgery. Granberg et al. (1996) concluded that there was little consensus as to the cause, developmental phases and clinical signs and symptoms of the ICU syndrome. This finding has prompted further research by nurses seeking to gain a better understanding of the syndrome and how it is experienced by patients (Granberg Axell, 2001; Laitenin, 1996). In particular, Granberg Axell’s study, “The Intensive Care Unit syndrome/delirium, patients’ perspective and clinical signs” (2001) provides a comprehensive description and investigation of the syndrome. However, in seeking to understand patients’ experiences within a clinical framework such as the ICU syndrome, participants’ accounts may be reduced to the identification and measuring of clinical symptoms and signs. Such an approach is not helpful to those seeking a greater understanding of unique human experience and exploring the complexity of the human experience. This view is supported by Richman (2000) who urges nurses not to consider the ICU syndrome as a mere
medical condition, but to recognise and try to overcome the profound effect it has on patients.

**Dreams, Nightmares, Hallucinations and Delusions**

Alterations in perception also encompass reports of bizarre dreams, nightmares, illusions, delusions and hallucinations. These terms are used interchangeably in the literature to describe unusual or abnormal dreams experienced by patients in the critical care environment. Overwhelmingly, the majority of dreams or hallucinations were recalled as being frightening and disturbing (Asbury, 1985; Chew, 1986; Easton & McKenzie, 1988; Jones, et al., 1979; Laitinen, 1996; Parker, 1997; Russell, 1999). Of interest is the finding that many participants were reluctant to share their dream experiences with others, as they perceived this might indicate they were mentally unstable or confused. This serves to highlight the importance for researchers exploring patients’ experiences to be prepared for aspects that may cause distress for participants.

In an early study by Jones et al. (1979), 100 former patients completed a structured questionnaire to ascertain their impressions of CCU including discomforts and confusion. Findings indicated that up one third of participants experienced confusion and hallucinations during their time in hospital. Asbury (1985) also explored the extent of problems experienced by CCU patients, and found several accounts of disturbing and confusing nightmares. Several years later, Easton and McKenzie (1988) sought to determine and categorise the occurrence and features of hallucinations, illusions and delusions in the CCU. Utilising semi-structured interviews comprising ten open-ended questions, ten former surgical CCU patients participated in the study. Findings indicated that 50 percent reported having
delirious episodes of a terrifying nature. The incidence of hallucinations and delusions was similar to that previously reported by Chew (1986) in her study exploring the extent to which psychological complications occur in CCU patients. Chew interviewed 13 patients following discharge from the CCU using a structured interview format. Reports of altered perceptions of reality, particularly in relation to the persons’ body were a common finding. These findings were echoed in further studies (Adler, 1997; Bergbom-Engberg & Haljamae, 1988a, Granberg Axell, 2001; Laitinen, 1996; Parker, 1997; Russell, 1999). The findings from the majority of these studies, although useful, have limitations. The research methods adopted were predominantly quantitative approaches using structured or semi-structured questionnaires and interviews, thus sufficient attention may not be given to fully capturing the patients’ perspective. In response, researchers interested in more fully exploring patients’ experiences have turned to alternative research methodologies.

A qualitative study by Laitinen (1996) of ten patients who had undergone coronary bypass surgery found that the majority of these people experienced confusion and an inability to distinguish what was real and what was not (Laitinen, 1996). Following this, Parker (1997) used interpretive phenomenology to explore the experiences of ten patients who were hospitalised in a CCU in a large metropolitan hospital in NSW for a minimum of two days. Data analysis revealed a number of themes, including what Parker termed “living in the shadows” (p. 104) which referred to participants’ experience of confusion, unreality, nightmares and hallucinations. Overall, the nightmares and hallucinations were very frightening, with participants describing the perception that they were being suffocated, and or tied down and held captive in a bizarre environment from which there was no escape. The perpetrators of their predicament were most often the nursing or medical staff, or their family members,
an experience that was very distressing. These findings are similar to those reported by Adler (1997) and Russell (1999), suggesting that this continues to be an ongoing and serious problem for CCU patients.

**Responses to Illness and Environment**

Studies also revealed other aspects that pertain to the critical care experience, with negative responses by participants to their illness and the critical care environment a common finding. In particular, reports of fear, anxiety and uncertainty feature throughout the literature. Anxiety is described as any subjective experience that threatens an individual’s wellbeing (Kapnoullas, 1988). Anxiety is a part of daily life, and is commonly experienced when people are confronted with unknown and or stressful situations. It is well recognised that critical illness and the critical environment can be very stressful for both patients and their families (Choate & Stewart, 2002). In the studies reviewed, fear, anxiety and uncertainty were most often related to: the unfamiliarity of the CCU environment; the inability to be able to effectively communicate with the nurses and relatives whilst on a mechanical ventilator; activity restrictions and restraints; insufficient explanation of events; loss of power and control; dependence on others; feeling depersonalised and dehumanised; and fears related to questions of survival and outcomes of the critical illness.

Ineffective communication due to the presence of an ETT and or the effects of sedation is a common finding. Hafsteindottir (1996) focusing specifically on communication and the mechanically ventilated patient found that communication experiences were mainly negative, as participants expressed the feeling that nurses did not always provide adequate information and explanation. These findings were
similar to those from a study by Holland et al. (1997) which examined the recollections of participants who had previously undergone cardiac (open-heart) surgery. In this study there were many instances where staff were perceived as not interacting with participants in any meaningful way during their time in the critical care unit. Such findings reflect those derived from an early study by Ashworth (1980), who explored communication between nurses and nurses’ perceptions of the factors influencing communication. Ashworth found that problems with communication were frequent, and that nurses rarely communicated with patients who they perceived were unable to communicate effectively. Despite the findings of this study and its recommendations, difficulties with communication continue to pose a significant problem for CCU patients (Casbolt, 2002).

Gries and Fernsers (1988) explored the mechanical ventilation experiences of nine adult participants who had previously been ventilated for periods ranging from one to eight days in one of three hospitals in the Mid-Atlantic region of USA. Data were collected using a semi-structured questionnaire format. Participants reported 11 different negative experiences associated with mechanical ventilation that related to activity restrictions, insufficient explanation of procedures by nurses, and an inability to effectively communicate whilst ventilated. Similarly, the study by Bergbom-Engberg and Haljamae (1988a) of 303 former CCU patients in Sweden found that over half of the 158 participants who were able to recall their experience reported feelings of anxiety and distress as a response to the serious nature of their illness, the strangeness of the CCU environment, and also being restrained and unable to effectively communicate by both word and touch (Bergbom-Engberg & Haljamae 1988b, 1989a, 1989b). It was interesting to note in this study that the participants’ ability and degree of recall increased with the length of time they spent mechanically
ventilated. This was a factor that was considered in this present study and provided a rationale for targeting participants who had been on long-term mechanical ventilation.

Following on from these studies, Johnson and Sexton (1990) examined patients’ perceptions of distress during mechanical ventilation. Fourteen people were interviewed six months after their ventilation experience, and from the interviews a list of 25 factors contributing to distress during mechanical ventilation was compiled. Factors identified most frequently were similar to previous studies, and included the inability to speak, pain and discomfort from the endotracheal tube, suctioning of the endotracheal tube, noise, and lack of sleep. However, findings from this study based in the United States of America [USA] are difficult to assess, as the authors did not provide any details of research methodology, design, participant characteristics, or method of data analysis.

In attempting to address the deficiencies of previous studies, Jablonski (1994) took a phenomenological approach to explore the experiences of 12 adult participants who had previously been mechanically ventilated for a minimum of 18 hours in a large teaching hospital in Philadelphia, USA. Data analysis revealed 15 clusters, whose main themes related to the experience of unpleasant sensations at the start, during and after ventilation, the discomfort associated with the performance of certain nursing procedures, and difficulties with communication. Jablonski (1994) concluded that health care providers, especially nurses, control the type of experience mechanically ventilated patients have, and she urged nurses to incorporate more empathic and reflective practice within their patient care. The issue of control was an interesting finding from this study as it bought to light the centrality of nursing
practice in patient care and the influence nurses have on patients’ perceptions of their experience and the care received. By taking a phenomenological approach and using in-depth interviews, Jablonski’s study extended the understandings derived from earlier studies.

In 1997, Logan and Jenny’s study of patients in a large Canadian critical care unit took a different focus and examined patients’ recollections of the weaning period of ventilation, with an overall aim of developing a nursing theory of weaning. Findings indicated that, for most patients, this was a mixed experience, with participants recalling some episodes of supportive nursing care amidst an overall impression that the experience was “painful, frightening and something they wanted to forget as soon as possible” (p.142). The authors concluded that mechanical ventilation and weaning are stressful experiences requiring a great deal of ‘work’ by patients. This study provides insight into another aspect of the mechanical ventilation experience and is useful for nurses managing patients in this phase of their treatment. Although patients found the whole episode unpleasant, this study revealed some positive recollections of nursing care pertaining to those nurses who took time to try to communicate with patients.

Another study conducted at this time was that by Adler (1997), who sought to explore the needs of critically ill mechanically ventilated patients. Twelve participants, who had been ventilated for a period greater than seven days, were interviewed some six to nine months following discharge from the critical care unit of a large teaching hospital in the northeast of the USA. This study used a number of qualitative methods, including phenomenology, grounded theory and ethnography. Participants expressed their feelings of fear and anxiety related to difficulties in
communication, dependency, dehumanisation and pain. Although findings from this study add to the knowledge of patient experiences, the range of research approaches and methods used rendered the applicability of the findings problematic.

Feeling dependent and dehumanised and or depersonalised has been recognised as common to many patients due to the hospitalisation process, and is not solely confined to the CCU patient. Previous research has shown that the way in which some nurses practise can depersonalise those for whom they care (French, 1991, p.37). The hospitalisation process sees the ‘person’ becoming a ‘patient’ in a new and very different social order. The assessment of the person’s needs may be treated as a routine exercise by CCU staff who may complete only standardised assessments that may attend only to those needs common to the particular disease or medical condition (French, 1991). Although critical care nurses espouse holistic care, this may not always be put into practice. Hence CCU patients may feel depersonalised and dehumanised if they perceive they are not being treated as an individual with unique needs.

The findings from Adler’s study are similar to those of Parker’s (1997) Australian study, which found that participants experienced feelings of fear, anxiety and uncertainty due to being voiceless, the unpleasant effects of technology, feeling helpless and dependent, and being close to sickness and death. Although Parker, similar to Jablonski (1994) and Adler (1977) explored the meaning patients’ attributed to their critical illness experience to a greater depth than previous studies, she concluded that her research achieves “a richer, albeit incomplete, understanding” (1997, p.126) of the experience. Parker challenged nurses to undertake further research into patients’ experiences of this phenomenon to allow care for patients to
be based on knowledge of what is important to patients, rather than speculation or ritualistic practice. In relation to the present study, Parker’s study provides valuable insights and background knowledge of a particular group of patients’ experiences. However, as only three of the ten participants were on mechanical ventilation for more than five days, the experience of specifically being on long-term mechanical ventilation was under-explored. This gap will be addressed in this study.

Studies by Russell (1999) and McKinley et al. (2002) also add to the knowledge and understanding of patients’ experiences of illness associated with critical care hospitalisation from an Australian perspective. Russell’s (1999) study examined patients’ perceptions, memories and experiences of being in the Royal Melbourne Hospital’s critical care unit. A total of 298 former patients participated in the study, and data were collected using a variety of qualitative and quantitative methods. Although not made explicit how many of the participants were mechanically ventilated during their hospitalisation, it can be assumed that the majority were, as approximately 70% of CCU beds are designated as ventilator beds (ARCCCR, 2000). A total of 86 participants were interviewed: 18 in their home using tape-recorded interviews and the remaining 68 via the telephone using written notes. Although different modes of data collection were used, all data were analysed in the same way, using a method of thematic analysis informed by what the author termed “a bio-psycho-social perspective” (Russell, 1997, p. 785).

Similar to previous studies, fear and anxiety related to the presence of vivid dreams, pain and noise was identified. Once again, the aspect of poor communication was identified, however, participants also reported several episodes of effective communication by nurses, which they found very supportive. Similar to the studies
by Adler (1997) and Logan and Jenny (1997), participants spoke of a power imbalance between themselves and nurses, and revealed how a perceived lack of control over self contributed to feelings of dependence. It was recommended that the issue of power and control within the CCU needed to be further explored to fully understand the implications for nursing practice and patient care.

Although Russell’s study (1999) provided valuable insights and contributed to an understanding of being critically ill in a CCU from the patients’ perspective, it does not explore the meaning participants attributed to their experience. Furthermore, how many of the 86 participants interviewed were on mechanical ventilation, and for what period of time, is not made clear in her study. Another limitation of the findings, acknowledged by Russell, is that the different means of obtaining qualitative data, ranging from short telephone interviews to in-depth audio-taped face-to-face interviews, affected the depth and quality of data.

The recent study by McKinley et al. (2002) also sought to gain an understanding of the experience of being a seriously ill patient in a critical care unit. Fourteen former patients, aged between 17-71 years who were hospitalised in a large CCU in NSW from three to fifty three days, participated in a series of focus group interviews three to six months after discharge. Data analysis identified a number of themes that represented participants’ experiences. Vulnerability emerged as a central concept, which was related to the extreme physical and emotional dependence inherent in the patient role. A perceived lack of information and depersonalising care were associated with fear, anxiety and increased vulnerability. Vulnerability was seen to decrease when patients were kept informed, received individualised nursing care, and when family members were present. Once again, a lack of sleep and inadequate rest
was a common finding, suggesting that this is another ongoing feature experienced by critically ill patients within a CCU.

Although McKinley et al. (2002) aimed to provide an in-depth account into the experience of being a seriously ill patient in the CCU, the research methods chosen did not fully support this overall aim. Specifically, the use of focus groups as a type of group interview does not replace individual interviewing (Fontana & Frey, 1998). Focus group interviews, if conducted well, have a number of advantages. They are relatively inexpensive, can elicit rich data, are flexible and aid recall as members can prompt other members’ memories (Fontana & Frey 1998). In addition, listening to others’ experiences may give individuals the strength to tell their own story. However, individual expression may be hampered if there are dominant members in the group, and the group format may also make it difficult to research sensitive and or painful issues. These factors would suggest that the use of focus groups in exploring individual patient’s experiences, which are often sensitive and painful to recall, may not be the most appropriate nor useful choice to answer the question posed by McKinley et al. (2002). Nevertheless, this study provided insights and extended understanding of patients’ experiences of CCU.

**Pain and Discomfort**

Pain and discomfort is another finding that is consistently reported in studies of patients’ experience of critical care illness and critical care hospitalisation (Ballard, 1981; Cochrane & Ganong, 1989; DeMeyer, 1967; Elpern et al., 1992; Grap et al., 2002; Green, 1996; Puntillo, 1990; Riggio et al., 1982; Simpson et al., 1989). Patients in the critical care environment are often very vulnerable to pain, due to their critical illness or injury, which may necessitate a myriad of medical (including
surgery) and nursing interventions. In these aforementioned studies, pain and discomfort was related to surgical intervention and or the initial injury, positioning in bed or manual handling by staff, or due to nursing interventions such as endotracheal suctioning and manipulation, and wound dressing procedures. The recent study by Grap et al. (2002) of patients’ experiences of having an endotracheal tube in place revealed that this treatment continues to be unpleasant and frightening.

Puntillo’s (1990) study into the phenomenon of pain and critical care nursing provides an important insight into the nature and extent of pain critically ill patients experience. Twenty-four participants took part in the study and, of these, 17 reported experiencing moderate to severe pain, mainly due to surgical incisions. Moreover, it was also found that nursing procedures often exacerbated pain. These findings are supported by Green (1996) who found that nursing activities and physiotherapy contributed to the frequency of pain reported by former patients. Both researchers found that there was no significant relationship between the amount of analgesic medication administered to patients and their ability to recall pain. This is an interesting finding and suggests that nurses should not assume that the administration of pain-relieving medication will dull or eliminate patients’ memories of their experience, including the presence of pain.

Discomfort related to sleep disturbances was another aspect reported in many studies (Ballard, 1981; Bradburn & Hewitt, 1980; Chew, 1986; DeMeyer, 1967; Green, 1996; Elpern et al., 1992). The early study by DeMeyer (1967) highlighted sleep disturbances as a major problem for patients in the CCU following cardiac surgery. Similarly, Chew (1986) and Green (1996) found that lack of sleep and sleep disturbance was identified as a frequent stressor for CCU patients. Sleep is an
Essential requirement for humans, and alterations in normal sleep patterns can cause significant physiological and psychological disturbance (Schwab, 1994). Sleep cycles are often interrupted in critical care units due to a number of factors such as noise emanating from the technology used in patient care, and the need to monitor the patients’ condition on a 24 hour basis. Noise levels of less than 35 decibels are generally required for someone to fall asleep. However, research has shown that ambient noise levels in critical care units are consistently above these desired levels (Schwab, 1994) and that the two main sources of noise in the critical care unit are staff to staff conversations and equipment (Evans & French, 1995).

**Comforting Factors**

Although the majority of the studies thus far have found that there are many unpleasant and uncomfortable aspects of patients’ experience of critical illness and being in a critical care unit, some comforting and positive features have emerged, particularly in studies conducted from 1990 onward. Comforting factors, which engender feelings of safety and security, were mainly due to the close presence of nurses, particularly those who were perceived as caring because of their efforts to communicate and be close by the patient. Comfort was also provided by the presence of family members and close friends, as well as the omnipresent technology that gave some participants feelings of security.

A study that examined how former CCU patients perceived nurse caring in the CCU found that nurses were perceived as supportive, skilful and understanding (Burfitt, Greiner, Miers, Kinney, & Branyon, 1993). These findings were similar to those of a later study by Wallis (1998) who found that professional nurse caring in a coronary
care unit is demonstrated by nurses who are technically competent, nurturing and who also provide information and structure to patients and their families.

In the study by Adler (1997) participants recalled how close surveillance by both technological support and health care practitioners, particularly nurses and medical officers, provided them and their and families with a feeling of safety. Russell’s (1999) study also demonstrated the importance of effective communication in the CCU for patients and their relatives in instilling comfort and security. In addition, this study also reported that the close presence of technology, particularly the mechanical ventilator, was very reassuring for participants. Feelings of security were also revealed in the study by McKinley et al. (2002), who found that seriously ill patients felt comforted when they were given adequate information, had their needs anticipated and met, received personalised care, and when their family were present and involved in their care.

**Summary**

This review of the literature on patients’ experience of critical illness and critical care hospitalisation highlights several issues. It was found that studies conducted prior to 1990 identified that patient experiences were in the main identified as negative. Study participants recalled how they had experienced communication difficulties due to insufficient explanation of procedures by nurses and the presence of the endotracheal tube, activity restrictions, anxiety and fear, nightmares and hallucinations, sleep disturbances, feelings of insecurity, dependency and depersonalisation, and discomfort related to equipment and various nursing procedures. Studies conducted since 1990 revealed similar findings, indicating that despite the increasing knowledge of patients’ experiences of critical illness and the
CCU generated from a growing body of research, patients in CCU continue to experience a myriad of problems. However, there were more reports of positive experiences related to nursing care, and nurse-patient communication. In addition, new findings provided nurses with further insight into patients’ experiences of critical care. The presence of technology, experienced by some as comforting and others as frightening, the perception of a power imbalance between nurse and patient, and the perceived lack of control in decision making expressed by participants extend our understanding of the patient experience.

Findings from these studies provide critical care nurses with some understanding of the experience of mechanical ventilation from the patients’ perspective, however some notable gaps exist. First, although the literature reveals that patients continue to experience many factors that are unpleasant and stressful, the significance and meaning of individuals’ experience of critical illness within the CCU has not been fully explored. This view is consistent with the summary of findings by Stein-Parbury and McKinley (2000) in their review of 26 research studies that focused on patient experiences deemed typical in intensive care units. Of the 26 studies examined, only those that investigated specific clinical experiences such as mechanical ventilation were included if they focused on “experiences typical in intensive care units and characteristic of ICU patients” (2002, p.20). However, the authors do not describe how they classified patient experiences as typical and characteristic. Findings from this review also highlight that researchers have not fully taken into account the meaning that the experience of critical illness and critical care has for individual patients.
Second, many of the studies had been conducted in North America or Scandinavia, where critical care practices differ markedly from the practice of Australian critical care nurses. For example, in the USA respiratory technicians manage the ventilator equipment and machine settings, whereas in Australia the critical care nurse responsible for the patient totally manages the ventilator and all associated patient care. Thus the findings from North America may have limited relevance for critical care nurses working in Australian settings. To date, the only Australian studies are those by Parker (1997) Russell (1999) and McKinley et al. (2002). While the findings of these studies extend our knowledge and understanding of patients’ experiences in Australia, none specifically focused on the experience of long-term mechanically ventilated patients. This is despite the finding that increasing numbers of people are receiving this form of treatment and also that many patients are able to recall their experience.

Conclusion

While previous studies have identified a number of factors related to patients’ experiences, this review identified that the meaning individuals attribute to being on long-term mechanical ventilation in a critical care unit has not been explored in any study reviewed. This gap in the literature is the focus of the present study. Findings from this study will increase understanding of the overall effects of long-term mechanical ventilation from the patients’ perspective, add a further dimension to critical care nurses’ knowledge base, and assist them to provide holistic and evidenced-based care through including the valuable source of information provided by patients.
In the next chapter, a discussion of the research methodology and its underpinning philosophical assumptions is provided.
CHAPTER 4

METHODOLOGY

Introduction

This chapter provides a description of the overall methodology of this study, and the philosophical underpinnings of this particular approach. The term methodology refers to “the strategy, plan of action, process or design lying behind the choice and use of particular methods” (Crotty, 1998, p.3). It is often taken to mean the study of method, where method refers to the specific procedures or techniques used to collect and analyse data. In order to account for the approach taken, it is necessary for researchers to make explicit the philosophical tenents inherent in their chosen methodology. The methodology chosen for this qualitative research study is ontological-hermeneutics, a phenomenological approach informed by the ideas of Martin Heidegger (1889-1976). Heidegger was a German philosopher who denied that his work was a methodology for the human sciences. Thus his philosophic ideas inform, rather than prescribe, the methodology of this thesis.

This chapter comprises seven sections. The first section locates the chosen methodology within the paradigm of inquiry and provides a rationale for using this particular phenomenological approach. Section two describes and defines phenomenology, and provides a discussion on the German phase of its historical development. Some of the main philosophical tenets underpinning Heideggerian phenomenology are described in section three, which clearly demonstrates the link between the chosen methodology and the research question. The next section provides an overview of hermeneutics with reference to the work of several philosophers including Heidegger (1927/1962) and Gadamer (1975). Following this,
I reiterate how the philosophical tenets of Heidegger as previously discussed are relevant to the research question and will be incorporated into the research process. Following this, I provide a brief review of some of the literature pertaining to nurses’ use of phenomenology, and also address the two main critiques relating to the use of interpretive methodology based on the philosophy of Heidegger. In the final section, a brief discussion of the limitations of using ontological-hermeneutics is included to demonstrate my understanding of the issues of using this particular qualitative approach. The chapter concludes with an overall summary of the methodology and emphasises the rationale for choosing this as the most appropriate means of inquiry to answer the research question.

The Paradigm of Inquiry

A paradigm is a worldview of how knowledge is perceived. It is a “basic set of beliefs that guide action” (Guba, 1990, p.17), and informs a researcher as to what is important and legitimate, when undertaking systematic inquiry. In the literature, there are a variety of classifications of inquiry (research) paradigms. One of the most frequently cited classification is offered by Guba and Lincoln (1994) who suggest that the four basic research paradigms are: positivism; post-positivism; critical theory; and constructivism (may also be referred to as interpretivism).

This study is situated in the interpretivist/constructivist paradigm, which is an approach that “looks for culturally derived and historically situated interpretations of the social life-world” (Crotty, 1998, p.67). Interpretivism/constructivism has been linked to the thought of Max Weber (1864-1920) who suggested that in the human sciences we are concerned with Verstehen (understanding) as opposed to the seeking of explanation and causality that is found in the natural sciences (Crotty, 1998, p.67).
In this particular period of time, the natural sciences were enjoying considerable success as a result of making significant contributions to technology in Western society, and the previously dominant knowledge base of philosophy (as in the metaphysics of philosophical schools) was seen as being less scientific (Omery, 1983). The scientific method became dominant in studying humans, and by way of objective, detached observation, sought to identify universal features of human existence and society. However, as a reaction to a denigration of philosophical knowledge and the objectification of humans by the natural scientists, the interpretivist/constructivist approach, which includes phenomenology, emerged. As described by Schwandt (1994, p. 125), “interpretivism was conceived in reaction to the effort to develop a natural science of the social. Its foil was largely logical empiricist methodology and the bid to apply that framework to human inquiry”.

When researching within the constructivist/interpretivist paradigm, there are philosophical assumptions concerning the nature of reality and the relationship of the researcher to that reality (Annells, 1999). There is a strong emphasis on relativism, which is the view that multiple constructions of reality exist collectively. When taking a phenomenological approach within this paradigm, the phenomenon is seen to be a created construction, with the phenomenologist interactively linked to the co-creation of the construction. The phenomenologist seeks to create a construction of the phenomenon from subjectively interpreting the words of the persons who have experienced the phenomenon. When using this approach, the researcher does not aim to take an objective stance (Annells, 1999).

Hermeneutic phenomenological inquiry is situated ontologically, epistemologically and methodologically within the constructivist/interpretivist paradigm. This is
because hermeneutics is the “interpretation, articulation, or ‘laying-out’ of our prior understanding of things” (Malpas, 1992, p.94). Thus hermeneutic inquiry is phenomenological in the sense that it seeks to disclose, or reveal, phenomena, and the inquiry process aims to identify and provide an understanding of the variety of constructions that exist about a phenomenon. Hermeneutic phenomenology seeks understanding, rather than theory. In contrast with Cartesian duality, its roots are within the work of Heidegger, whose phenomenology emphasises the ontological over the epistemological.

This study aims to reveal the meaning people attribute to their experience of being on long-term mechanical ventilation in a critical care unit. This question is about human experience. It is about experiencing a phenomenon as a person (or patient) in a particular situation at a particular time. Therefore, the methodological approach chosen to answer this question must be congruent with the question asked. Qualitative research, especially phenomenology, is particularly well suited to researching the human experience as its focus is on the whole human experience and the meaning attributed by people who have lived through a particular experience. The next section discusses phenomenology as methodology.

**Phenomenology**

Phenomenology is an interpretive, qualitative form of research that seeks to study phenomena. The word derives from the Greek word *phenomenon*, which means to “show itself” (Heidegger, 1927/1962, p.57), that is, to reveal something that can be visible in itself. Phenomenology focuses on the study of phenomena as they are perceived or experienced, and offers a means by which to identify the essential elements, or the essences of the experience. The purpose of the phenomenological
inquiry is to elicit a deeper understanding of the essence of the lived experience from an emic (insider) point of view (Madjar & Walton, 1999).

Phenomenological research begins by going to the things themselves, beginning with phenomena, not theories. It is the phenomenal world, the world of appearances that researchers who take this particular qualitative approach study. Phenomenology is, therefore, concerned with individuals and their views within their life world, or *Lebenswelt*, a term used by Husserl to refer to the all-encompassing world of our immediate experience (Spiegelberg, 1982, p. 747).

In contrast to the empirical approaches, phenomenology does not seek to impose structures such as hypotheses, nor generate theories and scientific generalisations. Instead, phenomenology aims at in depth description and insightful understanding of human experiences by bringing us into closer contact with the context of the life, which includes not only the physical and social environment, but also peoples’ life history. Phenomenological inquiry takes into account the unique meanings that individuals make of a situation, and also reveals the shared meanings that form the basis for social interaction (Madjar & Walton, 1999).

According to Madjar and Walton (1999, p. 3), “the distinguishing mark of phenomenology is its primary concern with the nature and meaning of human experience”. However, other research methodologies that take an interpretive approach also have this as a feature. The concern for researchers taking this approach is to be consistent with and adhere to the particular philosophical basis of its tradition.
As a research approach, phenomenology has been used in a number of disciplines including arts, psychology, sociology, anthropology as well as nursing. The historical development of the phenomenological movement, combined with its multidisciplinary usage, has given rise to a variety of interpretations and modifications of the phenomenological approach. As Cohen noted, “the philosophy has changed considerably both across different philosophers and within each philosopher” (1987, p. 31). Philosophy may be affected by culture and language, thus the different types of phenomenology will often reflect the cultural background and tradition of the philosopher. Hence German phenomenology differs from French phenomenology, and the phenomenology of North American is, according to Crotty (1996), much more reflective of American intellectual tradition than of its European origins. Lyotard perceives that phenomenology is an ongoing process that has many different accents, but retains a common phenomenological style (1991).

Through existential (being-in-the-world), and hermeneutic (interpretative) thought, phenomenology as a research methodology concerns itself with gaining access to the outer world (life world) from human experience (consciousness) through reflection and intuiting, leading to a thematic understanding of the meaning of the experience (van Manen, 1984).

Overall, there are two main phenomenological approaches that researchers may take in order to gain knowledge and understanding: Husserlian and Heideggerian. The Husserlian tradition is epistemological and has as its focus the description of the life world from the viewpoint of an observer. In contrast, the phenomenological tradition of Heidegger is based on an existential, ontological perspective that considers that the observer cannot separate him/herself from the world.
The methodology for this study is informed by the ideas of Martin Heidegger. As it is essential to demonstrate congruence between the philosophical underpinnings and the research approach taken, it is necessary to review the origins and historical development of phenomenology in order to make clear the distinction between Husserlian and Heideggerian phenomenological traditions and to demonstrate why Heideggerian phenomenology is appropriate for this study.

**History of Phenomenology**

The birth of phenomenological philosophy as a school of thought and as a research method arose in Germany in the late nineteenth century. It emerged as a result of a growing dissatisfaction with positivism being unable to provide an appropriate means of discovering and supplying answers to human concerns (Cohen, 1987). The positivist perspective encompasses the Enlightenment, which is generally referred to as the self-proclaimed “Age of Reason” that began in England in the seventeenth century and became widespread in France in the following century (Crotty, 1998, p. 18). The term “positivism” was popularised by Auguste Comte (1798-1857), a French philosopher and self-proclaimed scientist who believed that the human mind could only function at its best if all people embraced one scientific method society (Crotty, 1998, p. 19). To this end, Comte founded the *Societe Positiviste* in 1848, whose purpose was to encourage all people to become positivists as a means to establishing a stable and equitable society. Positivism takes the stance that the only true and valid form of knowledge is that derived through the application of the scientific methods of direct observation, experimentation and comparison. Positivism seeks to scientifically establish laws that can be used to explain predict and control society.
As previously discussed, the interpretivist/constructivist approach, which includes phenomenology, emerged as a reaction to a deprecation of philosophical knowledge and the objectification of humans by the natural scientists. Thus, phenomenology strives to understand human phenomena through interpretation of human beings in their social, historical and political contexts rather than employing the methods of external observation and explanation as used in the natural sciences (Ray, 1990).

In order to trace the development and increasing usage of phenomenology, Spiegelberg (1982) wrote a comprehensive history of what he referred to as the “Phenomenological Movement”. He used the term “Movement” to signify that phenomenology is not a stationary philosophy, but as one that changes across, and within, philosophers. He divided the Phenomenological Movement into three phases: the preparatory phase, the German phase, and the French phase. For the purposes of this study, which uses an approach informed by the ideas of the German philosopher Heidegger, only the German phase will be discussed. A brief overview of the work of Husserl is included in this discussion, acknowledging the important contribution he made to the development of the phenomenological movement. The ideas of Heidegger relevant to this study are then discussed, followed by a description of Heideggerian hermeneutics, with reference to the work of the philosophers Schleiermacher, Dilthey and Gadamer.

**German Phase**

**Husserlian Phenomenology**

The German phase of the phenomenological movement was dominated by the work of two philosophers: Edmund Husserl (1859-1938) and Martin Heidegger (1889-
However, Husserl is generally acknowledged to be the central figure of the phenomenological movement. Husserl was also a mathematician who strove to incorporate mathematical rigour in his method. This is reflected in the main tenets of his phenomenological philosophy that is underpinned by objectivity, researcher detachment, and suspension and bracketing of researcher assumptions and biases (preconceptions or pre-understandings).

Husserl based his philosophy on a critique of positivism, which remained the dominant worldview of knowledge inherent in the physical and social sciences of the time. This view ignored phenomena that could not be directly observed or measured. He believed that science needed a philosophy that could come in contact with deeper human concerns. His mission was to reinstate the discipline of philosophy to its former importance through the search for absolute knowledge (Cohen, 1987). Husserl believed that pure truth and a clear understanding of the essential nature of reality could only be discovered through the study of lived experience and systematic descriptions of the phenomena encountered by humans in their everyday lives.

