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**A Multicase Study of a Prolonged Critical
Illness in the Intensive Care Unit: Patient,
Family and Nurses' Trajectories**

**A thesis presented in fulfilment of the requirements for the
degree of
Doctor of Philosophy
In
Nursing**

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Abstract

A critical illness necessitating admission to an Intensive Care Unit (ICU) is a profoundly stressful event for patients and families. It is important nurses understand these experiences, to provide appropriate care. For most patients admitted to an ICU in New Zealand their stay is of short duration. However, as a consequence of advances in life-sustaining therapies a new group of patients has emerged. This cohort survives their initial critical illness but become dependent on life-saving interventions for a prolonged period, necessitating a protracted ICU stay.

This purpose of this study was to explore the experiences of the patient, their family and healthcare professionals during the trajectory of a prolonged critical illness in an ICU. A qualitative instrumental multicase study approach was used, informed by the Chronic Illness Trajectory Framework. Data collection involved six linked cases (patient, family and clinicians) in four ICUs over a two-year period utilising observations, conversations, interviews and document analysis.

Longitudinal data analysis revealed four sub-phases in the trajectory of a prolonged critical illness. These sub-phases were determined by the patients' physiological condition, with each sub-phase also representing different psychosocial needs. The patients' physiologically debilitated state made them prone to complications and added to the complexity of their illness trajectory. Families' trajectory, dominated by uncertainty, were informed by the patients' trajectory. Families worked hard to relieve the uncertainty by looking for signs of improvement. As their trajectory progressed the 'wear and tear' of prolonged uncertainty became more evident. Nurses' work was informed by the patients' trajectory, with different sub-phases representing different challenges. During the mid-phase, distress related to the uncertainty about positive patient outcomes and the suffering some patients endured. During the emerging with a failed body sub-phase, nurses were challenged to meet all patients' needs due to their overwhelming work priorities.

The identification of the specific sub-phases of a prolonged critical illness trajectory can result in interventions being targeted to each sub-phase to improve outcomes and experiences. Research and education can also be targeted to each sub-phase to explore specific issues and problems to continue to advance this body of knowledge.

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Abbreviations

CAM	Confusion assessment method
CCI	Chronic critical illness
CCNS	Critical Care Nurses Section
CCU	Coronary care unit
CPAP	Continuous positive pressure ventilation
DHB	District Health Board
DRG	Diagnosis-related group
ERS	European Respiratory Society
FTE	Full-time-equivalent
HDU	High dependency unit
HPCA	Health Practitioners Competency Assurance Act
ICU	Intensive Care Unit
ITU	Intensive Therapy Unit
JFICM	Joint Faculty of Intensive Care Medicine
LOS	Length of stay
LTAC	Long-term acute care
MSAS-C	Memorial Symptom Assessment Scale
NFR	Not for resuscitation
NOK	Next of kin
PFCC	Patient-family-centred-care
PMV	Prolonged mechanical ventilation
SBT	Spontaneous breathing trial
SCU	Special care unit
USA	United States of America
WFCCN	World Federation of Critical Care Nurses

Table of contents

Abstract.....	iii
Acknowledgements.....	iv
Abbreviations.....	v
Chapter 1 – Introduction and Background	1
Introduction	1
Positioning this study in relation to my clinical area of interest	1
Background to this Study.....	2
Intensive care defined.....	2
Development of the specialty of intensive care	3
Intensive Care Services in New Zealand	4
Intensive care services globally.....	5
Intensive care nursing.....	6
Summary.....	8
Chapter outlines.....	8
Chapter 2 – The Contexts of Experiences	11
Introduction	11
The patients’ experiences of intensive care	11
An altered body.....	12
An altered mind	13
Altered relationships.....	15
Confronted with one’s mortality	17
Perception of the environment of the ICU	18
An unfolding journey of a critical illness.....	20
The context of families’ experiences in the ICU	22
The need for closeness	25
The need for comfort, reassurance and support.....	27

The context of nursing in the intensive care unit	28
Nursing critically ill patients in a technological environment.....	28
Emotional burden of nurses’ work	31
Summary	33
Chapter 3 – The Case of a Prolonged ICU Stay: The Literature Review	35
Introduction	35
New group of patients	35
Long-stay patients in New Zealand and Australia.....	37
Definitions of chronic critical illness	38
Tracheostomy insertion	39
Prolonged mechanical ventilation	39
Defining by failure to wean.....	40
Chronic critical illness.....	41
Persistent critical illness.....	42
The theory of allostasis as a framework to manage CCI.....	44
Common Clinical Characteristics of CCI	46
The experiences of patients with CCI.....	47
Experiences of a tracheostomy and mechanical ventilation	48
Symptom distress.....	49
Families’ experiences of CCI.....	52
Nursing patients with CCI.....	55
Transitions to palliation for patients with CCI	58
Conclusion.....	60
Chapter 4 – Theoretical Framework	63
Introduction	63
Introducing the trajectory framework.....	63
Overview of the illness trajectory framework	64
Development of trajectory framework.....	64

Major concepts, definition and relationships	67
Trajectory	67
Biography	69
Work.....	72
The hospital as a work site.....	76
The contexts for an evolving trajectory	76
Research using the framework	80
The trajectory framework informing this study.....	82
Conclusion.....	83
Chapter 5 – Research Design and Method	85
Introduction	85
Case study	85
Definitions of case study.....	85
Classifications of case study.....	87
Identifying ‘the case’	88
Identifying ‘the phenomenon’	89
Identifying ‘the context’	89
Rationale for this approach.....	90
Methods.....	90
Justification for data collection throughout illness	90
Legal, Ethical, and Cultural Considerations.....	91
Negotiating access	92
Sampling choices.....	93
Recruitment of the case.....	93
Informed consent.....	94
Confidentiality and anonymity.....	97
Researching vulnerable groups.....	98
Conflicts of interest.....	100

Cultural considerations	101
Data collection methods	102
Reflexivity.....	110
Data Analysis.....	112
Single case analysis	112
Multicase analysis	116
Triangulation and confirmability.....	117
Generalisations	118
Trustworthiness	119
Conclusion	120
Chapter 6 - Context to the Cases	121
Introduction	121
The physical location of the ICU	121
Waiting areas	122
Access into the unit.....	123
The main unit	123
The physical 'bed space'	123
Allocation of patients to a bed space.....	124
The presence of health care professionals	124
The entwined physical space	125
Conclusion.....	126
Chapter 7 – The Phases of a Prolonged Critical Illness	129
Introduction	129
Aligning the Corbin and Strauss Trajectory Framework	129
Before critical illness	129
The Cases	130
Phase 1 – An overwhelming pre-set trajectory	130
Phase 2 – A long wavering trajectory	133

Phase 3 – Emerging with a failed body	140
Phase 4 – Working to piece it together	147
Aligning to the Corbin and Strauss Trajectory Framework.....	150
Conclusion	151
Chapter 8 – Relentless Uncertainty – The Family	153
Introduction	153
Being overwhelmed	153
Living in an uncertain world.....	156
An altering uncertainty	165
Uncertainty in a different location.....	168
Moving on.....	170
Conclusion	171
Chapter 9 – The arc of work.....	173
Introduction	173
The arc of work – this is intensive care.....	173
Phase 1 – Crisis – Lifesaving Work	175
Mitigation of Safety and Recognition of Risk.....	175
Mitigation of Safety and Recognition of Risk at the Expense of Other Work.....	177
Phase 2 – Acute - Multiple Contingencies	179
Mitigation of Safety, Recognition of Risk and Sentimental Work – The Waking Patient	179
Comfort work within the lines of work.....	181
Communication within the lines of work.....	183
Uncertainty through the lines of work.....	185
The family within the lines of work.....	189
Phase 3 – Stable – ‘Just Weaning’	190
Safety and Identification of Risk Work During the Wean	192
Comfort Work during the Wean	194

Sentimental work during the wean	197
The end of the wean	200
Conclusion.....	201
Chapter 10 – Discussion.....	205
Introduction	205
Navigating the Grey Zone	205
Working within a biomedical model of care.....	209
Dehumanised care	210
Safety and risk mitigation rule the environment.....	213
Emotional disruption from nurses’ work.....	216
Biographical re-casting following a prolonged critical illness	221
Conclusion.....	224
Chapter 11 – Conclusion and Recommendations.....	225
Introduction	225
Summarising the study	225
The case	225
Limitations of this study.....	227
Key research findings and recommendations for practice, education and research	227
The sub-phases of a prolonged critical illness	227
Contexts of care	229
Patient complexity	231
Concluding statement.....	232
References	235
Appendices.....	263

List of Figures

Figure 1: ICU Beds/100,000 population, (Murthy & Wunsch, 2012).....	6
Figure 2 Order of research planning.....	92
Figure 3 Recruitment and data collection procedures.....	94

List of Tables

Table 1 Clinical Characteristics of CCI.....	46
Table 2 Definitions of phases within the trajectory framework.....	66
Table 3 Definitions of concepts.....	67
Table 4 Work types during illness defined.....	72
Table 5 Types of work and definition.....	73
Table 6 Potential conflict problems and solutions.....	101
Table 7 Data collection hours and methods for each case.....	104
Table 8 Semi-structured interview participants excluding patient.....	109
Table 9 Techniques to demonstrate trustworthiness.....	119
Table 10 Demographic overview of cases.....	130
Table 11 Common Clinical Characteristics.....	134
Table 12 Complications developed through critical illness.....	138
Table 13 Physiological discomforts.....	141
Table 14 Example of white board.....	147
Table 15 Comparison of Corbin and Strauss phases and prolonged critical illness.....	151
Table 16 Strategies during family surveillance.....	159
Table 17 Examples of exhaustion.....	162
Table 18 Moving on.....	170
Table 19 Phases and overarching themes.....	175
Table 20 Terminology to describe weaning.....	191

List of Appendices

Appendix 1 Ethical approval	263
Appendix 2 Information Sheets	265
Appendix 3 Consent forms.....	271
Appendix 4 Information sheet for patients clinical notes	275
Appendix 5 Transcribers agreement.....	276
Appendix 6 Interview questions	277

Chapter 1 – Introduction and Background

Introduction

A critical illness necessitating admission to an Intensive Care Unit (ICU) is a profoundly stressful event for the patient and their family. It is important that nurses who work in an ICU understand those experiences and consider them in their provision of nursing care. Recognising and responding to those experiences can also contribute to quality improvement within the ICU setting and the potential to improve care outcomes. The goal of intensive care provided in an ICU is to treat patients who have a life-threatening illness, and for most patients this critical phase of their illness is of short duration. In New Zealand the median length of ICU stay in 2014/15 was 2.6 days (ANZICS Core, 2016). A consequence of advances in life-sustaining therapies is the emergence of a group of patients that survive their initial critical illness but then become dependent on life-saving interventions for a prolonged time, necessitating a protracted stay in the ICU (Kahn et al., 2015; Wiencek & Winkelman, 2010). Internationally, researchers demonstrate that 5 – 10% of ICU patients have a prolonged ICU stay, using 25 – 30% of ICU beds days (Crozier, Pilcher, Bailey, George, & Hart, 2007; Wiencek & Winkelman, 2010; Williams et al., 2010). Therefore, a prolonged ICU stay has serious implications for patients, families, clinicians and health services, especially when the outcomes may be uncertain (Nelson, Bach, Cox, Hope, & Carson, 2010).

This thesis is a case study of the experiences of the patient, their family and the healthcare professionals during the trajectory of a prolonged illness in the intensive care unit?

Positioning this study in relation to my clinical area of interest

My interest in patients with a prolonged critical illness emerged from my previous work as a staff nurse in the ICU. I have also had a particular interest in patients' experiences of critical illness within the acute care setting in relation to my current role as a lecturer to undergraduate and postgraduate students.

As a nurse working in the ICU for many years I noted the complexity of the patients' illness and the many differing views healthcare professionals had about care for this group of patients. Patients spent a lot of their illness awake and dependent on life-

saving therapies. Patients were often viewed as an easy patient for the less experienced nurses to care for because they required less technological and medical input. Furthermore, when patients were confused most nurses did not want to look after them resulting in a different nurse every shift. Patients had many psychological issues that nurses struggled to deal with such as anxiety, depression, being withdrawn and communication difficulties with an overarching sense of hopelessness. I knew I was interested in researching this group of patients but could not articulate what particular aspect of their experiences this pertained to.

It was not until I went back to work in an ICU for one day a week in an education role that I was able to refine a “researchable” question for my PhD study. This enabled me to observe the care of a critically ill patient who had been admitted to the ICU with severe pneumonia. Despite a poor outlook she did survive her initial critical illness, but then spent a prolonged period dependant on mechanical ventilation. Weekly I would note her slow progress, but what really made an impression on me was seeing her suffering over a prolonged period of time. She was depressed, withdrawn and appeared to have no hope. She was in the ICU for over six weeks before she was transferred to the ward. At a later stage, while in the ward visiting nursing students, I again saw the patient. She saw me and lifted her arm to wave at me with a grin on her face. As I was talking to her I noted a sparkle in her eye that I had not seen before. I asked her about this, she responded that “she now had hope” and wanted to get out of hospital to be with her new grandchild. This was a lightbulb moment and I knew I needed to be able to capture the complexity of a prolonged illness as it occurred because it would never be portrayed this way if captured retrospectively. My PhD question had evolved.

[Background to this Study](#)

This first chapter sets the scene for this study by providing an exploration of the historical and international influences that have informed the specialty of critical services and intensive care nursing today, with particular emphasis on the structural context of intensive care in New Zealand. Finally, an outline of the thesis chapters is provided.

[Intensive care defined](#)

Intensive care is a generic term for a range of health care services. The terms ‘critical care’ and ‘intensive care’ are used synonymously throughout New Zealand and

globally. Critical care services include adult and paediatric intensive care units or intensive therapy units (ITU), high dependency units (HDU), accident and emergency, coronary care units (CCU), neonatal intensive care and emergency retrieval services. Hence patients can be critically ill and need intensive care therapies, but may not necessarily be in an ICU (Martin, Hart, & Hicks, 2010). However, the focus of this study is on patients in a general adult ICU but patients may be transferred to an HDU as their illness progresses. The definition of an ICU, provided by the New Zealand Intensive Care Clinical Advisory Group is:

A specially staffed and equipped, separate and self-contained section of a hospital for the management of patients with life-threatening conditions. Such conditions should be compatible with recovery and have the potential for an acceptable future quality of life. An ICU provides special expertise and facilities for the support of vital functions, and utilizes the skills of medical and nursing staff experienced in the management of these problems (Intensive Care Clinical Advisory Group, 2005, p. 8)

They further define an HDU as:

A discrete unit within a hospital, able to supply critical care expertise at less intensive resource levels, providing a level of care that falls between the general ward level and the Intensive Care Unit. A high dependency unit should be able to provide monitoring and support to patients [but] should not manage patients requiring multiple organ support or mechanical ventilation (Intensive Care Clinical Advisory Group, 2005, p. 8)

Development of the specialty of intensive care

The development of the ICU is attributed to the polio epidemic in the 1950s due to the centralisation of patients within an area so they could receive more intensive observation and care. However the notion of centralising sicker patients to one area can be linked back to Florence Nightingale, who created a separate area proximal to the nursing station for battle injured soldiers during the Crimean war (Grenvik & Pinsky, 2009). The expansion of large hospital wards in the late 19th and first half of the 20th century saw the most seriously ill patients separated into semi-private areas and often cared for by special duty nurses. As early as 1927 a specialised area for post-operative neurosurgical patients was established and the concept of a specialised site for the care of the seriously ill patient expanded (Weil & Tang, 2011).

The development of the iron lung was the beginning of machinery existing in these areas and was seen as the foundation of intensive care, most likely due to the increased presence of medical staff. However, it was the practices of nurses with sicker patients

prior to this that inform the model for the ICU that emerged during the 1950s (Fairman, 1992). Despite there being a dearth of literature about nursing in this environment, nursing contribution to the development of intensive care is enormous. Nurses in these areas were required to undertake intensive observation, triaging¹ and grouping patients according to their physiological instability. The development of the Salk (polio) vaccine in the mid-1950s resulted in a decrease in the incidence of polio and a decline in the use of the iron lung. Patients with respiratory failure were then ventilated on the ward, but there was a high mortality rate due to failure of the mechanical ventilator (Crocker, 2007).

The progress of medical equipment and medicines, such as antibiotics and medical knowledge, over the next five to ten years, saw nurses continue to group patients together as medical staff found a correlation between nurses' level of knowledge and skills and patients' prognosis (Crocker, 2007). Furthermore, the number of sick and physiologically unstable patients in hospitals slowly increased due to new found expertise which could treat an illness that had previously been catastrophic (Fairman & Lynaugh, 1998). Nurses had to continue to adapt their practice to increase their skill levels to cope with these sicker patients. With a steady increase in the number of patient requiring mechanical ventilation, this prompted respiratory units to re-open and become known as intensive care units during the 1950s (Crocker, 2006).

Intensive care developed similarly in New Zealand to the rest of the world following the polio epidemic. A respiratory unit with the ability to provide positive pressure ventilation was established in Auckland, New Zealand in 1957, which developed into the first ICU in Australasia. It is from these beginnings intensive care medicine developed a new speciality, with a new type of medical specialist, the intensivist and intensive care nursing as a specific area of practice (Judson & Fisher, 2006).

[Intensive Care Services in New Zealand](#)

Within New Zealand most ICUs are in public hospitals and these are general adult ICUs, which have the capacity to care for paediatric patients for a short period of time. There is one paediatric ICU that serves the New Zealand population and one specialised cardiovascular ICU with tertiary ICUs having the capacity to manage a

¹ Triage is of French origin meaning 'to sort or choose' and has been adopted as a categorisation of patient from the critically ill to stable patients requiring little intervention

variety of clinical specialties (ANZICS Core, 2016). Some smaller hospitals may have combined HDU/ ICU or CCU/ ICU or mixed ICU/ HDU/ CCU (Intensive Care Clinical Advisory Group, 2005). For the year 2014/15 there were 18,615 admissions to ICUs in New Zealand. This was spread over the 247 ICU beds in 29 adult ICUs and the one paediatric ICU (ANZICS Core, 2016). There are three levels of ICU that support the role of a hospital. A level III ICU is a tertiary referral unit for ICU patients and should be capable of providing comprehensive critical care. A level II unit should be capable of providing a high standard of general intensive care, including complex life supports. A level 1 unit should be capable of providing immediate resuscitation and short-term cardio-respiratory support for critically ill patients (Drennan, Hart, & Hicks, 2008). Within New Zealand ICUs it is normal practice for intensivists to take the primary responsibility for patient care (Judson & Fisher, 2006).

Intensive care treatment is expensive. In New Zealand it costs approximately \$5,000 per day to treat a patient in intensive care (Pharmac, 2015) This, broken down into areas of costs, includes: two-thirds on staff, one-fifth on clinical consumables and the rest on clinical support and capital expenditure (Aitken, Chaboyer, & Marshall, 2015).

[Intensive care services globally](#)

The importance of strong international intensive care services, with international collaborations has become increasingly recognised as important for potential pandemic threats (Aitken et al., 2015). However comparisons between intensive care services internationally needs to be made with caution, due to the differences in definitions and infrastructure (Adhikari, Fowler, Bhagwanjee, & Rubenfeld, 2010; J. Martin et al., 2010; Murthy & Wunsch, 2012) and for example, the lack of universal definition of what an actual ICU bed is (Adhikari et al., 2010). Despite this lack of definition and data on the number of beds each country has, there is a demand for critical care beds globally. With an aging population and an increase in population sizes there is a projected increased need for critical care beds worldwide (Aitken et al., 2015).

The number of available ICU beds varies greatly between developed countries, as seen in figure 1. Compared with many other developed countries New Zealand has only 5.4 available beds per 100,000 of population, making this a scarce resource. The scarcity of ICU beds in New Zealand was highlighted in the winter of 2009 with the H1NI

influenza pandemic² with 19% of ICU beds occupied by influenza patients with many of this group of patients having a prolonged critical illness (The ANZIC influenza Investigators, 2009).

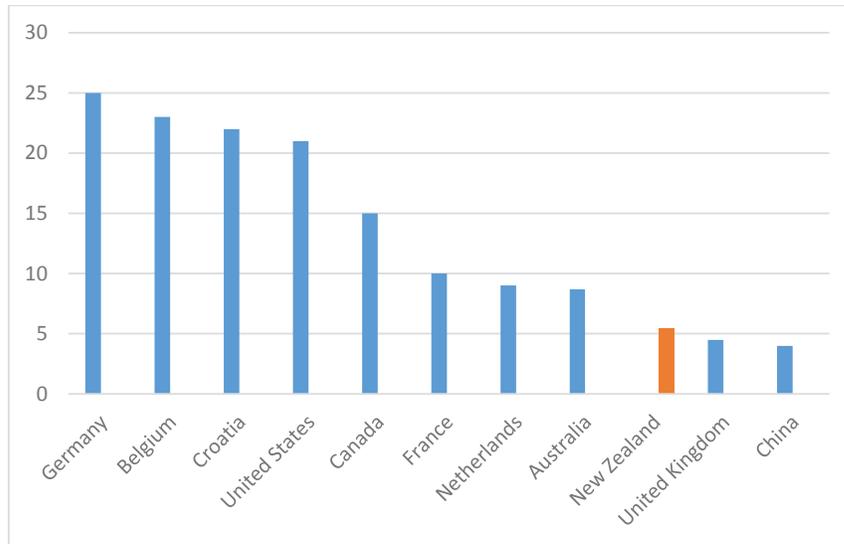


Figure 1: ICU Beds/100,000 population, (Murthy & Wunsch, 2012)

Intensive care services also differ significantly from country to country in terms of medical control and intensivist input, nurse-to-patient ratios, patient admission and discharge criteria, the number of available ICU beds, and access to life-saving technologies and medicines. However, despite these and many other differences, ICUs worldwide consume a disproportionate share of every country's healthcare expenditure (Chalfin, 2008). These differences need to be considered when reviewing international literature in relation to a prolonged critical illness.