Husserl sought to establish a science of phenomena as a science of cognition of essences or structures rather than of matters of fact proven by methods more accustomed to positivism. Thus, Husserl was concerned with essence, which has been defined as “a fact or entity that is universal, eternally unchanging over time and absolute” (Jennings, 1986, p. 1232). He classified his phenomenology as transcendental, whose purpose was to transcend or overcome the traditional scientific notion that only that which can be observed and measured using empirical methods experience is valid knowledge. The process of transcendental subjectivity is achieved through seeking to reach the genuine and true form of things themselves. Therefore,
Husserlian phenomenology attempts to describe the way the world reveals itself to consciousness without using theoretical constructs derived from philosophy and science (Palmer, 1994).

Husserl was concerned with “how do humans know what they know?”, thus his concerns were epistemological in nature. He believed that meaning and understanding could only be gained through direct experience of a phenomenon, and avoidance of theories and preconceptions. This stance reflects a Cartesian notion of subjects experiencing, and knowing, objects in their world. Husserl, like Descartes, places consciousness at the centre of his philosophy (Palmer, 1994), and sees it as the foundation of knowledge. However, Husserl’s notion of consciousness differed from Descartes in that he claimed that we are always conscious ‘of’ something. For example, one can’t just be frightened, or upset, one is frightened of something, or upset about something. Husserl names this intentionality, which he sees as being unique to the human mind and distinguishing it from all other things (Palmer, 1994). In response to situating human consciousness at the centre of his philosophy, Husserlian phenomenology sought to illuminate both the content and the method of the mind (Palmer, 1994).

Phenomenological reduction, which is also referred to as eidetic reduction or bracketing, is an important concept in Husserl’s phenomenological philosophy (Cohen, 1987). Husserl formulated the notion of the life world, or Lebenswelt, which he saw as the everyday world in which we live, the natural taken-for-granted attitude (Ray, 1990). Taking as his starting point this life-world, Husserlian phenomenology suspends and holds in abeyance the usual assumptions and presuppositions to get behind the ‘natural standpoint’ to find the underlying structure. Thus the researcher
takes a detached view, in order to let the phenomenon be seen from an objective stance. He saw this as the only means by which the phenomenon in question can be revealed in pure, uncontaminated consciousness. Husserl was committed to seeking absolute knowledge by peeling away the non-essential features of objects, and revealing the underlying essence (Jennings, 1986). Thus, Husserl’s phenomenological method went to the things themselves, bypassing previous knowledge and theoretical understandings in order to reveal the essence of a phenomenon.

Annells (1999) situates Husserlian phenomenology within the positivist research paradigm being as it is concerned with researcher objectivity and bracketing of the natural world. Husserl’s philosophical stance and phenomenological method, although providing an extremely useful approach to undertake some research questions, is not appropriate for this study which seeks to explore the meaning for people of being on long-term mechanical ventilation in a critical care unit. This particular question is an ontological question: it is concerned with what it means to be a person and experience a particular phenomenon in a particular context. As this study asks an ontological question, it requires an approach that reflects an ontological perspective.

I clearly identified in chapter one that my interest in pursuing this particular line of inquiry arose from my own interests and background as a critical care nurse who has cared for many patients on long-term mechanical ventilation. I therefore bring to this study pre-understandings arising from my own life experience, which I explain in more detail in the next chapter. I did not believe it was necessary or realistic to set aside my own pre-understandings in an attempt to bracket them. I therefore chose to
adopt the perspective of Heideggerian phenomenology, which also derives from the
German Phase, but whose philosophical underpinnings differ from those of
Husserl’s.

**Heideggerian Phenomenology**

Martin Heidegger was born in Messkirch, Baden-Württemberg in Germany in 1889.
He commenced study at the University of Freiburg in 1909, where initially he was a
student of theology, later switching to mathematics and philosophy. He was awarded
a Doctorate of Philosophy in 1913 for his thesis titled: “The Doctrine of Judgement
in Psychologism” (Guignon, 1993a, p. xix). He was also a student and colleague of
Husserl for a period of time. Although Husserl’s ideas initially impacted on and
influenced Heidegger’s ideas, it soon became apparent that his philosophical
concerns differed markedly from Husserl’s (Palmer, 1994). Whilst Husserlian
phenomenology was epistemological and primarily concerned with revealing the
essence of a phenomenon, Heidegger was more interested in applying
phenomenological method to a much deeper question – that of Being itself (Palmer,
1994). Heidegger used the term Being, with a capital B, to denote the being of
human beings.

Heidegger’s interest in and formulation of the question of being has been attributed
to his reading of Franz Brentano’s *On the Manifold Meaning of Being in Aristotle*
published in 1862 (Guignon, 1993a, p. xix). Heidegger believed that the ontological
question of what it means to be was primordial and should come prior to seeking
epistemological answers or questions of knowing. That is, he turned the
phenomenological focus from the Husserlian stance that sought to ask the
epistemological question ‘how do we know what we know?’ to an ontological
perspective that asks ‘what does it mean to be a person?’ (Leonard, 1989, p. 42). This shift by Heidegger from the epistemological stance of Husserl to an emphasis on ontological questions resulted in the development of a second branch of phenomenology, known as hermeneutic phenomenology.

Heidegger’s quest was to illuminate Being, and make it the central question of concern to philosophers. He did not seek to question being itself: instead he questioned the meaning of being. In his major work *Being and Time* (1927/1962) Heidegger aimed to proceed through a preparatory fundamental analysis of Being to an explanation of how time provides the horizon for the question of being. Although he never fully completed this work, *Being and Time* with its focus on the analysis of the condition of human existence provided an extremely important contribution to twentieth century philosophy (Frede, 1993).

In the first part of *Being and Time*, Heidegger considers the reasons why the question of Being has been overlooked, and attributes this to the view that Being was so universal and taken for granted, that philosophers did not see any reason or need to discuss it. He disagreed with this viewpoint, and instead saw Being as “the darkest concept of all” (1927/1962, p. 23), which could only come to light and be revealed through an examination of human ways of being. In so doing, he noted that since what things are (their being) is accessible only when they show for us as relevant in some way, we need a “fundamental ontology” that clarifies the meaning of things in general. And since our existence is “the horizon in which something like being in general becomes intelligible” (1927/1962, p. 274) Heidegger saw that the beginning task of fundamental ontology was to clarify the possibility of having any understanding of being at all.
Heidegger considered phenomenology as one way of bringing to light the ontological foundations of understanding Being. Like Husserl, Heidegger also refers to the lived world, and believed that an understanding of Being can be reached through “being-in-the-world”, and to what he sees as the pivotal notion of human everyday existence: Dasein (Annells, 1996, p. 3). Heidegger uses the term “Dasein” to depict human being. That is, the Being that belongs to persons, the nature of Being that gives rise to an awareness of the existence of Being. The word Dasein literally means being-there (Crotty, 1998, p. 219). Heidegger uses it to denote the being there of human beings, the place where Being is and manifests itself. Heidegger saw Dasein as the locus of human existence. Thus Dasein in a Heideggerain sense is the basic structure of humans, where each human’s own way of being is an issue for it (Guignon, 1993b).

In contrast to Husserl’s view of reduction and bracketing of pre-understandings, Heidegger considered that there was no ‘I’ separate from the world. Rather there is Dasein which is the “entity which each of us is himself” (1927/1962, pp. 27-28). Being-in-the-world is therefore an essential part of the structure of Dasein, and inseparable from it (1927/1962, pp.78-90). There is no pure vantage point to which we can retreat that will enable us to see the world from a disinterested and supposition free stance (Guignon, 1993b), and Heidegger repeatedly emphasises that the world and Dasein are not separate. Thus, Dasein cannot be comprehended without considering the world, since the world is an essential characteristic of Dasein itself (1927/1962, p. 92). As the world and Dasein are inseparable and since this being-in-the-world as human existence is the only position possible, there is no subject-object dichotomy of the world and Dasein. Phenomenology from a
Heideggerian perspective renders no possibility of separating the self from the world and so it is impossible for the researcher to bracket his or her assumptions and be separated in any way.

Heidegger’s fundamental ontology begins with a description of the phenomena that shows itself for us in relation to our being in the world and our pre-understandings of what things are all about (Guignon, 1993b). From being participants in a shared world we are able to grasp the being of entities such that the hidden meanings of these emerge and come to light. In Heidegger’s view, the hidden meaning of phenomena is revealed firstly through a description of everyday existence, a phenomenology of everydayness which when coupled with a hermeneutic (interpretation) brings to light the hidden meaning of the practical life world (Guignon, 1993b). That is, by examining human ways of being-in-the-world in we are able to bring to light the meaning of Being. In this way, Heidegger sees that there is a “clearing” in which specific forms of human existence are revealed (1927/1962, p. 171). This clearing allows that which is hidden to become accessible and show up as what they are. Dasein is said to be a clearing through which entities can stand forth and be revealed. This understanding of Heidegger’s notion of Being can be used to reveal meaning of Being for humans in a particular context, which is the focus of this present study. By examining the ways in which the participants in this study experienced being on long-term mechanical ventilation in a critical care unit, the meaning attributed to this phenomenon can be revealed within a clearing of this specific context.
Heidegger’s analytic of Being

This research study asks the question: *What does it mean to be on long-term mechanical ventilation in a critical care unit?* In examining Heidegger’s philosophy, it is important to further consider his analytic of Being. Through analysing Heidegger’s ways of Being, we are able to move closer to understanding the question of what it “means to be”. Although it is not necessary to give an account of all the Heideggerian analytic of Being, there are a number of tenets underpinning Heideggerian phenomenology that are relevant to exploring the research question and move closer to an understanding. Similar to Kellett (1997), I considered the following Heideggerian tenets to be useful and relevant for understanding: space, engagement, time, care and concern, and humans as self-interpreting beings.

**Space**

Heidegger uses the term space to refer to a situation in which to be (1927/1962, p. 134). Benner and Wrubel (1989) describe situation as the concerns, issues, information, constraints and resources at a given span of time and or place as experienced by a particular person.

According to Heidegger, entities can only show as what they are against a background of the situation, and the interpretive practices of a particular period of time, language and historical culture (1927/1962, p. 136). Thus, the situation shapes how human beings exist in the world, that is, their ‘being-in-the-world’. Situation helps us understand the kinds of people we are in everyday affairs by virtue of the practical contexts of worldly involvement in which we find ourselves. Self and world belong together in the single entity Dasein, with no subject-object Cartesian
dichotomy. Thus the ontological concept of ‘in’ is what makes one familiar with the world, and meaning is embedded within the everyday, taken for granted practices.

For Heidegger, understanding what it means to ‘be’ involves acknowledging Dasein’s relationship to the past, the future and its situatedness in our current world. Heidegger sees the world as the relational whole within which human beings exist and within which we are inextricably linked (Guignon, 1993b). Dasein involves itself in all kinds of projects and plans for the future. In a sense it is always ahead of itself, looking for possibilities in the future that exist within the relational world. At the same time it must come to terms with matters over which it has no control, elements from the past that loom behind it out of which Dasein is projected or “thrown” (Krell, 1993, p.22). Dasein not only has a history, it is also its own past. It lives in the present and gets caught up in the issues and affairs of the moment. Heidegger names these three constituents of Dasein “existentiality”, “facticity”, and Verfallen – a kind of ensnarement (Krell, 1993, p.22). Thus, one is embedded in a world where one has a past, present and future, all of which influence the current situation.

Any theoretical understanding of lived experience must therefore be context specific. Personal interpretation of the situation is bounded by the nature of the situation and the way the individual is in it. People live their experiences in the individual context of their lives. As Leonard asserts “persons not only have a world in which things have significance and value but they have qualitatively different concerns based on their culture, language and individual situations” (1989, p.40). Therefore, people are engaged in living their lives in their world, and it is unrealistic to assert that people’s interpretation of their life is unrelated to their Being-in-the-world. The concept of
‘Being-in-the-world’ acknowledges that the context of people’s lives is crucial in the interpretation of their life experiences.

The present research project that focuses on the meaning people attribute to their lived experience of being on long-term mechanical ventilation in a critical care unit, embraces this notion of being-in-the-world. Through Being-in-the-world of a critical care unit and experiencing long-term mechanical ventilation, the study participants will derive meaning of this situation from their own unique background and previous life experiences.

**Engagement**

Heidegger used the concept of engagement to characterise everyday involvement in the world. Heidegger believed that Being was already part of the world. That is, Being-in-the-world is to be embedded in the world, to dwell there and be involved with other people and things.

Heidegger (1927/1962, pp. 102-107) describes the different ways people are engaged in the world in terms of the different relationships between tools and people. He calls these *ready-to-hand, unready-to-hand, and present-at-hand.*

Ready-to-hand are objects we use and understand through their use. When we are actively involved in the situation, ready-to-hand equipment is unnoticed, and is seen as an extension of the body and action. As an example, a person may use crutches in a ready-to-hand way. The equipment may go unnoticed because it is an extension of the body. When a person is healthy, his or her body is ready-to-hand, unnoticed, and taken for granted. Also, the person who has adjusted to physical disability can
experience the body as ready-to-hand after becoming skilled and accustomed to disability.

However, when equipment breaks down and becomes noticed, it is said to be unready-to-hand. When something becomes unready-to-hand, the situation is altered, and the person loses the maximum grasp that was available in the ready-to-hand condition (Benner & Wruble, 1989). It is a situation that is “problematised” by the breakdown. The present-at-hand is the most detached objective view of the situation. Here, the person stands outside the situation and looks on. It is a mode of explaining objects in the natural or Cartesian tradition. From this viewpoint, the present-at-hand is seen as more objective and less involved. From a Heideggerian perspective, the taken-for-granted, ready-to-hand mode of engagement provides practical understandings, and precedes abstract, theoretical knowledge derived from the present-at-hand engagement.

Engaged involvement provides a way of seeing the world, and sets up possibilities through which meaning can be attributed to human existence. A present-at-hand analysis cannot provide an adequate understanding of the complexities of human existence, and the meanings people attribute to their existence. Thus, seeing the world through the ready-to-hand, taken for granted lived experience allows us to explore meanings that are often hidden in everyday practices.

The tenet of engagement is of relevance to this study. As the participants will have experienced an episode of critical illness or injury that involved admission to a critical care unit and the application of sophisticated life supporting technology (including mechanical ventilation), their level of active engagement in their world
may fluctuate. Although much has been written from the outsider perspective reflecting the present-at-hand, the findings from this study may bring to light new understandings of how people engage when critically ill in the world of the critical care unit.

**Concern and Care**

In a Heideggerian sense, the concept *concern* refers to a person’s active and engaged involvement in the world. It means caring about, and to be concerned means that the world is through a person’s ability to grasp a situation in terms of meanings and possibilities for the self. To understand something and to care about something is to understand it in the context of usage, or practical activity. Thus concern denotes the why and wherefore of engaged involvement (Benner & Wrubel, 1989).

Heidegger saw concern as one of the main characteristics of human existence (1927/1962, p. 57). He used the term “Besorgen” in a narrow sense to reflect the type of concern in which we involve, or concern ourselves with activities we undertake or things we attain. In a similar vein, he used the term “Sorge” to denote care for both ourselves and for others (Palmer, 1994, p. 337).

In this sense, we have care or concern for the world around us, our relational world that encompasses the natural and human world. He argued that being-in-the-world entails being-with-others, and it is essential that we acknowledge the Dasein of others (Palmer, 1994). Therefore, to have an authentic existence requires that we display caring and concern for others. That is, we need to express concern and care for beings, and for Being itself. We also need to display concern and care for the community.
According to Heidegger, care and concern are ways of being involved in one’s world in which people and things matter in an authentic way. Similar to engagement, these tenets are relevant to this study and may bring to light new understandings of care and concern when critically ill in the world of the critical care unit. The world of critical care is not the everyday world of participants, so seeking to explore how care and concern are manifested for people in this situation may provide new insights.

**Temporality**

Temporality is the way in which people simultaneously live in the present, are influenced by the past and are projected into the future (Benner & Wrubel, 1989). Temporality in this sense does not refer to the linear passage of time, but to the way the person is situated, or embedded, in a present that is made meaningful not only by the past, but also by the possibilities that may exist for the future.

Heidegger sees time as of prime importance in an understanding of Dasein, and “as the horizon for all understanding of Being and for any way of interpreting it” (1927/1962, p. 39). He aims to show how a temporal analysis allows us to get a grasp on the whole of Dasein from beginning (birth) to end (death). Heidegger sees death as a possibility that occupies one’s present, abbreviates one’s future, and monumentalises one’s past (Krell, 1993).

In this sense, time has a dimension that is infused with intentionality. It is specific and formed by what has gone on in the past, and what is anticipated in the future. Heidegger acknowledged that historicity and temporality are essential for the way in which human beings understand themselves (Benner & Wrubel, 1989). For
Heidegger, temporality is linked with meaningfulness about the person’s world, and understanding of Being can only be sought through an historical analysis of a person’s existence.

Temporality is another important concept for rendering meaning in this study. As we have seen, people are temporal beings whose past, present and future influences the way in which they would interpret their experience of this particular illness episode within their lives. The participants in this study may have been sedated and or experienced different levels of consciousness whilst they were on mechanical ventilation in the critical care unit and therefore were unable to disclose their story at that time. However on interview their story will be influenced by the past and is projected into the future. This can provide valuable insights and increase our understanding of a lived experience that is not examined in the present.

**Human beings are self-interpreting**

Heideggerian phenomenology expounds the view that people's foundational mode of existing is an interpretation and understanding. Heidegger (1927/1962) sought to reveal an understanding of the meaning of Being (Stumph, 1994). Heidegger believed that people are self-interpreting, and have the ability to reflect upon their existence whilst engaged in everyday activity. He saw humans as unique beings, not only because we think about and question Being, but by doing so we put our own Being in question (Palmer, 1994). Through Dasein, (being there, or there being), we are able to disclose Being, as Dasein is capable of reflecting upon its own existence.

Heidegger, therefore, saw Dasein to be the means to know and understand the human existence. Dasein recognises that people locate and describe their world against a
background of significance that relates to their culture and language (Rather, 1992). As self-interpreting beings, we take part in a shared background of common meaning that can be made public through dialogue (Benner, 1984). Therefore, Heidegger’s view that humans are able to interpret self is also relevant to this study. By reflecting on and interpreting their experience of being on long-term mechanical ventilation in a critical care unit in light of their own unique life histories, participants will be able to reveal a range of meanings and insights into a phenomenon that has not been fully explored.

In Heideggerian phenomenology the researcher focuses on people’s shared meanings and common everyday practices revealed in narratives, and interprets these in a process of interpretation called Hermeneutics. Hermeneutics and the hermeneutical process are the focus of the discussion the next section of this chapter.

**Hermeneutics**

The term hermeneutics means interpretation. It is derived from the Greek word *hermeneuein*, which means to interpret, and is thought to have originated from the Greek God Hermes who apparently discovered languages and writings and conveyed messages to human beings so they could in turn convey the message to others (Thompson, 1990). According to Palmer (1969), hermeneutics involves both interpreting and understanding texts, particularly where the process involves language. Because language is a shared experience for human beings influenced by social, historical and cultural factors, meaning comes to humans in different contexts as they live linguistically. The underlying assumption of hermeneutics is that humans experience the world through language that provides understanding and knowledge. Thus language enables humans to derive understanding of the world in
which they live. Hermeneutic interpretation, therefore, enables meanings in human understanding of being in the world to be revealed in a meaningful way.

Traditionally, hermeneutics referred to the process involved in interpreting biblical texts. Later it became an accepted means to interpret other secular texts such as in law and literature. In the nineteenth century hermeneutics took a practical turn, and formed the basis for all human sciences (Palmer, 1969). This was due mainly to the influence of two scholars, Schleiermacher and Dilthey, who both sought to extend hermeneutics beyond its traditional, specific role.

Schleiermacher

Friedrich Schleiermacher (1768-1834) was a Platonic scholar who first proposed a general hermeneutics, thus moving away from a specific theological, legal or literary exegesis (Palmer, 1969). He asserted that the principles underpinning traditional hermeneutics could be generalised into a set of laws by which meaning operates, which could be used to guide the process of extracting meaning from a text (Palmer, 1969). Schleiermacher proposed that such a science of understanding comprised two distinct parts that were both essential in the process of reaching meaning: understanding language, and understanding and re-visioning the thoughts of the author of the text. His contribution marked an important turning point in the development of hermeneutics as it became to be seen as the art of understanding language in any context.

Dilthey

Wilhelm Dilthey (1833-1911) continued to develop hermeneutics, seeing it as the only means by which human expression could be revealed meaningfully. At this
time, reductionist thinking inherent in natural sciences was also being extended into the domain of the human and social sciences. That is, a common belief pervaded that valid knowledge could only be derived from research that took an objective, atemporal stance. However, Dilthey asserted that human understanding could not be reached through such methods, but instead could only be gained from studying the experience of life itself (Palmer, 1969). Life experience, according to Dilthey (1985, cited in van Manen, 1990, p.35) involves our immediate, pre-reflective consciousness of life:

A lived experience does not confront me as something perceived or represented; it is not given to me, but the reality of lived experience is there-for-me because I have a reflexive awareness of it, because I possess it immediately as belonging in some sense.

Dilthey believed that the task of human science then, was to reveal the underlying structures that give meaning to an experience. A key feature of his work was the assertion that interpretation can only occur from within an historical perspective. That is, in order to understand the present, we need to be aware of and acknowledge the past. Dilthey believed that both the past and the future constitute the horizon, and it is only within this horizon that the present can be interpreted. Following on from the earlier work by Schleiermacher, Dilthey further developed the concept of the hermeneutic circle (Palmer, 1969), which involves the continuous circular movement between the background of shared meaning (the whole) and the individual experiences (the part) of the participants (Leonard, 1989).

Dilthey extended the concept to place the person within the circle, a move that effectively shifted the focus of interpretation from the author, as in Schleiermacher’s work, to the expression of lived experience. This focus was clearly
phenomenological in nature, and was influential in the development of Heidegger’s later work.

**Heideggerian Hermeneutics**

Heidegger is considered the prime instigator of modern hermeneutics (Annells, 1996). His work, starting as it did with a rethinking of Husserl’s phenomenology, also extended the work of Dilthey by further extending the concept of the hermeneutic circle. Rather than seeing it as part of the method for researching within the human sciences, Heidegger took the stance that it was central to all human knowing and understanding. Heidegger (1927/1962) believed that everyone exists hermeneutically through interpreting and finding meaning in their lived world, and he saw that hermeneutical inquiry could be applied to search for the meaning of Being. He, therefore, goes beyond Dilthey’s life experience view to situate hermeneutics ontologically.

Essential to understanding are three considerations that Heidegger termed the structure of understanding, or fore-structure. These three considerations he sees as integral to human interpretation and understanding that takes place within the hermeneutic circle (Gelven, 1989). Firstly, the *fore-having* relates to the taken-for-granted, background practices that are already understood and allow for interpretation to occur. The next part, known as *fore-sight*, relates to the particular point of view from which we make an interpretation, that is the awareness and background of the interpreter that directs him or her in a specific way towards phenomena. The third part, the *fore-conception*, is concerned with our expectations, and is linked to the previous two considerations. As a result of our fore-having and fore-sight, we anticipate a range of possibilities in an interpretation. The fore-
structure of understanding then is an essential component of Heidegger’s hermeneutics.

Heidegger believed that the way meaning is uncovered is through language, that is, language sets up the conditions for human understanding. In our everyday life, language makes meaning, and things and their meaning are disclosed to us though language (Thompson, 1990).

Heidegger’s perspective on hermeneutics is important for this study as it positions the researcher within the research process. That is, the researcher is with the participants and incorporates his or her own perspectives throughout the interpretive process to reach a fusion of horizon of understanding. This position reflects my own position as a nurse and nurse researcher. I have always aimed to be with patients and their relatives and not distance myself. The way in which I incorporate a Heideggerian hermeneutical perspective in data analysis is explained in the next chapter.

Following on from the work of Heidegger was another German Philosopher, Hans Georg Gadamer. Gadamer built on the work of Heidegger and extended discussion on many of the concepts underpinning hermeneutics. Although coming after Heidegger, a brief discussion of his ideas will now be provided as they assisted me in furthering my understanding of hermeneutics.

**Gadamer**

In his book *Truth and method* (1975), Gadamer (1975, p. xxii) asserted that all understanding is hermeneutical, because hermeneutics “includes the whole
experience of the world”. In common with Heidegger, Gadamer believed that understanding was an ontological, rather than an epistemological problem. He also emphasised historicity, asserting that it is impossible to understand human beings and society from an ahistorical perspective (Gadamer, 1975). That is, understanding occurs within the context in which people live. It cannot be derived through methods more aligned with the natural sciences that take an objective detached stance.

Fusion of horizons, the hermeneutic circle, prejudice and dialogue with the text and language are all constructs that feature in Gadamer’s hermeneutic interpretation.

_Fusion of horizons_

Gadamer extended and drew on Husserl’s concept of the horizon, and described how a fusing of horizons occurs through a process of understanding when researchers immerse themselves in the analysis of the text, allowing the horizon of the text to fuse with the horizon of their own meanings. This continuous interaction between the interpreter and the text introduces Gadamer’s notion of effective historical consciousness (1975), which refers to the conscious task of trying to understand the text by comprehending its historical and present contexts. Through this fusion of horizons, this joining of one’s own historical concepts and meanings with those of the text, a greater understanding can be achieved.

For Gadamer, hermeneutical interpretation involves a conversation between the interpreter and the text that is reciprocal in nature. The interpreter enters a thinking dialogue with the text in order to arrive at a more complete understanding. Like Heidegger, Gadamer considers it essential that the historical, social and biographical
location of both the text and its interpreter (the pre-understandings) are made explicit in the interpretation process.

The hermeneutic circle

The concept of the hermeneutical circle involves a continuous, circular process whereby the interpreter moves between the whole and the part of the text derived from participants. Polkinghorne (1983, p.227) describes the hermeneutic circle as:

The process of understanding is a movement of the first prejudgemental notion of the meaning of the whole, in which parts are understood, to a change in the sense of the meaning of the whole because of the confrontation with the detailed parts of the whole.

According to Leonard (1989), through the process of systematically analysing the whole, we gain new perspectives and an increased depth of understanding. This in turn is used to examine the parts of the whole, and then re-examine the whole in light of the insights gained from the parts. Moving back and forth within the hermeneutic circle gives rise to an increased awareness and understanding, and can also reveal meaning that may have previously been hidden or undisclosed. The hermeneutical circle includes both the participants and researcher. The participants tell their story from their own interpretation, and the researcher interprets this from his or her own background and experience as well as the participants. Thus there is a moving back and forth, especially if the researcher takes back to the participants the interpretation for their consideration.

Prejudice

Gadamer defines the concept of prejudice as preconceived ideas or notions that are derived from one’s background and past history. Gadamer’s (1975) concept of
prejudice is linked to Heidegger’s ideas of the three-fold structure of understanding, or fore-structure. Grasping this fore-structure of shared understanding, or prejudices, becomes the starting point of interpretation.

Dialogue with the text
Hermeneutical interpretation requires the researcher to continually engage with the text. In effect, the researcher (interpreter) is involved in a conversation or dialogue with the text that continues throughout the entire analytic process. Engaging in a dialogue with the text opens up new ways of looking at the world, as the researcher questions the text and reflects on the questions derived from the text. Dialoguing with the text enables the researcher to reach a greater understanding of the meaning of the participants.

Language
Hermeneutics emphasises the primacy of language. Gadamer sees the goal of hermeneutics is to examine the nature of human understanding, a goal that can only be achieved through a thorough and rigorous examining of language itself (1975). For Heidegger and Gadamer, language is the medium of interpretation, and the product of human culture. Only through language can we be said to have a world. Language is created and reproduced socially and historically, existing in our everyday lives and forming the background of shared understandings that form our prejudices and preconceived ideas. Thus, language is a way of being in one’s world.

Like Heidegger, Gadamer believed that understanding is derived from an historical and cultural perspective that is dynamic and changes over time. Thus, he believed it
was not possible to develop a systematic method for the human sciences, as this requires a static, detached and objective stance that will only abstract from the truth.

Taking a Heideggerian Hermeneutical Perspective

What does it mean to be on long-term mechanical ventilation in a critical care unit? This question is about human experience. Drawing on Heidegger’s tenets of Being discussed in this chapter, it is assumed that participants in this study are able to bring to light, and share a particular lived experience and give it meaning. Through the research process outlined in the following chapter, the data obtained from in-depth participant interviews of their stories, and my own field notes, enabled me to reach an ontological understanding of the research question. Heideggerain tenets of Being bring us closer to viewing the world from the inside. The tenets relevant to this study are:

- Human beings are situated in the world;
- Human beings are engaged in the world;
- Humans are temporal beings;
- Human beings have care and concern; and
- Humans are self-interpreting beings.

By adopting these tenets and being alongside the participants throughout the research process, I aimed to interpret and understand through a fusion of horizons the perspectives of the interpreter (self) and the participants as shared with me in their stories.
The following section will briefly review some of the literature that pertains to nurses’ use of phenomenology, and also address the critiques that have arisen from this use.

**Hermeneutic phenomenology and nursing research**

The very uniqueness of nursing lies in its concern with holism, which in its most abstract form is seen as “the totality of human experience” (Wilkes, 1991, p.230). Phenomenology is a way of viewing the lived experience of people, and the meaning they attribute to that experience. As nursing embraces a holistic approach to care, it is essential that people’s lived experience should be explored and described by research methods that can most effectively serve nursing’s goal. Therefore, it is apparent that connections exist between nursing and phenomenology, as nurses’ interests rest firmly in an understanding of the experience and concerns of patients as they exist and live their lives within the health care environment.

Phenomenology has gained respect in nursing as a valid approach to the study of nursing as a human science, and to the art and science of human caring (Munhall & Oiler, 1986; Parse, 1981; Paterson & Zderad, 1976; Watson, 1979, 1985). It offers a means by which human phenomena or the lived experiences of the life world of nurses and patients can be studied and understood (Madjar & Walton, 1999).

Taylor (1994) states that there are many positive features in using phenomenology to explore questions about nursing phenomena. These include: a valuing of persons who create personal meanings; a focus on the experiences of nurses and or clients existing in a health care system; a consideration of the context in deriving meaning; and seeking to uncover meanings embedded in everyday, taken for granted practices.
Similarly, Munhall (1994) argues that nurses need to understand the lived experience of clients in different settings to enable them to plan appropriate care.

Reeder (1985) sees many benefits in using a phenomenological hermeneutic approach for nursing research arising from its emphasis on the universality of language, and the deepening of understanding through the fusion of horizons of past, present and future of persons in different health care contexts. This view has been supported by a number of nurse researchers (Darbyshire, 1994; Diekelmann, 1993; Draper, 1991, 1996; Kondora, 1993; Madjar & Walton, 1999; Walters; 1994a, 1994b, 1995a, 1995b), signifying an increasing global awareness of the advantages to nursing possible through this approach to inquiry. As nurse scholars work towards the generation of knowledge, research using hermeneutic phenomenology can contribute enormously to expanding nurses’ knowledge base, provide evidence for practice thereby improving patient care outcomes.

However, as a research approach, hermeneutic phenomenology based on the philosophy of Heidegger, has generated criticism. The critiques relate to Heidegger’s personal politics, and also to the claim that nurses have misinterpreted Heidegger’s work. These two major critiques will now be addressed.

**Critiques relating to the use of Heideggerian Phenomenology**

**Heidegger and Politics**

The publication of Victor Farias’s *Heidegger and Nazism* in 1987 created fierce debate, and since then other authors (Babich, 1993; Sheehan, 1993) have also written about Heidegger’s involvement with the German National Socialist party. Generally, the debate takes two sides: those who condemn Heidegger for his political
involvement, and those who see his political stance as irrelevant to his philosophical thinking. According to Guignon (1993b), what has often been missing is a reflection on Heidegger’s place within the wider arena of events of the time. Guignon considers Heidegger’s contributions to politics and the Nazi party as insignificant, as they were within a context of the conservative revolution that swept the Nazis back into power, and a backlash against modernism and liberalism that was building steadily in Germany from the 1870s to 1933. In contrast, Holmes (1996) has questioned the appropriateness for nurse researchers to use Heideggerian phenomenology specifically on the grounds of his alliance with the Nazis and National Socialism. Whilst it is not possible to overlook the fact of this involvement, an awareness of the issue enables me, as nurse, researcher and interpreter, to always read his work critically and be aware of this in my writing. As advised by Sheehan, I do not adopt his philosophy totally, but instead use only those parts of his philosophy that I consider to be of value (1993). In this study I used the philosophical tenets that I considered relevant. At no time did I consider any of these reflective of Heidegger’s political ideologies, but instead a reflection of his philosophical assumptions of Being.