[Intensive care nursing](#)

During the 1960s as ICUs developed and became more advanced, the speciality of critical care nursing also expanded. This challenged the universal norm in hospitals to have a generalist nurse who could and would practice anywhere, and was the beginning of other nurses naming themselves according to their areas of practice (Fairman & Lynaugh, 1998). There were many factors that saw critical care nursing develop along with intensive care medicine. The partnership between nurses and doctors in this area, the development of technologies such as mechanical ventilators,

² Influenza A (H1N1) was new influenza virus which spread around the world through human to human transmission. On the 12 June 2009 the United Nations declared the spread of the influenza virus around the world had reached pandemic levels.

cardiac monitors and renal dialysis machines, and the recognition of the nurses' skills and staffing levels that improved patient outcomes, all facilitated the development of the speciality (Aitken et al., 2015; Fairman, 1992).

As the speciality of critical care nursing has developed, so has nursing education and the professional organisations. Worldwide there are over 37 professional organisations for critical care nurses (Aitken et al., 2015). Within New Zealand the Critical Care Nurses Section (CCNS) of the New Zealand Nursing Organisation represents intensive care nurses. They define a qualified critical care nurse as:

A nurse who has completed a speciality practice post registration programme that meets the New Zealand Standards for Critical Care Nursing Education (CCNS, 2010) or a nurse who has successfully completed another critical care nursing programme and is able to provide evidence of continued professional development reflecting their theoretical knowledge and clinical expertise that meets the standards outlined in the New Zealand Standards for Critical Care Nursing Education (Critical Care Nurses Section, 2010)

The CCNS has developed the New Zealand Standards for Critical Care Education and the Philosophy and Standards for Practice in Critical Care (New Zealand Nurses Organisation, 2012). Other standards that inform ICUs nurses specialty practice are the Joint Faculty of Intensive Care Medicine (JFICM) standards for ICU and the World Federation of Critical Care Nurses (WFCCN) (Aitken et al., 2015; Judson & Fisher, 2006). Apart from defining the knowledge, skills and attitudes of a critical care nurse these standards have been pivotal in informing nurse to patient ratios, educational standards and recommendations for required skill levels of nurses and staffing requirements. The CCNS state a critically ill and/or mechanically ventilated patient will require a minimum of 1:1 registered nurse-to-patient ratio, with a minimum registered nurse-to-patient ratio of 1:2 for an HDU patient. This is also supported by the WFCCN and JFICM. The CCNS recommends at least 50%, but optimally 75% of nursing staff must be qualified critical care nurses with at least one full-time-equivalent (FTE) nurse educator per 50 nurses on the roster, in order to provide unit-based education and development (New Zealand Nurses Organisation, 2012). In the 2014/15 core activity report for New Zealand and Australian ICUs 56.1% of registered nurses who worked in the specialty were trained in critical care nursing (ANZICS Core, 2016).

Summary

This chapter has provided an introduction to the research question and has provided a background for subsequent chapters. It has outlined the development of intensive care as a speciality, some key concepts, definitions and standards which inform practice both internationally and specifically to the New Zealand context. The New Zealand public health system and general adult ICU services provide the context for this case, and while unique it contains many features and influences from global ICU services and contexts.

Chapter outlines

In Chapter Two key literature related to the contexts of the experiences of ICU from patients, family and nurses is examined.

Chapter Three presents an examination of the literature in relation to the case of a prolonged critical illness. Key definitions for patients with a prolonged critical illness, clinical features and issues are examined. The literature is reviewed pertaining to the family's burden of a prolonged critical illness and the nurses' experiences of caring for this complex group of patients is critiqued.

In Chapter Four the Corbin and Strauss (1988) trajectory framework which provides the theoretical underpinnings for this study is discussed. Concepts from the trajectory framework are defined and critiqued for their application to the case. The contexts of the hospital as a worksite, and the development of technology are examined as is how it informs a trajectory.

In Chapter Five the approach of case study is described and explained as it is applied to this study. The research approach of instrumental multicase study as informed by qualitative principles and the ethical principles of research in the natural setting of the ICU with vulnerable participants are described.

Chapters Six, Seven, Eight and Nine constitute the case study and analysis of the case of a prolonged critical illness in relation to the contexts, patients, families and healthcare professionals' experiences.

Chapter Ten critiques the overarching findings of this study that have informed the shaping of the trajectory of a prolonged critical illness.

Chapter Eleven concludes this thesis. The overarching themes are described, which identifies the complexities of the case of a prolonged critical illness. The limitations of the study and key research findings are presented with recommendations.

“Nothing in the hospital or ICU, however, caters for the human reality that the institution should host its visitors” (Almerud, Alapack, Fridlund, & Ekebergh, 2007, p. 151)

Introduction

The previous chapter described the historical development and structure of intensive care services within New Zealand and the international contexts which envelop this study. This chapter will review selected literature on the differing contexts of experiences of critical illness that necessitates a patient admission to the ICU and their family’s experience of that admission. It also offers an insight into the challenges and complexities ICU nurses have to deal with on a daily basis. All these experiences are intertwined into the social contexts that describe and explain interactions within the ICU. Hence the growing body of literature on all experiences of critical illness informs the contexts of this study within the outer boundaries of the case of a prolonged critical illness.

The search strategies involved searching for selected key literature from the following electronic databases: CINAHL plus, SCOPUS, Web of Science, Medline and Google Scholar. The search terms included: *intensive care, critical care, patient experiences, family experience, nursing*, and excluded literature related to the *neonate, child and paediatric*. The focus of the search related to adult general intensive care and not any clinical sub-specialty.

The patients’ experiences of intensive care

Over the last 30 years many qualitative studies have explored the patient’s perspective of being critically ill, what it was like to be mechanically ventilated, and being cared for in the technological ICU environment (Granberg, Engberg, & Lundberg, 1998; Green, 1996; Lof, Berggren, & Ahlstrom, 2006; Roberts & Chaboyer, 2004; Russell, 1999; Stein-Parbury & McKinley, 2000). The main contributors to the qualitative literature on ICU patients’ experiences have come from Scandinavian countries with over 60% of the literature reviewed from this area, with most describing their research methods as interview-based phenomenology. Other geographical locations had

equivalent literature of about 10% or less. These countries were the United Kingdom, USA, Australia, Greece and one study from China.

As qualitative research helps us understand social phenomena in natural settings, it is important to know how these experiences are shaped throughout the illness, as this knowledge can then inform practice to improve outcomes. There was great variance in the timing of data collection, occurring from a few weeks to two years post discharge from ICU. Data were collected up to ten years post ICU discharge in one study (Storli, Lindseth, & Asplund, 2008). The length of ICU stay for inclusion in studies varied, with stays from 24 hours to 65 days. Inclusion criteria for other studies related to the period of time on mechanical ventilation, this ranged from 24 to 72 hours. No researchers investigated the experiences of patients within a specific length of stay, such as a patient with a long-stay or conducted a prospective study investigating the experiences over time.

In the following sections literature related to patients' experiences of a critical illness necessitating an ICU admission is reviewed. Key themes are adapted from Egerod et al.'s (2015b) meta-analysis of patients experiences of critical illness in the ICU:

- An altered body
- An altered mind
- Altered relationships
- Confronted with one's mortality
- Perceptions of the environment of ICU
- An unfolding journey of a critical illness

Although these experiences are separated into key themes patients' experiences are intertwined and encapsulate their experiences at various points in their illness progression.

[An altered body](#)

The patient's illness causes multiple physiological changes which they experience in many differing ways (Almerud et al., 2007; Engstrom, Nyström, Sundelin, & Rattray, 2013; Lindberg, Sivberg, Willman, & Fagerström, 2015; Svenningsen, Egerod, & Dreyer, 2016; Tsay, Mu, Lin, Wang, & Chen, 2013). In a phenomenological study of patients' lived experience as survivors of a critical illness, Papathanassaglou and Patiraki (2003) describe how patients, through their disorientation, felt their body was

changing shape and was continuously in motion or swinging. Their body is described as a stranger and disconnected from them as body sensations and perceptions become distorted (Fredriksen, Grethe Talseth, & Svensson, 2008; Johnson, St John, & Moyle, 2006; Tsay et al., 2013). Their body becomes overwhelmed with many physiological discomforts, such as feelings of being trapped due to body restrictions and oedema, pain, inability to sleep, thirst, and dyspnoea (Cutler, Hayter, & Ryan, 2013; Holm & Dreyer, 2015; Karlsson & Forsberg, 2008; Wade et al., 2015; Wang, Zhang, Li, & Wang, 2008). Not being able to move or even breathe was difficult for patients to bear (Engstrom et al., 2013; Lindberg et al., 2015; Wang et al., 2008).

The physiological changes which result from an inability to move or breathe with ease, creates a feeling of loss of control. This loss of control over their body impacts on patients emotionally, with feelings of being dependent and potentially powerless. Having no choice potentiates their suffering (Yang, 2016). Patients realise there is nothing they can do about it as nurses intervene with treatments (Almerud et al., 2007; Wang et al., 2008; Yang, 2016). The loss is compounded by the feeling that their body has been taken over by technology (A. Engstrom et al., 2013; Stayt, Seers, & Tutton, 2015). This forced dependence on technology makes patients feel passive and shut down (Almerud et al., 2007).

Intensifying this loss of control, communication is lost or difficult due to intubation and mechanical ventilation and is associated with feelings of fear and helplessness (Guttormson, Bremer, & Jones, 2015; Moen & Nåden, 2015; Stayt et al., 2015). Being voiceless is one of the most frustrating problems for patients while they are mechanically ventilated (Johnson et al., 2006; Karlsson, Forsberg, & Bergbom, 2012; Yang, 2016). Voiceless patients suffer more because they often cannot relay their fears, anxieties and discomforts to nurses (Engstrom & Söderberg, 2007; Yang, 2016).

An altered mind

Patients' experiences of ICU are altered due to what is described as being 'elsewhere' during a critical illness with unreal and delusional experiences (Cutler et al., 2013; Egerod et al., 2015b; Samuelson, 2011; Storli, Lindseth, & Asplund, 2007). Hallucinations and nightmares are described as terrifying, both at the time and in the memories after their illness (Eriksson, Bergbom, & Lindahl, 2011; Hofhuis et al., 2008; Johnson et al., 2006; Lof et al., 2006; Samuelson, 2011; Wang et al., 2008). There were many reports within the literature of patients trying to escape capture,

being kept in a dungeon, death, violence, surrealistic or alien characters, frightening transportation or travel (Karlsson & Forsberg, 2008; Samuelson, 2011; Svenningsen et al., 2016; Tembo, Parker, & Higgins, 2012; Wang et al., 2008). Dreams and hallucinations seem so real to patients that they often had difficulty distinguishing reality (Samuelson, 2011).

These unreal and delusional experiences produce feelings of isolation and being at the mercy of the ICU staff and technology that is controlling their life. Patients needed to call upon their survival instincts to get through the ordeal (Tembo et al., 2012). Similarly Wang et al. (2008) reported patients describing the need to have 'will power' and the 'right attitude' to endure their illness, otherwise they thought they might die in the ICU. This attitude prompted patients to look for signs of improvement, and with improvement came hope. The need for hope was also identified by Karlsson and Forsberg's (2008) study of patients' experiences of being conscious during mechanical ventilation. The most important need for patients psychologically, apart from having someone close to them, was keeping hope alive. These studies demonstrate that patients appear to draw on their inner strength to get them through a critical illness. However, it is not known if all patients can muster this strength which, in a prolonged critical illness, may be difficult to maintain.

A study of patients' recall of their memories at three and six month's post-ICU discharge demonstrated that their memories of these unreal experiences did not alter. The stability of their recall indicates how traumatic and emotional these experiences are (Lof et al., 2006). Svenningsen et al.'s (2016) study of former ICU patients' memories of delusions found they were particularly haunting and lasting, with their delusion a blend of reality and fiction. Patients described their experiences as being controlled by family and healthcare professionals who appear to 'take them over'. Patients felt abandoned when healthcare professionals appeared to be part of the game to hurt them (Svenningsen et al., 2016). Despite the trend towards lighter sedation of patients (O'Connor, Bucknall, & Manias, 2010) there still appear to be alterations to their level of consciousness, memory and unreal experiences and confused thoughts, as described in recent studies (Holm & Dreyer, 2015; Svenningsen et al., 2016).

Altered relationships

Due to patients' disorientation, relationships with nurses and their family are important to help them connect with reality and gain comfort and reassurance. As the nurse is providing the most direct care to patients over a 24-hour period, they have most contact with the patient and their family and so their relationship is pivotal (Hofhuis et al., 2008; Stayt et al., 2015; Wahlin, Ek, & Idvall, 2009). Communication is how the nurse-patient relationship is established and is important for forming a trusting relationship (Happ et al., 2011; Moen & Nåden, 2015). However, there have been extremes in communication difficulties between nurses and patients described in the literature (Alasad & Ahmad, 2005).

The fast-paced environment of the ICU and the physiological condition of the patient makes it problematic for effective nurse-patient communication (Happ et al., 2011; Khalaila et al., 2011; C. Williams, 2003). Common are the feelings of fear, anxiety and helplessness from not being able to talk due to the presence of an endotracheal tube (Engstrom et al., 2013; Guttormson et al., 2015; Karlsson et al., 2012; Samuelson, 2011). When nurses took time to communicate with patients, it reduced feelings of fear, which in turn reduced anxiety and aided the weaning process from mechanical ventilation (Hofhuis et al., 2008). Karlsson et al.'s (2012) observational study of patients who were conscious while on mechanical ventilation demonstrated that attentive nurses met their patients' needs to communicate or wanting something adjusting by being present and watching over them for signs of deterioration and discomfort. Engstrom et al. (2013) noted how over time nurses could understand patient's needs, which highlighted the need for continuation of the same group of nurses caring for a patient.

Communication that did not meet patients' psychological needs has been described as being task-orientated or inappropriate in nature (Dithole, Sibanda, Moleki, & Thupayagale-Tshweneagae, 2015; Meriläinen, Kyngäs, & Ala-Kokko, 2013). Patients felt objects of care when there were minimal interactions during nursing actions (Karlsson et al., 2012; Lindberg et al., 2015; Meriläinen et al., 2013). They were frustrated with failed attempts at communication, but also the perceived lack of information they received from nurses before care and about their condition (Guttormson et al., 2015). Inappropriate communication also included nurses not

taking patient's reports of hallucinations or disturbing dreams seriously (Hofhuis et al., 2008).

Human contact with healthcare professionals was also important for patient well-being (Cutler et al., 2013). When sedated, patients recognised the nurses' hands and voice as being caring and attentive (Olausson, Lindahl, & Ekebergh, 2013). Samuelson's (2011) study of patients' memories of the ICU while mechanically ventilated reported the demeanour of the staff was important for patient well-being. Nurses with positive attitudes and behaviours such as respect and empathy made aspects of ICU treatment bearable. Furthermore, comforting care, such as a relaxing, secure, positive environment created for daily routines was appreciated when being washed, bathed and shaved (Samuelson, 2011). Having trust in the nurse meant patients could become mentally prepared for examinations and interventions (Engstrom et al., 2013). In contrast, patients felt a lack of privacy, exposed and insulted when nurses performed personal cares and did not solely concentrate on their comfort and well-being, with patients reporting nurses having conversations with other nurses (Lindberg et al., 2015; Samuelson, 2011).

Being dependent on the nurse could change the nurse-patient relationship if the nurses did not recognise their vulnerability and the power imbalance in their relationship (Moen & Nåden, 2015; Yang, 2016). Hence the attitude of the nurse was important for patients to feel cared for as an individual. Attributes such as, compassion, encouragement, attention, comforting, relieving fear and creating security were important (Hofhuis et al., 2008; Lindberg et al., 2015; Stayt et al., 2015; Wahlin et al., 2009). Patients could feel alone and abandoned with loss of dignity when they felt they were not seen or taken care of (Egerod et al., 2015b; Fredriksen et al., 2008; Storli et al., 2008). Moen and Naden (2015) investigated patients' perceptions of how their dignity was maintained while in ICU. Patients reported feeling violated when they were not heard or seen by nursing staff; this was particularly so when they were unable to speak. Condescending attitudes from staff were also perceived as undignified. Being seen and heard as patients provided good experiences. This was associated with confirmation and invitation to the beginning of the nurse-patient relationship.

Throughout the unpleasant experiences that patients endured in the ICU, family and their familiar faces and voices become a comfort and lifeline to reality (Cutler et al.,

2013; Egerod et al., 2015b; Eriksson et al., 2011; Storli et al., 2008); family gave support and consolation that healthcare professionals could not provide (Engstrom et al., 2013). Svenningsen et al. (2016) reported even during periods of hallucinations and unreal experiences family could become part of the experience, but to the patient they were still the familiar and often sided with the patient in their fight for life. Despite some patients reporting they had no or few memories from their time in the ICU, patients did appear to remember that family were at the bedside most of the time in Eriksson's (2011) study of patients' and families' experiences of visiting in ICU. Although patients did not always know what was happening to them, the presence of family made them feel secure and that they were with them during their struggle for life (Eriksson et al., 2011). This was similar to other studies where family presence was associated with being inter-connected and whole, even when patients could not interact and were weak (Olausson et al., 2013; Wang et al., 2008).

Family support and encouragement is considered an important factor which contributes to patients' recovery (Wang et al., 2008). Family remind patients of their life outside of ICU, gave them strength to fight and something else to focus on (Cutler et al., 2013; Engstrom et al., 2013; Wang et al., 2008). The strength patients received from the presence of family was reported as significant to getting them through their critical illness, and when family were not there it caused great upset for the patient (Cutler et al., 2013; Eriksson et al., 2011; Storli et al., 2007). Feelings of loneliness and fear were described when family was absent (Engstrom & Söderberg, 2007). Relatives further provide the link between the patient and nurse because they were able to offer nurses a chance to know the patient on an individual level (Wassenaar, Schouten, & Schoonhoven, 2014).

Confronted with one's mortality

Patients' realisation that critical illness could have resulted in death is well recognised in the literature (Almerud et al., 2007; Cutler et al., 2013) and this realisation is profoundly confronting (Cutler et al., 2013; Samuelson, 2011; Wang et al., 2008). The thought that patients might die in the early phase of their illness was due to their physiological deterioration (Papathanassoglou & Patiraki, 2003; Samuelson, 2011) and then as their illness progressed in relation to the dreams they had (Magarey & McCutcheon, 2005; Papathanassoglou & Patiraki, 2003; Roberts & Chaboyer, 2004; Storli et al., 2008).

Fear and panic associated with the thought of dying sometimes related to the struggle to breathe or the use of the face mask with non-invasive mechanical ventilation³ (Samuelson, 2011). Patients described the fear caused by being so dependent on mechanical ventilation and this made them worry about death due to the potential of the mechanical ventilation failing them (Johnson et al., 2006; Wang et al., 2008). Engstrom et al. (2013) described how patients listen to the sound of the ventilator for reassurance when they were unable to breathe for themselves.

Storli et al. (2008) described how patients felt panic and thought other patients were dying near them. Similarly, another study reported the fear of dying and thought of patients dying around them made the room feel like a post-mortem room, with symbols of death and misery everywhere (Engstrom et al., 2013). Patients further describe believing that all other patients in the ICU were dead (Cutler et al., 2013).

Cultural interpretations of dreams in relation to dying were commonly reported throughout the literature. These included dreaming about people that patients knew had already died, and these dreams evoked fear (Magarey & McCutcheon, 2005). Similarly a Greek study found patients dreamed about dying, however these dreams did not cause anxiety but evoked peacefulness (Papathanassoglou & Patiraki, 2003). In an Australian study, dreams about conversations with their maker were described (Roberts & Chaboyer, 2004). Being close to death was described, with encounters of seeing the light at the end of the tunnel or bright lights or going to heaven or the black shadow (Johnson et al., 2006; Lof et al., 2006; Tembo et al., 2012).

Perception of the environment of the ICU

The perception of the ICU environment is interpreted through the patients' altered body and mind and so is described as a complex and multidimensional place that is ever changing and entwined into the patients' experiences (Olausson et al., 2013; Svenningsen et al., 2016). The ICU is a scary and strange place that is unknown and described as technologically intense to the patients (Almerud et al., 2007; Wang et al., 2008). Being surrounded by technological medical equipment makes patients feel invisible, as nurses at times appear to concentrate on machinery and not the patient (Stayt et al., 2015). Despite these feelings patients trust the technology because

³ A face mask is strapped tightly on a patients face to maintain positive pressure mechanical ventilation.

healthcare professionals do (Almerud et al., 2007). The presence of technology surrounding patients, at times, made them feel secure and provided them with a sense of optimism for their recovery (Stayt et al., 2015). However, technology alone does not make them feel safe, they also needed to feel trust and security through interactions with staff. Technology and healthcare professionals must both work together to provide a safe and secure environment (Olausson et al., 2013).