Nursing and Interpretive Phenomenology

The second critique concerns the way in which nurse researchers have used phenomenology as a methodology. The critique centres on the contention that nurses have misused traditional European phenomenology, and have instead adopted a new less critical approach. In his book, *Phenomenology and Nursing Research* Crotty (1996) provides an analysis of selected phenomenological nursing research projects, and argued that nurse researchers from North America have misinterpreted European phenomenological philosophy, and instead produced an uncritical exploration of
culture. Crotty’s point of contention was that this particular approach, which he termed the North American influence, should not be called phenomenology because it does not espouse Husserl’s constructionist epistemological position that Crotty regarded as essential to pure phenomenology. In particular, Crotty criticises nurses’ use of other people’s experiences as text for interpretation, and using shared practices to derive meaning, rather than searching for meaning per se. Crotty follows up this work with an article that further critiques nurses’ use of Heideggerian phenomenology (1997), a view supported by Paley (1998).

There have been a number of challenges to Crotty’s criticisms. For example, Darbyshire, Diekelmann and Diekelmann (1999) argued that it was Crotty, rather than nurse researchers, who was often misguided and ill informed in his view of Heidegger. These authors argued that the central task of interpretative phenomenology is to interpret everydayness in order to uncover possibilities that increase our understanding of being human. They point out that as nurses we do not have to experience a phenomenon ourselves in order to conduct a phenomenological study. Rather it is through understanding the shared meaning and textual interpretation of the experience of others that we can appreciate and better understand different perspectives. Benner (1996) also takes Crotty to task, and criticises his lack of impartiality, narrow viewpoint and rejection of nursing phenomenology. Unfortunately, Crotty’s untimely death in 1998 put an end to this dialogue. However, his work and the ensuing debate gave nurse researchers the opportunity to openly demonstrate their understanding of the issues, and defend their use of methods.
Taking a different perspective, Lawler (1998) cautions nurses against wholeheartedly embracing phenomenology, as there are difficulties in adapting phenomenology to practice, and in making the transition from philosophy to methodology to method. These discussions emphasise the importance of nurse researchers who take a Heideggerian approach in adhering to a sound interpretive and rigorous scholarship, and making explicit how this particular philosophy informs and guides their research findings. Thus it has been my intention throughout this chapter, and in the next chapter, to reveal how Heideggerian hermeneutical phenomenology has informed the research process and data analysis.

**Limitations of ontological-hermeneutics**

There are limitations associated with all research methodologies, and it is important that researchers acknowledge the specific limitations associated with their chosen approach. When using phenomenology, the researcher needs to be aware of the philosophical and methodological concerns surrounding this means of inquiry.

Throughout this chapter I have identified that those undertaking a phenomenological study must articulate and incorporate the philosophical underpinnings relevant to the type of phenomenology used. To do otherwise would invalidate a study’s credibility. In the previous section, the main critiques related to the use of Heideggerian phenomenology have been identified and addressed. Thus, in this chapter, and throughout the entire thesis, I make obvious how Heideggerian hermeneutical phenomenology has informed the research process and data analysis.

As a qualitative approach to research, it is acknowledged that phenomenology does not attempt to predict, generalise or generate theories. Instead phenomenology aims
to increase our understanding of certain phenomena, and the meaning individuals attribute to these. This is of value for those interested in human experience, and contributes to nurses understanding of patients’ perspectives. Moreover, this form of interpretive research can heighten our sense of awareness and appreciation of the human condition, and may provide possibilities for future research. It is therefore important that the methodological approach chosen reflects the aims and purpose of the research question. This has been clearly demonstrated in the present study.

**Conclusion**

This chapter provided a discussion of phenomenology that showed that it is an approach that is important in the study and meaning of human experience. The review of the historical development of the phenomenological tradition highlighted the two types of phenomenology, and identified that Husserl’s work provided a basis on which others could build, including Heidegger. It was also shown that the ontological-hermeneutical phenomenology of Heidegger was most appropriate to answer the research question, as it provided direction to allow me to uncover the meaning people attribute to their experience of being on long-term mechanical ventilation in a critical care unit.

This chapter also briefly described some of the nursing literature that has taken a phenomenological approach in order to answer those questions not suited to other methodologies, thereby demonstrating the usefulness of this approach for nursing. I also addressed the critiques relating to phenomenology that centred on concerns relating to philosophical and methodological congruency, and identified the limitations inherent in adopting this research approach.
In the next chapter I outline in detail the processes that enabled me to gain an understanding of the research question.
CHAPTER 5

METHOD

Introduction

In hermeneutic phenomenological inquiry the researcher seeks to explore and interpret participants’ descriptions of their experience of a particular phenomenon. For the participants in this study, the meanings they attributed to being on long-term mechanical ventilation in a critical care unit are revealed through analysis of in-depth interviews recounting the lived experience of this phenomenon. In the previous chapter, the methodology used in this study was discussed, and its relevance for this particular study was demonstrated. To advance this study and reach an understanding of the phenomenon of interest requires that the research method chosen is consistent with, and reflects, the philosophical tenets underpinning the methodology.

This chapter describes the method utilised in this study to explore the research question. A description of van Manen’s (1990) six activities for phenomenological data analysis is presented, and the justification for choosing this particular approach to analysis is provided. Included is the procedure for the selection and recruitment of the study participants, and a description of where the researcher is situated in the study, reflecting Heidegger’s stance of the researcher being involved in, and not separate from, the research. The procedures for collection and analysis of data are described in detail, and ethical considerations are outlined. I conclude with a discussion on rigour when using this type of research approach to demonstrate my understanding of the issues involved when using Heideggerian ontological-
hermeneutics, and make clear how I ensured rigour throughout the entire research process.

This chapter commences with a brief overview of the different methods for phenomenological data analysis in order to demonstrate how essential it is for researchers to utilise a method that is congruent with their selected methodology.

**Phenomenological Methods**

Although a range of established methods have been used for phenomenological research, these tend to reflect the philosophical assumptions of Husserlian phenomenology. For example, methods developed by phenomenological psychologists such as van Kaam (1959), Giorgi (1975), and Collaizi (1978), incorporate the concept of bracketing one’s assumptions and ideas about the phenomenon in question. They also tend to focus on description, rather than interpretation, of the particular study phenomenon. These methods, although helpful in phenomenological research that takes a philosophical stance aligned with the descriptive and epistemological phenomenology of Husserl, are incompatible with the ideas and philosophy of Heidegger. Therefore, they are not appropriate for this study.

The methodology utilised in this research study is a philosophical one informed by the ideas of Heidegger. Heidegger denied that he had developed a methodology or systematic method for hermeneutic phenomenology, and as such there is no established method to interpret data when taking this position. Indeed, Gadamer argues in his book *Truth and Method* (1975) that a preoccupation with rigid method and stringent techniques is inimical to the human sciences. Thus, researchers using
ontological-hermeneutic phenomenology have either developed their own methods through adaptation, or have sought methods that more closely align with the philosophical and ontological underpinnings of their research.

For example, Taylor (1994) in her Heideggerian hermeneutical phenomenological study of ordinariness in nursing created a method that emphasised the importance of the research context. Beginning with the context, Taylor (1994) then observed nurse-patient interactions, and systematically recorded participants’ impressions of these interactions in context. From this, a range of qualities and activities were identified that were found to illuminate meaning within each interaction. Finally, the process of finding meaning across each individual interaction involved re-immersion in the text and in the horizon of Taylor’s own nursing and life experiences.

In another example, Walter’s (1995b) hermeneutic study of the experiences of relatives of critically ill patients used a method outlined by Reinharz (1983). Reinharz viewed phenomenology as a dynamic process, and described the following transformative processes in data analysis.

1. The initial transformative process is performed by the study participant who transforms his or her private experiences into action and language, which are then made available to the researcher during the taped conservations.
2. The second transformative process is then conducted by the researcher, when he/she hermeneutically understands the experiences of the participant.
3. These interpretations are then transformed into themes that provide insight into the shared nature of the experiences of the participants. These themes emerge from a dialectical process of moving between a background of shared meanings,
and one of more focused meanings that are specific to the participant’s experiences. This process is known as the hermeneutic circle.

4. The themes are then transformed into meaningful accounts that enable the new knowledge to be publicly communicated.

van Manen (1990) offered an approach that described six activities for phenomenological research, but at the same time allows the researcher the freedom to individually adapt methods to suit the particular research question. He saw a need for a middle ground between a rigid set of rules and procedures that governs the project, and a process devoid of any structure. van Manen’s six activities for interpretive phenomenological research are:

1. turning to a phenomenon which seriously interests us and commits us to the world;
2. investigating experience as it is lived 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 orientated pedagogical [or nursing] relation to the phenomenon; and
6. balancing the research context by considering parts and whole. (1990, pp. 30-31.)

van Manen’s method reflects the philosophical assumptions of Heidegger in a number of ways. It aims to uncover meanings from the life-world, and does not attempt to bracket the researcher’s pre-understandings and assumptions. Moreover, the balancing between the whole and the part reflects the concept of the hermeneutic circle explicated by both Heidegger and extended by Gadamer. Although van Manen
developed this method to reveal the everyday lived experience of human beings in educational settings, and particularly for parents or teachers of children, it has been used and adapted by nurse researchers such as Fitzgerald (1995) and Kellett (1999).

**Phenomenological Method used in this Study**

As this study utilises a hermeneutic phenomenological approach informed by the ideas of Heidegger (1927/1962), it is imperative that the chosen method is congruent with the philosophical orientation. After carefully considering the various methods described above, I chose to use the method described by van Manen (1990). I believed that this particular method was most suited to this study, as it reflected the philosophical underpinnings of the methodology, and enabled me to draw on my own interest and experiences whilst closely interacting with the text. I was also impressed by the flexibility it offered in encouraging the researcher to follow his or her intuition. van Manens’(1990) approach, therefore, offered me a way of being involved and committed to the interpretive process, such that the horizons of the participants and myself came together to find a meaningful account of the phenomenon.

The following discussion outlines in detail how I incorporated and utilised van Manen’s six activities for data analysis in this study.

**Turning to the Phenomenon of Interest**

Phenomenological inquiry requires a commitment to reaching a fuller understanding of a certain question that deeply interests or concerns us (van Manen, 1990). This commitment to exploring the phenomenon of interest involves a focused and consistent thoughtfulness. That is, the phenomenological question sets the researcher
on a path of deep thinking and commitment to reach the goal of increased understanding.

**The background of the researcher**

My interest in exploring what it means for people to experience long-term mechanical ventilation within the critical care unit stems from my nursing background and clinical orientation. As previously explained, the location of the researcher within the hermeneutic circle is of prime importance in interpretive hermeneutic phenomenology. It is therefore essential that my background is taken into consideration when reading the interpretations of the participants’ stories, as my pre-understandings and assumptions will interact with the whole and part of the interpretive process. By making explicit my position within the hermeneutic circle consistency with the chosen methodological stance is achieved.

As discussed in chapter one, I have been involved in critical care nursing for nearly 20 years, and possess post-basic qualifications in this specialty area. I have held a variety of clinical and management positions in critical care units in both NSW and Queensland. The research topic chosen for my Master of Nursing (Hons.) study exploring rural peoples’ experience of critical illness and inter-hospital transportation grew out of my concern for a need for nurses to have a greater understanding of this phenomenon from the perspective of the patient. Currently, I am employed as a Lecturer in the Faculty of Nursing and Health, Griffith University, Gold Coast Campus. One of my responsibilities is to convene the Critical Care Programs offered by the School. Thus my career path has grown and developed within the area of critical care nursing.
Throughout my nursing career, I have cared for many people who required mechanical ventilation. I remember that I often asked myself the question: “I wonder what this must feel like?” For many years, that was the extent of my interest. That is, I regularly pondered the question, and even went as far as to ask my colleagues what they thought, with little or no interest shown. However, I didn’t take this question any further until 1997, when a chance encounter with a former patient triggered a commitment to exploring this question. This former patient, whom I shall refer to as Mrs Smith, approached me whilst I was doing my weekly grocery shopping, and proceeded to talk to me about her experiences of being mechanically ventilated in the critical care unit that I had been employed in at the time. Mrs Smith not only knew my name and that I had nursed her on several occasions, she was also able to clearly recall many of the procedures and events she experienced throughout her critical care hospitalisation. I remember feeling completely taken aback at this situation, as I knew she had been heavily sedated, as was usual practice, for the majority of the time she was mechanically ventilated. This experience jolted me into thinking about this question once again. I asked myself: “If people can remember their experiences, what can we, as nurses, learn from them?” As stated by van Manen (1990, p.31), phenomenological inquiry is a project arising from a person’s individual historical and social background that sets them on a quest to make sense of a specific aspect of human existence. Thus the circumstances leading to the formal exploration of this research question was a culmination of my professional and personal interests.

As discussed in chapter four, the fore-structure of understanding described by Heidegger is an essential component of hermeneutics. In making explicit how each
of these three aspects of pre-understanding relates to the context of this particular study, the pre-understandings I bring to this study are revealed.

My involvement and expertise in critical care nursing over many years has brought me to the study with a fore-having: a set of taken-for-granted, background practices that will allow interpretation to occur. It is through my understanding of the world of critical care nursing, and the practices involved in the management of mechanically ventilated persons, that the research question evolved and interpretation was made possible.

Fore-sight, relates to the particular point of view from which we make an interpretation, that is the awareness and disposition of the interpreter that directs him or her in a specific way towards phenomena. I bring to this study the point of view of an experienced critical care nurse. Prior to each interview, my background as a critical care nurse and a teacher of registered nurses undertaking post-graduate studies in critical care nursing was made known to the study participants. Thus, study participants could reasonably assume that I had an understanding of the context of their experience. This was evident in the many times participants would state: “You know what I mean, don’t you?”, thereby signifying their belief that I understood what they were saying. For example, Mark (study participant) questioned me about what he thought was termed “bottling”, and I was able to explain to him that the term he was referring to was “bagging” (See Glossary – Appendix A).

The third part, the fore-conception, is concerned with what possibilities we might reasonably anticipate in an interpretation. Thus, my fore-conception as an
experienced critical care nurse, teacher and manager means that I anticipate that I
will be able to derive meaning from participants’ stories.

Although I bring a range of pre-understanding to this study, I undertook the process
of interpretation with the anticipation of opening up new possibilities in the search
for meaning of being on long-term mechanical ventilation in a critical care unit.

**The Research Question**

In this study, I was deeply committed to reaching a better understanding and
awareness of the meaning people attribute to being on long-term mechanical
ventilation in a critical care unit. This ontological study is concerned with what it
means to be, and poses the following question to the study participants: *What does it
mean to be on long-term mechanical ventilation in a critical care unit?*

By asking this question and proceeding with this line of inquiry, I believe that critical
care nurses will gain insight into the meaning people make of this experience, which
will inform future practice, and aid in the provision of holistic and evidenced based
care.

**Investigating Experience as it is (was) Lived**

**Entering the field of inquiry**

This study focused on exploring and understanding the meaning of being on long-
term mechanical ventilation in a critical care unit. To do this, I as researcher needed
to turn to people who had experienced this phenomenon. The participants had all
experienced an episode of long-term mechanical ventilation in one of three critical
care units located in southeast Queensland. The size of these units range from six to
eleven beds, all of which managed the care of patients requiring long-term ventilation.

Initially, it was planned that the participants would be recruited from two critical care units: one in a tertiary hospital located in southeast Queensland and the other in a large district hospital located in northern New South Wales. However, due to an unexpected delay in gaining ethics clearance from the latter, mainly because of administrative processes, the decision was made not to recruit participants from this unit.

In order to locate and recruit participants, it was first necessary to gain the support of the Charge Nurse (CN) of the critical care units I had planned to access. Prior to commencing the study, I met with the respective CNs from each critical care unit, to discuss my proposed research. I described the aim of the study, and answered any questions that arose. This was an extremely important activity, as gaining access to participants relied heavily on gaining support and assistance of the nurses.

In the first instance I had to convince many of the nurses working in the units that this was a worthwhile and relevant research question. It was not uncommon to be informed that: “they never remember their time here, so what’s the point?” Such comments necessitated an appropriate response, and I was able to provide this by drawing on findings from the literature (Adler, 1997; Bergbom-Engberg & Haljamae, 1988a; Green, 1996; Heath, 1989; Holland et al., 1997; Laitinen, 1996; Parker, 1997; Parker et al., 1984; Puntillo, 1990; Russell, 1999; Simpson et al., 1989). This process of gaining support was a valuable learning experience, and highlighted two significant factors for me. The first factor was the importance of
adequate preparation by researchers prior to entering the field. If I had not been committed to this line of research, and had not had such a deep understanding of the aims, significance and relevance of the study, I doubt that I would have received the same level of support from nurses. The second issue related to my credibility, as judged by one’s peers. My background in critical care nursing, and previous experiences with the respective CNs through professional organisations, their involvement in tertiary studies at Griffith University, and social networking, all assisted in establishing my credibility and gaining the overall level of support for this study that I enjoyed from nurses of both critical care units.

The next step was to seek and gain ethics clearances from appropriate authorities. This process and the relevant ethical considerations are described in a later section in this chapter. After ethics approval was granted an Information Flyer (Appendix B) and an Information Sheet and Participation Consent Form (Appendix C) describing the purpose and aim of the study and contact details of the researcher were placed in the critical care unit from which I had gained ethics clearance. The CN of the critical care unit identified potential participants, who were then given the Information Sheet and Participant Consent Form at an appropriate time. This was generally after the person was discharged from the critical care unit to a general ward in the hospital. If the person appeared interested in participating in the study, the CN contacted me and provided the person’s name, contact details and proposed date of discharge from hospital. I then made initial telephone contact with the person after discharge from hospital, to further explain the study and answer any questions. A mutually agreed time and venue was then arranged for interviews with those persons who agreed to participate in the study.
Criteria for inclusion in the study

In the initial proposal, it was planned that participants were approached by the CN, and asked about participation in the study on the basis of the following criteria: They, i) were aged 18 years or over, and were able to read and speak English; ii) had been admitted with a critical illness or injury to the critical care unit located in either southeast Queensland or northern New South Wales between June 1999-October 2000, during which time they required mechanical ventilation for a period of seven days or more; iii) were conscious for some of the time throughout their critical care hospitalisation and time of mechanical ventilation, and were able to recall and articulate their experiences; and iv) were willing to participate in the study by giving their written consent following an explanation of the study and its aims, and the requirements for their participation.

Six people were recruited to the study from the critical care unit of the hospital in southeast Queensland from which I had received ethics clearance. In addition to this, during the data collection phase and due to ‘word of mouth’ three additional people contacted me to express their willingness to participate. These three individuals all met the study criteria, although they had been hospitalised in other critical care units in southeast Queensland.

The first person heard about my study via a work colleague at Griffith University. The other two people heard about my study from my husband, who mentioned the study at his work. Of these two, one was a work colleague, and the other a spouse of another work colleague. These people then asked my husband if they could contact me to discuss my study, which I agreed to. Although all three individuals had not
been originally identified, they met all other study inclusion criteria. Furthermore, they were very keen to participate. Consistent with the qualitative methodologies and phenomenology, there was no requirement for a representative sample of the population, in terms of age, gender, ethnicity or socio-economic status, to be obtained (Marcus & Liehr, 1998). Rather, the aim was to include participants who had experienced the phenomenon in question, and were willing and able to share their knowledge of that experience. With this in mind, I agreed that these three people were eligible to participate in the study.

*Study participants*

A total of nine people participated in the study. This number was appropriate, as it enabled me to manage the large volume of textual information that had been generated, and sufficient, rich data to provide an in-depth understanding of the phenomenon had been collected. That is, I considered that I had completed a comprehensive exploration of the phenomenon. This number of participants is congruent with phenomenological studies, where sample sizes tend to be small because of the large volume of verbal data that must be analysed (Marcus & Liehr, 1998). Of these nine participants, six were recruited from the one critical care unit in southeast Queensland via the CN. The other three were recruited via the process of ‘word of mouth’ as previously described. The nine participants, six males and three females whose ages ranged from 21 to 69 years, were given pseudonyms to ensure anonymity. They were called: Bert, Mark, Max, Shelley, John, Leanne, Don, James and Anne. Background information including age, gender, and number of days mechanically ventilated of each participant is provided in Table 5.1. Medical diagnosis was not included to ensure that participants could not be identified.
In the next chapter, chapter six, four of the participant’s stories are provided as paradigm cases to allow the reader to ‘get to know’ these people on a more individual basis.

**Making contact – being with the study participants**

The first contact with potential study participants was made in one of two ways: either by telephone or by visiting the participant in hospital prior to discharge home. All six participants recruited from the CCU via the CN had been given the Information Sheet and Participant Consent Form in the CCU and all verbally agreed to participate. Of these six, James, Bert and Leanne, were initially contacted whilst they were in-patients in the rehabilitation unit of the hospital, and Shelley, Mark and Don were contacted by telephone following their discharge from hospital. The remaining three participants Anne, Max and James who were admitted to the study via ‘word of mouth’ were also contacted by telephone. Following this initial contact,
I arranged a time to meet with each of them for the audio-taped interview. Each participant was asked where they would like the interview to take place, and I also informed them that they could bring a support person with them, for example a close family member, to the interview if they so desired. All participants requested that the interviews took place in their own home.

Following these initial contacts, I then met with each person as per the arranged schedule. Before commencing interviews, it was important that I established a rapport with each participant before starting formal audio-taped interviews. Therefore, I took the opportunity to reiterate the information given to them previously. That is, I am a Registered Nurse with qualifications and considerable experience in critical care nursing. I also further explained the purpose of the study, and the reasons why it was important that the study be undertaken. This explanation emphasised how sharing their experiences with me may be of benefit not only to critical care nurses and others involved in caring for long-term mechanically ventilated patients, but also for future patients requiring this form of treatment. This process of explaining my study, and sharing information about my self as nurse and researcher, enabled me to be with the participants in this journey of inquiry.

The next step was to obtain informed consent prior to commencing the interviews. The Information Sheet and Participant Consent Form (Appendix C) was then discussed with each person, and any questions the participants had about this, or other aspects of the study were also answered at that time. I also explained again the need to audio-tape the conversation so that I had an exact recording of their experience that would assist me in the analysis of data. None of the participants expressed any concerns about being audio-taped. Indeed the overwhelming and
unanimous response was that if they could help nurses and other patients in any way, then this was fine. They were appreciative that I was taking the time and effort to talk to them, and start to get to know them in some way. I was humbled by these expressions of good will and support, which gave me a great deal of positive affirmation as to the value of my study.

After obtaining written consent, I proceeded to set up the audio tape-recorder and interviews commenced. At the completion of each interview, it was usual that I stayed for a cup of tea and an informal chat. This was an extremely important part of the process as it allowed us to talk without the formality of tape-recording. Although the information obtained from these informal ‘chats’ is not included as formal verbatim text, it was used to assist me to interpret and make sense of the audiotaped data.

The audio-taped interviews – from stories to text

Audio-taped interviews were carried out over a period of eighteen months. The first interview took place in January 2000, with the last interview being completed in August 2001. An unstructured interview format was used. Audio-taped interviews lasting from 45 to 140 minutes were conducted with each participant. A total of fourteen interviews were undertaken.

I started by asking each participant to recall his or her experience of the phenomenon as best they could. Although I had no formal protocol, I started by asking the following open-ended questions:
• Please tell me as much as you are able to remember about your experience of being on a mechanical ventilator in the critical care unit of x hospital.

• What did this experience mean for you?

• You might like to start from the very beginning, and talk about how you first became critically ill (or injured – depending on the particular person’s medical history), were admitted to critical care, and your subsequent stay in the hospital.

The aim of these open-ended questions was to allow participants to respond in their own words. This allowed me to obtain a greater breadth of data as compared to more structured methods (Fontana & Frey, 1998). Open-ended questions also allowed participants to approach questions from their own perspective and to feel more relaxed in answering in their own language.

Once participants had addressed these initial questions, several asked if anything they said would be helpful. That is, they appeared to be seeking confirmation that what they said would be useful, and not, as one participant said “a lot of rambling” (Max, Fieldnote). I assured them that anything they would like to tell me would be helpful. After questioning why they were concerned about the usefulness or otherwise of their conversation, they revealed that they had previously thought that nurses and other health care workers would not be terribly interested in what they had to say. This was an interesting finding, and further highlighted the importance of nurses creating opportunities for therapeutic conversations with patients about their illness experience.
**Transcription**

The audio-taped interviews were transcribed as soon as possible after each interview. A total of fourteen tape-recorded interviews were undertaken lasting from 45 to 140 minutes. A Queensland Nursing Council Research Grant (No: RAN 0034) in 1999 provided funds to employ a qualified typist to transcribe the tapes verbatim. On receipt of the typed transcriptions, I proceeded to read them until I sensed I had gained an understanding of each participant’s story, thus beginning the process of engaging in dialogue with the text.

**Field notes as additional text**

I also took comprehensive field notes throughout the whole data collection process, which I later typed up myself. Field notes taken after interviews may consist of personal, methodological and interpretive writings that assist researchers in organising data and explaining how they reached particular interpretations (Clandinin & Connelly, 1998). The field notes I took contained demographic and descriptive data for each participant, informal discussions following the cessation of audio-taping, and also my personal impressions and thoughts. This source of information provided an individual context for each participant, which reflected the chosen methodology. As previously discussed, Heidegger (1927/1962) considered that individuals are embedded in a world where they have a past, present and future, all of which influence the current situation. People live their experiences in the individual context of their lives. Thus, to reach an understanding of the meaning each participant attributed to his or her lived experience of the phenomenon being researched required that I have some understanding of each participant’s background.
Field notes therefore assisted my analysis and interpretation of the interviews. In addition, I found them to be a useful prompt for my own recall of events when reflecting on data several months after the interviews had been completed.

**Follow up interviews**

Five participants were interviewed a second time. The reason I chose to undertake a number of second interviews was to more fully explore some of the initial themes from my preliminary data analysis. Shelley, Anne, Mark, Don and James were interviewed twice. After completing the second lot of interviews, I considered that I had full “taking in of occurrences” (Leininger, 1994, p. 106), and it would not be of any added benefit to continue to collect further data.

I prepared for the follow up interviews by writing down some specific prompts for additional information I wanted to elicit, if possible, from participants. As an example, one finding from initial data analysis was that all the participants had experienced horrific nightmares. Thus, on second interview, I asked Don and James to describe in more detail what these dreams or nightmares were like for them, and what did they mean? In addition, follow up interviews helped me to review my initial findings with some of the participants. The participants agreed with and were pleased with my interpretations. For example, Shelley said to me: “That’s exactly it, that’s exactly what I mean but you have put it into really nice words” (Shelley, Fieldnote). Thus, this process which van Manen (1990) describes as maintaining a strong and orientated relation, added further depth and richness to the data, and helped confirm the findings through repeated affirmation of the participants’ experience.
Ethical considerations

Before commencing fieldwork it was necessary to seek and gain ethics approval from the relevant bodies. The purpose of Ethics Committees is to ensure that research conducted on humans abides to ethical principles. Ethics is the study of standards of conduct and moral judgement, and ethical conduct by a researcher requires that ethical principles be taken into consideration throughout the entire research process. Thus, it is essential that the research study is conducted: without harming participants (principle of beneficence); only after informed consent from participants; and following a rigorous methodology and design (Polit & Hungler, 1997).

Throughout the study, I was fully aware of, and abided by these principles and requirements. I sought and obtained ethical approval from Griffith University’s Human Research Ethics Committee and the Ethics Committee of the participating hospital. I have not included this documentation so as to ensure anonymity of that particular hospital’s critical care unit.

After obtaining ethics clearance, I commenced recruitment of participants and data collection. The process for this is outlined earlier in this chapter under the section titled: “entering the field of inquiry”. Prior to interview, I read through the Information Sheet and Participant Consent Form with each potential participant, and answered any questions that arose prior to the signing of the Participant Consent Form. I provided each participant with a copy of the Information Sheet and Participant Consent Form to retain. I explained that participants were assigned a pseudonym, and no material would identify participants in the thesis or subsequent publications. Participants were also informed that the anonymous and coded
transcripts would be kept locked in my filing cabinet in a secured office at the University for the duration of the study, and for five years after the completion of the study. After this time they will be shredded and all computer files of the study will be destroyed. This procedure is in accordance with National Health and Medical Research Council guidelines.

I did not encounter any concerns about the ethical procedures required for this study to be undertaken. Overall the participants were pleased to assist, and were not worried about anonymity. However, I explained the necessity of adhering to the prescribed ethical guidelines, such that participants were fully aware of my responsibilities.

**Assessment of potential risk to participants**

It was anticipated that there would be little, if any risk in interviewing people about the meaning they attributed to their experience of long-term mechanical ventilation in a critical care unit. Indeed, it is well documented that people often find conversations regarding their illness experience with an attentive listener as “therapeutic” rather than stressful (Polit & Hungler, 1995, pp.658-659). My plans were that if participants exhibited any signs of distress during the interview, I would stop the interview and refrain from further questioning, proceeding only if the participant desired. As an experienced nurse involved in sensitive patient interviews and discussions for many years, I felt that I could reduce or minimise any risks for participants in being interviewed. If the participant appeared to need further counselling I planned to recommend that he or she contact his or her general medical practitioner or the hospital Discharge Planning Nurse for further assessment and follow-up.
Another factor I took into consideration was that of identifying unsafe health care practices. If during the course of the interview, participants were to inform me of any incident/s of hospital treatment practices that could be deemed unsafe or considered to put patients at risk, I would discuss this with the CN of the critical care unit, ensuring the participant’s anonymity. I informed participants of this prior to obtaining their written consent to participate in the study.

**Actual risks and researcher dilemmas**

Although strategies were planned for managing participants’ distress or discomfort, there was only one situation where a participant became upset, and this was for a short time only. In this particular instance, Mark’s recollection of his experience created some anguish, as he recounted the unpleasantness of the constant and prolonged nightmares he experienced during his episode of critical illness and mechanical ventilation. When I noted his distress, I immediately stopped the audiotape, and asked him and his wife (who was present at the time) if they wanted to discontinue the interview. I also gave them the opportunity to discuss this further with me if they wished. They indicated that they would welcome this, but would like to continue the interview if and when Mark felt it would be “okay”. Mark then revealed to me that, throughout much of the time he was in the critical care unit, he had often thought that he was losing his mind and his grip on reality, but he was too afraid to tell anyone apart from his wife in fear that others may question his sanity. I was able to provide a degree of comfort and reassurance to both of them by referring to the literature, where similar concerns had also been expressed by participants who had also experienced critical care hospitalisation. This interlude in the formal interview provided not only the opportunity to deal with a sensitive issue, but also
served to further increase the trust and degree of comfort enjoyed by myself and the participant. Following this, Mark informed me that he was ready to tell me the rest of his story.

Nurses undertaking research studies have written about the dilemma of the multiple role and distinguishing between being a researcher and being a nurse whilst doing field work (Borbasi, 1995; Lawler, 1995; Rudge, 1995). I was well aware of these potential dilemmas prior to undertaking this study, and this understanding, along with the pre-understanding I bought to the project, enabled me to combine aspects of the roles in a therapeutic manner. I believe this is well demonstrated in the situation of Mark and his wife, where I was able to draw on my clinical nursing experience and my understanding of the relevant literature to help them cope with a sensitive issue.

A number of other issues arose which were dealt with in accordance with the guidelines of my ethics proposal. In the two instances, participants complained of the “rough handling” and the “brutal” nature of the ward assistants from one particular critical care unit. This was in relation to manual handling procedures that are a necessary requirement, when patients are unable to manage their own mobility. I later arranged to speak with the CN from that particular critical care unit, and informed her of the concerns raised by the participants, ensuring that I did not identify the participants in any way. She was grateful for this feedback, and we discussed ways of managing this, with the aim to achieve an improvement in manual handling procedures and greater awareness of patient needs. Outcomes from this meeting included the instigation of additional in-service education on manual handling procedures for all staff involved with patient handling, and I was also
invited to present my ‘research in progress’ at a ward level meeting. This latter event was extremely successful, with many of the staff including nurses, medical practitioners, physiotherapists, and ward assistants in attendance. I made sure that I did not single out any one group of health care workers. However, I indicated that many of the participants were able to recollect in detail their experiences during their time in this critical care unit, and furthermore, some had found the experience of being manually handled by staff quite uncomfortable. The CN and I were hopeful that both these strategies would improve patient management where necessary, and she indicated she would closely monitor this aspect of care.

Overall, I enjoyed the fieldwork associated with this study. I valued the time I spent meeting and talking to participants, and I believe participants also enjoyed talking to an interested listener. At the conclusion of interviews, I thanked each participant for their time and involvement in the study, and later sent them a hand-written thank you card. I felt privileged that these people were willing to share their stories of their experience with me, and I endeavoured at all times to convey my thanks in a suitable and sincere manner.