Disturbances from noise, lighting, and the presence of people in the ICU is particularly bothersome at times. Reports of noise from loud voices and conversations between nurses was more annoying than the alarms from the machinery and was thought to hinder their recovery (Hofhuis et al., 2008; Wang et al., 2008). Noise affects patients' ability to have quality sleep (Hofhuis et al., 2008) and patients feel unprotected as the impact of noise could become so brutal they could not escape it, causing a lack of control (Johansson, Bergbom, Wayne, Ryherd, & Lindahl, 2012). Johansson et al. (2012) studied noise levels in the ICU, describing the noise within the environment over one day in ICU in correlation with the patients' physiological status. The overall mean sound level for all patients over a 24 hour period was 53 dB (LAeq) with maximum levels ranging from 82 to 101 dB (LAeq)⁴. Four of the seven patients displayed early signs of delirium, but on statistical analysis they found no correlation between high numbers of early signs of delirium and high sound levels. However, this needs to be interpreted with caution as they only observed patients over one day rather than the accumulative effects of high levels of noise. Tembo and Parker's (2009) study of factors that affect ICU sleep argued that noise produces a range of physical and psychological stress responses and associated problems, including negative changes in cardiovascular and respiratory signs and disturbed sleep. Sleep deprivation is another factor that has a strong correlation with delirium (Belanger & Ducharme, 2011).

Olausson et al. (2013) conducted a phenomenological study in which they investigated patients' experiences of being cared for in an ICU. Their study highlighted the importance of the aesthetic environment for the patients' well-being by illustrating how the interior of the room and personal belongings gave strength so the patient could

⁴ The World Health Organisation recommends that sound levels should not exceed 35dB LAeq in daytime and 30dB LAeq at night in rooms in which patients are being treated (World Health Organisation, 1999)

better endure their illness. A nearby window expanded the room and a view of nature was associated with being alive and reconnecting the patient with the world beyond (Olausson et al., 2013). The physical environment of the ICU with overhead lights can be hard for patients, regardless to whether the patient was sitting upright or lying in a bed, with horizontal lighting being hardest to tolerate (Fredriksen & Ringsberg, 2007). Merilainen et al.'s (2010) observational study of the ICU environment also noted how patients reacted to variation in lighting by cringing, as well as disturbance from noise resulting in poor quality of sleep. They concluded the stress caused to patients from noise, lighting and equipment may be harmful to recovery. Patients are in an environment which they cannot influence, but noxious stimuli can be reduced and managed by healthcare professionals.

Sharing a room with another patient complicates matters as patients struggle with their own problems but can see other sick patients with similar problems (Almerud et al., 2007). The presence of other patients, even if not seen, could be heard. The Johansson et al (2012) study found patients feel helpless hearing frightening noises from other patients. These patients are often separated from the other patient by a curtain so they cannot see one another, but they hear noises such as coughing, gurgling, vomiting and screaming. Realising patients are deteriorating, by listening to healthcare professionals' talk and perform interventions within earshot, was difficult to bear. Similarly the Olausson et al. (2013) study revealed hearing other patients' discomfort caused distress, since it was impossible to protect them or escape from this suffering. This increased the anxiety for patients regarding their own survival and therefore also depleted their energy.

[An unfolding journey of a critical illness](#)

Many studies of ICU experiences have not focused on the whole recovery process from a critical illness, but concentrated on the patients' recall of the ICU, and not their lived experience (Cutler et al., 2013). Over the last twenty years knowledge of long-term consequences of a critical illness has increased. Physical, cognitive and psychological problems are well recognised as post-ICU issues (Jones, 2014; Rattray, 2014; Rattray & Hull, 2008; Svenningsen, Langhorn, Ågård, & Dreyer, 2015). It has become recognised that critical illness should be viewed as a continuum to include transfer from ICU and follow up appointments when discharged home (Rattray, 2014; Samuelson & Corrigan, 2009). There is clear evidence that patients suffer a range of

physical and psychosocial problems during their recovery period (Svenningsen et al., 2015). Furthermore it has been demonstrated throughout the literature that the experiences of patients during ICU are often not integrated into their being until they are well enough to process them (Egerod & Bagger, 2010; Engstrom, Andersson, & Soderberg, 2008).

Waking up after a critical illness could be confusing and shattering. Patients had no idea where they had been or how long they had been unwell (Palesjö, Nordgren, & Asp, 2015). Nightmares and fragmented memories make it difficult to grasp what actually happened and are described as more vivid than normal dreams (Palesjö et al., 2015; Svenningsen et al., 2016). These frightening memories have been found to remain with patients for years (Storli et al., 2008; Svenningsen et al., 2016). More recent studies investigating former ICU patients' experiences of living with memories of critical illness have highlighted that many are still burdened with their memories years later. Storli et al.'s (2008) phenomenological study investigated the meaning of living with memories from ICU ten years later. Although the chronology of order had faded, the actual detail of the events as memory was still strong and flash backs could resurface without warning causing intense anxiety. Feelings of suffocation, tightening of the chest, and not being able to have anything or anyone touch their throat related to their experiences of being in the ICU. For a participant readmitted to ICU again a few years later, the feelings of being insecure resurfaced and was recognised as something that is permanently embedded in their being. Similarly, Zetterlund, Plos, Bergbom and Ringdal (2012) found that patients' memories had not changed between one and five years after ICU and that memories could also resurface unexpectedly, hence the need for follow up and debriefing about these experiences is vital to ensure patients can accept these and move on.

As healthcare advances and more patients survive their critical illness there is a growing body of evidence that indicates that patients encounter many unpleasant experiences within the ICU. Critical illness is clearly a significant life event and it important for nurses to understand these experiences to alleviate patients' anxieties. However, the studies described in this chapter provide an indication of patients' experiences of critical illness at one point in time and not throughout their illness and recovery. Therefore, there is limited knowledge of the key issues that emerge for patients throughout their critical illness experience on this continuum. Despite the lack

of prospective research on patients' experiences, critical reviews of patients' experiences have highlighted some common themes that have been portrayed in this review such as unreal experiences, proximity to death, perceptions of body changes, perceptions of the ICU environment and relationships with health professionals and support from family and friends (Cutler et al., 2013; Egerod et al., 2015a). To grow the body of evidence on patients' experiences of a critical illness studies need to consider the whole experience as it develops over time.

The context of families' experiences in the ICU

This next section reviews the selected literature on the experiences for family, while a family member is in the ICU. Firstly, it is important to understand that a contemporary family at any one point in a multi-cultural society is changeable. There is great diversity in the form of defining family in New Zealand today and therefore it needs to be considered in relation to this study. Family includes nuclear families, sole-parent families, blended families, families with gay or lesbian parents and extended families. Significant others, such as close friends, that are important to a person at a particular period in one's life may also be included as family during an illness. Within New Zealand when a patient is unconscious in the ICU, it may be difficult to know who may visit the patient and so this is generally referred to the next of kin (NOK) to inform nurses who is permitted to visit the patient. The CCNS Standards for Critical Care Nursing Practice require nurses to acknowledge, promote and respect the role of family/whānau during their family members critical illness (Critical Care Nurses Section, 2013).

Within New Zealand, Māori are the indigenous people and the Treaty of Waitangi is based on an agreement between Māori and the Queen of England, which established the rights of Māori as tangata whenua, or people of the land. Māori have a collective, rather than individual approach to whānau (extended family). Whānau are inclusive and made up of multiple generations, extending widely to include those who have a kinship tie. Often, when a whānau member is seriously ill, wider whānau will have a strong sense of obligation to visit and offer care for the immediate whānau members (Mitchell, Wilson, & Aitken, 2015, p. 206).

The importance of family presence for ICU patients' well-being has been documented in the literature (Cutler et al., 2013; Engstrom et al., 2013; Engstrom & Söderberg, 2007; Eriksson et al., 2011; Wassenaar et al., 2014). The unexpected admission of a

family member into the ICU with a life threatening illness can cause overwhelming anxiety and stress for family. It has been suggested their level of stress is influenced by the interactions they have with the patient, but also the healthcare professionals when visiting (Soderstrom, Savernan, & Benzein, 2006; Wong, Liamputtong, Koch, & Rawson, 2015). Early research into family needs, while their relative is in ICU, has been influenced from Molter's seminal study that resulted in the development of the Critical Care Family Needs Inventory (CCFNI). The CCFNI is a questionnaire in which family rank the importance of each need from a list of 45 (Molter, 1979). These needs have been categorised in similar order of importance. These are the need for information, reassurance, closeness, support and comfort (Ågård & Harder, 2007; Hinkle & Fitzpatrick, 2011; Lee & Lau, 2003; Obringer, Hilgenberg, & Booker, 2012; Olding et al., 2015; Verhaeghe, Defloor, Van Zurren, Duijneste, & Grypdonck, 2005). Since Molter's early work on the evolution of the concept of patient-family centred care there has been progress in advancing knowledge of families' needs that is grounded in mutual partnerships amongst healthcare professionals and patients and families (Mitchell et al., 2016)

The need for information

The need for information and knowledge about the patient's condition was ranked as of most importance to family in a review of 46 publications (Verhaeghe et al., 2005). However, a number of barriers identified within the literature complicates this need. Communication difficulties between family and healthcare professionals appeared to be the main barrier to families having their needs for information met (Paul & Rattray, 2007).

How information is shared can inform the experiences for family. One of the most important ways nurses connected with families was sharing information. The relationship with the nurse was described as setting the tone for the experience, dependant on whether they connected with the nurse (Eggenberger & Nelms, 2007; Soderstrom et al., 2006). Communication that is unsupportive hindered sharing of knowledge and information about the patient's condition. Wong et al. (2015) studied families' interactions and experiences with staff in ICU. This demonstrated how supportive and unsupportive communication affected the process of obtaining information. Supportive communication included reassurance, responding to

nonverbal cues, being able to obtain information at any time and the consistency of information between various staff members. In contrast, unsupportive communication included staff speaking abruptly, rudely or providing inconsistent information (Wong et al., 2015). Similarly Olausson et al. (2012) reported the way the family was introduced to the ICU was significant; the tone of their conversation determined the experience, with emphasis on the trust family put into healthcare professionals' competence and ability to take care of their family member.

The importance of the initial interactions which family have with healthcare professionals in the ICU has been shown to have a substantial effect on further interactions. Soderstrom et al. (2006) studied interactions between family and healthcare professionals using observations and interviews to demonstrate how explicit information about rules and policies of the ICU, the condition of the patient, and how to behave around the bedside was highly valued. However not all information was given clearly, or family became confused about the rules due to their high stress levels. When family felt confused about the rules they felt uneasy and they did not want to ask again due to confusion and stress. If they did not adhere to the rules, instead of healthcare professionals clarifying information and rules, some just ignored the family (Soderstrom et al., 2006). As demonstrated in another study, when relatives do not fully understand information about the patient's condition they are not able to cope as well with the stressful situation. Nurses were generally identified by participants as being able to give understandable information about the patient's condition and treatment in contrast to doctors who would use a lot of terminology that families did not understand (McKiernan & McCarthy, 2010). These studies highlight the need for nurses to clarify each family's understanding of the patient's condition and provide progress reports on an on-going basis.

Agard and Harder (2007) conducted a qualitative grounded theory study exploring relatives' experiences of having a close family member in ICU. This Scandinavian study highlighted the coping strategies that family used under stressful circumstances. The need for ongoing information resulted in family members being in a state of constant alertness and they were always asking for and clarifying information. Family also spent time observing the patients' monitors, the contents of drainage tubes, and watching the surroundings and listening to sounds. Making assessments for themselves about the patient's condition became part of their daily routine (Ågård &

Harder, 2007). This is comparable with Eggenberger and Nelm's (2007) study in which relatives described that as time progressed in the ICU, they were more able to gauge the progress of their family member's condition by their observations and by listening to healthcare professionals speak to each other about the patient.

Problems with obtaining information from healthcare professions was related to how it was conveyed and questions answered. Dreyer and Nortvedt (2008) studied the experiences of relatives with a family member who was sedated and ventilated in a Norwegian ICU. All participants reported insufficient information was received from healthcare professionals. There was no written information, and it was given at random intervals with relatives always having to initiate information exchanges (Dreyer & Nortvedt, 2008). Blom et al. (2013) found that information was needed continually and in several forms, such as verbal and in the written diary that accompanied the patient. Information given as a pamphlet combined with meetings have been suggested to facilitate better information exchanges and reduce anxiety (Paul & Rattray, 2007).

The difference in what family ranked as important compared to what healthcare professionals ranked as important has been found to be significantly different in many studies with the CCFNI. Family identified information and assurance as the highest priority with healthcare professionals ranking personal, cognitive and trust needs (Al-Mutair, Plummer, O'Brien, & Clerehan, 2013). The need for on-going information is clearly an issue that has been identified in both the qualitative and quantitative literature. Family are important in the care of critically ill patients as they provide on-going support to the patient, advocate for and consent to their treatment. The ability to meet the needs of family of critically ill patients is clearly an on-going problem.

[The need for closeness](#)

The strong desire for family to be in close physical proximity to the patient is clear throughout the literature (Kutash & Northrop, 2007; Lee & Lau, 2003; Linnarsson, Bubini, & Perseius, 2010; McKiernan & McCarthy, 2010). Eggenberger and Nelm's (2007) phenomenological study of family's experiences when an adult member has a critical illness demonstrated the need for closeness as a fundamental need for the family. Although the ICU was foreign and overwhelming, families report the need to be near the ICU and their sick relative. Families felt connected when close to their relative as they also endured their illness. Being close meant they could protect the patient emotionally, ensure they received trusted nursing care and the right decisions

were made. When nurses discouraged family involvement and displayed a task-orientated attitude towards the patient, disregarding the family, they felt a sense of distrust (Eggenberger & Nelms, 2007). The need to be close and to ensure family could see that patients were well cared for has been described in a number of studies (Blom et al., 2013; McKiernan & McCarthy, 2010).

Wanting to be close to their relative also involved wanting contact. When patients were sedated, family worried as it indicated the seriousness of the patient's condition. During their struggle to make contact with the patient, they wished the nurse would be nearby and offer security (Karlsson, Forsberg, & Bergbom, 2010). Being near the patient meant togetherness, it enables them to empower the patient to fight their illness (Blom et al., 2013; Olausson et al., 2012). However, this closeness is controlled; bedrails could prevent closeness and the presence of staff prevents any intimacy (Olausson et al., 2012).

Further to being close, the need to be doing something for the patient was also found to be important. Blom et al.'s (2013) study found some family members wanted to participate in care, but the way in which family were encouraged or allowed to participate differed. Their involvement was often based on routines or nurse's personal views without consideration of the family's prior involvement or the individual situation. When they were excluded it was distressing and they feared for the patient being dehumanised or objectified (Blom et al., 2013). Al-Mutair et al.'s (2013) review of family needs and involvement in the ICU reports evidence of many studies demonstrating family desire to be involved in care of the patient. These studies revealed when they were involved in care, the family's anxiety was reduced. Furthermore, it demonstrated that healthcare professionals had positive attitudes towards family and considered family as important as the care of the patient.

Wanting to be close to the patient was difficult to manage when family needed to care for children and/or carry out work commitments. This was a strain for family as the critically ill patient took priority (Eggenberger & Nelms, 2007; Linnarsson et al., 2010; McKiernan & McCarthy, 2010). Daily duties became unimportant and they lacked motivation at home to manage tasks (Linnarsson et al., 2010). There was a sense of guilt when they could not be near the patient (Eggenberger & Nelms, 2007)

and when family could not visit due to ICU restrictions, it caused frustration (Linnarsson et al., 2010).

The need to be close also involved periods of time in the ICU waiting room. A room that was nearby, comfortable and friendly was welcoming when family had to wait or needed to be alone (Linnarsson et al., 2010). Waiting outside could become stressful when the patient was unstable and needed interventions from healthcare professionals (Olausson, Ekebergh, & Osterberg, 2014). Waiting often involved sharing space with families who were also waiting. At times families felt exposed to others who were sharing similar experiences, which could result in them also becoming part of another person's suffering. In contrast, others have reported the waiting area to be a place where they could receive emotional support from other families (Kutash & Northrop, 2007).

The need for comfort, reassurance and support

The need for reassurance was found in some studies to be as important as the need for information (Verhaeghe et al., 2005). Furthermore the need for hope has also been identified as of great significance (Al-Mutair et al., 2013; Eggenberger & Nelms, 2007; Engstrom & Soderberg, 2004). Hope was found to be of greater importance when illness was sudden and serious (Verhaeghe et al., 2005). Spiritual activities were seen as significant to maintain hope, even if these activities had not been prominent in their life before (McKiernan & McCarthy, 2010). Family needed to trust their own ability to use their faith and maintain hope to endure the situation (Linnarsson et al., 2010).

Support from nurses and doctors was also imperative. Frivold, Dale and Slettebo's (2015) study of family members' experiences in Norwegian ICUs revealed support was crucial in helping relatives cope with frightening experiences. Nurses played a key role in providing a sense of security. Furthermore, a single nurse as a contact person to whom they could turn was ranked as highly important. Nurses who demonstrated personalised care and compassion towards them, facilitated them to be able to talk over their feelings and concerns (Frivold et al., 2015). These supportive nursing attitudes and actions that were significant for families' wellbeing were also identified by Blom et al. (2013), who identified how nurses gave relatives a sense of reassurance when they acted in a thoughtful and competent way. Furthermore, they also revealed that when family are familiar with the healthcare professionals, a sense

of continuity is created that gives them confidence. When family are supported by healthcare professionals it reduces stress. Soderstrom et al. (2009) studied families' adaptation to the ICU and demonstrated that when families were able to express feelings of despair and share their suffering it assisted with support for the family's adaptation. If suffering was not openly expressed then support may not be given (Söderström et al., 2009). Lack of connection with the nurse caused anxiety and mistrust for family (Eggenberger & Nelms, 2007).

Family roles and relationships were affected by a family member's critical illness, causing them to feel removed from their social context. Strong social networks were important to help them get through the ordeal. Family support was seen as strengthening or worsening with conflicts (Linnarsson et al., 2010). A strategy used by families to endure a critical illness was to gather the family together and stay close (Söderström et al., 2009). To support positive relationships with the patient and family, nurses need to consider introducing important values, beliefs and practices of the patients and their family and incorporate them into their care (Mitchell, Wilson, & Wade, 2015). Olding et al's (2015) scoping review of patient and family involvement in the ICU identified that although the relationships between nurses and family were significant, the wider organisational and contextual factors that shape the conditions of family involvement in ICU were largely under-researched. Although unit culture influences patient and family experiences, patients and family also have their own beliefs and culture that will impact on their experiences. The nurse should work in collaboration with the family to identify important cultural beliefs that should be observed during the patient's stay in ICU.

[The context of nursing in the intensive care unit](#)

Nurses working within the ICU are accustomed to providing complex nursing care to critically ill patients in highly technological environments. Within the next section, the literature on the overarching themes of nursing within this context include caring for critically ill patients within a technological environment and the emotional burden of working within this context.

[Nursing critically ill patients in a technological environment](#)

The proliferation of technology within the ICU plays a significant role in the nurses' experiences of providing care in this environment (Almerud, Alapack, Fridlund, & Ekebergh, 2008b; Olausson et al., 2014; Tunlind, Granström, & Engström, 2015;

Wilkin & Slevin, 2004). It has been acknowledged that a challenge for nurses is to remain focused on individual and human aspects of care while incorporating technology into their practice. This entails the mastery of technology that supports and develops nursing practice (Wilkin & Slevin, 2004). Mastery of technical competence for nurses in the ICU has been described as not just an adjunct to care, but the process of knowledge, skills and equipment needed to care for the individual patient (Crocker & Timmons, 2008). These attributes are learnt from experiences and sharing of knowledge within a team environment (Storesund & McMurray, 2009).

Price (2013) used an ethnographic approach to study nurses' ability to care for patients within the technological environment of the ICU. Her study demonstrated how nurses integrate care and technology as one in what they describe as a 'crafting process'. Although technology could take up a lot of nurses' time, as reported in other studies, nurses appreciated the aspects of caring with technology and they were not viewed as separate entities. The influences on patient care were seen as multi-faceted and complex, involving personal traits of staff, patients and family, as well as team dynamics, cultural norms and organisational priorities. Crafting these together enabled elements to work cohesively to achieve positive outcomes for patients (Price, 2013). Support and team work have been previously reported as crucial factors that influence the quality of nurses' work in the ICU. Support included debriefing, effective and respectful communication and education (Storesund & McMurray, 2009).

Nurses recognise the technological environment as unnatural, but to them it is normal and they believe technology does not interfere with their ability to care for patients (McGrath, 2008). Tunlind, Granstrom and Engstrom (2015) conducted a descriptive qualitative study with eight ICU nurses in Sweden, examining how nurses experienced performing nursing care in a highly technological environment. They revealed how technology was seen to facilitate nursing work and save time but equally it could also create more work. Modern beds facilitate patient turns, and monitors created safety by continually monitoring patients' physiological parameters, however, it also made some fundamental cares take longer because, of the technical equipment that needed to be managed. Nurses felt frustrated that it impacted on their ability to find a comfortable sleeping position for patients (Tunlind et al., 2015). This is contrary to McGrath's (2008) findings, which reported nurses had admiration for technology and perceived it as a normal part of their practice. However, nurses in this study did report

technology caused a number of issues for nurses as they witnessed the depersonalised control it has over patients (McGrath, 2008). Olausson et al. (2014) illustrated how technology characterises the ICU with its identity by transforming the critically ill body from something invisible to visible.

Almerud et al (2008b) conducted a phenomenological study of the meaning of being a nurse in the technologically intense environment of ICU. They reported technology was seen as a driver for treatment and control and the technology had a hierarchy with the clinicians at the top and the patient at the bottom. Technology was instrumental in the treatment and attitudes of the clinicians. Mastery of the equipment by nurses gave a sense of control and documenting technological procedures was seen as more prestigious than patient comfort. Machinery controlled all clock time and there was no quality time to comfort and listen to patients' needs (Almerud et al., 2008b). Price (2013) reported the unspoken elements, such as how routines and tasks were performed, that influenced nurses' working patterns within the ICU were so ingrained that they were not noticed, but affected patient care. Nurses felt pressurised to achieve tasks on time and wanted to be seen as busy.

For nurses, technology constituted safety and security and was seen to gradually become an extension of their body (Olausson et al., 2014). The patient could become lost amidst the technology, but the more experienced caregiver was seen to integrate care and technology as one (Almerud et al., 2008b; Price, 2013). Technology was also seen to create uncertainty (McGrath, 2008; Olausson et al., 2014). Nurses reported distress from caring for technology dependent patients who were dying and from doctors who were unwilling to make a decision about end of life care (McGrath, 2008) and critically ill patients, whose nurses were uncertain of the outcome (Olausson et al., 2014).

Close physical presence at the bedside is seen as essential to identify signs that indicate changes in the patient's condition (Kvande, Delmar, Lykkeslet, & Storli, 2016). Being vigilant and the use of surveillance are some of the strategies nurses use to detect subtle changes in patients' conditions (Price, 2013; Tunlind et al., 2015). Vigilance was also important to progress the patient toward recovery and involved practical and decision-making skills in physical, psychological and technical areas (Price, 2013). Close proximity to the patient not only creates physical safety but was seen as vital to build

a bond of trust with patients (Wassenaar, Boogaard, Hooft, Pickkers, & Schoonhoven, 2015).

Emotional burden of nurses' work

Repeated exposure to patients with life-threatening illnesses or trauma, and sudden critical events can be difficult for nurses working in this area, with the potential for an emotional burden from the progressive and repeated exposure causing emotional stress (McGrath, 2008; Olausson et al., 2014; Shorter & Stayt, 2010). There are many factors that influence stress levels for ICU nurses. One of the most obvious is the acuity of patients, which can make care complex, resulting in a heavy workload (Epp, 2012). Other factors include end of life issues (Coombs, Addington-Hall, & Long-Sutehall, 2012; Henrich et al., 2016), ethical decision making (Henrich et al., 2016), observing continuous suffering of patients (Choe, Kang, & Park, 2015; McAndrew, Leske, & Garcia, 2011), medically futile care (Sibbald, Downar, & Hawryluck, 2007), miscommunication (Choe et al., 2015; McAndrew et al., 2011), and dealing with distressed relatives (McAndrew et al., 2011). Furthermore, the work environment has become increasingly more complex, with advances in medical technologies requiring nurses to constantly extend their skills (McAndrew, Leske, & Schroeter, 2016; Olausson et al., 2014).

Siffleet et al. (2015) conducted a qualitative grounded theory study in Australia to explore ICU nurses' perceptions of emotional well-being in the work environment. Fifteen registered nurses with a mean age of 39.4 years were interviewed. The length of time working in the ICU ranged from 3 to 25 years. The main theme identified in this study was an ability to protect themselves from distress. Nurses were also able to describe experiences of emotional wellbeing. Nurses sought to avoid distress by a process of protection. This entailed a practice of delivery of best care to their patients and family to facilitate the nurse's emotional wellbeing. Nurses then validated care episodes through reflection with a colleague or with themselves. To avoid distress nurses used physical and psychological strategies to distance themselves, such as listening to music after a shift, and emotional barriers, such as avoiding difficult situations or communication and asking not to care for certain patients (Siffleet et al., 2015). Many previous studies about nurses' emotional wellbeing focused only on the aspects that cause distress (Azoulay et al., 2009; Choe et al., 2015; Poncet et al., 2007)

however, this study is important because it also reveals the factors that counteract this distress.

Whitehead et al. (2015) conducted a descriptive, comparative design study investigating moral distress among all healthcare professionals. Of the 592 participants, moral distress was present in all groups, however, nurses and other healthcare professionals involved in direct patient care had significantly higher moral distress. Watching patients suffer and poor communication with doctors were ranked as the highest for sources of moral distress. Nurses had the highest level of distress compared with other healthcare professionals and ICU nurses had the highest levels of moral distress across all groups. The study also demonstrated that moral distress was higher for clinicians, such as nurses, who are not the primary decision makers (Whitehead et al., 2015). These findings are similar to Wiegand and Funk's (2012) study determining clinical situations that create moral distress for ICU nurses. They revealed that distress was also related to factors that were outside the control of nurses. Issues, such as end of life care or care that was overly aggressive and futile, organ donation, and over or under administration of analgesic medications, all caused nurses moral distress. Hence doctors may have the legal responsibilities for the instigation of orders, but nurses are the ones carrying out the orders and witnessing distress in patients.

Van Mol et al. (2015) conducted a systematic review on the prevalence of burn out and compassion fatigue amongst healthcare professionals in the ICU, with an emphasis on preventive strategies available. Burn out was defined as "an emotional and behavioural impairment that results from repeated exposure to high levels of occupational stress, characterised by emotional exhaustion, depersonalisation and loss of personal accomplishment" (p. 3). Compassion fatigue was defined as a "state of physical or psychological distress arising from an ongoing process in caring relationships with vulnerable individuals" (p. 3). There are fewer studies on the prevalence of compassion fatigue versus burn out. Burn out was mostly measured using the validated Maslach Burnout Inventory, but despite this they reported the prevalence of burn out to vary significantly from 14% to 70%. This variance was attributed to the different measures used. Clearly there was a degree of emotional distress for healthcare professionals working within the ICU, but the extent of this phenomenon remains unclear because of the variance in measures used across studies

(van Mol et al., 2015). Similarly McAndrew, Leske and Schroeter (2016) conducted a synthesis of the moral distress literature, which revealed inconsistencies in measurements with conflicting degrees of moral distress. However, their synthesis of the qualitative findings did highlight a number of factors. Firstly, organisational barriers have been negatively correlated with moral distress. Organisational barriers to nursing autonomy, such as hierarchical relationships, poor team work, poor staff ratios, inadequate time to care for patients and technology that does not meet patients' needs, all potentiated moral distress for nurses. Communication problems between the nurse, patient, family and doctor during end of life care were also highlighted. Moral distress was associated with negative outcomes for patients and family, with avoidance behaviours by nurses, and potentially poor communication and inadequate nursing support (McAndrew et al., 2016). A range of intervention strategies were reported within the literature. These included educational programmes on emotional distress, improving family-centred care and communication skills, as well as personal coping mechanisms. Preventive strategies included improving the work environment, developing team building and focusing on social and individual coping strategies.

Summary

From the literature reviewed on the patients', families' and nurses' experiences of critical illness there is little doubt that human suffering is evident in all participant groups. However, the variance in studies, their aims, retrospective nature and recall bias means this does not give the individual trajectories for the different groups of participants throughout their illness experience. All these studies focus on general ICU patients, their family and healthcare professionals who care for them, at a particular time in their illness. No attempt has been made to consider the critical illness trajectory from a three-way perspective. Therefore, there is no understanding of how the experiences change as the patient's illness progresses and how the interplay between the groups influences each other's individual trajectory. As the critical illness journey is constructed by patients, family and healthcare professionals, it is appropriate to establish an understanding of how this three-layered interplay is shaped.

The next chapter reviews literature related directly to the case on a prolonged critical illness within the ICU. This included literature that reviews the development of this group of patients, differing definitions used to describe these patients, and clinical manifestations and clinical problems identified with this cohort. Literature related to

patients and their family's experience of a prolonged critical illness is reviewed along with literature that addressed the nurses' experiences of caring for this group of patients.

Chapter 3 – The Case of a Prolonged ICU Stay: The Literature Review

Advances in intensive care medicine have created a new disease called the chronic critical illness...it is a devastating condition (Desarmenien, Blanchard-Courtois, & Ricou, 2016, p. 1)

Introduction

In the previous two chapters the underlying contexts of the case, firstly related to the development and structure of the ICU was reviewed. This is followed by a review of the selected literature on patient and family experiences of a critical illness that necessitated an admission to the ICU, and the nurses' experiences of caring for patients in the ICU. This chapter reviews the literature concerned with the case of a prolonged critical illness that necessitates a prolonged ICU stay. The review begins with the recognition of a new group of patients and the different terminology used to describe these patients. It draws literature together on chronic critical illness (CCI) experiences from the perspective of the patient, family and the healthcare professionals who provide their care. In doing so I aim to highlight the gaps in the literature in relation to the case of the prolonged critical illness

The search strategies involved searches of the following electronic databases: Web of Science, CINAHL, SCOPUS, Google Scholar and Medline. The search terms were: *intensive care, critical care, long-term patient, prolonged mechanical ventilation, long-term mechanical ventilation, chronic critical illness, failure to wean and experiences*. The focus of the search related to adult general intensive care and not a clinical specialty.

New group of patients

The term CCI was first used in the literature in 1985 by Girard and Raffin from the United States of America (USA), to describe a group of patients who had survived their initial critical illness, only to then become dependent on intensive care therapies for a prolonged period of time. These authors acknowledged a number of the complexities involved in the care of this group of patients. Firstly, they described the decision making and ethical challenges related to the continuation of treatment or withdrawal of support in a group of patients with poor outcomes. Secondly, they

recognised the physiological impact of critical illness on body systems making patients prone to nosocomial infections, cardiac events and gastro-intestinal bleeding. Finally, they noted the unsuitability of a fast-paced environment to provide care to patients for a prolonged period of time. They recommended interventions such as mobilisation, adequate nutrition, careful fluid management and emotional support including the need for adequate sleep, to improve outcomes for these patients (Girard & Raffin, 1985).

As the number of CCI patients grew due to the continued development in intensive care therapies, the burden this group of patients placed on hospital services in the USA was substantial (Daly, Rudy, Thompson, & Happ, 1991; Douglas et al., 1995). These patients were viewed as 'unpopular' and 'unchallenging' by doctors and nurses within the fast-paced intensive care environment (Daly et al., 1991). Increasing financial costs, bed occupancy and a shortage of intensive care nurses saw the development of a special care unit (SCU) at The University Hospital of Cleveland. At this time patients requiring a long-stay represented 3% of the total number of patients admitted to the ICU but they used 28% of the total bed days (Daly et al., 1991).

Patients were transferred to the SCU after they had survived their initial critical illness phase but were dependent on mechanical ventilation for a prolonged period of time. The SCU was designed to have less technological monitoring, be family-orientated, and junior doctors were replaced with nurse managers who coordinated patient care with the senior doctor. The design of the unit included private rooms large enough to accommodate family presence. The patients' schedule was coordinated to allow maximum rest and sleep (Douglas et al., 1995). The nurses working in this SCU were all experienced critical care nurses with approximately eight years' experience, with the characteristics of professional maturity and a particular interest in this patient group, which were seen as vital to the success of the unit. A case management model directed all patient care by registered nurses (Daly et al., 1991).

Recognising the need for evidence-based care, for interventions to manage this group of patients, research programmes commenced, at the Case Western Reserve University in the USA (Daly, Douglas, & Kelley, 2005). Early studies showed the SCU was associated with significant positive outcomes. In-hospital mortality was lowered by 11%, patient readmission to hospital was reduced by 12% and there was a reduction

in cost of care by 20% (Daly et al., 1991; Douglas et al., 1995). However, these patients continued to have a high mortality rate of 85% at 1-year post-hospital discharge compared to other ICU patients with rates at 10-36%. As a consequence, debate about the futility of care for this group of patients emerged (Douglas et al., 1996). Research programmes investigated this population further with more emphasis on predictors of mortality, withdrawal of treatment and do-not-resuscitate practices (Carson & Bach, 2001; Daly et al., 1996; Happ, Swigart, Tate, Hoffman, & Arnold, 2007).

As the body of research increased on CCI patients, it was complicated by lack of common definition. Despite this, demographic information about this group of patients was collected and within 10 years this group of patients had doubled in USA hospitals to 10% of ICU patients. Half of these patients were over 65 years of age and patients with co-morbid conditions before their initial acute illness had a higher risk of CCI (Carson & Bach, 2002). Due to the increasing burden of CCI on hospital resources it was important to identify at risk patients. Studies looked at predictors for CCI such as prolonged mechanical ventilation (Seneff, Zimmerman, Knaus, Wagner, & Draper, 1996), the need for an elective tracheostomy for failure to wean from mechanical ventilation and extubation failure (Nierman, 2002). These studies added to the body of knowledge about this group of patients.

Long-stay patients in New Zealand and Australia

Comparing the limited Australian and New Zealand studies, the study by Crozier et al. (2007) aimed to define the long-stay patient in Australian and New Zealand ICUs and determine the characteristics of this group and the resource usage. Data was extracted from the Australian and New Zealand Intensive Care Society Adult Patient Database, which contained data on 70% of all ICU admissions in both countries. Of the 263,874 patients in the dataset, 6565 had a length of stay greater than 21 days, and had a mean age of 60.3 years. This accounted for 2.3% of all patients but they used 23% of the total bed usage. Metropolitan and tertiary hospitals had the highest proportions of long-stay patients. The most common diagnosis within this group was respiratory disease at 23.5% of all patients, with pneumonia comprising the largest sub-group. The three admitting diagnoses most strongly associated with long-stays were neuromuscular disease, burns, and cervical spine injury. Mortality was 28%, compared with 13.6% for patients with a shorter stay (Crozier et al., 2007). Given the economic and resource cost of long-stay patients, Carden, Graham, McLennan and

Celi (2008) conducted a study to identify factors that may predict the prognosis for this group of patients within a tertiary hospital in New Zealand. Retrospectively they reviewed data on patients with a length of ICU stay greater than seven days and a combined ICU/ HDU stay of greater than 14 days. Of the 3240 patients admitted to that ICU, 207 fulfilled the criteria and of these 207 patients, 28% died before discharge from hospital, and 40% died within one year of admission to ICU. Older patients were more likely to be dead at one year, as well as patients admitted post-cardiac arrest however, multiple trauma patients were more likely to be alive at one year. Patients who had a cardiac arrest in ICU or developed sepsis or renal failure that was not suitable for renal support therapy, were more likely to be dead at one year. During their stay in ICU, patients developed a range of complications similar to other problems reported in the CCI literature. These included cardiac arrests, acute coronary syndrome, sepsis, pneumonia, pulmonary embolus, hemorrhage and acute renal failure. Of note Māori made up only 3.8% of these patients, which could be related to the geographical area of New Zealand, where there is a lower percentage of Māori living, however Māori also have a higher rate of co-morbidities⁵ which, may mean they die earlier in their ICU stay and therefore could also explain this figure (Carden et al., 2008).

Definitions of chronic critical illness

Despite research into this group of patients, there is no consensus on the definition of what is a patient with a prolonged critical illness, making it difficult to compare any literature reporting outcomes and developments in care practices. Furthermore, the transition from an acute to prolonged critical illness is gradual and there is no defining point which adds to the complexity of definition for this group of patients. However, it is clearly acknowledged throughout the literature, that without contemporary life support therapies, CCI would not exist (Damuth, Mitchell, Bartock, Roberts, & Trzeciak, 2015; MacIntyre, 2012; Marchioni, Fantini, Antenora, Clini, & Fabbri, 2015)

There are many indicators which have been used to define this group of patients within the literature. These definitions will be discussed further. They are:

⁵ Māori make up 15% of New Zealand population, and have a higher percentage of co-morbidities compare to non-Māori

- Tracheostomy insertion at four to ten days of mechanical ventilation;
- Requiring prolonged mechanical ventilation;
- Failure to wean from mechanical ventilation;
- Chronically critically ill; and
- Persistent critical illness

Tracheostomy insertion

The placement of the tracheostomy tube after a failed attempt at weaning or on mechanical ventilation after four to ten days has been suggested by some authors as a point of demarcation in identifying CCI patients (Camhi & Nelson, 2007; Nierman, 2002). Tracheostomy insertion is the transition from an acute to a chronic condition with the expectation that the patient is going to require mechanical ventilation for a prolonged period (Carson, 2012; Cooper, Bernacki, & Divo, 2011). However, there are a number of difficulties related to defining a long-term patient by insertion of a tracheostomy tube. There are individual variations between doctors and ICU guidelines as to when they may consider the appropriate time to insert a tracheostomy (Carson, 2012). There are also patient factors that need to be considered such as hemodynamic stability to cope with the procedure of having a tracheostomy. This definition has practical implications because it allows for identification through searching for Diagnosis- related groups⁶ (DRG) codes that are linked to tracheostomy and mechanical ventilation within the ICU (Carson & Bach, 2002; MacIntyre, 2012)

Prolonged mechanical ventilation

Prolonged mechanical ventilation (PMV) is one of hallmark features of CCI patients and is often the reason why patients need the ICU for such a prolonged period, therefore it is another common criteria for defining this group of patients (Carson, 2012; MacIntyre, 2012; Nelson et al., 2010). The problem with this definition is that PMV has been defined as anywhere from 24 hours to greater than 29 days on mechanical ventilation (Carson, 2012; Wiencek & Winkelman, 2010). A uniform definition was seen as important for interpreting literature, analysing data outcomes and influencing reimbursement schemes in the USA. These problems were recognised and the National Association for Medical Direction of Respiratory Care Consensus Conference in 2004 defined prolonged mechanical ventilation as greater than 21

⁶Diagnosis-related groups: a classification of acute hospital episodes of patient care. Australia and New Zealand have their own DRG version

consecutive days on mechanical ventilation for more than six hours a day (MacIntyre et al., 2005). Despite this definition, it is still not used consistently in the literature. Concern about the high predicted mortality for patients requiring PMV for greater than the 21 days and the fact that severity scores could not predict mortality lead to Carson et al. (2008) demonstrating that a prognostic score (Prognosis for Prolonged Ventilation [ProVent]) could distinguish surviving to non-surviving patients. This score was later validated at other research sites, demonstrating a predicted mortality at day 21 of PMV of 48% (Carson et al., 2012).

Defining by failure to wean

Weaning from mechanical ventilation covers the entire process of liberating the patient from mechanical support and from the endotracheal tube (Boles et al., 2007). Recognition of when the patient is ready to have mechanical ventilation successfully withdrawn is shown to reduce the likelihood of complications (L Rose & Nelson, 2006). The weaning process starts with the spontaneous breathing trial (SBT) through a T-tube or with a low level of continuous positive-airway pressure ⁷(CPAP) or pressure support, for a period of 30 – 120 minutes. If the patient copes with this they may be considered ready for extubation. If unsuccessful this process can be tried again for up to seven days by which time they may be ready for successful extubation. Beyond this, the patient is considered a prolonged wean if after more than three trials of a SBT or if they are still on mechanical ventilation after seven days from the first SBT (Navalesi et al., 2014). The European Respiratory Society (ERS) Task Force has also defined the difficult-to-wean patient as one who requires more than seven days of weaning after their first SBT (Boles et al., 2007).

Failure to wean from mechanical ventilation within 48 to 72 hours reflects the severity of illness and underlying pathology (Wiencek & Winkelman, 2010). For the patient with CCI, ventilator dependence has been shown to be multifactorial and related to injuries from the initial critical illness, resulting in injuries to the lungs; critical care neuromyopathies; malnutrition; and drug therapies that all contribute to poor respiratory function. Furthermore, it has been argued that spontaneous breathing trials should not be attempted in patients needing PMV until the patient has managed some

⁷ CPAP: a method of ventilation by a flow of air delivered at constant pressure throughout the respiratory cycle. CPAP can be delivered through an endotracheal or tracheostomy tube or a tight fitting mask around the patient's mouth and or nose.

level of ventilatory support decrease (MacIntyre, 2012). As a consequence of weaning failure, patients undergo prolonged ventilator dependence, which is a hallmark feature of CCI (Ambrosino & Gabbrielli, 2010; MacIntyre, 2012; Nelson et al., 2010; Wiencek & Winkelman, 2010).

Chronic critical illness

From its early definition by Girard and Raffin, the term CCI has evolved to be recognised as a syndrome characterised by respiratory failure, requiring prolonged mechanical ventilation, and other multi-organ dysfunction. Nelson et al. (2010) argued that CCI occurs in patients with limited physiological reserve, due to older age and comorbidities who as a result of an acute illness are then prone to developing ventilator dependence and other clinical problems. However not all patients with CCI are older and have co-morbidities. Furthermore, although PMV has been recognised as a hallmark indicator of CCI, not all CCI patients require mechanical ventilation and may be dependent in the ICU due to protracted hypotension, dependence on dialysis and non-invasive ventilation (Cooper et al., 2011; MacIntyre, 2012).