**Hermeneutic Phenomenological Reflection**

Hermeneutic phenomenological inquiry aims to elicit and capture the essential meaning of a lived experience through thoughtful reflection on that experience. The explication of what it means to be on long-term mechanical ventilation in a critical care unit requires the researcher to become involved with and more fully grasp other people’s lived experiences and reflections of the phenomenon. van Manen (1990, p. 62) calls this involvement a borrowing and gathering of others’ experiences, which by so doing allows us to become more experienced and understanding ourselves.
Thus, to reach an understanding of the meaning of what it means to be on long-term mechanical ventilation in a critical care unit, I have borrowed and gathered the experiences of others from which to reflect on in a thoughtful and questioning manner.

**Entering the hermeneutic circle**

In a hermeneutic sense, interpreting and understanding texts involves a process whereby the researcher becomes immersed in the text so that meaning emerges. This does not occur in a linear or structured way (Benner, 1996), rather it encompasses a circular motion where the researcher moves back and forth between the whole and parts of the text. Moving between the parts and the whole in this circular fashion is known as entering the hermeneutic circle, and thinking within the hermeneutic circle allows the researcher to uncover and interpret the meaning embedded in text. In this study, the text was the transcriptions of the audio-taped interviews, as well as the field notes I had written on each participant.

In searching for meaning from the whole and the parts it was essential that I look to the meanings within each participant’s individual experience of the phenomenon in light of my background and the pre-understandings I brought to the study. Thus, I was continually moving towards an uncovering of meaning. The interpretations I formed and the judgement I used to interpret the texts were derived from my own horizon of understanding as an experienced critical care nurse and the interpretations of the experience made by each participant.
The whole stories

Throughout the initial recording of the interview, and then later when listening to the tapes and reading and re-reading the interview transcriptions, I was working with the whole story. That is, this initial part of the data analysis process involved trying to reach an initial understanding of the participant’s overall experience. As I listened and read, I entered into a dialogue with the text to help me gain an understanding of this particular person’s story, and situate it within their individual background. Entering into a dialogue with the text enabled me to ask such questions as: What do I know about this person? What do I know about their previous illnesses and experiences of illness and hospitalisation? What do I know about this particular illness episode? What does this person’s experience reveal?

After I questioned and dialogued with the text, I then proceeded to write a summary of each participant’s lived experience. Four of these are presented in detail in the next chapter as participants’ stories. Writing these summaries provided insight into each individual person’s experience, and provided the grounding for further analysis and hermeneutical interpretation. Throughout this process, I highlighted any words or phrases that stood out as meaningful, and returned to these many times as I moved between the parts and the whole.

Turning to the parts of stories

After focusing on the whole stories, I then proceeded to turn to the parts. The parts are the more specific ideas and findings in each text. After I read through each transcript again, prepared handwritten notes and highlighted individual sections, I attempted to do this activity in what is considered by some a more systematic way (Richards & Richards, 1998). As part of the funding I received from the QNC grant,
I was able to purchase a qualitative data analysis software package known as NUD*IST 4.0 (version 4). Although this tool has been used successfully by nurse researchers undertaking phenomenological studies (Fitzgerald, 1995; Kellett, 1999) and despite receiving a considerable amount of training on its use, I did not feel comfortable or proficient at any time with this package. I had become accustomed to using hard copies of data and working with highlighter pens, and I believed that this method was suitable for my own needs. Therefore after my initial attempt I did not use NUD*IST 4.0 (version 4) again, and instead returned to manual handling of data. Despite this, I considered this a worthwhile exercise as it allowed me to be an informed participant in debates regarding the usefulness or otherwise of data analysis software for qualitative research. Indeed, I was co-author of a published article in a well-known international nursing journal on this topic (StJohn & Johnson, 2000).

I therefore sought to develop my own system of handling and manipulating data. Each line and page of the individual participant’s text was numbered, as were the field notes pertaining to each individual. Throughout the thesis, particularly in the following chapters, excerpts from participant’s stories will be quoted in italics and followed by the pseudonym name given and the interview number For example, a paragraph cited from the transcript of Don’s first interview will be referenced as: (Don, int.1).

After I had numbered the text so that each transcript could be easily identified, and following on from the process of highlighting words and phrases from the whole stories, I proceeded to do the same at a more focused level. Thus, I read each transcript individually, and highlighted specific ideas and concepts and began to group these together. Throughout the process of interpretation, I was fully immersed
in the hermeneutic circle. I listened carefully on many occasions to the tapes, and read each transcription several times. I continued to analyse the data, reflected on at length, and maintained a dialogue with the text. I also spoke to several of my peers during this process, including critical care nurses and colleagues undertaking doctoral studies. This process was circular: as the meaning unfolded, I would return to the tapes and the transcriptions for further clarification and to reach a deeper understanding.

In the next chapter examples of how I undertook this process are provided to clearly demonstrate this process.

Revealing the meaning of being on long-term mechanical ventilation in a critical care unit

After this initial data analysis, I began to develop some major themes through the process of thematic analysis, which refers to “the process for recovering the theme or themes that are embodied and dramatised in the evolving meanings and imagery of the work” (van Manen, 1990, p.28). This is not a rule-bound process, as phenomenological themes are structures of experience revealed most accurately through a process of insightful discovery. In light of van Manen’s descriptions of what constitutes phenomenological themes, and reflecting on the methodological stance chosen for this study, I was aware that these initial findings were superficial and provided only a thematic description of the lived experience. However, I considered it essential that I initially present themes of the lived experience to ‘set the scene’ from which the phenomenological description of the experience is revealed. My reasons for presenting the findings in this way are explained in the following chapter.
As I was on a quest to reveal an ontological understanding, that is to disclose Dasein, the being there of the experience, I spent several more weeks reflecting on and analysing the data at a deeper level. I also discussed these findings with my supervisors and some of my work colleagues. By moving backwards and forwards between the whole stories and the parts, I believe I was able to uncover the meaning of Being on long-term ventilation in the world of the critical care unit. I believe my final data analysis and interpretation is a faithful representation of the meaning the participants attributed to their experience.

Before describing how the findings are presented in the following chapters, it is timely to address the issue of validity or rigour of this research study.

**The question of rigour**

When using qualitative research methodologies, the question of rigour or trustworthiness arises. This is mainly because these methodologies are unable to be assessed using the notion of validity that is aligned with traditional empirical research. However, whatever the chosen research approach and line of inquiry, it is necessary to demonstrate that one’s study is rigorous and judged by others as credible. With this in mind, several authors have offered ways of indicating rigour in qualitative research, particularly when using a phenomenological approach (Koch, 1994; van Manen, 1990; Walters, 1995b). Koch (1994) recommends that researchers provide a decision trail in order to clearly establish the trustworthiness of the study. Trustworthiness can be demonstrated by the concepts of credibility, transferability and dependability. In this sense, the term credibility is used to refer to the truth, value or believability of the findings that have been established by the researcher
through prolonged contact and interaction with the participants/s (Leininger, 1994). Transferability refers to whether particular findings from one qualitative study can be transferred to another similar context whilst preserving the particular meanings and interpretation of the original study (Leininger, 1994). The term dependability, or confirmability is often taken to mean agreement and reliance of a finding by direct and repeated affirmation (Leininger, 1994). These terms are often used as some of the criteria to judge the credibility or otherwise of qualitative research.

From another perspective, van Manen (1999) talks about the “phenomenological nod”, (p.270) as indicating affirmation by readers that they recognise and can relate to the described experience. Specifically relating to Heideggerian nursing research, Draucker (1999) identifies evaluation criteria that should be taken into consideration when critiquing studies based on this philosophical tradition. Draucker recommends that Heideggerian research should be evaluated by:

- the extent to which the philosophy informs not only the methodology, but the interpretation;
- the extent to which the vantage points of both the participants and researchers merge for a better understanding; and
- the extent to which Heideggerian ideas and concepts inform and enrich the research findings.

Throughout this study, I will clearly show how I have adhered not only to these criteria, but also reveal how my research findings and interpretations have received a phenomenological nod. The conclusion of the thesis will also summarise these issues and demonstrate how this study is rigorous and in line with the chosen methodological stance.
Presenting the findings

Although interpretations are never complete, it is necessary that the interpreter demonstrate that their interpretation is trustworthy by remaining close to the text. Throughout the process of data analysis, I considered how best to present the interpretation so that a meaningful account could be provided that not only did justice to the participant’s stories, but also clearly demonstrated the understanding that was reached. As evident in van Manen’s (1990, p.111) fourth activity of his phenomenological method for interpreting data, “describing the phenomena” requires that the researcher make visible the meanings and understandings that are derived from the text. The phenomenological text should therefore reveal and illustrate the phenomenon.

In the next three chapters I present the findings of this study. Chapter six is titled participants’ stories, and provides an in-depth description of the lived experience of four of the study participants: Shelley, John, Mark and Max. I chose to present four stories as paradigm cases to assist the reader to get to know some of the participants more closely, demonstrate the process of data analysis and interpretation I used, and to also ‘set the scene’ for the following two chapters.

Chapters seven discusses the major theme categories that were revealed from thematic data analysis. Four main themes emerged from the data. Each of these themes is presented, starting with the initial admission to the critical care unit, through the life-world of the critical care to the discharge from hospital to home. I chose this way to present the findings as it represented the totality of the experience from the viewpoint of the participants from which I was able to derive a
phenomenological description of the research question. Each of these themes reflected how the participants made meaning of their experience.

Chapter eight presents the phenomenological-ontological description of what it means to be on long-term mechanical ventilation in a critical care unit. Titled *Being at its most elusive*, this description discloses how participants experienced momentary lapses of the tenets that Heidegger (1927/1962) saw as essential to Being.

**Conclusion**

Throughout this chapter I have demonstrated clearly that the method I utilised for collecting and interpreting the data was congruent with the philosophical underpinnings of Heideggerian ontological-hermeneutics. The method I presented allowed me to gather and interpret data in a way that suited both the research question, and my own personal orientation. By adhering to this method, I was allowed considerable flexibility to uncover the meaning participants attributed to their lived experience of the phenomenon I was seeking to understand. I also discussed the topic of rigour surrounding the use of this approach, demonstrating my understanding of the issues.

In summary, the stories of nine participants in fourteen interviews were audio taped-recorded, transcribed verbatim and analysed rigorously for background shared meaning, and differences. The process of hermeneutic interpretation and the fusion of horizons between the study participants and myself allowed me to develop an interpretive summary that I present in chapters six and seven. Following this, an ontological-phenomenological description titled *Being at its most elusive*, is
presented in chapter eight that constitutes and reflects my understanding of what it means to be on long-term mechanical ventilation in a critical care unit.
CHAPTER 6

PARTICIPANTS’ STORIES

Introduction

The aim of phenomenological research is to seek meaning and understanding of human experiences in a particular context. The intention of this research was to find meaning and understanding in the experience of being on long-term mechanical ventilation in a critical care unit, from the participants’ (former patients’) perspectives. Patients’ perspectives on health care are increasingly seen as a valuable source of information for assessing outcomes and improving the quality of care delivered (Esteban et al., 2002). Thus, findings from this study presented in the following three chapters provide valuable insight for all those involved in the care of critically ill and mechanically ventilated patients, and offer useful insights that may have implications for and inform future nursing practices and enhance patient care.

In this chapter, stories from participants are presented to allow the reader to ‘get to know’ more closely some of the people involved in the study. The nine people who participated in this study shared their experience of being on long-term mechanical ventilation in a critical care unit during face-to-face interviews. Each told a story of his or her unique experience of this phenomenon, and described the meaning they attributed to this experience. In phenomenological research, participant stories provide the researcher with an in-depth, personal account of an experience that is contextually specific. According to Madjar and Walton (1999, p.6), “Phenomenological accounts of lived experiences of illness present the subjective, the personal, the authentic – experiences from the inside”.

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As nurses, we can learn from the experiences of others recounted through their stories. Stories such as those from participants in this study who related what it is like to experience long-term mechanical ventilation in a critical care unit can broaden our horizons and provide us with a greater understanding of these peoples’ worlds. In encouraging the participants to tell me their stories, I uncovered elements of critical care experience that may not have previously been considered.

The following three chapters present the findings of this study, which are derived through an in-depth and rigorous process of hermeneutical phenomenological interpretation. My position in the hermeneutic circle allowed me to question and interpret the data, drawing on my own professional, personal and historical background in the field of critical care nursing. Thus, the pre-understandings that I brought to this study enabled me to grasp the meaning of the experience of others, and bring it to light in a way that is useful for the reader.

**Setting the scene to reveal the phenomenon**

Considering and answering the research question, participants wanted to talk about the whole illness/injury episode within which this particular phenomenon occurred. For example, on commencing interview, Anne informed me that:

*I know you are asking me to tell how I felt about being on the ventilator, what it was like, but you need to hear the whole story leading up to it first to get a proper picture of how it was. I suppose you’ll get a different picture from someone else. Maybe you will, or maybe not. But I doubt you’d ever find somebody who enjoyed it.* (Anne: int. 1)

Thus, participants needed to ‘set the scene’ in order to discuss and describe the meaning of the specific phenomenon. They spoke of the events that led to or caused
their illness or injury and hospital admission, and recalled and described where possible, their entry into the critical care unit, being placed on the mechanical ventilator, and the time they spent on the ventilator in the critical care unit. They also related the events following the removal of the ventilator and their transfer to the general hospital ward, their discharge from hospital to home, and their life at home after discharge. In this way, each participant provided a unique description of his or her illness or injury experience, which enabled me to reach an interpretation drawing on my own, and each participant’s, historical and cultural background.

It is important to note that when we encourage people to tell us stories of their illness experience, that we also open ourselves up to hearing stories that may initially be incoherent or of questionable worth. Madjar and Walton (1999, p. 7) refer to the work of Frank (1995), who in his book *The wounded story teller: body illness and ethics*, urges those researching patients’ experience to listen not only to stories of courage and quest for meaning, but to also recognise and honour the chaos narrative. The chaos narrative is a term Frank uses to refer to stories of confusion, futility and helplessness that may lack coherence. Stories such as these may render interpretation difficult. Frank cautions us not to prejudge whether or not patients are able to tell a coherent story, but to instead respect the dignity of the human story.

I found Frank’s (1995) words reassuring, as they had particular relevance for this study. Many of the participants’ stories had parts that were chaotic and disordered. Indeed, a number of participants asked me whether I was interested in hearing about the parts of their experience that they felt were confused and very different to their normal, everyday world. I reassured them I was interested in anything that they could recollect about their experience, regardless of whether or not they could recall
the situation in its entirety, or in a logical order. In effect, I provided permission for participants to talk about all aspects of their experience without fear of being judged “crazy, paranoid or demented” (some of the terms used by participants to express how they felt, or must sound to others, when they had previously attempted to tell their stories). Many also expressed relief, and gratitude, at being given the opportunity to share with me their thoughts and feelings.

According to Richman (2000), being able to tell a personal story of critical illness may give people’s lives a purposeful destination, and provides a way of reaching meaning and interpretation of the event. The telling of an illness narrative, although often lacking consistency and a temporal sequence, can also provide a valuable resource for health professionals, and Richman too warns us not to disregard patient’s accounts of their critical illness episode.

Thus, I took the advice of Frank (1995) and Richman (2000), and chose to honour the chaos narrative. By allowing participants the opportunity to describe in detail their recollection of their experience, I was provided with a rich and vivid description of the phenomenon that had not previously been explored to such a depth. Although a superficial and shallow description could have provided a clinical, somewhat orderly and objective account of an experience, by seeking an in-depth account of the phenomenon a deeper and richer understanding was reached.

In this chapter I present an overview of some of the participants’ stories to provides a means of ‘getting to know’ these participants more closely. Although there were nine participants in this study, I have not included every story told to me. Instead I have chosen to select the stories of four participants as examples that stand out as
paradigm cases. Benner (1984, p.8) refers to a paradigm case as a particular experience that stands out and provides a means of reaching a rich understanding. The stories of Shelley, Mark, John and Max, that are included in this chapter, help bring to light the experience and individual meaning they attributed to being on long-term mechanical ventilation in a critical care unit. The important words, ideas and meanings derived from all participants, and the individual stories (the parts), are then related back (to the whole) in later analysis to reveal shared meaning.

**Shelley**

At the time of interview, Shelley was in her late thirties, divorced with a ten year old son for whom she had sole custody. As a result of respiratory complications following a surgical procedure, Shelley spent over three weeks in critical care, most of that time on a mechanical ventilator. I interviewed Shelley five days after she was discharged from hospital.

Shelley was the first person I interviewed for this study, and this particular situation provided me with a valuable learning experience that guided the subsequent participant interviews and interactions. From my initial interactions with Shelley, I learnt the importance of firstly establishing rapport and trust with participants before asking them to share their personal feelings and thoughts with a relative stranger. At the first meeting with Shelley, I provided a rather (in retrospect) brief introduction and some preliminary discussion, and then proceeded to switch on the audio-tape recorder. I invited her to talk about her experience of the phenomenon in question. After an initial hesitation, Shelley started to relate her story in a relatively calm, and matter of fact manner. At the end of her story, I was left feeling rather frustrated and dissatisfied with this particular interview. I felt that I had been unsuccessful in
getting any real depth in our conversation, despite my probing further, and seeking clarification when I thought necessary. It was apparent that I would have to make an appointment to come back for at least one further interview. I had a feeling of unfinished business.

After finishing the audio-tape recording, we then had a cup of coffee. At this time I observed that Shelley seemed to relax, and ‘wind down’ from the interview. Shortly afterwards, she began to go back over, and revisit her story. She opened up to me, and recollected her experience with far more depth and richness than the rather stilted and shallow account given only minutes previously. I then asked her if I could recommence audio-taping to which she agreed after confessing that she had felt awkward because she did not know if she had anything of interest that I really wanted to hear. After reassurance, I resumed the audio-tape recording, and this time there was no feeling of unfinished business. Indeed after finishing the interview some one and a half hours later, Shelley confessed that, although she felt quite drained and exhausted and had no more words left to tell, she felt that she had “done justice” to her experience.

Shelley’s story described her experience of being in a critical care unit for over three weeks, during which time she was ventilated, extubated (artificial airway removed) and then ventilated again after having a tracheostomy procedure. Although her story did not follow an orderly sequence, and “wandered all over the place” she provided a very rich and vivid account of her experience. For example, she constantly referred to the perceived lack of information provided by nurses and the importance of allowing patients to have more say in their care. Shelley’s story reflected her independent nature, as she described how she fought to walk around the critical care
unit and then later, the hospital, by herself, dragging the ventilator or oxygen cylinder behind her.

A finding in all of the participant’s stories was the notion of ‘waking up’. That is, when describing their experiences of critical care, participants likened their first recollections to a waking up, or a regaining of consciousness. Although they could all recall to differing degrees events prior to this wakening, the waking up indicated that there was a period of sleep, or unconsciousness that preceded the waking up. This period of unconsciousness may have been related to the medications administered to patients whilst they are mechanically ventilated, and or because of the severity of the illness per se, although it was not the aim of this research to decided upon this issue.

Shelley’s story began with a recount of how she woke up after six days in critical care “with a tube down her throat”, not knowing where she was or what time it was. It was difficult for her to recall her story in a logical order, but for her that is how it was: “a real mix up”. She talked about the ‘before’ and ‘after’ of her illness episode, with these seemingly being worlds apart:

*I went in [to hospital] on the 2nd December and woke up on the 8th December with a tube down my throat, which I didn’t know anything about at the time and I couldn’t talk and it just felt like a piece of hot stinking rubber, that was really yeck. I didn’t have anything to make me feel normal, so I still didn’t know where I was. One minute I am going in to have an operation, thinking that I will wake up in an hour or so and get on with getting over it, and the next thing it’s six days later in my life and totally different! Nothing was the same as before, or how it was supposed to be after an operation, and I’ve had those [operations] before you know. It was if I was taken away and plonked in a weird planet, like something not normal.* (Shelley: int. 1)
Many times Shelley referred to being under sedation, which she describes as a very “creepy experience”. I asked her to tell me what she meant by creepy. She explained it as follows:

**You know it’s not a proper, real sleep, a normal person’s sleep. And I have also had sleeping pills before. And it was not the nice lazy doepy feeling you get with those. Oh no, not like that at all. It was like, a bit, you know, I wonder if it is like LSD or something? I mean, it was [the] morphine they gave me, I remember them saying [the morphine was] to make me more comfortable. But even though I wasn’t in touch with my pain, I still knew it was there – like an out of body thing – you are aware but not aware enough to have control and that is creepy. Your body is not your own, and I don’t like that – I need to regain myself and take over – not have others take over me. And there was not a damn thing I could do about it.** (Shelley: int. 1)

Shelley told how she struggled to regain her sense of self in a strange world, and how the nurses seemed not to give her any information:

**They never volunteered anything, not until much later. I wonder if this was because they thought I couldn’t understand, or handle it, or would remember. But patients need to know what it is happening to help us make sense of our surroundings. And I think once we make sense, or a little bit of sense, then we can begin to cooperate, and move toward a future that takes you back to how life was before. But until they told me, or rather until I worked out why I had this awful bit of rubber shoved down my throat that moved and burned and tickled and made me cough, I didn’t really understand and kept fighting it. You know I think nurses think we fight to get rid of the machine. It’s not that, because at some stage you do work out for yourself that, “hey I need this, my life is depending on it.”** (Shelley: int. 1)

Shelley also told of her struggle to breathe independently, and become free from the ventilator and later, the artificial airway. Throughout her story she talked about the need to have some control over her situation, and how difficult it was to convince the nurses that she wanted some say in her management:

“**Shelley, you’re not supposed to be doing this**” [the nurses would say]. “**But I want to!**” “**You’re not supposed to**” [the nurses replied]. “**But I want to,**
Shelley believed that her need to have control and independence helped her deal with this illness episode and not “go under”. Shelley was discharged from the critical care unit to a medical ward after three weeks. She did not particularly enjoy her stay in the ward as she felt that she could have managed satisfactorily at home. She asked to be discharged after only two days of being moved out of critical care. She then went to a friend’s house for recuperation before returning to her own home where she lives with her young son. She was glad her stay in the critical care unit and hospital was over, and was enjoying being back with her son in her own place.

When Shelley had finished telling me her story, I felt that I had been privileged to a lifelike account of her time in the critical care unit. I could almost feel the discomfort she had experienced from the endotracheal tube. I had shared her struggles and frustration to ‘get back her self’ and regain control of her life. It also made me uncomfortably aware that, as nurses, we do tend to take control of critically ill and or ventilated patients, often from a belief that we know best, or that the patient is unfit or unable to make any sensible decision.

Like all the stories told by the participants, Shelley tells a story that did not follow a temporal sequence or logical order. In her very own words, it was a “real mix up”. Despite this, in the initial analysis of her interview, a number of words and phrases stood out as meaningful to the beginnings of an interpretation. She spoke of waking up six days after her initial admission to hospital. This sense of waking up suggests
that there were periods of time when her level of awareness and consciousness of the surroundings fluctuated.

Shelley perceived the critical care unit as a very strange place, unlike her everyday, normal world. There was nothing familiar to provide a means for her to make sense of her surroundings. She appeared to have had difficulty in distinguishing time and place.

Shelley spoke of sleep that was not normal, what she called “creepy”. She was aware of the difference between this type of sleep and her usual sleep, and thought this was due to the sedative and or analgesic medication she had been administered. In telling this part of her story, she revealed she experienced her body as unfamiliar. She felt out of touch with her body and not in control of its functions.

At times, Shelley was aware of some of the technology and equipment associated with being mechanically ventilated, and overall found the effects uncomfortable. For example, she described the endotracheal tube as “a piece of hot, stinking rubber that was shoved down my throat and made me cough”. However, she appeared to accept its presence and the necessity for being intubated, once she had worked its purpose: “I need this, my life is depending on it”. She viewed the mechanical ventilator as life supporting and relied on it for her survival.

Shelley described a lack of information sharing by nurses, and she appeared to be trying to work out the reasons for this. She wondered if this was due to nurses’ perceptions that patients are not able to comprehend or deal with what is happening to them. She found this lack of information unhelpful in her attempts to make sense
of and interpret the surrounding environment. Shelley’s need to make sense of the environment is reflected in her struggle to regain independence and control of the situation. She needed to move on and get her life back.

**John**

John was in his mid forties, married with four children. He had been in a critical care unit for a total of 15 days. Of these, 13 days were spent on a mechanical ventilator. He was admitted for treatment of a severe sepsis arising from a work-related injury that had caused systemic complications, including respiratory failure. I interviewed John six months after he was discharged from hospital.

John told of the events surrounding his admission to hospital and the critical care unit. He described how his condition had deteriorated rapidly soon after his arrival at the hospital, and he had memories of the hospital staff yelling all around him. This sense of panic and worry made him feel very frightened and concerned for his wellbeing. He spoke of being rushed through corridors to get to critical care:

> *When I first got there [Accident and Emergency Unit at the hospital] I can remember that doctor yelling all these orders out. It must have been to the nurses to get things for me. You know, like putting in drips, and taking more and more blood tests out of my arms. But then it became a bit fuzzy after that. I remember people looming over the top of me. But it was hard to make out faces because they were wearing masks. They were taking over and doing things to me. And then I went on a big trip, or so it seemed. Round and round and down and down, like it was miles and miles, but I’m sure it couldn’t have been. [It] just felt like it. There was a big rush to get me to critical care, because I heard it said many times. I just wasn’t sure what I was going to CCU for, but I knew it must be pretty serious. (John: int.1).*

John then described how he encountered what he called his “strange visitor”.

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Then this really strange thing happened, and I know it happened. My wife, and other people I tell, say: “John, you must have been hallucinating”, but I know I wasn’t. It happened, definitely, and I can recall it as plain as if it happened yesterday. I won’t ever forget. I call it my encounter with the visitor. As I said, I didn’t know where I was. But I know it must have been early on in the piece. I was lying quietly on my bed, it must have been in Critical Care, because I had this thing in my neck [tracheostomy tube] when I remember clearly this black faceless shadow came to see me. It just appeared over the top of me, maybe from the floor or the ceiling. And it said “come on John, time to come with me now, you are too tired to keep going”. And I can remember clearly to this day saying to it, or him “yeah you’re right, I am tired of this, I’ve had enough, yeah I think I’ll come soon”. So I wasn’t scared of this black shadow, I just thought, “yeah, he’s right, and I am really, really tired, I’ll just go with him”. No resistance whatsoever. And then later on the shadow came back to get me, saying “are you ready now John?” and I said “no way, just go away will you”. (John: int. 1)

John saw this as a close encounter with death, and was glad that he had resisted the offer to go over “to the other side”. Although he could only recall “bits and pieces” of his time in the critical care unit on the mechanical ventilator, the following two interview excerpts highlight how he experienced his physical body.

I remember how I was moved around. Some people had a very gentle touch, whilst others had a rough hurtful touch. I think it must have been the nurses who were gentle, because afterwards, when I woke up, they were gentle then. And they are mostly female, and females are gentle. I remember what felt really strange was, that at times, I didn’t know where my limbs were, I felt they weren’t in the right place. I wanted to touch [them] to see if they were still there and had not been chopped off or permanently damaged. It is a strange feeling when you can’t place your body in the right place where it should normally be. It is as if your body is physically there, it must be because you are on life-support to keep it there and kicking on. But you know, you’re not there, you know the person you are, or were before it all happened. (John: int. 1)

These statements reveal not only John’s awareness of his physical body and the presence of life support (mechanical ventilator), but also the difficulties he experienced in trying to situate himself in a meaningful way.
John also described difficulties in communicating with the nurses and his family:

> I was mouthing the words okay I thought – but they [family and nurses] missed a lot of what I said, and I was just too weak to write anything at first. I used to end up doing a type of charades. (John: int. 1).

John also told of his frustration in trying to regain independence. He related how he tried to get up and walk to the bathroom on his own “to help the nurses, and then to only end up on the floor with disconnected drips [Intravenous lines] and blood everywhere”.

After being transferred from the critical care unit, John spent over two months in the hospital’s rehabilitation unit before being discharged home. He continued to require ongoing physiotherapy, and consultations with his general practitioner on a fortnightly basis. He was left with disabilities including limb and hearing impairments.

Similar to Shelley, John talked about waking up, and referred to events prior to and after this. The impression that his level of consciousness fluctuated was evident in his descriptions of events prior to waking up, which he recalled were unclear and fuzzy at times. John’s admission to hospital was frightening for him, as he felt as if he was being taken over by people, who yelled and loomed over the top of him.

In the interview, John revealed there were times when he had questioned whether or not he would survive. He saw his transfer to the critical care unit as a sign that his condition was “pretty serious”, an impression reinforced by his encounter with a figure that to him represented death, a “going over to the other side”.
John also experienced his body as being different. His limbs felt as if they were out of place, and he was unable to situate his body. He also questioned the connection between his body and himself. It was as if he was unable to fully comprehend where he was situated in space and time. The tracheostomy tube that he had in place made normal speech impossible, so oral communication was impaired. John’s attempts at mouthing words were mainly unsuccessful, creating communication difficulties with family and nurses.

John’s drive for independence was evident in his efforts to undertake activities such as walking to the bathroom unassisted. At the time of interview, the ongoing effects of his illness were still apparent.

**Mark**

Mark was in his late sixties, and had spent nearly six weeks in critical care, the majority of that time on a mechanical ventilator for treatment of respiratory failure secondary to a medical condition. I interviewed Mark in his home two weeks after discharge from hospital. Mark’s wife was present throughout the interview, but she took little active part in the discussion. She very gently corrected a couple of statements he made regarding the exact dates of events, and sat beside him and held his hand.

Mark began his story by relating the events that led up to his admission to the critical care unit. However, he was unable to recall the sequence of events following his entry to critical care. Instead, he told of the ongoing and distressing nightmares he experienced for what he considered “a great deal of my time in CCU”. He told of his encounters with bloodthirsty natives, snakes and reptiles, and planes that deliberately
crashed with him on board. These nightmares were very distressing, as they were “very different to my normal nightmares”, and involved his wife trying to harm him.

I know I’ve got things out of context. I was conscious of being in a hospital and in a ward, but it was a strange place, nothing like I was used to. I used to look up and see nurses and they were all sewing things and it looked as if they were sewing uniforms except for one, she was making up a red wedding dress. But all the time they were plotting with [wife] to kill me. (Mark: int. 1)

On looking back on these unpleasant dreams, or nightmares, Mark appeared to be trying to come to terms with, or rationalise the reasons for their occurrence. He attributed them to the medications he received, and also being deprived of sleep. “I had in my mind that it was the drugs that had caused the hallucinations. A total fixation I have with illicit drugs. I was also dead tired”.

However, there were times when Mark was aware of his surroundings amongst the dreams, and he was able to describe glimpses of the ward life that went on around him:

They [nightmares] seemed to go on forever but, ah, there was a slight interaction between my hallucinations and what was actually going on in the ward. You know those sorts of signals that you have in the back of your mind like a musical signal. They were there at times, and seemed to coincide with somebody doing something to me. Like poking or prodding me, and sticking something down my throat to make me cough. (Mark: int. 1)

On describing this signal, Mark explained that:

No, it was one of those alarm type signals. It sort of followed me and I could hear it all the time and when I actually came to and could still hear it, it was quite disturbing. Do you have a process they called bottling? (Mark: int. 1)
On further discussion we ascertained that he was referring to the process of ‘bagging’, which is a term used to describe manual ventilation of the airway with a specially designed piece of equipment. Critical care nurses, doctors and physiotherapists use this procedure on a regular basis to manually oxygenate and ventilate the lungs of patients. Although he did not understand for the most part what was going on around him, Mark was aware of some of the procedures being carried out on him whilst he was on the mechanical ventilator. The above interview excerpt also captures the notion of ‘waking up’, which he referred to as “when I came to”.

Mark found it difficult and frustrating trying to communicate effectively whilst he was ventilated.

Well I think that’s frustrating all round. Like I said half my trouble was I’d use two words and make it into a great big thing. I would probably, instead of just saying “water”, I sort of say “thirsty” and of course everyone would be watching what I was doing but they couldn’t seem to work it out. (Mark: int. 2)

Mark also struggled to gain control and independence in some of his daily activities. The following excerpt describes how he worked out a way of getting permission to be discharged from hospital:

I was starting to scheme and connive to get out of hospital – I used to spend a good part of my spare time scheming to get out early. I had a couple of outings, a few walks around the ward, and what have you, but I felt good you know. I’ll wait and see if I can con P [doctor] into getting me out so I’ll start on S who is the physio [physiotherapist]. I’ll brainwash her to start. And I said: “S, I feel great.” She said: “well we’d better go and see if we can sort a few things out”. We went up just outside the ward, and she just had to do one or two little things before we launched ourselves into P. So I had to do all these things for P that I had never done before and look as if I could manage
Following this episode, Mark was given permission to go home into the care of his wife. When I interviewed him, he appeared quite weak and frail, and required a lot of rest. He was undergoing physiotherapy twice weekly in order to regain strength, as his long stay in hospital had left him feeling very weak, and he had a lot of muscle wasting. However, he and his wife were optimistic for the future, and were looking forward to a visit from their daughter the following week.