With increasing costs from the development of long-term acute care (LTAC) hospitals and minimal change in outcomes for this group of patients, the USA Research Triangle Institute, developed a definition of CCI to standardise payment methods (Iwashyna, Hodgson, Pilcher, Orford, et al., 2015). CCI became defined as greater than eight days in ICU with one of the other following criteria: prolonged mechanical ventilation (greater than 96 hours); tracheostomy; sepsis and other severe infections; severe wounds; and multiple organ failure, ischemic stroke, intracerebral haemorrhage, or traumatic brain injury (Kandilov, Ingber, & Morley, 2014).

Using this definition Kahn et al., (2015) showed 7.6% of ICU patients in the ICU in the USA, met the CCI criteria, and the most common eligibility conditions were prolonged mechanical ventilation and sepsis, with hospital mortality being 30.9%. They noted a steady increase in the incidence of CCI across the older age group, with a decline after 80 years of age due to early mortality. Importantly, this study found the incidence of CCI was steadily rising every year with hospital costs rising from \$15.6 billion in 2004 to \$26 billion in 2009. Further to this alarming cost, a recent systematic review and meta-analysis of 39 studies across 16 countries by Damuth et al. (2015) of long-term survival of critically ill patients treated with prolonged mechanical ventilation demonstrated the reported mortality at 1-year as 59%. However, the

mortality for the USA was 73% at 1-year compared with 47% mortality from other countries. These studies highlighted the need to have a clear consensus of definition across international intensive care communities and to develop interventions to shorten length of stay.

Persistent critical illness

The term persistent critical illness (PerCI) appeared within the literature in 2015. Proposed by Iwashyna et al. (2015) as a new concept which was viewed as a more appropriate term for patients and is used by clinicians in Australian and New Zealand ICUs. They suggest the concept of CCI encapsulates a range of syndromes such as a prolonged wean from mechanical ventilation, a prolonged ICU stay, and diseases with a prolonged intrinsic recovery time, hence the term CCI is insufficient to guide care and research (Iwashyna, Hodgson, Pilcher, Orford, et al., 2015). The authors hypothesis was that a substantial and growing group of patients appear to be intensive care unit-dependent because of a cascade of critical illnesses rather than their original ICU admitting diagnosis (Iwashyna, Hodgson, Pilcher, Orford, et al., 2015). With clinicians from Australia and New Zealand, Iwashyna (2015) developed a web-based survey to identify the characteristics of patients with PerCI. Their results revealed PerCI developed after a median of 10 days and occurs in 10% of all ICU patients and 50% of all patients with a prolonged ICU stay. The most defining feature of this patient group was the need for invasive mechanical ventilation (90%) and a tracheostomy (80%). The most common clinical problems identified were respiratory insufficiency (68%), delirium (59%), and acquired neuromuscular disease (54%). Outcomes were expected to be poor with only 10% of patients with PerCI being expected to be alive and home six months after ICU discharge. The most common recommendations provided from this survey were to improve multidisciplinary coordination and planning (20%), increase access to physiotherapy (16%), improve communication with families (10%) and improve nutritional support (8%). The use of a clinician as a liaison for each patient to ensure coordination of their care; along with improved access to natural light and the outdoor environment for the patient and other general improvements to ICU practices was recommended to improve care. They concluded that few studies are directly comparable with theirs (Iwashyna, Hodgson, Pilcher, Bailey, et al., 2015), however, much of the CCI literature has identified these characteristics, problems and outcomes. The difference is the variation in their study

population (which they have not alluded to) such as admission criteria and treatment options for patients within New Zealand and Australia which are significantly different from those in the USA.

Following this study, Iwashyna et al. (2016) conducted a retrospective, population-based, observational study in which they hypothesised that, among patients still alive in the ICU, the onset of PerCI can be identified as the day during critical illness which admission diagnosis and physiological illness severity, cease to predict outcomes. Data were obtained from the Australian and New Zealand Intensive Care Society Adult Patient Database, which included approximately 80% of all ICU admissions between 2000 and 2014⁸. Over the course of the patients' stay in ICU, the admission diagnosis and physiological abnormalities at predicting outcome progressively decreased and by day ten no longer predicted outcome, which they define as the onset of PerCI. This transition occurred between day seven and day 22 in the diagnosis based subgroup and between day six and day 15 across risk-of-death subgroup. Of patients who stayed longer than ten days they accounted for 5% of all patients in Australia and New Zealand, but their stay accounted for 32% of all ICU bed days and 14.7% of all hospital bed days. In 2014, the estimated annual population-based incidence of people who develop PerCI in hospital was 22.3 per 100,000 people (Iwashyna et al., 2016). Of note this study used data from the Australian and New Zealand Intensive Care Society Adult Patient Database, as did Crozier et al.'s (2007) study, in which included 70% of all ICU admissions who identified patients who had a stay of 21 days accounted for 2.3% of patients but used 23% of the bed days.

Iwashyna and colleagues suggestion that acute ICU patients' transition to a persistent state around day ten is similar to the theory proposed by Van den Berghe, de Zegher and Bouillon (1998) that endocrine dysregulation plays a critical role in the transition to CCI. Similarities are also apparent in various authors' theory of allostasis in which patients transit from the acute phase of their illness to a chronic phase (Bellar, Kunkler, & Burkett, 2009; Brame & Singer, 2010; Cuesta & Singer, 2012). Furthermore within literature on CCI, it is recognised as an illness that exhibits different physiology when

⁸ This is the same data base Crozier used in 2007 to define a long stay patient in New Zealand and Australia

compared with the acutely ill ICU patient (Carson & Bach, 2002) and therefore different psychosocial factors.

Iwashyna argues that the term CCI was not developed in collaboration with ICU health professionals and therefore the term may have minimal relevance to clinical practice. However, the early work on CCI from the USA was started from research projects to assist healthcare professionals deal with an emerging complex group of patients and therefore was clinically relevant to practice. Despite Iwashyna (2015) claiming that these patients show different clinical characteristics than their admitting diagnosis, this difference has been demonstrated in numerous studies on CCI patients (Carson, 2012; Nelson et al., 2010; Wiencek & Winkelman, 2010)

Regardless of terminology used to describe this group of patients, they all endured a prolonged critical illness. The terminology used is context dependent on countries' healthcare resources and treatment limits, as well as healthcare professionals' understanding of these terms. Until all healthcare professionals recognise that this a distinct group of patients, terminology will differ according to the context it is used. Furthermore, on-going advancements in healthcare and the impact those have on critically ill patients will result in this cohort constantly changing, making one definition unachievable. Therefore, the generic term of prolonged critical illness that is context dependent is appropriate for this study.

[The theory of allostasis as a framework to manage CCI](#)

During a critical illness the body is in a state of excessive physiological and psychological stress. The impact of infection or trauma starts a cascade of cytokines and hormones that are released in an attempt to restore homeostasis; this is the alarm stage of the classic stress response. It is during this time that medical interventions sustain life (Vermes & Beishuizen, 2001). Uncompensated stress can precipitate a pathophysiological cascade of multi-organ dysfunction and death. Importantly the stress response is the same whether the stressor is external or internal in that it activates the hypothalamic–pituitary–adrenal (HPA) axis (Papathanassoglou, Giannakopoulou, Mpouzika, Bozas, & Karabinis, 2010).

Before contemporary critical care therapies such as mechanical ventilation and drug therapy were developed people died, however critical care now can provide support for failing body systems and the body is supported by machines and medications

(Hollander & Mechanick, 2006). During this sustained stress response, allostasis allows the body to regain and maintain stability by adjusting the major physiological systems in order to survive. The main receptors of allostasis are the hypothalamus, the anterior pituitary gland, the adrenal glands, the sympathetic nervous system, and the immune system, which protects the body by responding to internal and external stress (Bellar et al., 2009). Allostasis is an adaptive process and central to the stress response as it can distinguish between systems essential for life, such as body temperature, pH balance, or oxygen tension and those that can be adjusted (Brame & Singer, 2010; Carlson & Chamberlain, 2005).

The theory of allostasis has been suggested as a framework to understand the physiological characteristics and the management of patients with CCI (Bellar et al., 2009; Hollander & Mechanick, 2006). Allostasis is defined as the adaptive process for actively maintaining stability through change. However there is cost to the body if the mediators of allostasis are released too often, leading to allostatic load, which can be described as accumulative 'wear and tear' (Korte, Koolhaas, Wingfield, & McEwen, 2005). Throughout critical illness allostasis allows the individual to respond to changes in their environment and cope with stress by equally initiating a response and terminating it once the threat has passed (Brame & Singer, 2010). This is the hallmark of an effective stress response. But in patients who survive their initial critical illness without regaining allostasis, the stress response becomes ineffective and prolonged (Bellar et al., 2009). This has been postulated to occur around day seven to ten of the critical illness (Hollander & Mechanick, 2006). This occurs in patients who have been critically ill for a prolonged period and who have sustained multiple organ and tissue damage from an ineffective allostatic response. Hence the concept of allostasis and allostatic overload are important in the consideration of the management of a patient with a prolonged critical illness.

After a prolonged period of critical illness, there is suppression of the hypothalamus and its releasing factors. This leads to the wear and tear of a prolonged critical illness due to the decrease of these mediators. Catabolic metabolism is favoured and fatty infiltration of organs leads to further organ damage (Bellar et al., 2009). The pronounced protein hyper-catabolism results in muscle atrophy and weakness which then contributes to difficulties weaning patients from mechanical ventilation resulting in a vicious circle of a prolonged critical illness (Hollander & Mechanick, 2006). This

cycle of prolonged critical illness is further accentuated by activation of stress responses from the psychological stress of mechanical ventilation dependency and anxiety (Papathanassoglou et al., 2010).

Common Clinical Characteristics of CCI

To better understand this group of patients it is suggested CCI should be considered a syndrome which is an ineffective physiologic adaptation to a prolonged critical illness (Cooper et al., 2011). Evidence further suggests that CCI is a syndrome of multisystem dysfunction, neuroendocrine and immunologic dysfunction and physiological abnormalities (Bellar et al., 2009; Mechanick & Brett, 2002; Nelson et al., 2010; Wiencek & Winkelman, 2010). A hallmark feature of CCI is respiratory failure requiring prolonged dependence on mechanical ventilation (Campbell & Happ, 2010; Carson, 2012; Nelson et al., 2010; Wiencek & Winkelman, 2010). The syndrome is characterised by a number of clinical characteristics as seen in Table 1.

Table 1 Clinical Characteristics of CCI

Clinical Characteristics of CCI
<ol style="list-style-type: none"> 1. Respiratory failure with prolonged dependence on mechanical ventilation (Campbell & Happ, 2010; Carson, 2012; MacIntyre, 2012; Marik, 2015; Nelson et al., 2010; Nierman, 2002; Tredant, 2010; Wiencek & Winkelman, 2010) 2. Organ failure/multi-organ failure (Tredant, 2010; Wiencek & Winkelman, 2010) 3. Profound weakness from myopathy and neuropathy (Nelson et al., 2010; Tredant, 2010) 4. Loss of lean body mass (Nelson et al., 2010; Wiencek & Winkelman, 2010) 5. Increased vulnerability to infection (Nelson et al., 2010) 6. Brain dysfunction manifesting as coma or delirium (Nelson et al., 2010; Wiencek & Winkelman, 2010) 7. Skin breakdown (Nelson et al., 2010) 8. Anasarca (Marik, 2015; Nelson et al., 2010)

Although these characteristics may present during acute critical illness, it is the duration that make them distinct to CCI patients (Nelson et al., 2010). The burden of these physiological problems of CCI on the patient is substantial. Studies have

identified significant multiple physiological and psychological symptoms which cause high levels of distress (Campbell & Happ, 2010; Nelson et al., 2004).

The definition for this group of patients continues to be challenging because of varying theories and terms used. From a global perspective, the epidemiology of critical illness and ICU resources differs significantly due to differences in availability and intensity of health service, therefore mortality and morbidity rates will vary between countries. Furthermore, a complex interplay of clinical decision-making will differ between countries in relation to limits on treatment and availability of beds. Differences in countries such as the USA, who provide support for elderly patients with comorbid illnesses in intensive care, will have a higher burden of critical illness associated with illness such as CCI (Adhikari et al., 2010). When comparing definitions and characteristics of patient groups these fundamental challenges need to be considered as they will influence characteristics of patient groups.

Regardless of what definition is used to define this group, on a practical level, these patients have all survived their initial critical illness and are dependent on intensive care supports for a prolonged period of time. With on-going advancements globally in critical care treatments, there is likely to be an ever-changing patient group with differing clinical characteristics, consequently the term given to this group of patients may be constantly under debate. The challenge for healthcare professionals is to recognise the ever changing patient groups and implement appropriate care early.

The experiences of patients with CCI

Due to the lack of a universal definition for this group of patients, it makes it difficult to find literature on the experiences of patients who have a long-stay in ICU. Literature on patients' experiences has used definitions of:

- CCI;
- Prolonged mechanical ventilation/ long-term mechanical ventilation; and
- Experiences of tracheostomy while in the ICU.

Due to the lack of definition on what are the physiological characteristics of a long-stay patient, there is also no set length of stay. One would anticipate that a patient's experiences of a stay in the ICU for three days compared with three to six months is going to be vastly different. The literature reviewed in this section relates to patients

who were mechanically ventilated for greater than seven days in the ICU and overviews their experiences. The main themes identified related to the burden of illness that cause distress, which is further categorised by:

- Experiences of a tracheostomy and mechanical ventilation; and
- Distress from symptoms

Experiences of a tracheostomy and mechanical ventilation

Having a tracheostomy is a point of demarcation in identifying CCI patients (Camhi & Nelson, 2007; Nierman, 2002), hence the literature on the patients' experiences of having a tracheostomy is important to understand for this patient group. Foster (2010) conducted a phenomenological study of patients who had a tracheostomy while in the ICU; although only a small sample group, all patients had a stay in ICU greater than 14 days. The distress from symptoms due to the tracheostomy were related to communication difficulties, painful procedures, and general discomfort from the tracheostomy. Examples of general discomfort were: ongoing irritation at times leading to persistent coughing, a sore throat and having the tube suctioned. All these discomforts compounded feelings of fear and anxiety (Foster, 2010). Similarly Breckenridge, Chlan and Savik (2014) studied patients' anxiety levels who had a tracheostomy to assist with weaning from mechanical ventilation, their study involved 116 patients, 51 of whom had a tracheostomy performed to assist with weaning from mechanical ventilation. Following placement of a tracheostomy, patients' anxiety levels did not significantly decrease. This study is contrary to Blot et al.'s (2008) study which found patients reported more comfort with a tracheostomy tube, compared with endotracheal intubation. However, anxiety and comfort are different experiences, and comfort may be increased with a tracheostomy tube in comparison to an endotracheal tube due to the gagging and choking sensations that can be provoked. Anxiety is still likely to be significant if communication difficulties are still present and pain from tracheal suctioning, shortness of breath and fear from the illness itself are still experienced.

Johnson et al. (2006) conducted a phenomenological study in Australia with the aim of describing and interpreting the meaning for patients of being on long-term mechanical ventilation. Nine participants who were in ICU for greater than seven days participated in this study. The study revealed how patients experienced living in a world so different from their usual, which was predominately described as unpleasant

and a frightening experience. At times they endured irritation and annoyance at the presence of endotracheal/tracheostomy tubes and ventilator tubing, with these devices causing the most significant discomfort. In addition participants also reported the unfamiliar, and persistent noise and sensations of choking and suffocating associated with intubation as the most unpleasant experience (Johnson et al., 2006).

Arslanain-Engoren and Scott (2003) conducted a phenomenological study of the experiences of patients who survived prolonged mechanical ventilation to identify salient factors that contribute to successful weaning from mechanical ventilation. This study included seven participants who had an average hospital stay of 37 days, however the length of time in the ICU is not stated. Participants reported being scared, frightened and angry about their need for ventilatory support and were fearful they would not be able breathe again on their own. Participants reported a determination to be freed from ventilatory support and to go home free from the tracheostomy which they all had inserted to assist with mechanical ventilation weaning. The need for a strong will-power was considered essential to breathe independently (Arslanian-Engoren & Scott, 2003). The many emotions patients experienced during weaning from mechanical ventilation was also identified in Chen, Lin, Tzeng and Hsu's phenomenological study in China. This study consists of 20 participants who had a mean stay of 43 days in a respiratory care centre. Patients worried about the removal of the ventilator and whether they would be able to breathe independently, feelings of breathlessness and fatigue meant patients felt helpless, increasing their anxiety (Chen, Lin, Tzeng, & Hsu, 2009). The feelings of breathlessness and anxiety during weaning were also described in a phenomenological study of ten participants in a Turkish ICU who had a mean length of stay in ICU of 44 days (Tosun, Ayla, Ünver, Akbayrak, & Hatipoglu, 2009). These studies demonstrate a high level of anxiety and discomfort throughout their illness experiences in the ICU. The on-going burden of this constant state of anxiety and stress is likely to be detrimental to the weaning process for this group of patients and ultimately delaying recovery.

Symptom distress

Symptom management is a fundamental part of nursing care, however communication difficulties can hinder nurses' awareness of the exact nature of the suffering ICU patients' experience. The severe burden of symptoms which patients with CCI endure

has been reported and a number of studies have alluded to this (Nelson et al., 2004; Nelson et al., 2006; Rose, Nonoyama, Rezaie, & Fraser, 2014). One of the earlier studies that introduces the concept of distress for CCI patients examined the symptom burden patients experienced. Nelson et al. (2004) conducted a prospective cohort study in a 14 bed respiratory unit that accepted CCI patients. They used the Condensed Form of the Memorial Symptom Assessment Scale (MSAS-C) to obtain self-reports of symptoms twice a week from patients who could understand the scale and communicate their responses in some form. Data were obtained from 50 participants with a median age of 73 and a median length of stay in ICU of 15 days. Among participants responding to symptom assessment, approximately two thirds were cognitively intact during the majority of assessments and approximately 90% were symptomatic. The symptom that caused the highest level of distress was pain with 44% of participants reporting this. More than 60% of participants reported psychological symptoms, such as sadness, worry and nervousness, at the highest level. Approximately 90% of patients reported the highest level of distress due to difficulty with communication. The prevalence of the other symptoms at the highest level of intensity was unsatisfied thirst at 80% and dyspnea at 60% (Nelson et al., 2004). This study was the first to focus specifically on CCI patients and examine symptom intensity during their ICU stay. The feelings of thirst have been described in other studies of long-term patients with the feeling that thirst was severe and led to dreaming about water (Rose et al., 2014; Tosun et al., 2009).

Nelson et al. (2006) then went on to examine cognitive dysfunction in CCI patients. They conducted a prospective cohort study of 203 patients at multiple points during their illness and after discharge. Prevalence and duration of coma and delirium using the Confusion Assessment Method (CAM) for the Intensive Care Unit with the Richmond Agitation-Sedation Scale were used. Before hospitalisation, 75% of the patients lived at home, 56% were completely independent and 82% were cognitively intact. During their time in the respiratory care centre, 30% were comatose throughout their stay. Patients spent on average 17.9 days in a coma or 25.6 days delirious and half of the participants were still delirious or comatosed on discharge from the respiratory care unit. At six months, post discharge, 68% of survivors were profoundly impaired and unable to respond to telephone cognitive assessments. Less than 10% were living at home without brain dysfunction as measured by the CAM. This study

demonstrated that brain dysfunction is another prominent feature of CCI, which if prolonged was associated with longer lengths of stay and poorer functional outcomes (Nelson et al., 2006).

The burden of symptoms remains apparent in a recent study by Lamas et al. (2016). This study using semi-structured interviews with 30 CCI patients and 20 family members in a long-term acute care hospital addressed quality of life, expectations and planning for setbacks. Of the patients in the long-term acute care hospital, 40% required mechanical ventilation via tracheostomy either continuously or intermittently with the remainder being weaned off mechanical ventilation but still had a tracheostomy. One of the main issues described by patients was their poor quality of life, with distress from symptoms such as hunger, thirst, difficulty communicating, boredom and poor mobility. One participant described his day dependent on mechanical ventilation as “torture...all day like this, it’s awful” (Lamas et al., 2016, p. 359). Foster (2010) describes how participants in his study found deviations from normal communication, coughing, swallowing and being feed as so abnormal. The loss of normal body functions had a huge impact on patients, causing constant worry even when the discomfort may have ended.

Anxiety is one of the most commonly reported symptoms in patients who receive prolonged mechanical ventilation (Breckenridge et al., 2014; Chlan & Savik, 2011; Rose et al., 2014; Tate, Dabbs, Hoffman, Milbrandt, & Happ, 2012), reported up to 85% of the critically ill patients assessed using the Anxiety Faces Scale (Karnatovskaia, Johnson, Benzo, & Gajic, 2015). There are numerous factors that cause anxiety in this patient group but loss of control for patients is a common factor (Johnson et al., 2006; Rose et al., 2014). The connections between anxiety and patients’ inability to communicate appear to be closely related, due to patients not being able to share their physical and emotional needs, which is the foundation for on-going anxiety.

Communication is reported in a number of studies as a distressing problem (Johnson et al., 2006; Nelson et al., 2004; Rose et al., 2014; Tosun et al., 2009). Verbal communication is a fundamental aspect of social interaction, therefore when this is lost, patients’ identities are lost (Foster, 2010). Being without speech meant patients

were unable to indicate their needs to nurses and family adding to their anxiety. Being unable to communicate was also ranked as the most bothersome in a study of patients' recall after prolonged mechanical ventilation (Rose et al., 2014). Foster's (2010) study participants described frustration at not being able to communicate verbally. In addition, not being able to write their needs down due to weakness and lack of coordination, resulted in some patients becoming psychologically withdrawn and not wanting to interact with family and healthcare professionals.

The high burden of symptoms, inability to communicate their needs and loss of control led to feelings of helplessness, anger and despair resulting in patients wanting to give up. Jubran et al.'s (2010) prospective study of patients on prolonged mechanical ventilation in a specialised weaning centre in the USA, identified 42% of patients had developed depressive disorders. Patients who had depressive disorders also had a higher rate of weaning failure at 31% and increased mortality by 10% (Jubran et al., 2010). However a study by Johnson et al. (2006) reported that some participants tried to reclaim their life by re-engaging with staff and family, seeking control over treatments and attempting to communicate. Gaining control occurs with self-determination, as demonstrated in Arslanian-Engoren and Scott's (2003) research where patients credited a positive attitude and determination with successful liberation from mechanical ventilation, as to be liberated from the ventilator was associated with the patient trying to become normal again.

These studies all highlight the high burden of symptoms endured by a patient with a prolonged critical illness. However, they have only focused on a specific aspect of illness experience. The prolonged duration of these symptoms has the potential to impact on outcomes and increase length of stay. Protracted stress throughout a critical illness, according to the theory of allostasis, causes on-going damage to organs and potentially accentuates the illness. Hence, it is important to consider the phases of the illness so that interventions can be targeted specifically.

Families' experiences of CCI

Families prolonged exposure to stress because of an uncertain trajectory due to complications and a poor outcome for the CCI patient can deplete the family's ability to cope. Literature from the USA has highlighted that family members have distinct

characteristics and needs and it is important to recognise their needs are different when acute illness became chronic. Nelson et al. (2005) conducted a qualitative study to investigate what information is relevant and important for doctor-patient/family communication as critical illness became prolonged. Patients, their family member (who was their decision maker) and healthcare professionals involved in their care, from an urban tertiary respiratory unit in the USA were invited to participate. From their interviews, six domains of information for communication and decision-making were identified as important by all participant groups. Firstly, the need for information about the nature of the illness and proposed treatments should be communicated as the illness enters a chronic phase. The need for prognosis information at the time of transition from the acute to the chronic phase including prognosis about the potential for liberation from mechanical ventilation. Information about potential pain and distressing symptoms was wanted by family members, furthermore, families of patients who survived hospital, but died soon after discharge described that if they had known about the potential for pain and suffering, with a poor outcome, they may have chosen not to have treatment. Patients and family thought potential complications should be part of communication and decision making during the transition to the chronic phase of their illness. Expectations of the long-term effects of illness on the patient was also considered important for family as well as information about alternatives to continuation with treatment. Which healthcare professional group gave the information was not considered important by family as long as they were sensitive, honest, unhurried, and communicated in a language that could be understood (Nelson et al., 2005).

Following on from their previous research, Nelson et al (2007) investigated the information needs of patients with CCI and their families, to evaluate the extent to which these needs were met in practice and identify factors associated with communication of information about CCI. The decision makers, two patients (98 lacked capacity) and 98 family members, were the participants in this study. From their previous qualitative study, the six domains that were identified as important were developed into a four-point Likert scale for use in a questionnaire. These six domains were: 1) nature of patient's illness and treatments; 2) prognosis for outcomes including ventilator independence, function and quality of life; 3) impact of treatment on patient's experience, including symptom burden; 4) potential complications of

treatment; 5) expected care needs after hospitalisation; and 6) alternatives to continuation of treatment. For 16 of 18 items, more than 98% of the participants agreed that information on the topic was important for decision making when the illness became prolonged. However, almost half the participants still received no information about the majority of the items in the questionnaire. Most participants received information about the need for a tracheostomy and the immediate implications of that, but received no information about short-term consequences of CCI, such as distressing symptoms, complications and risk of mortality or the long-term burdens and effects of CCI (Nelson et al., 2007).

Most patients with an acute illness lack capacity to make decisions about life-sustaining treatments. Literature from the USA has focused on decision making by family members (surrogates) on treatment options when the illness becomes prolonged in relation to care in long-term weaning facilities (Camhi et al., 2009; Hickman, Daly, & Lee, 2012; Hickman & Pinto, 2014). However, they acknowledge that the psychological distress of critical illness and a lack of knowledge regarding the illness progression, can hinder the decision making capacity for family members and lead to regret at a later stage (Hickman & Pinto, 2014).

Douglas and Daly (2003) examined the patterns of depression in family members of CCI patients at discharge from hospital and six months later. They found that 51% of family members had some degree of depression upon hospital discharge which continued after discharge. Furthermore, six months after hospital discharge, primary family carers reported a drop in physical health. Further work by Douglas, Daly, O'Toole and Hickman (2010) demonstrated greater odds of being depressed if patients were discharged to a care institution rather than residing at home. There is no doubt that the uncertainty surrounding prolonged critical illness elicits states of enduring stress. The family are vulnerable to ongoing stress due to the nature of the patients' severity of illness and ongoing complications. Ongoing exposure to prolonged stress has detrimental effects on the family as the illness progresses. Literature on families' experiences of CCI is limited to studies from the USA and so caution needs to be taken when considering the New Zealand context because of cultural and social differences.

Nursing patients with CCI

There is limited literature that deals with the nurses' experiences of caring for CCI patients. Many of the complexities in the care for this group of patients are subtly alluded to in studies about nurses' experiences of caring for patients weaning from mechanical ventilation, or communication difficulties or causes of moral distress within the ICU.

Roulin and Spring (2006) recognised the problems of caring for this group of patients in the fast-paced environment of a traditional 18 bed ICU in Switzerland, where the slow progress of these patients became a source of frustration. A programme was developed to address these problems and the aims were to improve the nursing care of the CCI patient, increase staff knowledge about this patient group and develop specific interventions with the goal of improving patient outcomes. Emancipatory practice development⁹ guided the project. Initial analysis recognised the difficulties perceived by staff as patient characteristics and organisational/nursing problems. The combination of these problems was believed to result in frustration and burnout among staff. Two main themes were identified to improve outcomes for CCI patients and to diminish frustration, these were: 1) to better know CCI patients as individuals and 2) increase nurses' knowledge about specific problems and care interventions. With the overarching theme of 'knowing the patient', a number of new strategies were introduced. These included nurses obtaining a specialised patient history with emphasis on knowing the person's biography before the ICU admission, nursing rounds to improve care continuity and coordination and the introduction of patient diaries. Unfortunately this programme was never evaluated (Roulin & Spring, 2006).

Roulin, Boul'ch and Merlani (2012) went on to compare staff satisfaction between two models of care for CCI patients in two separate units. The first model, a patient-centred programme of care was evaluated in a traditional ICU, in the second model, patients were hospitalised in a multidisciplinary ICU ward that was dedicated to CCI patients only. Evaluation was performed using questionnaires completed by 147 healthcare professionals. Participants were more satisfied with the first model of care,

⁹ Emancipatory practice development focuses on getting evidence into practice and creating a culture of innovation and effectiveness, by breaking down barriers to taking actions with the assumptions that best practice is locally defined and contextualised and that research will not be used in practice, unless it is owned and regarded as relevant (Heyns, Botma, & Van Rensburg, 2017)

with the exception of relational conflicts about CCI patients, which was more problematic in the second model of care. In the qualitative findings participants' satisfaction was linked to the relationship with the patient and family as well as seeing the patient's progress. Nurses were satisfied with the possibility of offering patient-centred care, which was linked to better knowledge of the patient's history, thereby facilitating individualised care. In both phases of the study, nurses expressed dissatisfaction linked to the burden of care, with the patient not corresponding to the image of a typical ICU patient and there was lack of motivation for their care. Nurses described caring for this group of patients as punishing and downgrading, labelling patients as difficult and demanding. Professional development was identified as a predictor of staff satisfaction, which could be related to staff feelings of empowerment and greater autonomy (Roulin et al., 2012).

William's (2003) doctoral study, from the United Kingdom, explored the interaction between nurses and intubated patients in the ICU and the factors that influenced the development of such interaction. Of interest in her study were the attitudes of nurses in relation to long-stay ICU patients, who were considered attention seeking and demanding. Nurses stated they failed to challenge them because they did not meet the expectation of a genuine ICU patient. There was an assumption that this group of patients were unchallenging, resulting in them being allocated to junior nurses and, at times, nurses requested not to care for these patients creating problems with continuation of carers (Williams, 2003). These findings are similar to Crocker and Scholes (2009) ethnographic study to understand how nurses used technology to wean patients from mechanical ventilation. Patients who were weaning from mechanical ventilation were perceived as not so interesting and nurses would request not to care for the patient again. Similarly, Kydonaki's (2010) ethnographic study of approaches to weaning long-term ventilated patients, noted nurses often only cared for the patient once, following an algorithm during weaning. However, for complex long-term patients an individualised weaning plan is more appropriate and this was highlighted in Cederwell et al.'s (2014) study of nurses experience of management of weaning long-term patients from mechanical ventilation. This Canadian study defined prolonged weaning as greater than seven days of active weaning from mechanical ventilation, in which they noted the need for a patient-centred and targeted approach to weaning to achieve the best outcomes for the patient.

There is only one New Zealand study which has explored nurses experiences of caring for CCI patients, Butt's (2010) Master's thesis, used a qualitative exploratory design with five nurses. The main findings from this study were frustrations nurses had caring for these patients, and the lack of control they felt they had over the patients when they were awake. The patients' disorientation and inability to communicate, left the nurse with symptoms of work-load stress, exhaustion and fatigue. Nurses used many strategies to avoid care of these patients. The issue of some nurses not wanting to care for this group of patients it likely to be a complex phenomenon. Williams (2007) suggests patient groups who are described as unpopular, are long-term, or weaning or confused and agitated or high dependency patients. Why these patients are viewed as 'unpopular' may relate firstly to the constant vigilance required to ensure their safety. Opportunities for interaction can become very demanding of the nurses' time, and often interrupt nurses' hourly routines. Secondly these patients may deplete nurses' physical and psychological energy. Finally, patients may not meet the nurses' expectations of a 'typical ICU patient' failing to challenge them mentally (Williams, 2007). A study investigating the experiences of nurses when verbally communicating with critically ill patients, demonstrated how, when patients were awake, they were considered 'unpopular' by nurses because they were more difficult to care for and communicate with. Nurses wanted to care for unconscious and sedated patients due to their inability to initiate communication (Alasad & Ahmad, 2005). However, the reason why nurses do not want to actively communicate may not only be related to the difficulties and length of time it takes and this raises questions that need further exploration to understand nurse attitudes towards these groups of patients.

Leung et al.'s (2015) study on understanding the nurse's experiences of patients with CCI and their family, highlights the internal distress while caring for this group of patients. Their Canadian qualitative study with 16 ICU nurses reported internal tension nurses experienced with the knowledge of patients' poor prognosis and anticipated death, while simultaneously wanting to protect the family from suffering. Nurses reported shielding families from disturbing experiences by actively concealing aspects of the patient's condition that they felt may cause upset. To manage this, nurses were reluctant to initiate dialogue with the family. Distress was further reported for the nurses when they had to deliver care that they felt prolonged life and caused the patient undue suffering. This internal tension was deemed to be related to the challenges of

preserving hope and trust with the family and finding an appropriate way to engage family in discussions about the patient's condition and their responsibilities to be able to provide a 'good death' for the patient (Leung et al., 2015).

This burden and emotional distress while nursing CCI patients was highlighted in Siffleet et al.'s (2015) study investigating how nurses maintain their emotional wellbeing within the ICU. Nurses reported feelings of distress when care delivery was of a complex nature. Particular situations and patient characteristics were identified as impacting on nurse perceptions of achieving or failing to deliver best care. Long-term patients were one of the patient groups described in their study (Siffleet et al., 2015). This study raises the issue that nurses may distance themselves from this group of patients due to the burden of care and ethical issues that are commonly encountered. The complexities of this phenomenon need to be understood through the many issues which nurses may encounter throughout the trajectory of the patient's illness and not just a snapshot of one issue.

Transitions to palliation for patients with CCI

Although patients with CCI survive the acute phase of their illness, the unpredictable trajectory, with repeated complications, means that some individuals with CCI will require end-of-life-care as their condition becomes terminal. Hospital mortality rates for this group of patients is difficult to compare across hospitals and countries due to different admission criteria (Carson, 2012; Nelson et al., 2010). However, hospital mortality rates have been reported as high as 47% (Wiencek & Winkelman, 2010). As research also demonstrates poor outcomes there is a potential for treatment to be limited or withdrawn (Camhi et al., 2009; Nelson & Hope, 2012; Scheinhorn et al., 2007).

Earlier research identified problems with treatment plans in this group of patients related to prolonged ICU stays being expensive and often followed by death (Teno et al., 2000). Studies identified the low rates of discussion by doctors with patients and family about preferences for life-sustaining treatment and prognosis (Happ, Swigart, Tate, Hoffman, et al., 2007; Nelson et al., 2005; Nelson et al., 2007; Teno et al., 2000). Many patients reported they would have preferred their care to focus on palliation, with 47% reporting this did not happen (Teno et al., 2000). The need for improved

communication between healthcare professionals, mainly doctors, with patients and their family was highlighted to ensure patients received treatment that met their goals and preferences.

The communication difficulties identified within the literature in relation to end of life care are complicated by a number of factors. Firstly, patient survival in the acute phase gives the family hope (Nelson & Hope, 2012), secondly, placement of the tracheostomy is a further sign to the family of improvement (Nelson et al., 2005). The unpredictable nature of CCI challenged nurses ability to engage with family because of difficulties communicating expected outcomes, as nurses felt information could positively or negatively influence families' hope and cause distrust (Leung et al., 2015). As decision-making often defaults to the family due to the patients' physiological status, the burden can become overwhelming (Camhi et al., 2009). The involvement of patients in decisions about treatment was demonstrated in Happ et al. (2007) study where patients did participate, despite not being fully capacitated, as decision-making was shared and negotiated with healthcare professionals, family and patient. Despite this optimistic approach, Flannery, Ramjan and Peters (2016) reports difficulties with communication in relation to decision-making, which is not unique to this group of patients, and there is evidence of an overwhelming problem within the general ICU population as well.

The acute care focus has been identified as a barrier to implementing palliative care principles. A meta-analysis of transition to end-of-life care for CCI patients identified the ambiguous expectations of ICU treatment which saw initial aggressive treatment with healthcare professionals portraying the need for hope. (Leung, Angus, Sinuff, Bavly, & Rose, 2016). The poor prognosis for the patient caused internal tension for nurses as they often wanted to shield the family of CCI patients from the potential poor outcome (Leung et al., 2015), findings which are also supported in the general ICU literature (Coombs et al., 2012; Kisorio & Langley, 2016). The challenge for nurses regarding communication about end-of-life has been reported as problematic across all patient groups within ICU (Kisorio & Langley, 2016; Shannon, Long-Sutehall, & Coombs, 2011).

The transition from acute focus to palliation for this group of patients is likely to follow a similar trajectory. Care initially focuses on life saving treatment as a priority and the

problems arise between the phase of life-saving treatment and the dying phase. Identified within the CCI literature was the notion that healthcare professionals routinely provided life-sustaining treatment to patients when it was perhaps more appropriate to have a palliative care focus (Leung et al., 2016). This is similar to Coombs et al.'s (2012) study which identified three phases patients transitioned through when dying in ICU. Although this study did not focus on CCI patients, some patients had a stay of up to 22 days. The transition from curative to palliation was challenging for healthcare professionals due to identification of patients who may not survive, feelings that treatment was futile, which in turn threatened dignity and caused suffering. Long-Long-Sutehall et al.'s (2011) study on dying trajectories within the ICU revealed a number of possibilities in relation to withdrawal of treatment, one being the patient whose condition remained in a static position for days or weeks with nurses perceiving delays between medical teams agreeing to withdraw treatment .

The literature demonstrates the burden of impaired and inconsistent communication, unrelieved symptoms and distress with unclear goals and wishes for this group of patients (Koesel, 2008; Nelson et al., 2005; Nelson et al., 2004; Nelson et al., 2006). Due to the high burden of symptoms, communication difficulties about treatment and transitional planning for this group of patients, it is recommended that the principles of palliative care are essential components of care, such as holistic care, person-centred care, integrated care and treatment of symptoms, particularly as patients illness becomes chronic (Nelson & Hope, 2012). Palliative care is not seen as an exclusive alternative to life-saving care, but as integral component of comprehensive care because as palliative care is based on needs which, for this group of patients, is significant (Aslakson, Curtis, & Nelson, 2014). Hence this approach may be more successful at relieving the high burden of symptoms this patient group endures than the cure-orientated model of care (Leung et al., 2015).

Conclusion

In 1985 Girard and Raffin introduced the notion of the emergence of a new group of patients in the ICU. Since then, there has been no definitive definition for this group of patients, however the literature highlights the distinctive characteristic of this group of patients. Chronic critical illness is a devastating illness which imposes a heavy burden on patients, their families and healthcare professionals who provide care. The need to understand the interplay of experiences for patient, family and healthcare

professionals throughout the long-stay in ICU is imperative to be able to provide care that is appropriate. The emergent body of international literature since Girard and Raffin's publication has highlighted many of the complexities of care for this group of patients. However, there has been no attempt to understand the journey of a long-term illness in ICU. This review of existing literature assisted in the design of this study in several ways. Firstly, there was no literature found that deals with the experiences from a three-way perspective and therefore how each person's trajectory influences the others. Insights into the phenomenon of a prolonged critical illness from multiple perspectives will assist with understanding the complexities of implementing interventions to improve outcomes. Secondly, there is limited literature from both New Zealand and Australia which has explored the experiences of a prolonged critical illness from the patient, their family or the healthcare professionals' viewpoint.

The next chapter presents the theoretical framework underpinning this case study. The illness trajectory framework developed by Corbin and Strauss (1988) to understand chronic illness provides a lens to inform the development of this research approach and data collection and analysis. The illness trajectory framework is a complex and multifaceted framework, not only encompassing the physical manifestations of an illness, but also the impact on the individual and family's social and psychological wellbeing, and the work involved in managing and shaping an illness.

Chapter 4 – Theoretical Framework

We confront a universe where nothing is strictly determined, a world that is complex, often ambiguous, evincing constant change as well as periods of permanence, where action itself although routine today may be problematic tomorrow; where answers become questionable and questions produce ultimately questioned answers (Strauss, 1993, p. 19)

Introduction

This chapter presents the theoretical framework underpinning this study. As identified in chapter one the aim of this study is to examine the experiences of the patient, family and healthcare professionals throughout a prolonged patient stay within an ICU. In the previous two chapters, the findings from the literature have demonstrated multiple factors and influences which inform the experiences for patients, their family and healthcare professionals who provide their care. In this chapter the illness trajectory framework developed by Strauss and associates (Corbin & Strauss, 1988; Glaser & Strauss, 1968; Strauss, Fagerhaugh, Suczek, & Wiener, 1985) is proposed as a framework that can provide an insight into the issues and influences pertaining to a prolonged critical illness in the ICU by informing how the illness course is shaped and managed through the interrelationships and contexts that influence the trajectory's. The chapter includes an overview about the development of the illness trajectory framework along with the key concepts that inform the trajectory framework. Strauss's theoretical ideas that influenced the trajectory framework and the application to this study is addressed within the current healthcare contexts. Finally, a justification for this theoretical framework is given, which informs the analysis and structuring of the data, in line with the next chapter on the case study approach.

Introducing the trajectory framework

The chronic illness trajectory framework is a conceptual model developed by Corbin and Strauss and published book *Unending Work and Care* (1988). Trajectory refers not only to the physiological process of a disease, but the total organisation of work that needs to occur over the course of an illness, the impact of that illness and the associated work for all people involved, including the patient, family and healthcare professionals. With the idea that chronic illnesses have a course that varies and changes over time, the trajectory can then be analytically subdivided into phases, with each phase having fluctuations (Corbin & Strauss, 1992b). Corbin and Strauss's

(1988) trajectory framework is based on a sociological perspective, which allows insight into the complexity for all involved to get the work done to manage the illness. There are many conditions that influence the management of a trajectory, such as personal, interpersonal and socio-political conditions influencing daily management (Corbin & Strauss, 1988). These influences on the trajectory allows the researcher to observe and organise factors that shape the trajectory experience. It is this process that allows the researcher to understand complexity by gaining knowledge of the relationships between variables which may have been previously explored, but observed in isolation. Hence the trajectory framework, within this study, provides a lens to understand the experiences of all key participants in the case of a prolonged critical illness, to be viewed not in isolation, but as an interactional experience of all participants.