Mark was also living with the aftermath of his illness episode. Mark’s story is dominated by the unpleasant hallucinations and nightmares he experienced during his time in the critical care unit. On looking back at these, Mark tried to rationalise and make some sense of their occurrence, relating this to the medication he was receiving and sleep deprivation. His level of consciousness also fluctuated. At times he was aware of the surroundings: “I was conscious of being in hospital” and was able to recall signals emanating from the ambient equipment and the effects of nursing procedures such as endotracheal suctioning and manual ventilation of the airway. Once again, communication difficulties and the need to regain independence and control were evident in Mark’s story.

Max

Max was in his early thirties, married with one young child. He had been hospitalised for over three months for treatment of complications following elective surgery. He spent most of this time in critical care on a mechanical ventilator. I interviewed Max five months after he was discharged from hospital.
Max was able to recall many aspects of his stay in the critical care unit, and his overall perception was that it was a very unpleasant experience that he never wanted to repeat again. However he did not appear to be unduly stressed or upset, and indicated that he was pleased to be home and back working in his usual occupation.

Throughout his life, Max had several hospitalisations and operations for a congenital condition. Max told how he had put off having this particular operation, as he “hated hospitals and being a patient – they [hospital staff] take over all the time”. He had preconceived ideas and expectations arising from his past experiences.

Max told how things seemed to have been going smoothly prior to the operation. He had been informed by the surgeon that his stay in the critical care unit “should only be for a short time, just overnight so the nurses could keep an eye on me”. However due to unexpected complications, Max needed to return to the operating theatre a further two times. Other complications had ensued including respiratory and septic complications, necessitating treatments including the insertion of a tracheostomy tube.

Although Max told me at the start of the interview that he could remember “many things” about his experience, his story did not follow a temporal sequence. Instead, his story ‘jumped all over the place’. He spoke of events “before I woke up and knew what was going on, and later told of “when I was out to it”. He gave the impression that he was annoyed that he could not clearly remember everything that happened to him during that time, but acknowledged that this may have been due to being sedated: "they probably doped [sedated] me up to keep me quiet".
Max spoke of losing track of time and “the real world”. At times he did not know where he was or what was going on around him. This was a frightening experience for him.

*Yes, at the beginning I couldn’t distinguish what was real and what wasn’t. So anyhow um you know, I just had this feeling of being, no, knowing, that I was absolutely terrified. It was when I didn’t like what was happening to me, having no decision-making ability, no power.* (Max: int. 1)

Max told me that he “hated being on that thing” [ventilator]. He felt that he was always “struggling to get comfortable”, and how every action he attempted was impeded by this piece of equipment. He was aware that he needed the ventilator to assist him to breathe, but resented the situation and being reliant on technology to breathe: “You know you have to have it [mechanical ventilator] otherwise you’ll probably die, but I sometimes wanted to chuck the bloody thing out the window”.

Max also resented the loss of independence and control associated with being reliant on others: “I couldn’t even wipe my own bum”. He was very relieved when he started to assume more and more of his own personal care. He told how he would try and get the nurse’s attention: “I’d deliberately push things off my bed-tray onto the floor to get their attention, let them know I was still there”.

Throughout the whole hospital stay, Max’s family, which included his wife, child and parents, provided him with enormous comfort and support. Although he told me that at times he was probably not always “aware they were there, they helped keep me sane, you know in touch with the real world outside”. There were times when he felt that he was not always treated like a person, and that the staff could have told him and his family more about what was happening:
“You know, it is really important to tell the family the truth, even if the answer is ‘we don't know what is happening’. Relatives are not stupid and can usually come to terms with truth and fact but not with bull. And doctors shouldn’t forget that patients are a person, and respect their dignity. They [critical care staff] may see sick and dying people every day, but for the patient and their family this is hopefully a one off event. They shouldn’t be blasé. (Max. int. 1)

Max explained that, on looking back on the experience, he wouldn’t have been an “easy patient because I like to be in control”, and didn’t like others doing things to him. He finished his story by reassuring me that although he did not like being in critical care, he thought most of the staff, especially the nurses, “do a wonderful job in difficult circumstances”.

Max’s previous experiences of hospitalisation no doubt impacted on how he perceived and interpreted this particular episode in his life. His drive for independence and control is evident throughout his story, as is his resentment of being reliant on the mechanical ventilator and the nurses. He highlights the difficulties and discomfort he experienced from being on a ventilator. Max also referred to losing time and contact with the real world, and not knowing what was happening around him, and outside the hospital. The presence and support of his family were important in helping to keep in touch with events happening outside the world of the critical care unit. Like many of the other participants, Max felt that the critical care staff could have provided more personalised information.
Beginning interpretations

On reviewing all the participants’ tapes and transcripts, I was indeed confronted with stories that were chaotic, lacked coherence and did not follow a temporal sequence. However, rather than being daunted by the task of seeking and revealing individual and shared meanings, I was instead challenged by such an opportunity. The extant literature examining the experience of critical care illness and mechanical ventilation had not explored such experiences from an ontological perspective, or to any great depth. Now was the chance to do justice to the stories told by these people and overcome the gaps of previous studies.

The four stories I have presented provide a glimpse into these peoples’ experiences. A number of concepts emerged from the initial interpretation of these stories. The concept of being abruptly taken over, and entering a strange world featured in all of the stories. Shelley referred to the total difference between going into hospital for a supposedly routine operation, and then being “plonked into a not normal, weird planet”. John described how the doctors and nurses took over the situation, with him being a passive recipient of treatment, and then rushing him to the critical care unit. Max also spoke of hospital staff taking over. To Mark, the critical care unit was a strange place, far removed from his normal everyday life, and for Max it was not the real world.

Several aspects associated with ‘being-in-the-world’ of the critical care unit emerged. The concept of fluctuating levels of awareness of the surroundings featured in all the stories, as did the occurrence of unpleasant and bizarre nightmares and hallucinations, the inability to distinguish time, and the inability to determine what was real and what was not. Many of the participants spoke of being dependent on
technology for survival, and were able to describe the effects of the treatment, including procedures associated with the mechanical ventilator. Being confronted with the prospect of death led many to question their chances of survival.

The need for control and independence, and getting back to normal was a common finding, although the means by which each individual sought to do this differed. The presence of loved ones, and certain nursing actions, were seen to provide comfort and support.

Many of the participants were left with some form of disability resulting from this episode of critical illness or injury. On looking back over this event in their lives, participants sought to make meaning and sense of their experiences.

After examining all of the parts of the participants’ stories and identifying these initial concepts, I then undertook to relate these concepts back to the whole of the stories to advance the analysis to a deeper level. The next two chapters provide the findings of this study derived from a rigorous process of hermeneutical phenomenological interpretation. The next chapter presents the thematic analysis of the experiences of the participants’ critical illness or injury episode. From this analysis, an ontological description of the meaning of being on long-term mechanical ventilation is presented in chapter eight.
CHAPTER 7

THE LIVED EXPERIENCE OF CRITICAL ILLNESS

Introduction

Chapter six presented four of the participants’ stories, and provided a beginning interpretation of the stories. This chapter follows on from the previous chapter and presents a thematic analysis of the experiences of the participants’ critical illness and mechanical ventilation episode. It encompasses: the events prior to and during their admission to the critical care unit; the time they spent in the critical care unit; their transfer to the general ward in the hospital and discharge home; and their life at home after discharge. Presenting the findings in such a way provides a contextual background from which to reveal the meanings the participants attributed to being on long-term mechanical ventilation in a critical care unit. This is described in the next chapter.

The initial analysis undertaken revealed words and phrases that stood out as useful to the interpretation of the meanings attributed to the phenomenon. After highlighting these meaningful words and phrases from the individual stories (the parts), it was necessary to relate these back to the whole stories and look for shared meanings, and differences. Thus, the process of entering and re-entering the hermeneutic circle was evident, as was my ongoing dialogue with the text. Through dialogue, I asked questions such as: How did the nightmares or hallucinations impact on the meaning of the experience? What was it like to live in a world so different from normal? These types of questions were used to formulate further discussion with the participants, which gave me the opportunity to explore more deeply the meanings
these people attributed to their experience of the phenomenon, and construct a phenomenological account that was rigorous.

The hermeneutic process of reading, re-reading and dialoguing with the text revealed a number of themes that began to represent the shared experiences of the participants. This was an extremely time-consuming and involved process, as I found that I was continually reflecting, questioning and re-reading, to ensure that I was being true to the experience and disclosed meanings as faithfully as possible.

In chapter six the stories of Shelley, John, Max and Mark were presented. In this chapter, parts of the stories of the other five participants Anne, James, Bert, Leanne and Don are also included to fully demonstrate the meanings that emerged through thematic analysis of the shared experience. Four main themes relating to participants’ experiences emerged from the data, and each of these themes reveals how participants made meaning of their experience. These themes are: being thrown into an uneveryday world, existing in an uneveryday world, reclaiming the everyday world, and reframing the experience. Each of these themes has a number of sub-themes that together comprised the main theme. Throughout the description of each main theme, excerpts from the interviews with participants are provided to demonstrate and illuminate the interpretations that I have constructed.

Table 7.1 outlines the themes and sub-themes revealed through a thematic analysis of the participants’ stories of their experience involving long-term mechanical ventilation in a critical care unit.
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Being thrown into an uneveryday world

Being thrown into an uneveryday world characterised what it meant for participants to experience an illness or injury of such severity that they required admission to the critical care unit for management and treatment of this condition.

Participants explained how their admission to the critical care unit (CCU) was not a gradual situation for which they had warning or could prepare for. Instead, they described how they felt as if they were uprooted from their everyday lives and catapulted or thrown into the unfamiliar world of the CCU. All spoke at great length and in vivid detail about how their critical illness experience was so different from their “normal life”, the “everyday world”. Nothing was normal or familiar in the CCU environment.

*It was like throwing a baby into a cold swimming pool – all that is familiar and comforting is suddenly gone. Instead there you are in this place that is unknown.* (Anne: int. 1)

The CCU is a very different place from the home, and studies have shown that patients and relatives find this environment frightening and very unfriendly (Bergbom et al., 1988a). Participants in this current study experienced the CCU as unfamiliar, very strange, and a far cry from the comfort of their own home. For example, the constant noise emanating from the machinery, telephones and the staff conversations was particularly irritating. Alarms and signals from surrounding technology were also confusing and participants commented that they were often unsure of whether the alarm signals they heard were coming from their own equipment or from those of other patients. Noise levels below 35 decibels are required to allow people to sleep, however, research has demonstrated that ambient
noise levels in busy critical care units are consistently above 80 decibels (Eveloff, 1995). In Australia, it is recommended that noise levels in a hospital do not exceed 45 decibels during the day and 35 at night. However, findings from these particular research studies have consistently demonstrated that the main sources of noise in the CCU are staff conversations and equipment noise, which was also evident in this present study.

The theme Being thrown into an uneveryday world meant a severing, or discontinuity of the everyday world, being desituated, being disengaged from the everyday world, and being taken over by others.

It is interesting to note that the concept of ‘throwness’ is Heidegger’s way of revealing and expressing the existential experience of Dasein “as thrown, [Dasein] has submitted to a world, and exists factically with Others” (1927/1962, p.435). For Heidegger this throwness is the environment that one is cast into at the moment of birth and involves the language, culture, ideology and other beliefs that have been constructed within this environment. Heidegger’s concept of throwness is relevant to this theme as the participants as a group of people have been thrown from their familiar environment into the unfamiliar environment of the CCU.

Discontinuity of the everyday world

Participants referred to the ‘before and after’ of their experience of being admitted to CCU and having been placed on long-term mechanical ventilation. The before was prior to this particular episode of critical illness or injury, and referred to the period of their life before being admitted to hospital. This was when life was familiar and normal, when they were not critically ill and were able to go about their usual
lifestyle. However, following the onset of the critical illness or injury, their normal way of being-in-the-world was disrupted. They were unable to continue with their life as before.

The after is the period of time after the CCU admission. The after takes place in a strange, unknown world that bore little resemblance to the before, known world. Being thrown into an uneveryday world meant a discontinuity of the normal, familiar, everyday world of the person.

I remember waking up from the operation and thinking: “This is not right, this is not my bed”. And then I don’t remember anything until I woke up in ICU. I don’t remember anything whatsoever except going down for the operation, waking up for a short time somewhere, and then, waking up later in ICU. I was going to have a routine operation. I knew what was supposed to happen, no big deal supposedly. I was only supposed to be in for a day and a bit, my life hardly interrupted. And then, this thing happened. One minute before, I’m fine, going about my normal business. The next thing, crash. Here I am in CCU. No warning and the next thing is like I’ve been sent to Mars by mistake. (Bert: int. 1)

An episode of critical illness creates an enormous impact on the day-to-day functioning of not only the patient, but also their loved ones such as family members and friends. In the above excerpt, Bert described how his life was suddenly changed from the before, when he had been scheduled for (supposedly) routine surgery. However, due to intra-operative complications he was admitted to CCU for intensive nursing and medical management, including long-term mechanical ventilation. For Bert, the aftermath of this was that his usual mode of being-in-the-world was discontinued. There was little or no relationship between the before and after, as his normal world ceased to exist.
Being sent down there [to the CCU] is like two different things happening. Before you go there life is okay, not too bad really when you think about it. You just go about your normal business. And then next thing here you are after something goes wrong with you, and it’s like as if you’re in a totally different place. Things don’t go on the same after that. (Bert: int. 1)

In another example, James described how an abrupt onset of respiratory illness resulted in his transfer to hospital, and admission to CCU. He referred to the before as his normal way of life, which was discontinued when he became critically ill and was hospitalised.

So any way the night before it [illness and CCU admission] happened, I was having a peaceful relaxing time just lying down. Lying around the boat not doing much. Probably what caused the congestion in the lungs overnight. In the morning I felt really crook, so I rang the ambulance. They raced me to the Emergency Department there, at the hospital. Next thing I’m up in CCU. One minute I’m lying on my deckchair, the next I’m in CCU, probably could’ve died. From then on I can’t quite remember all that happened in any real order. (James: int. 1)

For these participants, admission to the CCU heralded an abrupt discontinuation of their usual way of being-within-their-everyday-world. They felt cut off and disconnected from their normal environment and way of life. There was no time to plan or prepare for such a life-threatening and life-changing event. Within their own homes people are connected; they feel connected with themselves and their way of life. However, once they enter the CCU as a patient they feel disconnected. Life does not continue on as before, as James reveals in the following excerpt: “The whole thing was like being taken from your own safe calm world and thrown headfirst somewhere else. At times you can’t make night or day out, and when things happen, you have no control” (James: int. 1).
**Being desituated**

The unfamiliarity of the CCU environment provoked a perception of being displaced. Participants spoke of feeling out of place, lost and not belonging, in the CCU. Indeed, Anne likened CCU to “the scariest of scary movies”.

Hospitals are often impersonal, unfamiliar and unhomelike institutions. The physical layout and environment, omniscient technology, variety of uniformed staff, and the specialist language spoken by health care workers all give rise to a culture that is unique to hospitals. And nowhere is this more evident than in the highly specialised and artificial world of the CCU. In a foreign environment such as the CCU, patients may feel that there is nothing familiar or known that they can grasp and make meaning from.

Participants described the unfamiliarity of the CCU environment using terms such as “claustrophobic, enclosed, and prison-like”. Critical care units traditionally have been areas that have not incorporated to any large extent the external environment. Until recently, most critical care wards had little or no natural sunlight, minimal windows, and no views to the outside world. Lighting is usually provided by fluorescent lights, which are often switched on 24 hours a day. The rationale behind this has been that patients are too sick to notice what is going on around them. However, the importance of sleep and a pleasant ambience in patient care is now well documented (Eveloff, 1995; Kahn, et al. 1998; Southwell & Wistow, 1995; Topf, 1992), and many modern CCUs are now designed with large windows, garden views and outside courtyard access. The CCUs in this study had some natural sunlight, however, none provided patients with accessible views to the outside world.
Thus, for participants in this study, their first glimpse of the outside world did not occur until they were transferred from the CCU to a general ward.

Participants described how they felt disorientated and confused from being cut off from a known situation, and thrown into the unknown situation of the CCU. The feeling of being without a situation, or desituated, manifested itself throughout many of their stories.

*Well, noises and sounds of people coming and going. I knew I was, like, hooked up to things, because I could hear them. I don’t really remember distinctly any noises that could tell me what was happening outside. Yes, I know I haven’t really given you a straight, start to finish story, but it’s not like that. It’s more like a jumble of pictures and things that go round and round in a circle. A strange place – have you ever been drunk? I don’t really know how to describe it. It was just, it was like being in another world but not really being there.* (Don: int. 1)

In another example, Leanne described her experience of being desituated:

*Well when you are home, or going about your usual life, you know, going to work, going out with your friends. Even the mundane stuff like housework, cooking, cleaning. That’s all part of what you do, you don’t really think about it too much, do you? Until something like that happens, and then all those normal day to day little things aren’t there any more. I mean, I normally have a shower in the morning, have breakfast then race off to work. But there [in CCU] none of that happens, no shower for starters! Nothing that is like what you normally do at home. How can you feel like yourself, or any sense of belonging? Someone once told me that autistic people, you know children with autism? Well they feel like that all the time. That they don’t belong in their world. I can really sympathise with them now. Apparently there is a show on the television that is supposed to be funny – I forget what it’s called, that is about people who come from another planet and try to fit into earth. Well it’s not funny. It’s actually really frightening when the world you’re in is not your own. Plus you don’t have a choice, which makes it even worse.* (Leanne: int. 1)
**Being disengaged from the everyday world**

When people feel displaced or desituated, the level to which they are actively involved, or engaged in their world, can change. Heidegger (1927/1962) used the concept of engagement to characterise everyday involvement in the world. He described the different ways that people are engaged in the world using the terms “ready-to-hand”, “unready-to-hand”, and “present-at-hand”. Being actively involved and seeing the world through the ready-to-hand, taken for granted lived experience allows us to explore meanings that are often hidden in everyday practices. Engaged involvement and the ready-to-hand provides a way of seeing the world, and sets up possibilities through which meaning can be attributed to human existence.

In contrast, when something becomes unready-to-hand, the situation is altered, and the person loses the maximum grasp that was available in the ready-to-hand condition. For the participants in this study, their experience of being on long-term mechanical ventilation in a CCU created the perception that they were no longer involved in their usual life in an unnoticed and taken-for-granted way. Instead, they felt disengaged from the everyday world, as their usual way of being involved was broken down, and disrupted. Their whole world became unready to hand. Being disengaged was revealed through alterations to the normal functioning of their body. What had been unnoticed and taken for granted became unskilled and problematic. Bodily functions such as movement, and even breathing, become noticeable. Being unable to be involved as before in their everyday world, participants disengaged and felt no longer at home, or comfortable, within their own bodies.
Well it’s all a bit hazy. And then I was lying on a bed, looking up, not sure where I was. I’m not sure if I even knew then if I was in hospital or not. I think I must have known, ’cause I can remember that doctor telling me how sick I was. I wasn’t there any more. I wasn’t involved in what was happening. I felt distant from what was happening. The things that I would normally do, like lift my arm up, or move my leg to a more comfortable position, were really difficult at times. It just didn’t work the same as normal – I noticed that. (James: int. 1)

Here James described how his level of engagement in the world was altered as his ready-to-hand skilled habitual body broke down. For James being unready-to-hand meant that his usual way of being involved in the world changed. He noticed that his body was not working as smoothly and as normally as before, instead normal actions became noticeable and a cause for concern.

Anne described what being disengaged from the everyday world was like for her. She used the term “scary” several times throughout our interview to highlight how frightened and helpless she felt as a patient on long-term mechanical ventilation in a CCU.

What normally happens, didn’t! Your body belongs to someone else. I remember trying really hard to move my shoulder to roll over, and nothing happened. No matter what I did. You think things will work as they normally do, and when you go to do them and they don’t, it’s scary. It’s like you can’t even rely on your own body, yourself, any more. Scary. (Anne: int. 2)

**Being taken over by others**

Being thrown into an un-everyday world was also noticeable through participants’ perceptions that they were taken over: “It’s not a giving over. It’s a taking over. They go to work on you from all angles. It’s like an all out assault. I know they have to do it, but it’s full on all right” (Bert: int. 1.).
In his story, Bert explained how he experienced the medical and nursing activities performed on him following his admission to CCU. The purpose of CCUs is to treat patients who have potentially life-threatening illness or injuries. When patients first enter the CCU environment, they are confronted with a highly technological setting that may converge upon them, as the CCU staff “get into action” and direct their efforts towards the goal of maintaining or sustaining life. Often this involves the instigation of numerous complex medical regimes that are invasive in nature and require the support of sophisticated technology as well as skilled nursing care (CACCN, 1996). In the emergency and life-threatening situation, staff will do a lot of things to and for patients, and hence they may not always give a lot of thought to whether the patient wants this or not, or how it might be experienced by the patient (Adler, 1997).

Similarly, Leanne also felt as if she was taken over by others, with very little say in her treatment.

*It seemed such chaos at the time. Everyone shouting around me and sticking needles in my arm, and my neck, and everywhere else. I didn’t know who half of them were. But I know that they were busy and seemed to rush around.* (Leanne: int. 1)

The feeling of being taken over by others for these participants was evidenced through their perceived lack of participation and consultation in the medical decision making process. Although participants did acknowledge that many of the activities of staff were aimed at treating their illness, being taken over was experienced as being a passive spectator in their own health care.
Existing in an uneveryday world

The theme existing in an uneveryday world disclosed how participants experienced long-term mechanical ventilation and the day-to-day world of the CCU. This theme also revealed what it meant for participants to exist, live through and survive the many physiological and psychological effects arising from their critical illness episode, whilst enduring the ongoing rituals that are part of the management of the long-term mechanically ventilated patient in a CCU.

For these participants, existing in an uneveryday world was, for the most part, unpleasant and frightening. To exist in an uneveryday world meant experiencing fluctuating levels of consciousness, being unable to distinguish reality and time, experiencing hallucinations and nightmares, living in an unfamiliar body, experiencing technology and others, relying on technology and others for survival, and questioning survival.

Experiencing fluctuating levels of consciousness

Participants described many situations when they felt as if they were moving “in and out of consciousness”. Although each participant told a unique story of an individual experience, no one was able to fully recall the experience in its entirety. There were parts of their experience they could recall, and other parts for which they had little recollection. For example, Don recalled that when he was discharged from CCU to the general ward he was surprised to see all the equipment that had been used in his management.

I didn’t know what it was like all the time. I have memories of endless time, and thinking to myself: “Am I ever going to be me again?” Because of the pain and my broken wrists I was even more helpless anyway. You just lie
there wanting it to be over with, but then time seems to go really quickly, and it’s another day gone I think – but then at times it seems like never ending time, just standing still while everything happens around me. I was on all that machinery until I left ICU because I was in a private room and they wheeled me past my door handle and I looked back and just saw tons of machines. I just said to my nurse: “Was I on all them?” and she said: “Yes.”  

(Don: int. 1)

Being in a state of fluctuating and often decreased consciousness for differing amounts of time made it difficult for participants to piece events and happenings together in a meaningful way. For example, events such as undergoing chest physiotherapy, which involved a considerable degree of patient handling and touch was remembered vividly by some, but others had no recollection at all. Don did not remember experiencing chest physiotherapy in the CCU, and repeatedly asked the physiotherapist after he was transferred to the general ward for confirmation that he had actually had the treatment.

Being in and out of consciousness was experienced as frightening for many of the participants, as they felt unable to totally grasp what was happening around them. Leanne, in particular found this to be quite disturbing.

*I felt shrouded in a fog that I was unable to move out of. I knew at times that I was in hospital, and pretty sick, but I couldn’t reach up and pull the fog away and see the clearing. It kept misting over and drowning me in it. It was pretty traumatic.*  

(Leanne: int. 1)

Bert remembered periods when he was awake and conscious whilst being mechanically ventilated, but other times he cannot recall what he called “great chunks” of his time in the CCU.

*I don’t know how long I was in CCU, I still don’t know today how long I was in there. I only know from what the wife tells me. At times I actually knew*
what was happening. I had the tube in me but I was conscious like, you know. For an hour or so when I first woke up, then on and off, I don’t know how long in between. So I was really on the respirator then consciously, like you know what I mean, and then I wasn’t conscious and I didn’t know about it. It was like I was in and out of it [consciousness] throughout the whole time. (Bert: int. 1)

Experiencing hallucinations and nightmares

Participants also referred to hallucinations and unpleasant dreams or nightmares that were unlike anything they had previously experienced. Terms such as “awful dreams”, “bizarre dreams”, “unreal fantasies” and “hallucinations” were used interchangeably. Although the terms differ, a common characteristic was that these were totally different to their usual “at home” dreams. At no time did any of the participants describe dreams or hallucinations that were in any way pleasant. However, participants indicated that sharing their accounts with me was helpful, as this lessened the impact of this part of their experience. Bert told of the unpleasant nightmares he experienced:

It’s so vivid. I mean these dreams I had that time were so bad. They were really horrific and I will never forget it because I weren’t asleep. Because I was having too many drugs going into me and I couldn’t sleep. The ward closed like a shopping centre closes at 5 o’clock. We seemed to go to the, ah, not in the ward but over the ward on the other side of the ward, and there was a big party in full swing. I saw the surgeon’s face, the one that cut me up – operated on me – better not say cut me up – operated on me, and he was dancing. I was lead onto this floor but it was on a tilt like that, on an angle about a 20° angle, and I was lying downwards. Because I weed [was incontinent of urine] they super-glued a plastic cup over my private part. And because I messed myself, [was incontinent of faeces] they super-glued a plastic cup over me bum, you know, and the party carried on around me. Now that was the most frustrating thing was that I couldn’t tell anybody about it. All the time I was trying to get out of bed, that’s why they were restraining me. I was fighting to get out of bed, not to go home and not to run away, but to go up to the office in the main hospital. Because I knew I was in the A hospital or I should have been in the A hospital. You know, I knew that. But I felt somehow I got waylaid at somebody’s party and that was what I was trying to do, to get outside and go up to the office and tell them that I didn’t want to be were I was. I wanted to be in a proper hospital so I could get better. Do you know what I mean? But the nurses, because we
couldn’t communicate, thought I was faking it, and trying to rip my tubes out now, but I wasn’t. That dream stayed with me, and I just didn’t believe that I was in the A hospital, not until I actually looked around and was able to have a really good look at the place. (Bert: int. 1)

Participants’ accounts of hallucinations and nightmares resonated with feelings of being threatened by loved ones and or the staff of the CCU, and of drowning and suffocating. The following excerpt from John is another example of a very disturbing nightmare/hallucination about being suffocated.

*It was about black slippery slime. It was just so realistic, you know. The people from work. The whole scene was so close to life that even now I can remember it vividly. And I still have to be convinced that it didn’t really happen. You know when you normally dream that you can tell that it is only a dream, because often the people and places don’t make sense. Well these ones did. The workmate’s real, everything was exactly as it is, that’s what made it so frightening. Anyway, I was trying to save B [workmate] because the river was rising and he was going to get drowned if I didn’t save him. That was because there was this thick, black suffocating slime, like quicksand that kept rising and rising and rising, and it was pulling us under. And I was trying to save him, but we were going under and it was getting in our throats and our mouths and eyes. And I knew we were going to die. I just knew that was it. There was no going back. We were going to do out here in the green slime. And I was trying so hard to warn him and save him.*

*Later, it was much later, the dream went on and on, and I couldn’t escape it. Well, when I woke up from the dream, I was drenched in sweat. I think I must have been moving a lot, really agitated you know, so they gave me something to stop me moving around the place. But I didn’t want to go back to sleep, because I was frightened to in case the dream came again and the slime. I was terrified to go back to sleep because I was going to suffocate in the black slime. That was one of the most frightening things in my whole life. I fought not to go to sleep, and they [family and nurses] kept telling me to relax, but how could I when my friend was drowning and I couldn’t save him and I didn’t want to be suffocated and smothered in black slime. It was so real, like quicksand, and I just couldn’t escape it coming up to smother me up. All in my nose and mouth, fighting to get some air, fighting to get air.* (John: int. 1)

This concept of trying to escape was found in several other stories. For example, Shelley described how she kept thinking she had been discharged home, only to wake up and still be in CCU. These nightmares or hallucinations were therefore very
terrifying, and several of the participants became fearful of falling asleep. Others fought to escape and get away, whilst other participants told how they struggled and fought to overcome the feeling that they were drowning or suffocating.

_Inability to distinguish reality and time_

In conjunction with the hallucinations and nightmares, participants also reported that at times they had difficulty determining what was real, and what was not. For example, one participant described how she kept questioning her “grip on reality” (Anne: int. 1), as she thought she was losing her mind. Another spoke of thinking he had gone “completely balmy” (James: int. 1), whilst Max (int. 1) likened his attempts at determining reality as a search for “the real world” and “trying to keep sane”.

Grappling to make sense of time was also evident throughout the stories. Participants described how their usual temporal relation with their known world, where time dictated many of their activities, was totally disrupted in the uneveryday world of the CCU.

> My clock seemed to be back to front still and so far so I haven’t worked it out right. I never knew what was day or night, or how much time had passed. You know, if it was day or night or even the same day. This continued on and on. How can anybody work things out? (Leanne: int. 1)

Participants talked about loss of time, particularly in relation to the number of days. Some “lost” one or two days, others spoke about losing many days out of their lives.

> And I remember it was one day I was lying there trying to breathe so hard, and then the next thing I was in a coma induced before I had the tracheotomy. I was lying there for days, lying there in a half-induced coma, and I lost days out of my life I will never recapture. And I couldn’t work out what day or time it was. I couldn’t speak, and I wanted them to shut up.
However, now I look back on it, I had to at some time, I can’t remember exactly when, to accept mentally that for a while there time had no meaning, and what was real and not real was all out of whack. (James: int. 2)

Losing time and being unable to distinguish reality meant that participants were unable to continue their usual way of life, and make meaning of their surroundings based on prior knowledge and experience. They felt dislocated from the “real” world that is based in time and a sense of reality.

**Living in an unfamiliar body**

A human body is not a ‘thing’. People exist in their body, experience their body and own it. In this study, participants also spoke of how they felt a loss of their usual and familiar body. It was as if their known body had been replaced by, or subsumed by an unfamiliar body that did not physically respond in its usual way. Living in an unfamiliar body is another feature of existing in an uneveryday world. They told how they experienced their body’s failure, or inability to respond in its usual, taken for granted way, what Heidegger (1927/1962, p. 103) referred to as “the-ready-to-hand”. Examples included being unable to move their limbs in the usual way, and being unable to talk and communicate in a meaningful way. As a result, many participants found themselves living in a body that did not react as expected, and was immobile, uncoordinated, or as one participant put it “totally unreliable” (Anne: int. 1). Some felt that they were not able to participate in any meaningful way, or have control over, their world. In the previous chapter John described how strange it felt to him when he could not locate his limbs, or situate his body in a meaningful way. In a similar vein, James spoke of his experience of an unfamiliar body:

*My legs and arms felt really heavy and floppy. You know, like you want to move but you can’t because your body won’t obey, or is too tired or lazy. I*
struggled to move and do things, even small things. But I think in the end it was all too difficult, and I must have given up. For a while anyway. (James: int. 1)

Bert provided another vivid and illuminating description of living in an unfamiliar body and not being “himself”:

 Looking back on it, at times I was just occupying space. It wasn’t me. My body felt like just a thing, you know. I was there, but I couldn’t do my normal things, just lying there. Not much meaning to that, is there? Like I said, I was just taking up space. (Bert: int. 1)

Regardless of the cause, severity or duration, a critical illness often implies a loss (Adler, 1997). The loss involved can range from temporary loss of function to loss of life. Loss has significance for all involved, including the patient, the family and members of the health care team. Each individual reacts differently to the loss experience. Physical alterations or possible limitations can be very disturbing since the body with its parts and functions are tied to objects in the environment, social interactions, and one’s psychological self. Thus, loss of normal bodily function can be a new and frightening experience for the critically ill person. The person may even feel betrayed by their non-complaint body (Adler, 1997).

These feelings of betrayal and loss are understandable when viewed from a phenomenological perspective, where the body is the basic mode of one’s being-in-the-world. The human body is the beginning point for understanding and interpreting human experience (Madjar, 1997). In health, people experience their body as “ready-to-hand”, and take for granted many of the body’s functions and activities. However, when the person’s health is altered or changed in any way, then the person becomes aware of their body in differing ways. Madjar (1997, p.56)
refers to this as the “capacity to call forth the awareness of the body”. Thus, a potentially life-threatening event such as a critical illness, and the application of technology to the body in order to medically treat that illness, creates a changed situation when the experiencing person’s perception and awareness of his or her body is altered. Moreover, when the body does not respond in the usual “ready-to-hand” way, the person experiences a loss of the familiar and known. In John’s words: “If your body doesn’t do as it should, you know things aren’t right” (John: int. 1).