Overview of the illness trajectory framework

The core concept of the chronic illness trajectory framework is the trajectory or illness course. Although the terms illness and disease are often used interchangeably there is a distinct difference. Disease refers to pathological changes in the body, such as an alteration in structure and function (Larsen, 2009; Radley, 1994). Whereas illness considers the person and their personal experience of signs and symptoms, and how that impacts on their life and family (Larsen, 2009). An illness course varies and changes over time and can be shaped and managed, although shaping does not always mean altering the direction of the course (Corbin & Strauss, 1992b). The course of an illness can be extended, stabilised and symptoms can be controlled and each phase can be mapped retrospectively to show the course of an illness. Each phase may be further broken down into sub-phases, with movement between the phases occurring in any direction and with variable duration (Halcomb & Davidson, 2005; Jablonski, 2004). The framework is representative of complex and complicated work required to manage a chronic illness on a daily basis, often by patients and family, which can be largely invisible to clinicians and the medical record (Klimmek & Wenzel, 2012; Strauss, Fagerhaugh, Suczek, & Wiener, 1982b).

Development of trajectory framework

The development of the trajectory framework goes back to the 1960s (Corbin, 1991; Corbin & Strauss, 1992b) with early work carried out by Strauss. During the course of his work, Strauss has collaborated with many scholars who have influenced his

ideas. His early work was influenced by Herbert Blumer and Robert Park in the field of symbolic interactionism at the University of Chicago, where he gained his doctorate in sociology. This work focused on issues of social organisation and challenged the view and meanings of professions as segmented, particularly within medicine (Maines, 1991).

Strauss's move to the University of California in the 1960s saw him collaborate with Barney Glaser and a nurse Jeanne Quint. Their research "Awareness of Dying" was the first publication of grounded theory as a qualitative method to understand the basic social process (Glaser & Strauss, 1968). Their focus on the process of dying revealed that dying takes time and is managed by the patient, family and healthcare professionals who help to shape the course of the dying process. Emerging from their work were the concepts of trajectory and work that underpinned the process of dying for the patient, their family and healthcare professionals involved (Corbin, 1991; Glaser & Strauss, 1968).

Strauss was not the first person to use the concept of trajectory as a sociological term. It has its historical links with Davis (1991) in his longitudinal research conducted during 1953-1957 on children and families affected by polio. Davis demonstrated how families moved through different stages of their illness, with the initial realisation of a serious illness to the final stages of dealing with the illness within the hospital setting. They also reassessed how the family functioned and the community's attitude towards them as a family. However, Strauss made no links to Davis previous work in his writings on dying trajectories.

Strauss's interest in chronic conditions grew following teaching and researching with nurses about patients with chronic conditions (Corbin & Strauss, 1992b). His growing interest in the prevalence of chronic illness saw him publish: *Chronic illness and the Quality of Life* in 1975. This work refined the concept of trajectory and the emphasis on the work to manage an illness further (Corbin & Strauss, 1984; Strauss et al., 1984). Following this work, Strauss collaborated with a number of other renowned scholars and theorists during the 1970s to 1980s covering many projects related to chronic illness management at home and in hospitals. Each study had a different focus, such as pain and medical technology, which provided deeper understanding of the many aspects of living with and managing a chronic illness and these studies further

validated and refined their concepts (Corbin & Strauss, 1992b). Within Strauss’s studies on trajectories, there is a clear focus of attention on organisations in healthcare. Strauss’s study on *The Social Organisation of Medical Work* (1985) is an example of his work, embedded within the increasing advancement of the hospital, in which they demonstrated the links between everyday work within the larger structural organisation of the hospital. The connection between the organisational contexts is important within Strauss’s work as it demonstrates the “context of organisational possibilities, constraints and contingencies” (Strauss et al., 1985, p. 266) that shape a trajectory.

Juliet Corbin, a nurse, who was immersed in sociological research, provided the foundation for developing the framework across the continuum of chronic illness. This was based on the management of care at home, with spouses/ partners experiencing a different trajectory phases (crisis, acute, stable, comeback, unstable, downward and dying) as seen in Table 2. Corbin and Strauss (1988) inductively conceptualised and tested the framework using qualitative methods and suggested their theory met the four criteria for judging the practical application of a theory. These are: 1) the theory must fit the practice area; 2) it must be readily understandable; 3) the theory must be applied to multiple and diverse situations; and 4) it must give the user partial control over the structure and process of situations as they change over time.

Table 2 Definitions of phases within the trajectory framework.

Phase	Definition
1. Pre-trajectory	Before the illness course begins
2. Trajectory onset	Signs and symptoms are present
3. Crisis	Life-threatening situation requiring emergency/ intensive care
4. Acute	Active illness or complications that require hospitalisation
5. Stable	Illness course/symptoms controlled by regime
6. Unstable	Illness course/ symptoms not controlled by regime
7. Downward	Progressive deterioration in physical/mental status characterised by increasing disability/symptoms
8. Dying	Immediate, weeks, days, hours preceding death (Corbin & Strauss, 1992b, p. 17)

Major concepts, definition and relationships

The major unifying concept in the framework is ‘trajectory’ which refers to the illness progression and unites all the other concepts within the framework. These other concepts all have a relationship or influence on the illness course or its management and therefore to the core concept of the trajectory (Corbin & Strauss, 1992b). These concepts are defined in Table 3 before the concepts of biography, work and trajectory phasing are discussed in further detail, as the major concepts that informed this study.

Table 3 Definitions of concepts

Concept	Definition
Trajectory	An illness course.
Biography	Refers to the life course, made up of many aspects of self
Work	A set of tasks performed by individuals or groups in order to manage one or more aspects of an illness
Trajectory phasing	Trajectory segregated into phases which give it shape as seen in Table 2. Phases are representative of the physiological status of the patient
Trajectory scheme	The formulated plan of care, which may be developed by healthcare professionals but also patients and family as they consider implications of treatment
Trajectory projection	Prediction of how the illness will progress, which can be made by healthcare professionals, patients and family. Projections will differ depending on how information is interpreted
Trajectory management	Represents the process by which the illness course is shaped, through all its phases, by the trajectory scheme
Contingencies	Unexpected events that may arise in the course of an individual’s biography or trajectory that may affect work and course of illness (Corbin & Strauss, 1988)

Trajectory

The key concept of the framework is trajectory which indicates the illness course or path (Corbin & Strauss, 1992b). Trajectory denotes more than a course of an illness, it encapsulates the physiological events as well as the work of every participant involved in controlling and shaping the illness, and the relationships amongst every participant (Corbin & Strauss, 1992b; Hannigan & Allen, 2013; Strauss & Corbin, 1988). The trajectory concepts recognise illness rather than disease, which can be altered by an interplay of medical, social, political, economic, biographical and

psychological forces (Wiener & Dodd, 1993). It does not just consider the physiological unfolding of a disease, but also the total organisation of work done over the course of illness, plus the impact on those involved (Corbin & Strauss, 1988; Wiener & Dodd, 1993). Researching trajectories means attending to people's experiences and to the entirety of the work which is done, rather than the activities performed on members of one or more groups, hence the focus is on the work of the trajectory (Hannigan & Allen, 2013). As Strauss has refined the concept of trajectory over time, its meaning has become more than a course of action, it has come to encompass the interaction of multiple actors and contingencies that may be unanticipated and not entirely manageable.

Trajectories do not just form, they are shaped by work done or not done, throughout the illness. Although each illness or injury has a general course that it is expected to take, each individual trajectory has a slight variation (Halcomb & Davidson, 2005). These variations are based on a number of factors including interventions to increase positive outcomes: for example, good pain management, early mobilisation after surgery to prevent complications and adequate nursing staff to deliver all interventions or negative outcomes: for example, poor pain management, slow mobilisation after surgery causing complications and nursing shortages meaning only essential care is delivered. Trajectories can be more complex than this simplified version. Strauss (1985, p. 160) describes how trajectories can also turn into what he describes as a "cumulative mess", as a set of actions produce unanticipated consequences, which then produce more problems. He illustrates this with an example of a doctor who thinks they have made a clear diagnosis of a patient's disease and puts a plan of treatment into action. But when unexpected problems arise, with the multiple interventions and work required, the trajectory is disrupted. With each new set of actions required, there are potentially unanticipated consequences which add to the complications both with the illness itself and to the working relationships amongst all the workers. The articulation of all work involved in managing a multitude of problems becomes more complex and difficult (Strauss, 1993; Strauss et al., 1985).

According to Strauss (1993) when studying a trajectory course, the phenomenon can be seen as it evolves over time, as well as the actions and interactions contributing to this evolution. A phenomenon does not just spontaneously unfold; it is shaped by interactions of concerned actors, some phenomena do not change for sustained periods

of time, and it is important to understand what interactions have assisted that stability. Over time, trajectories will be influenced by combinations of structural and interactional conditions which change the phenomena as the illness trajectory progresses. Different phases emerge representing changes in the status of the illness and each phase is associated with unique characteristics, tasks and a shifting focus (Jablonski, 2004).

Biography

Corbin and Strauss (1992b) define biography as life over time, and its continual experiences that shape the individual. They view people as unique individuals due to their life course and experiences along the way, with these experiences of life becoming the cornerstone for how they interpret events and situations. It is important to understand a person's biography, as all individuals are different and their biography will influence the shaping of their illness and their trajectory (Corbin & Strauss, 1988). A chronic illness is seen as causing a disruption to the patients biography, with many aspects such as conceptions of self and one's body threatened by the illness and the management (Corbin & Strauss, 1988; Diederiks & Bal, 1997).

Corbin and Strauss (1988) define three elements of biography: 1) biographical time, 2) conceptions of self, and 3) body. Biographical time represents past experiences that influence the interpretation of who one is at present, with the past and present together influencing who one shall be in the future. This all happens in clock time, which is articulated into one's biographical time and time will be experienced at varying speeds dependant on circumstances. Conceptions of self represent the uniqueness of each individual because of their life course and associated experiences that are different. Finally, body is the medium through which self-conception is formed, with all interactions occurring through the body. Hence, the body can take on many forms depending on the interactions such as: a communicator, an object, a social agent, and a task performer. The term 'biographical body conceptions' or 'BBC', together form the subjective experience of self at any point in everyday life. While these activities take place, conceptions of one's self become established and re-established and so, through an illness, experience of these will change (Corbin & Strauss, 1988).

According to Strauss et al. (1984) people have at least three types of biographies during illness. Firstly, they have a chronological experience of their illness. Secondly, they have biographical experiences with healthcare professionals. Lastly, they have

social biography, meaning personal history with friends, family, work colleagues and other social/spiritual/cultural groups. All these parts of the person's biography interplay and inform the trajectory. Other players involved with that person, such as family and healthcare professionals also influence the trajectory. Every player will have their own biography which they bring to any situation, adding to the complexity involved in any trajectory. Therefore, these aspects of a person's biography during illness will make their illness experience 'unique' to them. Although literature may suggest a serious illness creates a state of crisis in one's life and threatens their personal biography (Bury, 1982), the consideration of one's personal biography, culture, age, gender and social contexts all help shape that illness experience (Faircloth, Boylstein, Rittman, Young, & Gubrium, 2004). This individualised approach to each person within a trajectory as 'unique' aligns within the contexts of nursing and patient-centred care.

Strauss (1995) further notes, to understand people and their biography, you must also understand the historical contexts which influenced their being. Every social world creates its own histories, which can greatly influence the lives and identities of its members. The definition of a social world will include the history of a nation and encompasses occupational and professional worlds. Together, these produce collective and personal histories which form a person's biography. Faircloth et al. (2004) note that failure to acknowledge a person's biography, by treating all patients as the same, results in poorly designed interventions, as one's biography within the context of one's work, also influences the trajectory. Hence, the interplay of medical, social, political, economic and psychological contexts will all influence one's biography and the contexts in any trajectory. Likewise, when nurses do not understand their patients and their family as individuals it is going to impact on how the trajectory is shaped and may become problematic because care does not consider specific needs.

Corbin and Strauss (1988) use the term 'performance' to describe how the body and mind coordinate together to complete an act and the body is the medium through which all interaction occurs. However, during illness, the physical and mental processes may not synchronise and is referred to as 'failed performance' and is interpreted by the person as body failure. Body failure is perceived in three ways 1) the body's ability to perform an activity; 2) the body's appearance; and 3) the body's physiological functioning at a cellular level. For a long-term ICU patient the first indication that

something is wrong is often when they cannot perform their usual tasks, such as moving a limb, they may then feel their body's oedema, with the realisation that something is happening at a cellular level to produce these signs and symptoms. The degree of body failure and failed performance is then measured against biographical time, self-conceptions and body. These all work together potentially changing one's biography, thereby changing one's life course (Corbin & Strauss, 1988, 1992b). Strauss (1993, p. 110) further extended the concept of the body to identify the body as 'the agent for an action to occur through'. When an interaction does not occur it can become an 'object'. The body is not an object to itself only to an actor, such as a nurse performing a physical task on the patient, without any interaction with the patient. However, the person can feel their body is an object if there is failure of interaction from the actor.

Corbin (2003) describes how the body communicates to the person through sensations that are anchored in meaning. As was demonstrated in the previous literature chapters, ICU patients perceive unreal sensations and experiences during their illness, these experiences while in a semiconscious or delirious state, all impact on the person's perception of conception of self at that moment and into the future. According to Corbin and Strauss, a person's biography comes from the past, is shaped in the present and into the future as they reconstruct their life around their illness experience. Corbin and Strauss (1988) describe the biographical body conceptions (BBC) as the way patients interpret their body, time and their conceptions of self by making sense of the situation they are in. Biography work is inner work, it is invisible, but there can be no biography without biographical work. Strauss (1993) suggests we only need to look at illness and other personal crises to see biographical work being done. Only by looking through the lens and considering the BBC chain during a critical illness can we begin to understand the impact illness has on biography, both at the present moment and once processed into one's future biography and therefore the impact of illness is an individual experience.

The concept of biography in relation to illness has been explored widely in the medical sociology literature, mostly in relation to chronic illness. Bury (1982) contended that illness, mainly chronic illness, is an experience where the structures of everyday life are disrupted. The onset of illness drastically disrupts and dominates life, creating feelings of uncertainty with the possibility of death. Bury notes that illness brings

individuals, family and social groups together face to face with this reality and attention is focused on bodily states which one is not generally conscious of. This causes a person to rethink their biography and self-concept, resulting in mobilisation of resources. Critical of Strauss's work, Bury describes his categories of interaction as too descriptive and lacking analytical linkages to the wider cultural and structural forms. However, his criticisms are based on Strauss's early work, before the trajectory framework was further conceptualised, as Strauss acknowledges the many players and their biographies that shape a trajectory.

Work

The role of work within an illness has been developed by Strauss and his colleagues to broaden the scope and dimensions of this concept. Corbin and Strauss (1988) define work as “a set of tasks performed by an individual or a couple, alone or in conjunction with others, to carry out a plan of action designed to manage one or more aspects of the illness and the lives of ill people and their partners” (p.9). Their framework recognises the interplay of three types of work required during illness: biographical work, everyday work and illness related work as defined in Table 4.

Table 4 Work types during illness defined

Types of work	Definition
Biographical work	Refers to work to define and maintain an identity over one's life (Corbin & Strauss, 1988)
Everyday work	Refers to “the daily round of tasks that helps keep a household going” (Corbin & Strauss, 1988, p. 90)
Illness related work	Refers to all tasks necessary to manage or treat an illness –the phase of the illness and type of work will determine if healthcare professionals, patient or family are doing the work (Corbin & Strauss, 1988)

The value of Strauss's concept of work is to understand how the phenomena of a prolonged critical illness can be constituted to focus on the coordination of the components of the trajectory and the multiple types of work which all players are undertaking. Tasks and lines of work within a trajectory need managing and articulation of work is required to ensure that all collective efforts by all players are effective, without discrete and conflicting elements of work being done (Strauss et al., 1985). The focus on the work for patients and their family is often unnoticeable to health professionals because of the invisible nature of this work (Strauss et al., 1982b).

Illness is not just experienced, it must be managed and management of an illness requires work. In hospitals, healthcare professionals manage illness with or without patients and their families input. The specifics of illness work, in relation to type and amount, will vary according to the phase of the illness (Strauss & Corbin, 1988). Hence during the crisis phase of an illness, as described by Corbin and Strauss (1992b), work would mainly be carried out by healthcare professionals. Strauss emphasises that healthcare work is different from all other types of work because it is what he refers to as people work. Within the trajectory there are many different kinds of work, mainly done by healthcare professionals which include: comfort work, clinical safety work, machine work, sentimental work, patient work, plus the work of coordination between all of the tasks involved in the total arc of work (Strauss et al., 1985). All these different types of work will be prioritized by healthcare professionals' dependent on the trajectory and phasing. The different types of work are defined in Table 5 below, before they are further discussed.

Table 5 Types of work and definition

Type of work	Definition
Comfort work	Work done to relieve patients discomforts
Clinical safety work	Work management and evaluation of risks to patients in relation to interventions
Machine work	Involves work with or around machines during patient care
Sentimental work	Any work that is done with or on a patient, by a healthcare professional, and it is the psychological effect on the patient which is central to the work.
Patient work	All the work the patient does to manage their illness, including work that could be done by healthcare professionals
Coordination of work/ articulation	Involves the coordination of lines of work accomplished by mapping out the work and the arrangements made. Is the organisation and coordination of the various types of work that is necessary to operationalise any plan to manage the illness

As work is people work, meaning one person does work for another person, it is important to understand the role of the interaction in carrying out work (Strauss, 1993). Every player involved in the work can affect the course of the trajectory, implicitly or explicitly. Due to the critical conditions of patients in the ICU, the work carried out can be complex because of the need for continuous monitoring, the use of medical

technologies at the bedside and the need to work closely with allied healthcare professionals (Tummers, van Merode, & Landeweerd, 2002). Due to the instability of patients, nurses may need to carry out different types of work simultaneously (Abbey, Chaboyer, & Mitchell, 2012), which will be influenced by the total arc of work within the setting.

Through the many lines of work that need to be undertaken to control an illness course, throughout the phases and sub phases, it is the total arc of work that defines the overall goal of work that needs to be completed (Fagerhaugh, Strauss, Suczek, & Wiener, 1987; Strauss et al., 1985). The arc of work is an important concept in relation to where the trajectory is played out. The workers will need to have specialist skills and the ward area will need the appropriate equipment and supplies in relation to total arc of work, so within the ICU, the total arc of work is to perform life-saving interventions on critically ill patients. Because of the overall uncertainty while caring for patients with life-threatening illness, it makes work unpredictable. Firstly, this is due to a greater number of patients suffering from physiological instability and at risk of sudden deterioration. Secondly, there is always potential for the unexpected arrival of a new admission, because emergency admissions are very common (Tummers et al., 2002). So within the ICU nurses' lines of work will be organised according to the arc of work, which means nurses will also need to put clinical safety work before comfort and sentimental work because of the life-threatening nature of their work. Recognition of this overall goal of the total arc of work allows a deeper understanding when analysing the work in relation to why the types of work are being done this way within the contexts of the ICU (Strauss, 1985).

As safety work potentially dominates nurses' work in the ICU, comfort work can be displaced for many reasons. Firstly, as patients' conditions become more complex there is likely to be more than one discomfort. Secondly, the intensity of safety work will always be a priority over comfort work. Thirdly, healthcare professionals may all have differing priorities, creating barriers to providing comfort care (Fagerhaugh et al., 1987). Failure on the part of the healthcare professional to acknowledge or relieve these problems can potentially impact patients' social and physical well-being thereby producing discomfort. Comfort work is embedded in clinical work, because performing an intervention on a patient will potentially inflict some form of discomfort

physically or psychologically which should therefore be recognised (Fagerhaugh et al., 1987).

The way work is interrupted by the patient and the effect it has on their psychological well-being is called sentimental work, as it the effect it has on the patient which is central to this type of work. It is present in any work in which the patient is conscious and responding (Strauss, Fagerhaugh, Suczek, & Wiener, 1982a; Strauss et al., 1985). For example, a fundamental skill such as a nurse giving a patient a bed bath is not sentimental work, but how the nurse makes the patient feel while she is giving them a bed bath is sentimental work. Strauss argues there are many influencing factors that make this work complex and difficult. Firstly, this work is carried out by people, healthcare professionals, who do not know the biography of the patient. Therefore, a patient being given a bed bath by a stranger who is not sensitive to their individual needs may potentially affect the patients' well-being. Secondly, the medical aspects of the work take priority, hence, strangers focus on the medical aspect of work and not the patient. Thirdly, sentimental work is often invisible to healthcare professionals performing this work and to bystanders, as the nurse may not know how she made the patient feel while giving them a bed bath (Fagerhaugh et al., 1987; Strauss et al., 1982a). Fourthly, the duration of this work is cumulative to the patient, so if the nurse does this task efficiently according the patient's needs it will have less of an impact. Finally, the amount of sentimental work also required by the patient, because of their dependency, has an cumulative effect. A patient who has become totally dependent for a prolonged period of time and has to endure many bed baths of varying levels of comfort will experience an accumulative effect on their well-being. Hence, the long-term intensive care patient will endure prolonged sentimental work due to their level of dependence over a period of time.

As noted by Strauss et al. (1985) medical work will always have a temporal context. Work that unfolds over time creates an illness trajectory, through a structured timeline of activities, events and occurrences (Reddy, Dourish, & Pratt, 2006). When only one temporality is appreciated through a trajectory, such as clock time, there is no understanding of human experience (Caldas & Berterö, 2012; Jowsey, 2015). Considering trajectories in clock time views each event as existing in a linear time line, with emphasis on tasks, schedules and procedures which can dehumanise the human experience as it does not consider individuality (Jones, 2001). Time is

enmeshed in all social relations (Davies, 1994) and so all work through a trajectory will have different meanings to each individual. This is particularly pertinent when viewing the semi-conscious ICU patient, who has no concept of time, and the nurse who may have many routine tasks to perform at a certain time.