Such descriptions reflect what Madjar (1997, p. 57) terms the “loss of the habitual body”. The habitual body is the familiar, known body in which we live, and whose function we take for granted. Losing the habitual body through illness can be further accentuated by other factors such as altered physical appearance, and having artificial devices attached to one’s body to perform certain life-sustaining activities such as breathing and circulation. These factors are particularly relevant to this study. Technological devices, including the mechanical ventilator and its attachments, complex intravenous therapy and medication regimes, and sophisticated monitoring and diagnostic tools are standard devices used to medically manage the long-term ventilated person within the critical care unit. Moreover, the application of such technology to a person’s body may create the perception that they look different as viewed by others. As an example, Bert described how he didn’t want his grandchildren to visit him during his stay in CCU, because they might become frightened by his altered appearance:

Yes well, this is why I told my wife not to bring the grandchildren in. I don’t believe that they should see people like that, especially people they love because it’s more frightening like. And I didn’t want people looking down at me, when you weren’t aware of what you looked like. Thinking that they’ll come in stand and see you with all the tubes and that’s a frightening
experience to actually go into a room and see somebody they love with tubes in their throat. (Bert: int. 1)

Thus the use of sophisticated technology in patient care, particularly the mechanical ventilator and its necessary attachments such as the endotracheal tube and the ventilatory tubing, intensified participants’ awareness of their changed body and they did not want others to have to experience seeing them in this altered state.

**Experiencing technology and others**

As previously discussed, the critical care unit is characterised by the presence and usage of highly specialised technology. Technology is the application of practical or mechanical sciences, or the knowledge and skills available to human society for art, science or industry (Ashworth, 1990). Thus, the expression ‘highly specialised technology’ refers not only to complex equipment and machines, but also to the human knowledge and skills involved in developing and using them (Barnard, 2000).

Participants in this study described how the technology used in their care affected them. Their ability to recall events whilst being on the mechanical ventilator in the CCU was incomplete and varied greatly between participants. At times they appeared totally unaware of the technology that was on and around them, and were surprised when they moved and discovered a foreign tube or piece of equipment attached to them. At other times they were irritated and annoyed by its presence, and found the effects of its application unpleasant and uncomfortable. The mechanical ventilator and the endotracheal tube seemed to be the pieces of technology that had the most significance and caused the most discomfort to the participants in this study.
I found one thing that I really hated was the sucking out of spit from my throat, at first it felt really unpleasant and sort of panicky, and suffocating, but then it started to really hurt, if they rammed it down too far, the area became really tender and sensitive. Yes it really hurt, and I wished they’d stop doing it, but I also knew it had to be done. (Shelley: int. 1)

Similarly Anne found endotracheal suctioning unpleasant, and likened it to being choked of breath. She stated that she would “never go near a dentist again for the rest of my life”. Max also found this activity unpleasant, and described how he gagged and coughed whenever the suction tube was introduced: “it gets you so you cough and heave and your eyes water”. In another example, James described endotracheal suctioning as follows:

The suctioning was awful. I had such a sore dry throat. I tried to show the nurses how far to put tube down so it wouldn’t hurt so much. At one time I tried to cough it up, it was so ghastly and irritating, I just wanted it out. But I also knew that I probably needed it, and the nurses weren’t doing this just to be cruel or for something to do. So I ended up I gave up. What did it matter how I felt? I didn’t matter. I just had to get used to it. I asked for suction to make me better. Even though I knew that it would be awful, I ended up banging on the side of the bed for the nurse to come and suction me, so that my breathing would get easier and clearer. (James: int. 1)

Don also experienced equipment that covered his face, as well as the noise emanating from the equipment to be quite distressing.

And oxygen masks that they have like, I can’t stand them. There was one point where the nurse put on the oxygen mask on me just after I came out or something like that – I kept knocking it off so she put the tubes back in. But I also do remember the constant noise – sometimes it went up and down which meant things were changing, people were all around. The nurses used to tell me to keep still. I remember that. Also they’d tell me not to bite it [endotracheal tube] but you just can’t help it, you just want this thing out – you can’t escape it. (Don: int. 1)

Mark also found the noise of the CCU disturbing:
At times it was this constant humming and chugging, and beeps that jolted you at times – I wasn’t sure if that meant that I was getting sicker or what. And then just as I got to sleep, someone would always jerk me awake to do something. I wish they could have done it all at the one time and let me get a bit more rest. (Mark: int. 1)

Thus the unfamiliar and persistent noises, and the sensations of choking and suffocating associated with the presence of an artificial airway, and oxygen face-mask were experienced as the most unpleasant aspects of technology for the participants. Experiencing a lack of oxygen, gasping for air, obstruction to the airway and or feelings of suffocation are frightening experiences at the best of times. To feel sensations associated with an impeded airway within an unfamiliar environment during a critical illness episode is surely a frightening experience.

Another concern for all participants, directly related to the presence of the endotracheal tube, was their inability to effectively communicate. Being without speech meant that they were unable to indicate to the nurse, family and others their needs, feelings and intentions. Thus in many instances communication was inadequate and impaired. Participants were unable to interact and have meaningful contact with those around them. In the following excerpt, Leanne describes her frustrations at not being able to communicate:

*Communication was a major problem. I used a point board, but we found that it was frustrating for family. They were trying so hard, but they often couldn’t get what I was meaning, so I would get frustrated or angry and give up which probably made them upset, but I suppose you tend to focus on yourself, because you can’t escape it. Sometimes the nurses really knew exactly what I wanted, and sometimes they didn’t, so I liked it when I had the nurses who seemed to be able to pick up what you meant easier. It was also like they got a bit of a kick out of working it out, maybe like winning at charades.* (Leanne: int. 1)
Literature reviews that have examined the issue of nurse-patient communication in the intensive care unit revealed that patients experience acute anxiety when they are not able to effectively communicate with nurses (Ashworth, 1980; Leathart, 1994; Llenore & Ogle, 1999; Casbolt, 2002). Moreover, many patients in these studies found the level of communication during their time in intensive care unsatisfactory. In regards to the present study, although the endotracheal tube is an essential component of mechanical ventilation used to safeguard a person’s airway and allow the delivery of assisted respiratory support, its presence had profound effects on the person’s ability to communicate meaningfully. In effect, it rendered them voiceless.

Other invasive devices also caused discomfort, but to a lesser extent. For example, Bert found the presence of an indwelling urinary catheter (IDC) unpleasant, and something he was conscious of as being abnormal. The sensations arising from the IDC were annoying for him, as he was not always aware of the reasons for its use, and would pull and tug at the catheter in an effort to relieve the irritation it caused. Shelley disliked the sensations associated with nasogastric tube that was used to feed her, as did Anne and Max.

In addition to the discomfort caused by technology, participants also told of the pain inflicted on them by some of the staff during procedures. Although this was described in only two of the nine participants’ stories, it is a significant finding as it highlights the vulnerability of patients in this situation. In the previous chapter, John described how some of the staff were quite rough in their handling of him. This finding is echoed by Don:
I remember how rough and brutal the men helpers [wardsmen or orderlies] were at times. They just seemed to come in and shove you over, regardless of how much it might hurt. They never told you, they just did it. But the nurses were much kinder. And they would tell you what they were going to do, not just do it. After a while I began to dread them [wardsmen or orderlies] coming. Not all of them, just one or two I think it was. I tensed up. (Don: int 1)

Madjar (1997) refers to the nature of clinically inflicted pain, which she described as pain experienced by patients as a direct result of any procedure or task performed on them by health practitioners. The participants in this study were subject to many instances of clinically inflicted pain. Procedures such as endotracheal suctioning, the placing of invasive equipment such as endotracheal tubes, intravenous and arterial lines, and indwelling urinary and nasogastric catheters were experienced as painful. In addition, the need to manually handle critically ill patients to perform pressure area care, chest physiotherapy and investigative tests such as X-Rays and scans are further instances where clinically inflicted pain may occur. Even though recall of their experiences in the CCU was incomplete and spasmodic, there were instances reported of pain and discomfort arising from nurses’ and other health practitioners’ actions.

**Relying on technology and others for survival**

The need for technological interventions and close surveillance by CCU staff created perceptions of reliance on others besides self for survival. A critical illness alters a person’s sense of wellbeing, physical integrity, and ability to be self-sufficient in the activities of daily living. Attached to equipment, invaded by tubes, covered with dressings, and having problems meeting basic physiological requirements such as breathing, swallowing, eating, moving or eliminating, renders the critically ill person dependent on others to meet their needs. When these needs involve processes that
are essential to life such as breathing, perfusing or eliminating, a critically ill person may feel a tremendous sense of dependence, vulnerability and powerlessness.

When I woke up I had the tube down my throat in and I had to depend on the respirator [ventilator] and all the drips and tubes for my very life. It was terrifying at first because I couldn’t help thinking “what if something goes wrong with one of these machines, and nobody knows?” After all, machinery is not infallible, is it? I tried so hard not to panic too much, but your whole life seems to lie in balance in the hands of a bit of machinery. And then later on, sometimes that was quite distressing because, then they put me back on the ventilator and it seemed more difficult to breathe as I was trying. It’s difficult to explain, but I’m trying to take a breath in, it felt like the ventilator wasn’t letting me. And the tube in my throat, yuck. Oh much worse than that. I can’t really describe it to you, it’s like having a Coca Cola bottle shoved down your throat, and you can’t breathe with it and you can’t breathe without it. And you want so much for someone to come and take it away. But you know if they did, maybe it’s your lifeline. So it was a really awful dilemma at times. (Leanne: int. 1)

Leanne’s description revealed her fear and vulnerability as a patient reliant on a mechanical ventilator. Medical technology has provided the tools for modifying and controlling many aspects of the body. The increasing utilisation of technology, particularly within the critical care unit, created feelings of vulnerability and dependence in patients. Because the staff members, particularly nurses in the CCU are in charge of and control the technology, perceptions of vulnerability and reliance intensified. It was interesting to note that after a while, several of the participants viewed the mechanical ventilator as a support to help them breathe adequately, and expressed anxiety when it was removed. For example, one of the participants named the ventilator after herself: “I called her Shelley”. Thus the technology used in the CCU was perceived in a fluctuating way: from friend to enemy, and from nuisance to scary.
**Questioning survival**

Being reliant on technology also created feelings of doom, fear of death and questions of survival for many of the participants. The need to be on a mechanical ventilator meant that participants felt at times they would not survive. Fear for the future and the question of surviving this episode of critical illness was an overwhelming response experienced by the participants. Participants described their fear of dying as a result of their illness and the subsequent need to go on a mechanical ventilator, “a life support machine”. Several also expressed concern about dying while asleep, during procedures and in the weaning process where they were required to resume breathing on their own.

The disruption to the taken-for-granted life that results from an episode of critical illness brought to the foreground the possibility of imminent death. This was exacerbated if patients witnessed other patients dying within the CCU. Seeing others die or viewing an apparent emergency reinforced fears for their own mortality and their future survival.

One participant, after describing the onset of her illness, told of her thoughts when she was placed on a mechanical ventilator:

> When they first put that respirator on me I thought that I was going to die there and then. Once you are on that thing, or need to be, then that’s it, I thought. There’s no going back from here. The things that mattered to me, how I felt or what I wanted wouldn’t matter any more. They [staff] would take over and do the lot. I didn’t count any more. It’s a survival thing, but the person as a person is not always considered. (Anne: int. 1)

As described in chapter six, John described his encounter with a black shadow, which he termed “the visitor”. He experienced this as being close to, or confronted
by death and “going over to the other side”. Thus death as a possibility was evident throughout participants’ stories.

Reclaiming the everyday world

In the second theme, participants described what it meant, and what it was like, to exist in the uneveryday world of the CCU. Feeling that their lives may be threatened by their illness seemed to arouse the need to get away from the CCU environment. To move out of this world, participants needed to reclaim the everyday world.

This third theme describes how participants sought to reclaim their everyday world through reclaiming the self. Reclaiming the everyday world encompassed participants’ attempts to gain some measure of control, and move back to their known world. Within this theme the significant role played by nurses, and participants’ families, in assisting them to get through this experience, is revealed. Reclaiming the everyday world involves re-engaging with staff and families in the critical care unit, gaining comfort through families and nurses, seeking control over treatments and attempting to communicate, and questioning and interpreting the environment and reclaiming self.

Re-engaging with staff and families in the critical care unit

In spite of the difficulties experienced by patients in communicating with their caregivers and families, participants sought to reclaim the everyday world through seeking to connect, or re-engage with staff and families in the CCU. Re-engaging meant feeling connected in a meaningful way to other people within the CCU, be it staff members, family members or both. Participants reported that when they were able to re-engage with their others, they felt that they were making positive progress
towards recovery and moving out of the CCU. They perceived that they were slowly getting back their own world and their own way of being.

*I first thought I would make it and get out of there [CCU], and that it would really happen, when I had the same nurse for a while, and we got to know each other. She was great – her name was Nurse A. She used to come in each morning and tell me all about what she had been doing, what was happening and so on. I felt that I mattered to her, I was important and we were friends. Even though I couldn’t talk because I was still on that ventilator, we somehow got along all right. She really made a difference in making me feel that I was gonna get out of there okay.* (Mark: int. 1)

Thus, re-engaging with others assisted in participants’ journey to recovery and a return to their known, everyday world.

**Receiving comfort from families and nurses**

This study has revealed that there are many unpleasant aspects experienced by critically ill patients whilst in CCU. Patients suffer in many ways related to the pain and discomfort associated with their illness and the technology used to manage it, the loss of control over their ability to effectively communicate, loss of normal bodily functioning, and reliance on others for survival. In this study, when staff and family members acknowledged their reliance on others and discomfort, and instigated measures to minimise or overcome this, participants felt comforted and encouraged.

*Nurse B got me through it – she got me through that time when I thought “Oh no, I just can’t do this”. She came along and said: “yes you can, you can do this.” It made such a difference – the human touch. Amongst all that pain.* (Don: int. 1)

Max’s family provided him with enormous comfort and support by helping “keep me sane, you know in touch with the real world outside” (int. 1). Anne also recalled feeling comforted by her family:
Having them [family members] around, knowing they were there and they loved me, and wanted me to get better, made it so much better. At times like that you feel so vulnerable and afraid. Having N [husband] with me was so good. I didn’t feel all alone. Where would we all be without our family to care for us, and be with us in times of need? (Anne: int. 1)

James highlighted how important the presence of nurses was for him during his time in CCU.

I felt that all the nurses were really attentive. Well, it’s just that I felt their presence there, around me all the time. I may not always have been able to see them, or even know them, but I just knew, or I felt that they were always close by. Because you knew they were always there, right beside you and would come straight away. Even when they had to do things to you, if they explained then this was okay most of the time. So I would say that nurses, I think it was always nurses, I can’t remember too many other people, you know like doctors and physiotherapists. The nurses were close by, with you all the time. (James: int. 1)

I asked James to describe how the close presence of nurses made him feel. He replied that:

I think it makes you feel safe, because the nurses are always hovering. I had the greatest nursing of my whole life up there [CCU]. As soon as I coughed, or later on gestured for some ice, they knew exactly what I wanted. D [nurse] was brilliant, he always took the trouble to try to find out what I wanted. He tried hard to communicate. He would watch my lips and mouth, because I couldn’t use the board very well. I was so weak, and I forgot how to spell, just couldn’t seem to get it together, I was all groggy. You know, if someone is close by then things will be all right, things shouldn’t go wrong. Well, as I said, they always seemed to be there, and were very close. (James: int. 1)

It was apparent that the presence of people who are perceived as caring provided an enormous source of comfort for participants.
Seeking control over treatments and attempting to communicate

Reclaiming the everyday world also involved participants trying to take back some part of the control of their life that they had handed over to staff on admission to CCU. Participants told of the many measures they used whilst on the mechanical ventilator to wrest back, or gain some control, over their treatments. Measures included tapping the pulse oximeter on the side of the bed or deliberately pushing things onto the floor in order to gain the nurse’s attention, striving in a number of ways to initiate effective communication, and refusing to submit to treatments. Participants used these actions to indicate that they wanted some control over what was happening to them. They wanted to reclaim their everyday world and regain a more active role in their care.

Well this is probably the date where, yeah, I think it was only about two or three days before they actually took it out like, [tracheostomy tube] you know what I mean. But the feeling of being able to talk, you can’t explain how that felt. It just felt so good, really, really good to know that, it was like coming back alive again. It was like ‘I’m a human being instead of a ‘vegetable’, I can actually talk to somebody and tell them what I want instead of lying here going “erh erh erh erh erh”. Making weird noises and just that feeling of being human again. It actually made it feel like you were a human being again. You are happier in yourself which also makes you get better when you’re happier with yourself and it wouldn’t be frustrating for anybody. You know the nurses would be able to turn around and know what you wanted to tell them and you would feel better because you could tell them. I think they should invent some way where you could just put your finger over a hole like I did at the end so you could just say that. Or even something simple. If you got the nurses attention and you wanted to say something she could just slide something across you know what I mean and then you could put your finger there and tell her like. Some sort of device where you could move it just so that when you wanted to talk, you could talk. I know you can’t talk for too long because it’s bad for you when you’re on a ventilator. Your lungs are not getting the proper amount of air. Just say for a couple of seconds to say: “Could I have some ice?” (Bert: int. 1)

As previously discussed, the inability to communicate whilst on a mechanical ventilator is an anxiety-provoking event for CCU patients. Thus for the participants
in this study, being able to communicate effectively was a major step toward their recovery and being able to move out of the world of critical care.

Questioning and interpreting the environment and reclaiming self

Staff working in highly technical areas such as the CCU may view illnesses such as cardiac disease or renal failure as conditions to be treated or managed (van der Reit, 1997), but to the critically ill person they represent a totally new experience. Max cautions staff not to become desensitised to the needs of critically ill patients and their families, but instead recognise the uniqueness of each situation: “They [critical care staff] may see sick and dying people every day, but for the patient and their family this is hopefully a one off event. They shouldn’t be blasé” (Max. int. 1).

There is no frame of reference within which critically ill people can judge their illness state. In order for reclaim their everyday world, participants began to focus on their surroundings and start to make some sense or meaning from their situation. Being able to question and interpret their world was another major step toward regaining their own sense of being and self.

Yes. I think I was more scared not knowing, because I didn’t know what was happening to me. I couldn’t move, I couldn’t talk, couldn’t communicate, you know, I couldn’t see. I was just lying there like a vegetable in the bed and like, one of the nurses eventually, and I haven’t seen her since because I’d like to thank her you know for telling me what was wrong with me in layman’s terms. You know, maybe not telling me they hoped to protect me. But then my mum brought in something that a friend had got off the internet about what I’ve got, and it was actually written by a neurologist. He’d written exactly what it was about and all the difficulties there was with G [patient’s medical condition], what they know about it, and what the success rate was at, and about getting better. That helped me so much. (Leanne: int. 1)
In another example, Anne talks about the relief she felt at being able to interpret her surroundings.

*I knew I was going to make it out of there the time I could look around and work out what was happening – it was like the fog had lifted and I was back to being me again. I wanted to shout out loud, but all I could do was cry. What a relief.* (Anne: int. 2)

**Reframing the experience**

The final theme relates to the ways in which participants made meaning of their critical illness experience and the impact of this event on their life. This main theme is comprised of the sub-themes: Reflecting on the experience; being a survivor; rationalising unfamiliar behaviour and experiences; living with the aftermath; and re-appraising the past and re-evaluating the future.

**Reflecting on the experience**

All of the participants looked back over their experience of being on a mechanical ventilator in the CCU. They reflected on the aspects that they could recall, and where recall was missing or disjointed, they tended to ask family members who visited them in the CCU to “fill in the gaps”. It was as if they were trying to put the pieces of a jigsaw puzzle together by slowly putting the pieces in order. By putting the pieces together they could begin to focus on making meaning of the experience.

*I haven’t got, I’ve got a slight problem with memories but not anything major. But there are so many things that I have to, I try to remember, that happened to me, but my brain gets overwhelmed with it all. I want to know what happened to me and Mum read to me some of the notes that the doctors and nurses had made over the time that I was coming in to hospital. But reading the notes has helped me a lot because it helps me make sense, and I kind of think “Yeah I remember that”.* (Leanne: int. 1)
Richman (2000) saw reflection, and the repeated retelling of personal illness narratives as a valuable healing tool. Therefore, it seems that reflecting on the event and retelling the story provided an opportunity for participants to construct an interpretation, derive meaning and reach a reconciliation of this significant event in their life.

Participants also reflected on past behaviours and lifestyle choices to assess if these had in any way caused their episode of critical illness. For example, James, Anne and Bert all tended to blame their history of heavy cigarette smoking as a contributing factor. “It’s my own fault. If I hadn’t kept on smoking so much, even when I knew it was no good for me, I mightn’t have ended up there [in CCU]” (Bert: int. 1). Thus, reflecting on the experience also included a search for reasons why the critical illness occurred.

**Rationalising unfamiliar behaviour and experiences**

Reflecting on the experience and talking to others helped participants in their efforts to make meaning from this critical and disruptive episode in their life. However, there were times when the happenings at that time were so unfamiliar or foreign to their usual way of being that they were unable to account for their behaviour. To deal with this and attempt to overcome the dissonance associated with this specific occurrence, participants tended to create a new meaning through externalising the cause. It was common to hear them blame the medications they may have been given, or the severity of their illness, as contributing to their experience.

*I was fighting and kicking the nurses, and making really rude gestures. You know finger gestures? That wasn’t me, I never am aggressive or nasty. How could I be to the very people who are trying to save my life? And help me. It must have been the drugs they had to give me to keep me under.* (James: int. 1)
Being a survivor

Being judged medically able to be discharged from hospital to home signified that participants were on the road to recovery. They had “got through” their critical illness episode, endured being on long-term mechanical ventilation, and were able to start to “get on with life”. They had survived a very serious situation that at times threatened them with the possibility of death. Being a survivor was another aspect of the critical illness episode, and involved an appreciation and gratitude of being-in-the-world, of being human and alive.

*I am so grateful to still be here, to not have died. I must be tough, I guess. Or just plain stubborn, as my Mum says. But I somehow survived and here I am now. It was awful, but I made it.* (Leanne: int. 1)

An episode of critical illness necessitating long-term mechanical ventilation in a CCU is a life-threatening situation. The possibility of death is ever present. Confronting death will create an impact in people’s lives, and surviving a critical illness meant was a constant reminder for them, and their families, of what they had lived through, endured and survived.

Living with the aftermath

Being a survivor for participants also meant living with the aftermath of their critical illness and mechanical ventilation episode. Following their discharge from hospital to home, they continued to experience in varying degrees on-going physical, psychological and or social difficulties. For example, several people required intensive rehabilitation treatments to manage resultant physical disabilities, whilst others appeared physically unimpaired but were suffering the effects of disturbed
sleep and rest patterns, relationship strain and financial hardships. They dealt with these in a number of ways, and acknowledged that recovery may not be quick or total.

*I’ve had to accept that you just don’t get over something like I’ve been through overnight. It’s going to take quite a while. But it’s pretty frustrating. I’ve got three positions I can sleep in but I can’t sleep in them continuously and ah its having to move all the time that is adding to this broken sleep that I’m getting at night. So I’m going to do two months of physio and ah if that doesn’t fix it they’re going to operate.* (Mark: int. 1)

**Re-appraising the past and re-evaluating the future**

For the participants, being back in their own homes, their known ‘before’ world, was a time to re-appraise the past and re-evaluate the future in terms of their own unique history.

*I’m nice in a way, although it’s an awful thing to happen in a way a lot of good things have come out of it. I haven’t smoked for two whole months, you know, and I’ve met so many wonderful people and it has put lots of things into perspective. What’s really important and what’s just not worth worrying about. Things are going to change, some ways for the better.* (Anne: int. 1).

The confronting realisation that they may not have ‘got through’ and survived the experience had a profound effect on all participants. Without exception, all spoke of how their perspectives on what was important in their life had changed. In the excerpt above, Anne described how the adversity of her critical illness had led to a re-appraisal of what she valued in the future. Other participants told of a reawakening of the appreciation of life itself, and the simple pleasure of seeing the sun rise each morning. There were also feelings of sadness related to the uncertainly of life, however, these were intermingled at times with joy at surviving the crisis. What was apparent, however, was a changed perspective on life.
I am a different person now than I was before. Although the whole family is still getting over it [episode of critical illness and long-term mechanical ventilation], I think it has bought us together closer. Made us a closer family. We are far more aware of what matters in life, and how much we care about each other. (Max: int. 1)

Interpretive Summary

Four main themes emerged from data analysis of the experiences of the participant’s critical illness episode. The first theme centred on the meaning participants attributed to their admission to the critical care unit and being placed on mechanical ventilation. In this theme, participants described how unfamiliar the critical care environment was, and how they felt as if they had been thrown from the comfort of their own known world into an uneveryday world.

The second theme describes what it was like for the participants to exist and live through this unfamiliar, uneveryday world, and endure the experience of being on long-term mechanical ventilation. In this theme, feelings of losing time, reality and consciousness, and being subject to terrifying hallucinations and dreams, were apparent. Participants described how they endured the technology and the discomfort of the various nursing activities associated with the management of the mechanically ventilated patient. Being on mechanical ventilation, that is being “on life-support”, raised questions and concerns of survival, and fear of death for these participants.

There were, however, features of the critical care environment that participants found comforting, although not in the initial stages of their hospitalisation. The close presence of nurses, and having the mechanical ventilator nearby, afforded the participants some degree of security after they made sense of their situation. That is,
once participants understood where they were, and why, they were able to interpret their surroundings in light of their own circumstance.

In the third theme, participants told of the ways in which they sought to move away from the uneveryday world and reclaim their known world, and self. Strategies they used to do this involved gaining control over treatments, especially the mechanical ventilator they were reliant on, and seeking to re-establish communication and engagement with staff and family. By doing this, they were able to begin to question and interpret their world, and try to make some sense of their situation based on their own backgrounds.

The last theme relates to the ways in which participants reframed their critical illness experience. Participants reflected on their experience on an individual basis, and also with the help of family members who tried to “fill in the gaps”. There were many residual issues resulting from the illness and mechanical ventilation experience, including on-going physical, psychological and social aspects, and participants dealt with these in a variety of ways. When participants felt that they could not reasonably explain, or account for their behaviour or experience at particular times, they tended to rationalise this by attributing it to external causes such as the illness, and side-effects of the technology and or medications. After they were back in their own homes and their known ‘before’ world, they also underwent a process of re-appraising the past and re-evaluating the future.

**Conclusion**

This chapter presented the data as a thematic analysis of the lived experience of participants’ critical illness and mechanical ventilation episode. Throughout these
themes, the meaning participants attributed to their experience was revealed and made explicit to the reader. Presenting the data in this way provided the means to derive a meaningful ontological description of the essence of being on long-term mechanical ventilation in a critical care unit. This is presented in the next chapter.
CHAPTER 8

BEING AT ITS MOST ELUSIVE: AN ONTOLOGICAL DESCRIPTION OF BEING ON LONG-TERM MECHANICAL VENTILATION IN A CRITICAL CARE UNIT

Introduction

This chapter presents the findings of the study in the form of an ontological description of being on long-term mechanical ventilation in a critical care unit. Following a thematic analysis of participants’ lived experience of critical illness involving a mechanical ventilation episode, it was then my task to uncover and draw out the essence of what it means to be on long-term mechanical ventilation in a critical care unit.

According to van Manen (1990), a good phenomenological description is an adequate elucidation of some aspect of a person’s lifeworld. To provide a good phenomenological description, one that captures the essence of what it means to be on long-term mechanical ventilation in a critical care unit. It was necessary to review and reflect on the themes derived from the rigorous process of data analysis, as these provided a means for an ontological description of the particular phenomenon in question (van Manen, 1990).

The experience of being on long-term mechanical ventilation in a critical care unit, and the meaning attributed to this was unique for each participant. The degree to which each participant was able to recall the event differed, and recall was quite sporadic at times. However there were a number of commonalities across the stories
that revealed the meaning of the experience and provided the means for an explicit ontological description to be constructed. The description presented in this chapter provides an ontological account of the meaning participants attributed to the phenomenon of being on long-term mechanical ventilation in a critical care unit.

An Ontological Question

On reflection, it was a very complex question that I set out to explore in this research project. The study sought to uncover the meaning people attribute to their lived experience of a particular phenomenon, namely the experience of being placed on a mechanical ventilator, for a period of seven days or more. The question, therefore, involved the experience and meaning of the application of life-saving technology for a period of time equal to or exceeding one week. Furthermore, this event took place in a specific setting, namely a critical care unit in an acute hospital. The context was, therefore, a central feature that impacted on the way in which people experienced and made meaning of their experience. When seeking to answer the question it was, therefore, essential that the interpretation I derived encompassed and reflected the complexity of the question.

Being at its most Elusive

What does it mean to be on long-term mechanical ventilation in a critical care unit? In this study I set out to reveal Dasein, the ontological nature of being on long-term mechanical ventilation in a critical care unit. As previously discussed, Dasein is the being-there, or the there-being, a term Heidegger used to denote human being – not as human subject per se, but as the locus where Being manifests itself (Crotty, 1998, p.96). Thus, to uncover where Being manifests itself and reveals the underpinning
essence of human existence in this particular context, Heidegger’s philosophical assumptions of Being were used as a lens to bring to light the meaning of Being.

In chapter four I presented a discussion of Heidegger’s philosophical assumptions, or tenets of Being, that demonstrate the underlying ontological foundations of our existence. Heidegger’s tenets of Being relevant to this study are:

- Human beings are situated in the world;
- Human beings are engaged in the world;
- Care and concern are characteristics of human existence;
- Human beings are temporal beings; and
- Human beings are self-interpreting.

It is evident throughout the themes presented in the previous chapter that the aspects described by Heidegger’s philosophical tenets of Being were impacted on and explained the way in which participants interpreted and made meaning and sense of their experience of being on long-term mechanical ventilation in a critical care unit. However, the uniqueness of this study was not that these tenets of Being provided a means for understanding the way participants interpreted their unique lived experience. Instead, it was the very elusiveness of these existential tenets that made it difficult for participants to find meaning in the situation. They were often at a loss to make sense of their experience, as their ability to recall events was influenced by their fluctuating level of consciousness and awareness of their surrounds. Thus, to be on long-term mechanical ventilation in a critical care unit is to be in a fluctuating state of Being, or to be suspended between being and Being. Is this not then the experience of Being at its most elusive?
Although the presence of pain, discomfort and loss of control featured throughout the stories, and should not be underestimated, these were overshadowed by participants’ struggle and search to make sense and meaning of their experience and the world in which it took place. The extent to which each participant struggled to make meaning differed. However, a central feature was the loss, or lapse of one or more of the tenets that Heidegger sees as essential for defining Being. These lapses dominated and were central to participants’ stories, creating enormous fear, anxiety, uncertainty and distress. Participants experienced lapses of situation, engagement and temporality, of care and concern, and of the ability to self-interpret. These lapses were momentary: they were fleeting and transitory and could not be defined in definite linear time. They were elusive and illusory, thus Being at this time is at its most elusive. It was these momentary lapses of the tenets of Being that define, and underpin the essence of the phenomenon of what it means to be on long-term mechanical ventilation in a critical care unit.

**Momentary lapses of situation**

According to Heidegger (1927/1962) lived space, or spatiality is a term that belongs to the existential world. Spaciality is a fundamental characteristic of Dasein (the being there or situatedness). Lived space is felt space, and the space in which people find themselves affects the way they feel. Heidegger’s concept of Being-in-the-world emphasises the importance of being situated in present everyday meaningful activities. For Heidegger, being situated makes it possible for a person to understand self and grasp meanings directly from the context.
van Manen (1990, p.102) suggests that we take on and become the space we are in. As the home is a known, familiar space where people feel secure and comfortable, home is a place where we can be ourselves and be what we are. In contrast, van Manen (1990) uses the example of walking alone in an unknown, foreign and busy city as creating feelings of lostness, strangeness, vulnerability and even excitement. For the people in this research study, not only were they away from home in a geographical sense, but they were also in a place that was not at all homelike and bore no resemblance to their home and usual way of being-in-the-world. They felt displaced from their usual everyday world. As previously described, critical care units are strange, foreign environments. The unfamiliarity and uneasydayness of the critical care space rendered them unable to derive understanding of the context in any meaningful way. It is no wonder that in the context of the critical care unit, participants experienced momentary lapses of situation and being situated.

Leanne’s account on page 161 was a very powerful and vivid description of the impact for her of being in an unknown unusual world, and of being desituated. She likened her experience of being in the world of CCU to that of being autistic, which she viewed as not belonging to the real world. When she became aware of her situation and was able to begin to situate herself in a way that had meaning, she remembered feeling enormously relieved, and less frightened.

Benner and Wrubel (1989) see a person’s situation as signifying a place to stand, and a place to be. Awareness and understanding of the situation is important for a person to feel humanness. Although the situation of the CCU may be well defined and familiar for the staff, it is anything but familiar for the patient. As van Manen (1990, p.103) points out, there are cultural and social dimensions associated with lived
space that adults have learned through experience. However, nothing really prepares people for the world and space of the critical care environment, as many of the dimensions are so unfamiliar. In the past, admission to a critical care unit has been likened to being drawn into the “web of institutionalisation” (Roberts, 1986, p.180). The person’s clothes are removed and their body is exposed to staff, supposedly for ease of access, or to keep any equipment that may be placed on them in full view. Personal belongings are kept to a minimum, and intimate questions are asked about all aspects of the person's life, for which they are often granted minimal choice of answering. In effect, the critically ill person becomes ‘hospital property’. Personal space is taken over by nurses and doctors, who do many invasive and highly intimate things to patients who are critically ill. There is little to suggest that this situation has changed over the last 15 years, as the practices within CCU discussed in the contemporary literature, and evident throughout this study, continue to reflect this.

It is also interesting to note Heidegger’s (1927/1962, p.137) reference to the importance of the sun in determining place. He described how the sun, whose light and warmth are in everyday use, has its own places – sunrise, sunset, midday, sunset, and midnight. This he saw as discovered in circumspection and treated distinctively in terms of change and the useability of what the sun bestows. The sun is something that is ready-to-hand with uniform constancy, and although it keeps changing; its places become accentuated ‘indicators’ of the regions that lie in them. Taking this into account, it is small wonder that participants in this study struggled to situate themselves meaningfully. Being unable to distinguish night and day was another aspect that influenced participants’ perceptions of being desituated and displaced.
Participants also described how they had difficulty distinguishing reality, that is, what was real and what was not. This blurring between reality and unreality meant that participants had difficulty in defining where they were situated in the world. They spoke of losing their world, and searching for the real world where they could be situated in a meaningful way.

All of the features described above that were brought to light in the participants’ stories, revealed that situation is an essential tenet for understanding Being in a particular context. However, for these participants the situation was often elusive and obscured, rendering them unable to reach a meaningful understanding of the situation. Thus, being on long-term mechanical ventilation in a critical care unit included experiencing momentary lapses of situation.

**Momentary lapses of engagement**

As described in previous chapters, the concept of engagement from a Heideggerian perspective characterises a person’s everyday involvement in the world. Being actively involved in the world and seeing the world through the ready-to-hand sets up possibilities through which meaning can be derived and understanding of the world reached. That is, being actively engaged in the world in a ready to hand way is to be embedded meaningfully in the world and be meaningfully involved with other people and things. However, for the participants in this study, being displaced or desituated meant that their level of active engagement in their world was altered.

Many aspects of the participants’ experience gave rise to the perception of a loss of meaningful engagement in the world. Fluctuating levels of consciousness, being unable to distinguish reality, experiencing terrifying hallucinations and nightmares,
the loss of the ability to effectively communicate, being voiceless, experiencing an unfamiliar body, and experiencing the effects of technology and others, particularly the actions of critical care nurses, are all features of the lived experience of being on long-term mechanical ventilation in a critical care unit that are underpinned by the perception of a loss of meaningful activity and active involved engagement in the world. For example, participants described how they were aware of what was happening to them, and described the discomforts associated with the technology, for example the experience of being suctioned via the endotracheal tube and their attempts to communicate with others, especially the critical care nurses, and their family. And yet at other times, they were unaware and disengaged from activities going on around them and being done to them. And in another example, Don was unable to remember having chest physiotherapy, which involves the application of intermittent and firm physical touch and endotracheal suctioning, but he was able to recall some manual handling procedures that he later described as rough and painful.

Phenomenologically, the body has an ontological capacity to relate to meaningful situations. However, when meaning is difficult to define the body is unable to respond in its usual way. The loss of the familiar body, or what has been termed “the habitual skilled body” (Madjar, 1997, p. 56) makes the body feel foreign. This was evident for the people in this study, who found that what was normally unnoticed activity, became effortful. This is highlighted in several stories, including that of John (p. 142) who described how abnormal his body felt and it let him down by not obeying the demands he put on it. Finally, in another example, Bert (p. 171) revealed how the loss of active engagement with his body caused the perception that he was just “occupying space”, and was not really situated in a way that was meaningful.
Being critically ill and placed on a life-supporting device such as a mechanical ventilator means that people are placed in a situation where they are removed, or disengaged, from their usual way of being-in-the-world. They are reliant on technology for their very survival. Thus, the usual ready-to-hand becomes unready-to-hand as they experience their body in ways that are unrelated to their usual level of active engagement. That is, they experience a loss of connection and engagement with their body and the world around them, and instead perceive their body to be desituated, unreliable and unfamiliar.

Human beings are able to express themselves through language and share their experiences of the world around them with others in ways that enables them to be understood. However, for the participants in this study, experiencing fluctuating levels of consciousness, hallucinations and nightmares, and being intubated with an endotracheal tube, meant that they were unable at times to think and speak coherently. They were disengaged from their normal way of being in the world, and felt displaced from their usual way of being-in-the-world.

Experiencing fluctuating levels of consciousness, that is being “in and out of consciousness” meant that the participants also experienced a state of fluctuating engagement in the world. Due to the severity of their illness and or the medications they were receiving whilst on the mechanical ventilator, there were many times when participants were unable to be actively involved in the world around them. Because of this, their level of engagement in the world was diminished, and they could not make meaning of their situation. In addition, the “unreal” nightmares and
hallucinations that all participants described intensified the perceptions of disconnection and disengagement from their usual way of being-in-the-world.

Bert’s description on (p. 183) of regaining the ability to verbally communicate highlights the importance for people of being active participants in their world. Bert described how happy he felt after he had a tracheostomy tube put in place that enabled him to talk. He saw that being able to talk to others, such as his family and the CCU staff, and be understood by them as the turning point of his critical illness. He likened this experience to a “coming back alive again”, “being human” and “not a vegetable”. Bert’s depiction of this event is a powerful example of how human beings derive meaning of their Being in a situation through active involvement and communication with others.

Therefore, many aspects of these participants’ experience gave rise to the perception of a loss of meaningful engagement in the world. Momentary lapses of engagement are therefore evident throughout the lived experience, and are another essential feature of the phenomenon of being on long-term mechanical ventilation in a critical care unit.

**Momentary lapses of concern and care**

Heidegger’s (1927/1962) view on what it is to be a person describes concern (Besorgen) as a person's involvement in the world through things that matter to them. That is, concern is also a way of being involved in one's own world. The role of concern is the ability to have people, including oneself, events and things matter in meaningful way. Anything that touches on that concern has meaning for the person.
According to Benner and Wrubel (1989) concern from a phenomenological stance is a meaning term that defines involvement. For the people in this study, there were many instances when they lost concern and care for themselves and others. Like concern, care (Sorge) is used by Heidegger to denote care for both ourselves and for others. Therefore, from this perspective care and concern are one of the main characteristics of human existence.

In this study, they were many instances when participants experienced lapses of concern and care. As concern is the ability to have people, events, and things matter in a constructive and motivating way, being placed on a mechanical ventilator is an event that disrupts or displaces one’s usual concerns and care.

Anne (p. 179) provides a vivid depiction of how her concerns were lost when she was placed on the ventilator, and how she felt that her own individual needs and concerns were irrelevant to others. She perceived that staff concerns would be directed at the equipment and not the person attached to it. James (p. 174) also described how he gave up on his concerns about what mattered to him in order to cope with the unpleasantness of the endotracheal tube and being suctioned. In asking the question: “what did it matter what I felt? It didn’t matter”, he revealed how his own concerns no longer had any meaning.

The inability to effectively communicate with others meant that participants are unable to actively engage with others in a meaningful way. Being unable to engage also meant that participants lost the opportunity to instigate constructive interactions. As James pointed out: (p. 169) “I couldn’t speak, and I wanted them [nurses] to shut up”. In another example, Bert (p. 171) described how he was unable to do anything
but lie in bed. He saw this as having no meaning. He was unable to communicate or interact in any way, so things did not matter. Care and concern for himself and others was missing. In another example, John (p. 142) revealed how he nearly gave in to what he perceived was the black shadow of death. In this description, he told how he was so tired that he had no resistance and wanted to give in to all that mattered to him.

In being subject to the effects of technology and others in the CCU, participants’ concerns are often taken over by the ‘system’. That is, the day to day activities which comprise the management of the CCU. Participants concerns are lost in a world where technology, controlled by critical care staff, takes over basic physiological functioning and human expression. For example, a lack of concern for a patient’s comfort was illustrated in Mark’s story as staff constantly interrupted his sleep in order to get their work done. Similarly, Don and John describe how some staff members were quite rough when handling them, an aspect that could be interpreted as a lack of care.

Participants all described the discomfort of the endotracheal tube and endotracheal suctioning. Associated with this were feelings of suffocation, and of gasping for air. These effects are related to the application of technology, and were experienced as an indicative of a lack of concern and care by others. In one example, Don (int. 1) described how his concerns for comfort were overlooked: “the nurses used to tell me to keep still…Also they’d tell me not to bite it [endotracheal tube] but you just can’t help it, you just want this thing out”. By overlooking his concerns and what mattered to him, the nurses in this instance denied him the ability to have his concerns matter.
Being taken over by others is another example of how participants’ concerns were taken over and overlooked. Being taken over by others overrides the individuals’ unique concerns and subsumes them within the concerns of others. In this study, the critical care staff took over and administered treatment to participants. However, participants perceived this taking over as a lack of consultation and participation. As previously discussed, in emergency or life-threatening situations, staff will do many things to patients without always considering their wishes or perceptions. Therefore, what is of concern to patients may not always be of concern to the staff and the patient experiences a loss of the ability to have their concerns matter in a meaningful way.

Max felt that his and his family’s concerns were unimportant to staff. Furthermore, he revealed that critical care staff did not always see patients as people with individual needs and concerns. Loss of concern and care is also related to perceptions of lost independence. For example, Max described his embarrassment of having others attend to his intimate hygiene needs. Thus not only did the participants experience lapses of their own individual care and concern, they also experienced a loss of care and concern by others.

However, there were many instances of care and concern for them shown by others. The enormous comfort and support provided by their families and the critical care staff, particularly nurses, helped them “get through” their experience and make some meaning of their critical illness experience.

Therefore, being on long-term mechanical ventilation in a critical care unit also means experiencing momentary lapses of concern and care. In these situations,
participants struggled to find concern and care and have things matter to them in a meaningful way.

**Momentary lapses of time**

Temporality encompasses the dimensions of past, present and future that constitute the boundaries of a person’s temporal landscape (van Manen 1990). Heidegger (1927/1962, p. 39) viewed time as the horizon for all understanding of Being and for any way of interpreting it. He did not view time as linear. Instead, he saw it as linked with making sense of the world in a meaningful way. That is, human beings exist in the present, are influenced by the past, and are thrown into the future. From this perspective, time has a qualitative dimension that is permeated with intention and meaningful activity (Benner & Wrubel, 1989).

Benner and Wrubel (1989) consider that historicity (one’s background and history) and temporality are essential for the way human beings understand themselves and make meaning of their surroundings. In this sense, a person’s identity and how they interpret their being in the world is linked to the notion of temporality.

Time and temporality featured significantly throughout the participants’ stories. However, rather than time being pivotal to their understanding of their world, it was its loss or inability to distinguish time that was a feature of the experience. It was as if time had disappeared, along with their ability to make meaning of their situation. They felt disconnected and displaced from their real world, the everyday world, where time provides the basis for interpreting the situation and creating meaning. Participants had difficulty grasping time in a meaningful way, and often they could not distinguish what time or day it was. This is illustrated in Leanne’s description (p.
169) of the difficulties she had in determining what time of day or night it was, and how she also perceived time to be endless.

From a Heideggerian perspective, it is not surprising that these participants were unable to derive a meaningful understanding of the situation when time is an essential feature of his analytic of Being. Participants also struggled to make sense of their CCU experience even after discharge, as they could not utilise time in a meaningful way in their interpretations and reflection on the experience. Therefore, being on long-term mechanical ventilation in a critical care unit also means experiencing momentary lapses of time.

**Momentary lapses of the ability to self-interpret**

Heidegger (1927/1962) considered human beings unique in that they have the ability to question their own existence, that is their Being. The ability to bring into question one’s Being is a human condition that sets us apart from other beings in the world. We are able to locate, describe and interpret our Being-within-the-world from our own individual standpoint. When human beings are conscious of themselves and their surroundings, and are able to view and reflect on their lived experience, possibilities are created for interpreting and giving meaning to experiences.

For these study participants, the ability to derive meaningful interpretations of events whilst on long-term mechanical ventilation in the CCU was impaired. It is usual critical care practice to sedate mechanically ventilated patients during the acute phase of their treatment, using continuous intravenous sedative regimes including, but not limited to, a combination of intravenous opioids and benzodiazepines. Moreover, a critical illness can also cause alterations in a person’s level of consciousness. Such
factors meant that participants were unconscious, or experienced fluctuating levels of consciousness and subsequent loss of awareness of their surroundings. Thus they had difficulty reaching an understanding of what was happening to them during that time.

In addition, the experience of bizarre and frightening nightmares and hallucinations that were a central feature of many of the stories greatly affected the ability of participants to make sense and meaning of their experience. Therefore, they experienced momentary lapses of the ability to self interpret what was happening around them.

In the previous chapter Leanne (pp. 184-185) described how she did not know or could not work out was happening to her. Because she could not communicate effectively, and could not see clearly due to the effects of her illness, her usual means of communication and interpretation were absent. It was not until her eyesight improved, and her level of consciousness returned to normal, that she able to begin to make sense of her surroundings. Similarly, John and Bert described how their experience of bizarre nightmares rendered them unable to distinguish reality from unreality, and make sense of their world.

Participants also told of how the severity of critical illness, and the disruption to their usual way of being-in-the-world caused by it, brought to the foreground questions of their existence and survival. Several participants recalled visions of death, such as black shadows. However, they were unsure if these visions were another nightmare, a side effect of the medication they were prescribed, or an actual event. They found it difficult to understand and determine exactly what was happening, and what was a
real event and what was not. Participants continued to struggle to find meaning and make sense of the events well after discharge from the CCU. Therefore, being on long-term mechanical ventilation in a critical care unit also means experiencing momentary lapses of the ability to self-interpret.

**Conclusion**

In this chapter, an ontological description of what it means to be on long-term mechanical ventilation in a critical care unit was presented. Titled *Being at its most elusive*, this description revealed that the central feature of the experience was the momentary loss, or lapse, of one or more of Heidegger’s tenets of Being. Thus, the description revealed that participants experienced momentary lapses of situation, engagement, care and concern, temporality and the ability to self-interpret. Throughout this ontological description, specific examples and reference to participants’ stories were included to demonstrate how I reached this particular interpretation of the study data and captured the essence of the experience.

The description presented in this chapter revealed that the momentary lapses of Heidegger’s (1927/1962) tenets of Being were the central and dominant feature of the experience. Lapses of these tenets created enormous fear, anxiety, uncertainty and distress in participants, highlighting how essential these tenets are to our way of Being in the world in a meaningful way. Thus, when people are on long-term mechanical ventilation in a critical care unit, Being is elusive, and people struggle to make sense and meaning of their surrounds.

This chapter has therefore brought to light the relevance and applicability of Heidegger’s tenets of Being utilised in this study. In doing so, I have revealed how
Heideggerian philosophy can contribute to an understanding of a phenomenon that is of interest to nursing.

In arriving at the ontological description of the essence of the experience, it was brought to my attention by a colleague that I had managed to bring a sense of coherence to the chaotic. That is, in honouring the chaos narrative described by Frank (1995), I had achieved coherence and given a voice to a previously silenced and not well understood phenomenon.

In the final chapter, a summary and discussion of the findings is provided, and the implications for nursing are identified including recommendations for future nursing research.
CHAPTER 9

DISCUSSION AND CONCLUSION

Introduction

The purpose of this research was to explore what it meant for people to be on long-term mechanical ventilation in a critical care unit, and to extend knowledge and understanding of the meaning they attributed to this experience. The research question asked: *What does it mean to be on long-term mechanical ventilation in a critical care unit?* Using an phenomenological-ontological perspective informed by the philosophical tenets of Heidegger (1927/1962), this study examined the lived experience of former patients who had previously been hospitalised in one of three critical care units in southeast Queensland, Australia, during which time they were placed on a mechanical ventilator for a period of seven days or more.

This chapter discusses the overall findings of this research project, compares and contrasts the study participants’ perspectives with the relevant literature, and makes explicit the unique findings and contributions of this study. A number of recommendations for clinical practice and education are outlined, and areas for further research are suggested. The limitations of the study are then discussed, issues of rigour are examined, and a conclusion to the study is provided.

Overview of findings

Being on long-term mechanical ventilation in a critical care unit was described by the study participants from the context of their own unique illness experience. In order to tell me about their individual experience of this phenomenon, participants needed to talk about their critical illness episode from the onset of the illness or injury
through to hospital discharge and the return to their home. A thematic analysis of the experience of their critical illness episode was undertaken in the first instance, and the findings from this were presented in chapter seven.

Four main themes emerged from data analysis of the lived experience of the participants’ critical illness episode. The themes were titled: *Being thrown into an uneveryday world, existing in an uneveryday world, reclaiming the everyday world,* and *reframing the experience.* These themes reflected the critical illness episode, including the admission to the critical care unit, being on long-term mechanical ventilation in the critical care unit, the transfer from the critical care unit to the hospital ward, and discharge from hospital to home.

Overall, being on long-term mechanical ventilation in a critical care unit was a mainly frightening and unpleasant experience. Although the participants in this study expressed their relief and gratitude at surviving the experience and being able to return to their own home, none of them wanted to experience this life event again. Indeed, several people revealed that they did not believe they had the “strength to get through”, and would “rather die than go through that again”. This experience therefore had a significant impact on these peoples’ lives.

This study found that participants experienced the critical care unit as strange, unfamiliar and totally unlike their everyday world. The major theme *Being thrown into an uneveryday world* revealed that experiencing a critical illness or injury and being admitted to the CCU meant a severing, or discontinuity of one’s usual way of being-in-the-world. Participants felt displaced or desituated, and disengaged from their everyday world. Entering the CCU was found to be disruptive and unexpected,
with participants describing how unprepared they were for this event. Thus, being admitted into the CCU was likened to being uprooted from the everyday ‘before the critical illness’ world, and thrown into an unknown world where others assumed control. Loss of control was related to the perception of being taken over by critical care staff, who “did things” to participants, often with a lack of consultation. A loss of control was also evident in other aspects of the experience, expressed through a reliance on technology and others in order to maintain body functioning, and survive the ordeal.

This study also highlighted many aspects related to being on a mechanical ventilator as a patient in the critical care unit. These aspects were revealed in the second main theme titled: _Existing in an uneveryday world_. This theme revealed what it meant for participants to exist, live through and survive the many physiological and psychological effects arising from their critical illness episode, whilst enduring the ongoing rituals that are part of the management of the long-term mechanically ventilated patient in a CCU. The research uncovered how participants experienced fluctuating levels of consciousness, and were unable to distinguish reality and time, and also revealed the frequent occurrence of terrifying hallucinations and dreams. The perception of living in an unfamiliar body also emerged, as participants related how their body at that time felt unknown and unreliable. These particular aspects permeated all the participants’ stories, and impacted substantially on the meaning and interpretation that they attributed to the experience.

Without exception, the application and presence of technology was found to be extremely unpleasant and uncomfortable. In particular, the presence of an endotracheal tube and endotracheal suctioning caused great discomfort, creating
unpleasant sensations such as uncontrolled coughing and gagging, extreme thirst, a sore throat, and feelings of loss of air and choking. In addition, having an endotracheal tube in place was seen as a ‘double whammy’, as it also rendered the person voiceless. The loss of the ability to verbally communicate was another aspect of the experience that created anxiety, fear and uncertainty. Being unable to communicate meant that participants were unable to effectively convey their needs and emotions to others, namely the staff members who were managing their care, and also their family members and loved ones who were with them in the CCU.

Other invasive devices such as intravenous lines, indwelling catheters and nasogastric tubes were also seen to be irritating and uncomfortable. The research also showed that some nursing activities associated with the management of the mechanically ventilated patient were experienced as unpleasant and uncaring at times. It was also rather disturbing to find that the manual handling procedures of ward assistants were experienced at times as rough and brutal. Although this finding related to two instances only, for these patients this created undue concern.

This research also showed that being on mechanical ventilation, which participants described as being “on life-support”, raised questions and concerns of survival, and fear of death, for many of them. That is, for these participants, being on a mechanical ventilator was an indicator of the seriousness of their illness or injury. Moreover, several participants described images of death, and being visited by death-like creatures beckoning them to follow them into the next world.

Findings from this study also revealed how essential it was for participants to regain control of their lives and reclaim their everyday, known world. The third major
theme derived from thematic analysis was titled: *Reclaiming the everyday world*, which disclosed the ways in which participants sought to move away from the uneveryday world of the CCU and reclaim their known world and self. It was found that the comforting and supporting presence of both the critical care nurses, other staff members, and families, played a significant and essential role in enabling participants to “get through” the experience, and “move on” out of the CCU and toward recovery. Although the mechanical ventilator initially indicated a possibility of death, some participants later regarded it as supportive, as it provided a sense of security.

In order to move on and reclaim their everyday world, participants re-engaged with critical care staff and families in the CCU, and increasingly attempted to communicate their needs. They also instigated a number of measures to gain control, including deliberate acts to attract the nurses’ attention, and questioning their environment. Through these efforts, participants started to interpret their world, and tried to make some sense of their situation at that time.

It was also found that, following the removal of the mechanical ventilator, and discharge from the CCU, participants needed to review their critical illness experience in order to derive an understanding of the CCU experience and being a survivor. The final theme titled: *Reframing the experience* relates to the ways in which participants interpreted their critical illness experience and the impact of this event on their life. When looking back and reflecting on their experience of being on long-term mechanical ventilation in a critical care unit, participants tried to recall as many aspects of this episode as they were able. Where recall was hazy, confused or disjointed, they tended to ask their family members to “fill in the gaps”. Filling in
the gaps and putting the pieces together enabled them to begin to interpret and make sense of their experience.

This study also revealed that there were many residual issues resulting from the critical illness and mechanical ventilation experience, including on-going physical, psychological and social aspects. When participants felt that they could not reasonably explain, or account for their behaviour or experience at particular times, they tended to rationalise this by attributing it to external causes such as the illness, and side-effects of the technology and or medications. After they were back in their own homes, the known ‘before’ world, they also re-appraised the past and re-evaluated the future. Many saw their experience of being on long-term mechanical ventilation in a critical care unit as not only a life-threatening event, but also life changing.

These themes served to provide a contextual background and framework from which to reveal the essence of the meaning of being on long-term mechanical ventilation in a critical care unit. It is from these themes that a meaningful phenomenological description of the research question was revealed, and this was presented in chapter eight. Titled Being at its most elusive, this description brought to light and illuminated participants’ struggle and search to make sense and meaning of their experience and being in the world in which it took place. The extent to which each participant struggled to make meaning differed, however, a central feature was the loss, or lapse of one or more of the tenets that Heidegger (1927/1962) saw as essential for constituting Being. This study found that participants experienced momentary lapses of situation, engagement and temporality, of care and concern, and of the ability to self-interpret. Thus, Being at this time as described by Heidegger
was at its most elusive. It was these momentary lapses of the tenets of Being that defined, underpinned and captured the essence of the experience.

The next section of this chapter will explore the overall findings of this study in relation to the relevant literature.

**Discussion of Study findings in Relation to the Literature**

This study provided a rich description and interpretation of the meaning a group of people (former patients) attributed to their lived experience and what it meant to be on long-term mechanical ventilation in a critical care unit. The insights derived from this study confirm and extend the findings of previously published research in a number of ways. The results of this study showed that the participants perceived that they were thrown into an uneveryday world when they first entered the critical care unit, which involved a discontinuity of the everyday world, feeling desituated, disengaged and taken over by others. Although no previous study identifies the perception of being thrown into an uneveryday world, several studies have reported that participants experienced feelings of being displaced and disoriented during their time in the CCU (Adler, 1997; Granberg Axell, 2001; Parker, 1997). Participants in these particular studies experienced the CCU as strange and foreign, and were disorientated by the alarms and noise emanating from the omniscient equipment and staff conversations, features also reported in this present study.

This research study also found that participants reported feelings of reliance and dependence on technology and others for survival. This finding confirms the findings of a number of previous studies that featured descriptions of dependence (Adler, 1997; Granberg Axell, 2001; Jablonski, 1994; Parker, 1997), helplessness
(Adler, 1997; Granberg Axell, 2001; Parker, 1997), and vulnerability (Granberg Axell, 2001; McKinley et al., 2002). Such findings highlight that critically ill patients on mechanical ventilation are an extremely vulnerable patient group who are dependent on the technology, and the staff who manage it, to maintain and sustain not only their life, but to also manage their most intimate body care.

Aspects associated with living in an uneventful world concur with previous research, suggesting that these predominantly unpleasant features remain an ongoing problem for mechanically ventilated patients in CCU. Granberg Axell (2001, p. 31) reported that participants in her study described “losing awareness” and “being in and out of it” [consciousness]. Similarly, Adler (1997) reported that participants had fluctuating levels of conscious awareness of their surroundings. This present study also found that participants experienced bizarre hallucinations and nightmares, and were unable to distinguish time and reality. Although each individual participant’s experience was unique, these findings are similar to those of previous studies that reported that the majority of dreams or hallucinations recalled by participants were frightening and disturbing (Asbury, 1985; Chew, 1986; Easton & McKenzie, 1988; Jones et al., 1979; Laitinen, 1996; Parker, 1997; Russell, 1999). Although it is simplistic to attribute these aspects of the experience to any one causative factor, it has been suggested that they are related to the ICU (Intensive Care Unit) syndrome, which is described as a state of severe mental disorder that develops in certain ICU/CCU patients. The ICU syndrome is characterised by a disturbance in consciousness and cognition that tends to fluctuate throughout the day, and is thought to be related to a combination of factors including the severity of the person’s critical condition, pharmacological treatment, and or sleep deprivation (Granberg Axell, 2001). However, to group these findings under the umbrella of a medical term such
as the ICU syndrome is helpful only if we also acknowledge the individual’s unique experience of these aspects of their critical illness episode.

Several studies examining the experience of being critically ill in the CCU have reported that participants perceive their body to be unfamiliar and unreliable (Adler, 1997; Granberg Axell, 2001; Parker, 1997). This current study confirmed these views and extends the knowledge and understanding of this aspect of the experience. This finding illuminates the difficulties confronting participants when their “habitual, skilled body” (Madjar, 1997, p. 57) breaks down or becomes unknown. This brings to the fore the enormous impact that the loss of the taken for granted, or “ready-to-hand” (Heidegger, 1927/1962) body has for people and their ability to actively engage in the world around them.

This study also found there were numerous discomforts and unpleasant sensations associated with the application and use of technological devices. In particular, the presence of the endotracheal tube and endotracheal suctioning was not only uncomfortable but also created anxiety and fear. It is recognized that technologies devised to manage breathing and facilitate gaseous exchange in people are, by virtue of their position in the throat and degree of invasiveness, uncomfortable and persistent. Research in the late eighties and early 1990s showed that the presence of an artificial airway for the management of respiratory failure is extremely unpleasant, and fear of ventilator failure or disconnection is capable of provoking high levels of stress (Bergbom-Engberg & Haljamae, 1988b; Gries & Fernsler, 1988; Jablonski, 1994; Johnson & Sexton, 1990; Smith, 1993). The findings from this present study concur with more recent studies, which indicate that little has changed (Adler, 1997; Granberg Axell, 2001; Griggs, 1998; Logan & Jenny, 1997; Parker,
1997; Russell, 1999), with patients continuing to report the procedure as frightening and painful. This is an issue of concern for critical care nurses that has not been adequately addressed, indicating the need to change practice.

Participants in this study also experienced anxiety, uncertainty and fear related to ineffective communication due to the presence of the endotracheal tube and the effects of pharmacological agents, such as sedatives. Although the endotracheal tube is an essential component of mechanical ventilation, and is used to safeguard a person’s airway and allow for the delivery of assisted respiratory support, its presence has profound effects on a person’s ability to communicate meaningfully. The present study’s findings reflects those of previous studies (Adler, 1997; Ashworth, 1980; Bergbom-Engberg & Haljamae, 1988b; Granberg Axell, 2001; Gries & Fernsler, 1988; Hafsteinddottir, 1996; Holland et al., 1997; Jablonski, 1994; Leathart, 1994; Logan & Jenny, 1997; Johnson & Sexton, 1990; Parker, 1997; Russell, 1999), highlighting that despite a plethora of published findings demonstrating the difficulties in communication that mechanically ventilated patients experience, this is another ongoing and major issue in patient care.

Other discomforts reported in this study relating to technology and staff activities also concur with findings of previous studies (Adler, 1997; Jablonski, 1994; Parker, 1997; Riggio et al., 1982; Russell, 1999). However, although discomfort was reported, pain was not a central feature of this experience, despite several of the participants having undergone surgical procedures. This finding contrasts with those of several studies that reported pain as a frequently occurring and major problem (Ballard, 1981; Cochrane & Ganong, 1989; DeMeyer, 1967; Elpern et al., 1992; Green, 1996; Puntillo, 1990; Simpson et al., 1989). However, the present study
supports the findings of a recent study by McKinley et al. (2002) who attributed the low incidence of pain reported by participants in their study to close monitoring by nurses, and improved management of pain and sedation levels by critical care staff. Although there were variations in the participants’ ability in the present study to recall their experience, this may be a factor that influenced this particular finding. Another consideration may be that the emotional distress caused by the lapses of Being was of more importance and overrode physical discomfort.

The central role of critical care staff, particularly the nurses, in providing comfort and promoting a sense of security highlighted in this study is consistent with the findings of a number of research studies (Adler, 1997; Burfitt et al., 1993; McKinley et al., 2002; Russell, 1999; Wallis, 1998). This finding further confirms the important and essential role critical care nurses play in providing a comforting and supporting presence to patients at such a critical time in their lives.

Participants’ families were also found to be of prime importance in providing support and comfort. The presence of family members has been shown in several studies to be a major supportive factor for critically ill people (Adler, 1997; Hammond, 1995; McKinley et al., 2002; Parker, 1997; Russell, 1999). The findings of this study provide additional evidence of the positive contribution made by family members of long-term mechanically ventilated patients in the CCU.

The finding that participants in this present study confronted the possibility of death and questioned their survival, and also re-evaluated their past life and re-appraised their future, reflects findings from studies by Adler (1997), Jablonski (1994) and Parker (1997). This serves to highlight that being critically ill and on long-term
mechanical ventilation in a critical care unit is a life-threatening and life-changing event that has a major impact on peoples’ lives. In addition, the finding that the majority of participants continued to experience ongoing effects including physical disabilities, recurring nightmares and sleep disturbances well after discharge from the hospital shows that the impact of this experience does not end once the person is removed from the mechanical ventilator. This finding affirms those from a number of previous studies which found that a substantial portion of people who had been critically ill experienced signs of ongoing stress and disturbed functioning after discharge from hospital (Schydner, Moergeil, Trentz, Klaghofer, & Buddeberg, 2001; Ursano et al., 1999; Williams, Weir, & Waldmann, 1994). This is a significant factor that needs to be considered when planning for patient discharge from both the CCU and the hospital.

Another finding from this study was that people needed to reclaim their everyday world and self by re-engaging with staff, seeking control and questioning their world. This finding supports the results of previous research and extends knowledge and understanding of the role patients can play in determining aspects of their own care. The loss of a self-identity, and feeling depersonalised and dehumanised have been reported in several studies (Adler, 1997; Granberg Axell, 2001; Jablonski, 1994; Parker, 1997). Findings from this study support these findings in several instances, as participants revealed feeling lost, not themselves, and not human. The issue of a perceived lack of control by participants and a power imbalance between nurses and patients has also featured in other studies (Adler, 1997; Logan & Jenny, 1997; Russell, 1999). This present study provides a further dimension to this aspect as it revealed the ways in which participants sought to reclaim power and control. This finding may be related to a number of factors including an increased awareness of
the medical treatments and technologies that are available to treat illness and disease, and also increased knowledge of their rights as patients and health care consumers. This finding is important for critical care nurses. When viewed in conjunction with the finding that participants in this study perceived that they were taken over by others, it suggests that patients are increasingly seeking more say and control over their treatment in the CCU.

Finally, the need for participants in this study to reflect back on their experience and try to reach some sense of meaning supports the findings of studies by Adler (1997) and Parker (1977). Reaching an understanding of what happened and why this was important for participants, as they needed to interpret their experience within the context of their own background. Coming to terms with their experience involved asking family members to fill in the missing gaps, in an attempt to rationalise and explain unfamiliar behaviours.

In summary, the findings from this study confirm many of the findings from previous studies. In addition, this study builds on and extends the findings of these prior studies as it provides a more in-depth and rich description of the experience.

The Unique Contribution of this Study

This study also provides several new dimensions that further add to knowledge and understanding, and also bring to light new evidence pertaining to the experience and meaning of being on long-term mechanical ventilation in a critical care unit. The perception of being thrown into an uneveryday world uncovered an aspect of the experience not previously referred to in this way in the literature. This aspect of the experience revealed that a person’s way of being-in-the-world is abruptly shattered
once they enter the critical care environment. This particular finding demonstrates a need for critical care staff to recognise the profound impact the unfamiliarity of the CCU environment has on patients.

Being taken over by others and actively seeking to regain control, are also findings arising from this study that have not been previously identified in the literature reviewed in this thesis. This provides another valuable new insight into the phenomenon, and increases our understanding and awareness of the patients’ perspective of being on long-term mechanically ventilation in the CCU.

However, the most significant and unique contribution of this study is that it has brought to light a deep ontological understanding of the research question. That is, rather than a mere discussion of the lived experience of this phenomenon, this study provides a rich ontological description and interpretation underpinned by Heidegger’s tenets of Being (1927/1962). Being at its most elusive captures the essence of the experience and reveals Dasein, the ontological nature of being on long-term mechanical ventilation in a critical care unit.

**Humanising the Experience and Recapturing Being: Implications and Recommendations for Practice, Education and Research**

The findings from this study have numerous implications for nursing practice, education and future research. The next section of this chapter discusses these implications and provides a number of recommendations aimed at improving clinical nursing practice and critical care nurse education. It also offers suggestions for future nursing research.
The ontological description of the experience of being on long-term mechanical ventilation in a critical care unit revealed that participants experience momentary lapses of one or more of the tenets that Heidegger viewed as essential to Being. Therefore any recommendations for critical care practice, education and future research should be aimed at recapturing patients’ Being and humanising the critical care experience.

**Implications and Recommendations for Practice**

Phenomenological research provides nurses with the opportunity to see the experience of others and relate this to the way they and others practise. Findings from rigorous phenomenological studies, such as this one, facilitates nurses’ awareness of patients’ perceptions, and the responsibility that nurses have in influencing the care and the experiences of patients in CCU, and beyond. In this way, phenomenology can meaningfully inform practice by providing valuable evidence on which to base nursing practice.

Nursing is grounded in interaction with others, and the interaction between the patient and the nurse is of prime importance in health care. As nurses comprise the largest group of health practitioners, nursing is well placed to develop and sustain meaningful relationships with patients, so as to ensure quality health care delivery.

This study has highlighted that being on long-term mechanical ventilation is mainly a frightening and unpleasant experience, which is of major concern. This finding suggests that, despite nurses’ increasing interest in exploring patients’ perspective of illness and hospitalisation, there are many aspects that require further consideration and improvement. Whether or not this can ever be a totally pleasant experience for
patients is uncertain, nevertheless by incorporating practices based on research evidence, critical care nurses can minimise or overcome many of the discomforts related to this form of medical treatment.

The results of this study confirm previous research findings by highlighting the CCU environment as a significant factor in determining participants’ meaningful situation and engagement in the world. This study identified that the CCU was a very strange and unfamiliar place. The omniscient lights, noise and sophisticated technology of the CCU created the perception of an uneveryday world in which participants felt displaced, desituated and disengaged. In light of these findings, it is imperative that nurses are aware of the impact that the CCU environment has on patients. Preoccupation with technology, unnecessary ritualistic practices and rigid management protocols create an environment where the human dimensions of health care can become lost. Nurses, therefore, need to review the environment and incorporate strategies to make it less threatening, more patient friendly and more humanised. Reviewing or re-visioning the CCU would involve constructing spaces that are more connected to the total needs of the patients, not just the treatment of physical aspects of the critical illness or injury.

The challenge for nurses in re-visioning the CCU environment and constructing connected spaces is to incorporate the necessary technologies and modalities required for the medical management of the critically ill patient, whilst being attuned and sensitive to the lived experience of the patient receiving this treatment. Although patient safety is paramount, there are a number of strategies that would lessen the impact of the environment on the patient. These include: minimising the use of alarms emanating from technological equipment or turning the alarms down to
the lowest level; promoting a quiet environment by keeping staff to staff conversations at an acceptable noise level, particularly throughout the night; minimising the use of strong artificial lighting and using natural sunlight wherever possible; encouraging patients’ families to bring in personal items for the patient and keep these close by; and incorporating a restful and less clinical décor. Even though patient care activities need to be performed on a 24-hour basis, every attempt should be made to reflect the day and night of the outside world. That is, wherever possible nursing and other patients care activities should be structured in such a way to allow patients to rest for long periods of time undisturbed, particularly throughout the night. Although these are somewhat simple measures, they could help reduce the strangeness and unfamiliarity of the CCU setting. Moreover, providing and repeating information, and ensuring a clear explanation of all procedures to patients and their families at all times is of paramount importance.

The issue of perceived lack of control and decision making participation identified in this study also has implications for nurses. Although many people admitted to the CCU have decreased levels of consciousness and or neurological deficit, nurses should not withhold explanations and information giving on the assumption that patients are incapable of understanding and or deciding what is happening to them. Furthermore, wherever possible, patients should be asked about the decisions being made about their care.

The finding that participants are reliant on technology and others for their survival raises a number of issues for nurses. Nurses need to be aware of the extreme vulnerability and dependability of critically ill, mechanically ventilated patients, and work to promote trust and a secure environment. Strategies to achieve this include
maintaining a close and vigilant presence, clearly explaining all procedures to the patient and family, and performing all nursing activities sensitively and with due diligence. Of extreme importance is the need for critical care nurses who have specialty knowledge and skills to provide safe and competent care. It is therefore essential that nurses working in critical care units are competent to manage the technology associated with patient care, and seek further educational training when necessary.

The Australian College of Critical Care Nurses’ position statement on intensive care nursing staffing recommends 10 key points and principles to meet the expected standards of critical care nursing in Australia (ACCCN, 2002b, p. 6). These standards articulate with those outlined by the Australian College of Healthcare Standards and the Australian and New Zealand College of Anaesthetists (ACCCN, 2002b, p. 6). The first standard is that all ICU patients, including mechanically ventilated patients, require a nurse/patient ratio of at least 1:1. These standards therefore recognise the significant work of critical care nurses in providing safe and competent care, and enable them to provide a close presence. In light of the findings from the present study, it is imperative that all CCUs in Australia incorporate the staffing guidelines recommended by the ACCCN (2002b).

Nurses also need to be aware that patients on long-term mechanical ventilation in the CCU are subject to a myriad of unpleasant and distressing aspects associated with their illness and medical treatment that impact on them significantly, both during and after the critical illness event. The finding that all participants in this study reported frightening and bizarre hallucinations and nightmares points to the need for nurses to be sensitive to the possibility of patients experiencing these, even though they cannot
observe or measure their occurrence. Being attuned to patients for signs of restlessness or agitation may indicate when patients are distressed. Instigating measures such as gentle touch, explaining where they are, what time and day it is, who the people are around them and what has happened to them, and continual reassurance may provide comfort and support for patients at this time. Although it is a common critical care practice to sedate mechanically ventilated patients, currently there is no consensus as to what constitutes the most appropriate means and type of sedation for this group of patients. For example, one study found that the use of high doses of the sedative agents midazolam and fentanyl was linked to more severe delirium in patients (Granberg Axell, 2001). The issue of sedation in the CCU is therefore one that requires further research. Whilst it is imperative that patients be kept as comfortable as possible, nurses need to be mindful of this factor and be alert to any side-effects that may arise from the sedative agents used in patient care.

The finding that participants experienced fluctuating levels of consciousness, and difficulties in distinguishing reality and time, highlights the importance of nurses maintaining a close and supporting presence, and providing clear explanations at all times. In addition, constructing the CCU environment to more closely reflect the outside world and structuring patient care activities more thoughtfully may minimise some of these effects. For example, making space for the patient to have personal articles such as photographs, audio equipment such as radios, cassette and or CD players, and toiletry items may help them to remind them of their everyday world outside the CCU.

This study also found that much of the pain experienced by patients was related to the equipment and staff, particularly nurses’, activities. Hence it is important that
nurses ensure that any patient care procedure they undertake is performed as carefully and gently as possible, even if the patient is receiving sedative and analgesic medication. In particular, as the procedure of endotracheal suctioning was experienced as extremely unpleasant, nurses should aim to perform this only when required and as gently as possible, whilst ensuring appropriate removal of secretions. The finding that some participants found that manual handling procedures carried out by non-nursing staff was quite rough points to the need for all staff involved in the care of patients in CCU to be aware of how their activities are perceived by patients, and indicates the need for further staff education in this area of practice.

Critical care nurses also need to be aware of the frustrating effects of ineffective communication for intubated patients. This study found that the efforts of those nurses and other health care staff who were seen to be patient and persisted in their efforts to communicate with and understand participants, were greatly appreciated. Communication aids such as alphabet charts, writing boards and computer designed communication devices, if used consistently and patiently, may help to overcome some of the frustration associated with the patient’s inability to verbally communicate. In addition, assisting family members to communicate with the patient may also alleviate some of the distress experienced by the patient. As difficulties with communication have been well identified in the literature, it is imperative that nurses continue to explore new methods of communication for intubated patients, and support research that has this as its aim.

Findings from this study also confirmed the important role of critical care nurses in helping patients “get through” their critical illness episode and being on long-term mechanical ventilation. Nurses need to be aware of the positive effect that providing
a close and supportive presence has on the patient, and ensure that they apply technologies and treatments in a way that recognises and is sensitive to the lived experience of individual patients. Moreover, nurses should aim to develop a relationship with the patient and his or her family that is based on open communication and trust.

Families were also identified as playing a significant role in helping patients get through and endure their time in the CCU. Nurses must therefore ensure the primary role played by families and loved ones is recognised and incorporated in all aspects of patient care. With this in mind, CCUs should look to adopting unrestricted visiting policies, and regulate visits according to the individual patient’s needs rather than rigid protocols. Although it is common policy that only family members are able to visit patients in the CCU, consideration should also be given to allowing close friends to visit. Clear explanation of patient care activities should be given to the family, and information about the CCU and its procedures should be readily accessible and easy to comprehend. For example, booklets such as that recently published by Chaboyer and Johnson (2002) provide patients and families with easy to read information about what happens in the CCU and after discharge. Nurses should also support and instruct, where appropriate, those family members who may wish to help with patient care activities. By developing an understanding and appreciation of the role of family and loved ones in the CCU, nurses can assist family members in their supportive role.

The finding that participants sought to take back some control over their care whilst in the CCU also raises implications for practice. Although critically ill, long-term mechanically ventilated patients are extremely vulnerable, and dependent on
technology and others for survival for a great deal of the time they are in the CCU, nurses need to recognise the patient’s right to participate in their own care and the decisions made about their care. Once again, the importance of providing clear explanations cannot be over-emphasised and, where possible, patients should be included in discussions about their plan of care and ongoing management in the CCU. Nurses need to also be aware of the potential power they can have over patients, and ensure that they do not abuse this by disregarding or not considering patients’ wishes to have some say in what is happening to them.

This study also found that participants experienced ongoing physical and psychological disturbances long after discharge, which points to the need for effective discharge planning for all patients transferred out of CCU. Critical care nurses should discuss the transfer process with patients and their families prior to leaving the CCU, and provide information about what to expect both in the general hospital ward and on going home. It is recommended that there be a designated nurse position for discharge planning in the CCU to follow through patients, promote continuity of care and identify and prevent adverse reactions. Follow up services such as outpatient clinics specifically for former CCU patients should also be considered.

Finally, the need for participants to reflect on and make meaning from their experience of being on long-term mechanical ventilation in the CCU highlights the essential role that nurses can play in assisting patients to recollect and understand their experience. To help patients construct a more coherent story, critical care nurses should encourage, where appropriate, family members to journal events, and allow them to take photographs of their loved one in the CCU. Another strategy
aimed at aiding debriefing by patients and families is the compilation of a personal diary by critical care nurses of the patient’s stay in the CCU (Bäckman & Walther, 2001). This strategy is worthy of further investigation, as the results from this Swedish based study found this to be a useful tool for both survivors of ICU, and their families. Providing opportunities for former patients and their families to visit the CCU and or discuss their CCU hospitalisation is another strategy that may also assist in reflecting on and understanding their experience.

In summary, the findings from this study have identified a number of areas that could enhance critical care practice. Although several of the recommendations put forward have been identified in previous studies, the need to incorporate these into the critical care practice arena is still evident.

It is acknowledged that findings from phenomenological studies cannot be generalised. With this in mind, the following recommendations are offered for consideration to critical care nurses.
Table 9.1  Summary of recommendations for practice

<table>
<thead>
<tr>
<th>Environment</th>
<th>Critical care nurses need to:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>• be aware of how patients view the critical care unit</td>
</tr>
<tr>
<td></td>
<td>• re-vision the critical care unit with the aim of making it more patient and family friendly</td>
</tr>
<tr>
<td></td>
<td>• minimise the use of alarms in CCU</td>
</tr>
<tr>
<td></td>
<td>• promote a quiet workplace, particularly throughout the night</td>
</tr>
<tr>
<td></td>
<td>• minimise the use of strong artificial lighting and use natural sunlight wherever possible</td>
</tr>
<tr>
<td></td>
<td>• allow patients to have some personal items close by</td>
</tr>
<tr>
<td></td>
<td>• construct a restful and less clinical décor</td>
</tr>
<tr>
<td></td>
<td>• provide clear explanations of activities at all times</td>
</tr>
<tr>
<td></td>
<td>• structure patients care activities to allow patients to rest for long periods of time undisturbed, particularly throughout the night</td>
</tr>
<tr>
<td>Patient involvement</td>
<td>Critical care nurses need to:</td>
</tr>
<tr>
<td></td>
<td>• be aware of the potential power they have over patients</td>
</tr>
<tr>
<td></td>
<td>• be aware that patients may want more control and say in their treatment</td>
</tr>
<tr>
<td></td>
<td>• provide opportunities for patients to have input into decisions made about them</td>
</tr>
<tr>
<td></td>
<td>• provide opportunities for patients to have input into their care planning and activities</td>
</tr>
<tr>
<td></td>
<td>• recognise that patients may need their assistance in understanding their CCU experience</td>
</tr>
<tr>
<td>Patient care</td>
<td>Critical care nurses need to:</td>
</tr>
<tr>
<td></td>
<td>• be aware of patient’s dependence and reliance on them, and technology</td>
</tr>
<tr>
<td></td>
<td>• be aware of the importance of maintaining a close and supportive presence for the patient</td>
</tr>
<tr>
<td></td>
<td>• maintain competence in all aspects of patient care, and seek training/education if and when required to ensure ongoing competence</td>
</tr>
<tr>
<td></td>
<td>• undertake nursing activities with sensitivity and gentleness, regardless of the patient’s level of consciousness and the sedation and analgesia being administered</td>
</tr>
<tr>
<td></td>
<td>• provide patients with information that orientates them to their surroundings and why they are in CCU</td>
</tr>
<tr>
<td></td>
<td>• be patient, tolerant and persistent in their efforts to communicate with patients</td>
</tr>
<tr>
<td></td>
<td>• incorporate communication aids such as alphabet charts, writing boards and computer designed communication devices</td>
</tr>
</tbody>
</table>
**Family involvement**

Critical care nurses need to:
- be aware of the important role of the family in the CCU
- assist family members to communicate with the patient
- adopt unrestricted visiting policies
- regulate visits according to the individual patient’s needs rather than rigid protocols
- provide clear explanations of patient care activities to families
- provide easily accessible and comprehensible information about the CCU
- support family members’ involvement in patient care activities
- recognise that families may need their assistance in understanding their relative’s CCU experience
- provide opportunities for follow up contact of families once their relative is discharged from CCU

**Workplace issues**

Critical care nurses, and nurse unit managers, need to:
- adopt the recommendations of the ACCCN on ICU nurse staffing levels
- provide opportunities for follow up contact of patients once they are discharged from CCU
- be aware that patients may experience ongoing physical and psychological disturbances following discharge from CCU
- plan for effective discharge of patients whilst they are in the CCU
- promote the adoption of a designated nurse position for discharge planning
- promote the establishment of follow up services such as outpatient clinics, especially for former CCU patients

**Implications and Recommendations for Education**

The importance of adequate educational preparation for specialty practice such as critical care nursing, and the need for ongoing education is well recognised (CACCN, 1996a; Senate Community Affairs References Committee Inquiry into Nursing, 2002). As discussed in chapter two of this thesis, to function effectively in the critical care environment, nurses must possess a variety of advanced nursing skills. Such skills encompass a comprehensive knowledge of advanced physiology and pathophysiology, problem solving and communication skills, research skills, a sound knowledge of legal, ethical and professional issues, and advanced clinical and psychosocial assessment skills, (CACCN, 1996a). The recent Senate Community
Affairs References Committee Inquiry into Nursing (2002) recommended that nurses be informed of their continuing education support and options and encouraged to undertake continuing education courses. This recognises the rapid changes occurring in health care, and the need for nurses and other health care workers to have access to appropriate up to date education.

The findings of this study serve as a basis for the following recommendations for education:

- Specialty courses in CCU nursing traditionally emphasised the development of advanced clinical skills, pathophysiology and management of disease. Findings from this study have pointed to the need for further education and the development of knowledge and expertise in areas additional to that emphasised in critical care education programs. Education courses for critical care nurses should therefore include more in-depth information of the psychological and social aspects of patient and family care, and incorporate strategies to both assess and manage problems. In addition, education in communication and counselling would assist nurses caring for mechanically ventilated patients, and their families.

- The issue of preparing patients and their families for discharge from both the CCU and the hospital, and providing adequate information about this points to the need for specific education of the factors involved in discharge planning. In order to carry out this role effectively, critical care nurses need to have appropriate knowledge of what this entails.
• Another recommendation for education is the need to include more advanced research skills training and utilisation of research findings. This strategy has the potential to heighten nurses’ awareness and appreciation of the value of incorporating evidence into clinical practice. As previously discussed, despite the findings from numerous studies that identified that mechanically ventilated patients in the CCU experience many discomforts relating to technology and nursing activities, reports of discomforts continue to persist in recent literature. This suggests that critical care nurses may not be incorporating evidence from research, and are unaware and or unappreciative of patients’ perspectives.

• Finally, the finding that some non-nursing staff practices were found to be rough highlights the need for all health care staff involved in direct patient care to have access to appropriate and ongoing training and education in areas such as manual handling and communication skills.

One outcome of this study’s findings has been the incorporation of specific lectures and workshops focusing on patients and families experiences of CCU in the Critical Care Programs offered in the School of Nursing, Griffith University. Evaluations by students have been extremely positive. Written data has indicated that such information has raised student’s awareness and understanding of patient and families’ perspectives on CCU, and caused them to reflect on their critical care practice.
**Recommendations for future research**

The findings from this study provide valuable information and knowledge for all those involved in the care of long-term mechanically ventilated patients in the CCU. Many of the findings confirm and extend those derived from previous studies. Of more importance, unique insights were revealed that provide a new perspective on this patient experience, adding significant evidence on which to base critical care nursing practice and education.

The findings of this study serve as a basis for the following recommendations for future research studies:

- The examination and comparison of different sedative and analgesic protocols and their effects on the incidence of nightmares and hallucinations reported by CCU patients.

- Replication of this study in a group of patients from different cultural or ethnic backgrounds would assist in ascertaining if culture or ethnicity impacts on the meaning people attribute to this experience. Australia is a multicultural country, and nurses are often required to care for people from different cultural and ethnic backgrounds. Findings from such studies would assist in ensuring the delivery of culturally appropriate care.

- Evaluation of the efficacy of current methods for communicating with intubated and mechanically ventilated patients in the CCU.
• Studies should be conducted to develop, test and evaluate the efficacy of new methods for communicating with intubated and mechanically ventilated patients in the CCU.

• Examination of CCU patients’ perceived level of control and power. Findings from such studies would help determine the extent of this issue, and provide knowledge on which to base further studies aimed at developing and testing the efficacy and appropriateness of interventions.

• Exploration of the extent and type of involvement patients would like to have in their care whilst in the CCU. Findings would provide critical care nurses with evidence on which to plan for patient care activities.

• Investigation of the extent and type of problems experienced by CCU patients after discharge. Findings would help determine the need for, and types of services required, and assist critical care nurses in planning for successful discharge, both from the CCU and the hospital. Data from such studies could then be used to develop, test and evaluate interventions and services.

• Exploration of the usefulness and appropriateness of personal diaries for individual patients as an aid to assist in understanding their CCU experience. An examination of the compilation of diaries by both critical care nurses and or relatives of the patients would provide a wider scope of data on which to base further studies and recommendations.
Finally, examination of the value of follow up contacts by CCU staff to former patients and their families. Findings would provide an indication if this type of staff contact, either by telephone of mail, is useful in helping people understand the CCU experience.

Conducting research studies concerning CCU patients will always be challenging. This is a time when patients are confronted by questions of life and death, and their usual way of being-in-the-world is disrupted and disturbed. Therefore, research seeking to examine CCU practices and CCU patients’ experiences should be directed at uncovering, developing and evaluating methods of care delivery that result in improvements in patient care and more positive patient outcomes.

**Limitations of the Findings**

Although it has been clearly shown that this thesis successfully answered the research question, there were limitations to the findings. In chapter four the limitations associated with taking a phenomenological approach were articulated. As explained, the intent of this research was to explore peoples’ experience of being on long-term mechanical ventilation in a critical care unit and to extend knowledge and understanding of the meaning they attributed to this phenomenon. It was never the aim of this study to predict, generalise or generate theory, thus the approach taken was congruent with the purpose of this study.

One limitation of the study is that it is retrospective in nature and relied on participants’ recollection of their lived experience after the event. The stories were told after a period of two weeks through to six months following the experience. Previous studies have shown that the ability to recall events differs markedly
between studies and over time (time (Adler, 1997; Bergbom Engberg & Haljamae, 1988a; Green, 1996; Heath, 1989; Holland et al., 1997; Laitinen, 1996; Parker, 1997; Parker et al., 1984; Puntollo, 1990; Russell, 1999; Simpson et al., 1989). Therefore, whether the accuracy of recall may have been distorted as a result of the passing of time is difficult to determine. However, in honouring the chaos narrative of these study participants, there was no requirement to obtain fully coherent and complete stories. It was also apparent that this experience was an emotional one that was vividly remembered by participants.

Another limitation may be related to participants in this study being hospitalised in one of three critical care units situated in a specific geographical location, namely southeast Queensland. The majority of critical care units in Australia that provide long-term ventilatory care to critically ill patients are located in metropolitan areas and large regional hospitals. Although these units may seem to have many similar characteristics to the units in this study, the findings of this study were derived from a specific context.

Finally, all of the participants were of a Caucasian background and spoke English as a first language. Different interpretations and meanings derived from this experience may have emerged if people from difference cultural and racial backgrounds were recruited to the study.

In summary, although there are limitations to the findings, the knowledge derived from this study substantially adds to our understanding and what is currently known about what it means to be on long-term mechanical ventilation in a critical care unit, and may inform critical care practice.
Evaluation of the Research Process

The need to ensure rigour in the research process was discussed in chapter five. With this in mind, a review and evaluation of the research process of this study will now be presented to demonstrate how rigour was achieved.

Providing a clear decision trail

Throughout the entire study, I have demonstrated how the chosen methodological approach and method utilised is congruent with the research question. In the three chapters of research findings, reference has been made to the text derived from the participant interview where ideas have been revealed in order to clearly show how the understandings and interpretations were derived from the data.

Credibility

“Credibility is used to refer to the truth, value or believability of the findings through prolonged contact with the participant/s” (Leininger, 1994, p. 105).

In this study I clearly detailed the processes I used to make contact with the participants, set up the interviewing schedule, and met with each participant on an individual basis. Furthermore, the process of in-depth interviewing, follow-up interviews, and informal conversations meant that I was in contact with each and every participant for a considerable amount of time. I was also extremely methodical in the way I detailed the method of data analysis.
**Transferability**

“Transferability refers to whether particular findings from one qualitative study can be transferred to another similar context whilst preserving the meanings and interpretation of the original study” (Leininger, 1994, pp. 106-107).

Whilst detailing the limitations of the study, it was acknowledged that the findings of this study were derived from a specific context. However, I have presented papers derived from this study at a local, state, national and international level. Each time the audience, which consisted mainly of critical care nurses, indicated that the study findings were of value to them in their particular work context, suggesting that the findings are transferable to other critical care units and may inform others who care for mechanically ventilated patients.

**Dependability**

“Dependability or confirmability is often taken to mean agreement and reliance of a finding by direct and repeated affirmation” (Leininger, 1994, p. 105).

Where appropriate and possible I have included direct quotes from the participants to demonstrate agreement of the finding. That is, I have not presented an interpretation without providing substantiating textual quotes to reveal how I reached such an interpretation.

**The Phenomenological Nod**

“The phenomenological nod indicates affirmation by readers (or audience) that they recognise and can relate to the described experience” (van Manen, 1999, p. 27).
Throughout the course of this project, I have received many “phenomenological nods” that have affirmed my findings and given me the momentum to continue with this line of research. Of prime importance is the phenomenological nod given to me by several of the participants when I returned for follow up interviews and presented my interpretations. When participants nodded and said to me: “yes, that’s it, that is what I meant”, I realised that I had captured a true and real picture of the meaning they attributed to their experience.

In another example, after presenting some of my findings at the 8th World Congress of Intensive and Critical Care Medicine in Sydney, 2001, I was approached by a number of critical care nurses who conveyed that they could really relate to my presentation, and that it had “struck home”. Furthermore, they expressed the view that my research brought to the fore the participants’ perspective.

*Taking a Heideggerian Perspective*

Throughout this thesis, I have consistently and clearly demonstrated how the phenomenological-ontological perspective informed by the philosophical tenets of Heidegger (1927/1962) have underpinned the research process and the interpretation. I have made clear the pre-understandings I brought to the study and my position in the hermeneutic circle. The phenomenological description of the research findings provided in chapter eight revealed how Heidegger’s philosophical assumptions, or tenets of Being were used as a lens to bring to light the meaning and essence of the experience.
**Conclusion**

Despite the growing interest by nurses over the years to explore and gain a greater understanding of patients’ experience, with the aim of improving patient care, this research study found that being on long-term mechanical ventilation in a critical care is, in the main, an unpleasant and frightening experience. *Being at its most elusive* showed that the central feature of the experience was the momentary loss, or lapse, of one or more of Heidegger’s tenets of Being. The ontological description presented in this study revealed that participants experienced momentary lapses of situation, engagement, care and concern, temporality and the ability to self-interpret.

Critical care nurses place the highest priority on recognising and meeting the needs of the critically ill person. Findings from this study add a further dimension to the knowledge and evidence base of what it is like for people to be on long-term mechanical ventilation in a critical care unit. These research findings are significant for critical care nurses, educators and researchers, as they can assist in the planning and provision of holistic and evidenced-based practice. In conclusion, I leave the reader with this thought:

Critical care nurses caring for patients on long-term mechanical ventilation need to aware of, and not underestimate, the extent to which these people suffer. Even if nurses are unable to observe, measure, or quantify the degree of personal suffering and discomfort, this must not distract from attempts to ensure patient comfort and support. A critical care unit should be a place for the patient to live as a human being, not just a place in which to survive.

I trust that the findings from this research study contribute towards this aim.
APPENDIX A

Glossary

This glossary of terms used in this thesis is provided to assist the reader in clarifying and understanding the terminology used in this research study.

All definitions provided are adapted from:


**Bagging**

Providing manual ventilation to the patient with an endotracheal tube by means of a specially designed bag with a one-way value connected to oxygen.

**Continuous Positive Airway Pressure (CPAP)**

Positive airway pressure applied by a machine to a patient during spontaneous breaths. It is used to enhance oxygen transfer during respiration.

**Electrocardiograph**

A device for recording changes in the electrical energy produced by the action of the heart muscles. It produces an electrocardiogram that gives graphical information concerning the spread of electrical activity to the heart. Is used to diagnose heart rhythm and conduction disturbances, and pathological changes.
Endotracheal Tube (ETT)

A flexible plastic breathing tube inserted in the mouth into the windpipe (trachea). This tube is used to deliver oxygen to the lungs, help with breathing and allows the removal of excess mucous or secretions. This tube is usually attached to a mechanical ventilator. The ETT usually prevents the patient from talking.

Mechanical Ventilator

Mechanical ventilation is the artificial control of the breathing cycle by means of a machine. Patients who required ventilation are usually mildly sedated to make sure they are comfortable.

Naso-Gastric Tube

A flexible plastic tube inserted in the nose and passed to the stomach to remove excess fluid, or give nutrition.

Positive End Expiratory Pressure (PEEP)

Positive airway pressure applied by a machine to a patient at the end of expiration of ventilator (machine) driven breaths. It is used to enhance oxygen transfer during respiration.

Tracheostomy

A small hole placed into the patient's windpipe (trachea) to provide an open airway, assist breathing and allow the removal of excess fluid or mucous from the lungs.
Tracheostomy tube
A short tube that provides the best route for long-term airway maintenance, and avoids the complications associated with oral and pharyngeal endotracheal intubation. The tracheostomy tube may be attached to the mechanical ventilator.

Weaning
Weaning is the gradual withdrawal of mechanical ventilation and the reestablishment of spontaneous breathing by the patient.
APPENDIX B

Information Flyer For Relatives

Patients’ Experience Of Being On Life Support

Nurses working in critical care units (CCUs) are often required to care for people who have an illness or injury that requires them to be on life support (a mechanical ventilator/respirator). CCU nurses would like to find out more about what is like for their patients.

Patricia Johnson, a CCU nurse and PhD student at Griffith University Gold Coast, with assistance from the nursing staff of this CCU, is undertaking a study to look at how people have experienced life support in a CCU. She would like to talk with former patients of ………Hospital CCU who were on life support for 7 days or more. Your relative or loved one may be asked to help with this study. If you would like more information please see ……………, Charge Nurse CCU.
APPENDIX C

Information Letter And Participant Consent Form

CHIEF INVESTIGATOR: Patricia Johnson, Doctoral Student in the School of Nursing, Faculty of Nursing and Health, Griffith University, Gold Coast Campus

Contact Phone No: Ph: (07) 55948849

PROJECT TITLE:

The experience of long-term mechanical ventilation in a critical care unit

Nurses working in critical care units in hospitals often care for people who are on a mechanical ventilator (respirator). Sometimes people need mechanical ventilation for a period greater than seven days. This is often referred to as long-term mechanical ventilation. Recent studies have shown that the number of people requiring long-term mechanical ventilation is increasing.

This study has been designed to find out what it means for people to experience long-term mechanical ventilation in order to build up an authentic picture from the perspective of the experiencing person.

Although the study may have no direct advantages for you, findings from the study will provide nurses, doctors and other health care workers with a greater understanding and awareness of the experience from the patient’s perspective. This may lead to an improvement in the care of people who require long-term mechanical ventilation in the future.

Your participation in the study
This would involve one or two interviews lasting approximately one hour. The second interview will only be required if it is agreed that more time is needed for discussion. At the interview, I will ask you to describe your experience of long-term mechanical ventilation in the critical care unit. The interview/s will be conducted at your convenience and you may choose the time and place. In order to work with the information gathered, it will be necessary for me to tape record and transcribe the interviews. All information gathered at the interview/s will be treated in a confidential manner, and your name will be changed to ensure anonymity. All tapes and transcripts will be kept in a locked filing cabinet in my office at the University.
Tapes will be destroyed on completion of the study, while anonymous transcripts will remain in the locked filing cabinet.

You are free to withdraw from the study at any time without any penalty. I will be happy to answer any questions you may have and to accept your decision if you decide to withdraw from the study. Your decision will not affect any care that you may receive at the hospital in the future.

You may telephone me on the number at the top of this page, or my supervisor Dr. Winsome St John on (07) 55948935 if you have any further questions about this study. In addition, The University requires that all participants are informed that if they have any complaints concerning the manner in which a research project is conducted this may be discussed with the researcher, or, if an independent person is preferred either:

The University’s Research Ethics Officer, Office for Research, Bray Centre, Griffith University, Kessels Road, Nathan, Qld 4111, telephone (07) 3875 6618 or;

The Pro Vice-Chancellor (Administration), Bray Centre, Griffith University, Kessels Road, Nathan, Qld 4111, telephone (07) 3875 7343.
Statement by Participant

I .................................................. have read the information above and any questions I have asked have been answered to my satisfaction. I agree to participate in this study, and for the interview to be audio tape-recorded, realising that I may withdraw at any time. I agree that research data gathered for the study may be published, provided that my name is not used, and no information that could identify me, is provided.

..................................................................................................................  ........................................

Investigator                                      Date

Phone:   (07) 55948849

..................................................................................................................  ........................................

Participant                                      Date

I .................................................. wish/do not wish to receive a synopsis of the study on completion. I provide my name and address where this can be sent.

Name:

Address:
REFERENCES


NUD*IST Qualitative solutions and research. Victoria.