[The hospital as a work site](#)

Strauss et al. (1985) refers to the hospital as a large work site, with an assortment of workshops, all with a purpose. Within the acute hospital setting, the workshops/wards are organised around similar trajectories according to their medical specialities. Other wards are organised around trajectory phases, for example intensive care is organised around the crisis phase of the trajectory with emphasis on treating a life-threatening situation. Units are also organised around work requirements associated with differing degrees of risk and danger stemming from different types of illness trajectories or phases (Fagerhaugh et al., 1987). Within each workshop/ ward, the arc of work fits within its common trajectory phases or trajectory conditions, so for common trajectories within that workshop/ward, healthcare professionals have general knowledge and skills to deal with the everyday management of these patients. When a trajectory is unpredictable, problematic and long, or the organisational structure to manage the multiple contingencies may not be available, this makes the trajectory challenging. Likewise, when it is not the usual trajectory for the workshop/ward it may also become problematic because they are not working within their usual arc of work.

[The contexts for an evolving trajectory](#)

Corbin and Strauss (1988) argue that it is important to understand concepts that are used in research as they are instrumental to the research, and therefore they are constantly evolving. Hence the concepts and their definitions guide the researcher, enabling them to focus on a particular phenomenon throughout their study. Hence in this study it is important to understand the concepts of trajectory, work and biography and how they shape an illness. It is also important in any trajectory to consider the contextual components, although it does not determine the experiences or actions, it does identify the conditions where problems, situations and phenomenon occur (Corbin & Strauss, 2008). To understand the contextual components that impact on the phenomenon, Strauss et al. (1985) used the term conditional matrix, as an analytical tool to assist in understanding a complex web of broader to narrower

conditions and consequences. Within the critical care context, it is important within the conditional matrix to consider wider aspects that influence and shape a trajectory.

To understand the work of managing an illness and the influences that can shape the trajectory in the ICU today, Strauss et al. (1985) proposes that the structures and organisational forms need to be analysed from their evolution to current state. This highlights the complexity of macro-micro relationships and the reciprocal impacts on the organisation and work within the area. These influences within the ICU are numerous and their relationships are highly complex. Since the inception of intensive care services in the mid-1950s there has been constant change and widening in the scope of care. Originally, the intensive care units were a place needed for close observation of patients, then it progressed to a place with technology such as when mechanical ventilators were introduced, now it is a dedicated space in the hospital for the most critically ill patients which extends to other areas, so that it has become 'critical care without walls'¹⁰. This means critically ill patients can be cared for beyond the physical location of the ICU (Crocker, 2007). As noted by Strauss (1985) to do justice to the full complexity of contexts and processes, it must be analysed through the multiple domains, but it must first be discovered for relevance.

A multitude of domains of changes since the inception of ICU have impacted on patient trajectories. The development of positive pressure ventilation during the polio epidemic in Copenhagen, during 1954 rapidly reduced the mortality rate for patients with polio (Le Fanu, 2001; Weil & Tang, 2011) and demonstrated the advances in medical equipment. Larger hospitals with developing specialties of medicine and advancing knowledge now had the potential to create new complex trajectories. Following on from this development, news of this treatment in Copenhagen spread and a doctor from the United Kingdom's Radcliffe Infirmary wanted to perform this new treatment on a sixteen-year-old girl with Guillan-Barre syndrome. Her care was controversial, with some healthcare professionals raising objections believing it was unethical to keep her alive when her sense and reason were intact but she was trapped

¹⁰ Concept of 'critical care without walls' came from the United Kingdom following a review of critical care services, that critical care was to be driven by patient need, not by geographical location or speciality with the critical care outreach team as a solution to one of the problems (Coombs & Dillon, 2002).

in an immobile body (Le Fanu, 2001). However, this patient's survival made it certain "that no patient could die from respiratory failure at the Radcliffe without being ventilated" (Le Fanu, 2001, p. 78). This patient was also the first documented long-term patient in an ICU and this demonstrates how these rapid improvements created a new group of patients and trajectory. As stated by Strauss (1993, p. 256) "each and every procedure taken for granted today has its history as do each of the participating professions and the hospital itself". Hence according to Strauss's conditional matrix there were many factors that influenced and shaped the trajectory for this patient at the Radcliffe that can be directly related back to developments in Copenhagen with the treatment of polio patients.

The new dilemmas and consequences of advances in medical technology were referred to as 'halfway technologies'. This term first used by Lewis Thomas (1971, p. 1367) is described as "the kinds of things that must be done after the fact in efforts to compensate for the incapacitating effects of certain diseases whose course one is unable to do very much about". Halfway technologies were characterised as technical fixes that were inefficient, requiring expansion of hospital resources with little societal benefit. Halfway technologies are not curative, but designed to support disease and postpone death. The iron lung can be seen as the first halfway technology to be used in intensive care. It represented medical technology in a palliative form, prolonging life but at the cost of quality of life (Maxwell, 1986), however it had positive benefits in the long-term. Strauss et al. (1985) noted these halfway technologies had made care of chronic illness more complex as both patient and healthcare professionals become more dependent on technology throughout the course of illness, and it also increased the organisation and work involved for all participants.

Strauss et al. (1985) further observed that improvements and increased use of technology also produced a lengthening of trajectories. Fagerhaugh, Strauss, Suczek and Wiener (1987) referred to trajectories as 'stretched-out', both at the beginning and at the end of life. The consequences of these on-going advancements are seen in patients in hospital today who are sicker than previously because the boundaries are constantly changing. To put this into perspective, patients who 20 years ago would have been in the ICU are now HDU patients. HDU patients are now nursed as general

medical surgical patients and previous ward patients are now day-cases and discharged home. Technology also has the ability to create new phases of illness (Corbin & Strauss, 1992a; Hawthorne, 1992). Importantly, noted by Strauss et al. (1985) in relation to medical and technological advancements, there is an ongoing impetus for further technological innovation, creating changing trajectories. One could argue that illness is not static and both acute and chronic illness are continually changing as medical advances prolong and change the course of trajectories. Hence the acute/chronic paradigm within an illness becomes blurred, as is seen with a prolonged acute critical illness that has become known as a chronic critical illness. This poses new problems in relation to medical work, organisational work and biographical work resulting in nurses needing to amend their practices in order to be able to facilitate care which is both relevant and evidenced-based.

Despite the on-going advancements, it is worthy to note that the prominent characteristics of chronic illness, as defined by Strauss et al (1985), are still relevant today. These are: 1) long term; 2) uncertain; 3) require proportionately large efforts at palliation; 4) tend to be multiple diseases; 5) are disproportionately intrusive upon patients and families; 6) provide potential for conflicts for patients and healthcare professionals; and 7) are expensive to treat and manage. These characteristics highlighted 30 years ago, reinforce much of what is reported within the contemporary literature in relation to the chronically critically ill patient group.

There is no doubt that the continued advancements in intensive care medicine and technologies have enabled more patients to survive an acute illness who would previously have died. This new era has also created new groups of patients, new phases and prolonged trajectories. The emergence of a new group of patients, the chronically critically ill (CCI), is argued to be a direct result of advances in technology and intensive care therapies (Bellar et al., 2009; Leung et al., 2015; Nelson et al., 2010; Wiencek & Winkelman, 2010). Hawthorne (1992) used the trajectory framework to conceptualise cardiac illness and noted the impact which new and changing technology had on a group of patients in ICU; they were CCI patients. She emphasised the importance of applying the trajectory framework to research this group of patients, however unfortunately, this never occurred. Corbin and Strauss (1992a) also

recommended their framework should be used to research new emerging trajectory phases.

Research using the framework

A considerable amount of literature has been published using the chronic illness trajectory framework to study the experiences of many differing chronic conditions. These include end stage renal failure (Jablonski, 2004), stroke (Burton, 2000; Kirkevold, 2002), HIV/ AIDS (Nokes, 1992), multiple sclerosis (Smeltzer, 1992), diabetes mellitus (Walker, 1992), heart failure (Granger, Moser, Harrell, Sandelowski, & Ekman, 2007; Willems, Hak, Visser, Cornel, & van der Wal, 2006), transplant patients (S. Martin, Stone, Scott, & Brashers, 2009) metastatic breast cancer (Reed & Corner, 2013) and cancer survivorship (Klimmek & Wenzel, 2012).

There has been limited application of the framework to more acute unexpected conditions. The single example is the use of the illness trajectory for mapping traumatic brain injury (Halcomb & Davidson, 2005). Other studies have used the framework to analyse the caregiving trajectory for adults and the elderly and the day-to-day care (Robles-Silva, 2008). Hannigan and Allen (2013) studied the day-to-day complexities of community mental health care and highlighted the complex and dynamic nature of trajectories in relation to who was doing the work, such as skilled professionals or unqualified care givers and unpaid workers, with many workers involved in one trajectory. Mesman (2008) used Strauss's trajectory in her representation of neonatal practice. Unfortunately, the experiences of the nurses and doctors prevailed with little acknowledgement of parents and babies, but it highlighted how technologies controlled the trajectory. In relation to the concept of work involved within the trajectory, there are limited studies that have used the framework in its entirety and analysed the impact of work and biography in shaping the trajectory.

The trajectory framework has also been integrated with other models and reframed to produce new ones. Christensen (2015), wanting a model that was not developed with an illness focus, used the Chronic Illness Trajectory Framework with Mishel's Uncertainty in Illness Theory to create the Health Change Trajectory Model. Her rationale for developing this model, was the notion of a global emphasis on health promotion and prevention of illness in which this model could be used by nurses to

assist people to cope with health changes. Within this model a ‘change in health’, replaces illness, based on the assumption that most people will experience some change in health status over their lifespan and therefore this broadens the scope of the clinical situations to which their model can be applied. Their new model defined a health change trajectory as a “course of structural, physiological, and psychological balance including individual perceptions of health and action taken by self and others to manage, reduce or eliminate change” (Christensen, 2015, p. 61).

Within Strauss’s framework, organisations are viewed as a temporal matrix with multiple lines of work, which have a past, present and future (MacKintosh, 2012). A number of studies have focused on the organisational impact on patients’ trajectories. For example the organisational aspects of the emergency department have been studied using Strauss’s framework, demonstrating how healthcare professionals have to negotiate the bureaucracy within the hospital to organise patient care (Nugus, 2007; Nugus et al., 2010; Nugus & Forero, 2011).

Recognising there was limited literature on the study of social organisations of medical care, except for Strauss’s work, Allen, Griffiths and Lyne (2004), used the trajectory framework with Elias’s Game Model to understand why integrated service provision is so difficult. Elias’s work acknowledged the need to explore how different components of social wholes are related to another and proposed a series of game models. These models allowed for understanding interaction through the influence of multiple players. Elias’s work extends beyond Strauss to focus on how social actions are intertwined to highlight how social networks become transformed over time. The Allen et al. (2004) framework, Care Trajectory Game (CTG), was based on the analysis of adults who had suffered an acute stroke and their associated network of care. The combination of work by Elias (1978) and Strauss (1985) was used to examine how trajectories took shape and how the many players were shaped by the other games in which they were engaged and how these interacted with the patient’s care trajectory. It highlighted the lack of inter-professional and interagency collaboration, seamless services and individually tailored care which despite policy, were in place. It called into question the importance of relationships between players and the differences in culture, goals, training and ethos that halts inter-professional collaboration.

Allen et al. (2004) were critical of Strauss's linkage of a trajectory to the organisational contexts, because he had not provided a basis for analysing this relationship and the organisational context, inter-professional relationships and negotiated process are hidden (Allen et al., 2004). Critical of the term 'illness trajectory', the term 'care trajectory' is conveyed to reflect the combined health and social care contributions made in community and hospital settings with long-term mental health patients (Allen et al., 2004; Hannigan & Allen, 2013).

The trajectory framework informing this study

There are a number of factors which make the trajectory framework suitable to inform this research. Firstly, this framework was developed from research with patients and their family's experiences of chronic illness within the hospital setting. The framework broadens the experience of illness beyond the medical view of disease to incorporate the social contexts, relationships and activities of illness in relation to the organisation of work of all those involved over the illness's course. It considers the experience over time, and with the acknowledgment of one's biography, it demonstrates how individual factors and commonalities shape an illness.

The patient is central within the chronic illness trajectory framework. It respects both the patient's biography and their family, who work together to shape the illness experience, acknowledging that illnesses have different meanings to all. It reflects the complexity of all participants that shape an illness, as it is a "means for analytically ordering the immense variety of events that occur in illness – as patients, their family and staff seek to control and cope with those illnesses" (Strauss et al., 1985, p. 9).

The framework has been developed from a series of qualitative research projects about patients with chronic illness. Throughout its development, there has been nursing involvement with specialised knowledge of chronic illness. The framework explicitly discusses the link between theory and the concepts of interest to nursing, such as person, environment, health and nursing.

Although this framework has been developed to illuminate the complex issues of managing a chronic illness, the main concepts of trajectory, biography and work are also appropriate for studying complex illnesses within the acute setting, such as a prolonged critical illness. Developed within the hospital setting and community, the framework considers the work of family and patients but also the healthcare

professionals who shape an illness. Although the characteristic phases of chronic illness described by Corbin and Strauss (1992b) may not quite fit the trajectory of a prolonged illness, they allow for analysis to occur across the illness to reveal phases unique to this group of patients and allow for identification of problematic phases.

Conclusion

This chapter has drawn together the theoretical underpinnings of the chronic illness trajectory framework informing this study. The key concepts of trajectory, work and biography that will inform data collection and analysis have been discussed in depth. It has demonstrated how this framework can provide insights and understanding into the issues and influences that shape the trajectory of a prolonged critical illness with the ICU. It is highly suitable to capture the multiple contexts and it acknowledges multiple participants that will shape a trajectory. The next chapter presents the research framework and includes the design and methods.

Case study is not a methodological choice but a choice of what to be studied. If case study research is more humane or in some way transcendent, it is because the researchers are so, not because of the methods. By whatever methods, we choose to study the case. (Stake, 2005, p. 443)

Introduction

This chapter gives an introduction to case study, which is the chosen research method for this study. In the first section of the chapter, case study is discussed in terms of an approach to explore the research question and aims. The ethical issues in relation to collection of data in the natural setting of the ICU with vulnerable participants is addressed in the section on planning and implementation stages of data collection. The final section focuses on the data collection methods and analysis of single cases and cross-case analysis. This chapter finishes with discussion of triangulation and confirmability of data and trustworthiness of the research findings.

Case study

The beginning of case study as a research approach is embedded within the social sciences (Anthony & Jack, 2009; Simons, 2009) and a number of these disciplines have influenced its development mainly within anthropology and sociology (Bergen & While, 2000; Hamel, Dufour, & Fortin, 1993). There is a great deal of confusion around the term case study (Anthony & Jack, 2009; Hancock & Algozzine, 2006; Luck, Jackson, & Usher, 2006; Zucker, 2001), with the origins of the study being linked to case history used in medicine and psychology (Hamel et al., 1993; Simons, 2009). Many healthcare professionals think of case study as a clinical description of a person with unique characteristics or symptoms, but case study research implies a much broader view (Hancock & Algozzine, 2006). Case study is used in many disciplines including psychology, sociology, political science, anthropology, social work, business, economics, education, planning and nursing (Hentz, 2012; Yin, 2009).

Definitions of case study

Throughout the literature, there are many definitions and interpretations of case study and these are under constant debate (Hentz, 2012; Jones & Lyons, 2004; Luck et al.,

2006; Simons, 2009; Zucker, 2001). This is due to its use in differing research traditions across the disciplines, according to the underlying philosophies (or paradigms) involved. Hence it can be used qualitatively and/or quantitatively, with an inductive or deductive approach to theory which can focus on one case or multiple cases (Appleton, 2002; Walshe, Caress, Chew-Graham, & Todd, 2004).

Case study as a research strategy has been explored by many writers. Yin (2009) gives a definition of case study as “an empirical inquiry that investigates a contemporary phenomenon within its real-life context, especially when the boundaries between phenomenon and context are not clearly evident” (p.3). In contrast, Stake (1995) describes case study more loosely – defining the case as “a specific, and complex, functioning thing...with each case being an integrated system with a boundary and working parts” (p.2). Merriam (1998) defines case study as “...an examination of a specific phenomenon, such as a program, an event, a group, a person, a process, an institution, or a social group” (p. 9). These authors show how case study exists within the continuum of the quantitative-qualitative spectrum; with Stake’s work at one end and Yin on the other end, with Merriam sitting in the centre (Appleton, 2002; Brown, 2008). Therefore, it is important for the case study researcher to identify their definition, and to ensure it is appropriate within their theoretical framework (Appleton, 2002; Luck et al., 2006) .

Despite the paradigmatic boundaries case study is best used for understanding a phenomenon in its real-life context (Yin, 2009). So according to Simons (2009) case study definitions have in common a commitment to studying a phenomenon or situation in its real-life context. Case study is further defined as interest in individual cases rather than methods of inquiry (Hyett, Kenny, & Dickson-Swift, 2014). Case study is a design frame that may incorporate a number of methods but according to Stake (2005) “case study is not a methodological choice but a choice of what is to be studied” (p.443). So case study consists of an in-depth examination of a case using a variety of methods to investigate the phenomena in question (Hamel et al., 1993) and a key characteristic of case study research is the use of multiple sources of evidence to provide an in-depth understanding of the case (Anthony & Jack, 2009; Hancock & Algozzine, 2006; Merriam, 1998).

Classifications of case study

There are many subtle differences within case study, which are influenced by paradigm, study design and selection of methods, as case studies are designed to suit the case and the research question (Hyett et al., 2014). Yin identifies case studies as descriptive, explanatory or exploratory. He further classifies them as holistic - focusing on the global nature of phenomenon, or embedded, more than one unit of analysis, with a single-case or multiple-case design (Yin, 2009).

Stake identifies three types of case study; intrinsic, instrumental and collective. An intrinsic case study is created when the researcher is focused in a particular case of itself and wanting to develop generalisations or to build theory (Stake, 2005). Instrumental case study allows the researcher to gain insight into an issue or to redraw a generalisation (Stake, 2005). The case is of secondary interest as it uncovers knowledge about a phenomenon, which may not be the case itself (Luck et al., 2006). However, Sandelowski (2011) argues that all case studies are ultimately instrumental because they are theory-dependent, as no case can be discussed without theorising it or placing the case that is to be studied in the context of other cases. In a collective or multicase study, the researcher may study a number of cases jointly in order to understand an issue, population or general condition (Stake, 2005). The benefits of multicase study are dependent on the number of cases chosen, if too few are chosen the case study will not be able to demonstrate the phenomenon in depth, however, if too many cases are chosen they will provide more individuality than the researcher can understand. This highlights the importance for the researcher to understand what connects the cases together. Understanding the phenomena is dependent upon defining the case well (Stake, 2006).

This study uses Stake's (2006) qualitative instrumental multicase study approach with the theoretical underpinnings drawn from Corbin and Strauss's (1988) Chronic Illness Trajectory Framework to answer the research question:

What are the experiences of the patient, their family and the healthcare professionals during the trajectory of a prolonged illness in the intensive care unit?

The research aims for this study are related to the ICU context:

- Examine the patient's perspective of the trajectory of the prolonged critical illness;
- Investigate how families experience a family member's prolonged critical illness
- Explore how healthcare professionals experience the daily care of patients with a prolonged illness; and
- Explore the interplay that occurs throughout the prolonged critical illness between the patient, their family and healthcare professionals.

Identifying 'the case'

Stake (2005) urges researchers who use case study to “seek what is both common and what is particular about a case” (p. 447). This involves consideration for the nature of case, its historical background, its physical setting, contexts such as economic, political, legal and aesthetic, other cases and informants through whom the case can be known (Stake, 2005). This aligns with Strauss's (1985) stance that relationships amongst interactions and events are complex and the use of the conditional matrix assists in recognising relationships between micro and macro problems.

It is important too for the researcher to define their working definition of the case as there are different descriptions as to what a case is (Casey & Houghton, 2010; Luck et al., 2006; Ragin, 1992). However, the difficulties researchers have in defining their case is recognised as philosophical, theoretical and disciplinary orientations will influence how a case is determined (Merriam, 1998; Yin, 2009). As I wanted to highlight the complexities that occur throughout the prolonged stay, the case for this study is **‘the prolonged-stay patient in the ICU’**. This fits with Merriam's (1998) view that a case is bounded in time and Yin 's (2009) perspective that the case can be an entity other than a single individual. As the case is bound by time, place, event or activity, these boundaries assist in limiting data collection (Luck et al., 2006).

As noted by Yin (2009) the boundaries of the case can be informed by what is known about the topic. As highlighted in chapter three, there is no set definition as to when this patient group is deemed to have a prolonged critical illness. As the phenomenon of interest in this study was the trajectory of a prolonged critical illness in the ICU, it was important to start data collection throughout the patients' ICU stay to capture all

the complexities within the case. From the literature some key physiological indicators were identified for patients likely to have a prolonged ICU stay. Firstly, the concepts of allostasis during a critical illness with the acute phase lasting seven to ten days before there were physiological changes suggestive of a chronic phase (Bellar et al., 2009; Hollander & Mechanick, 2006). Hence day seven was deemed a day on which potential cases could be recruited if they met other physiological indicators that were identified in the literature which indicated the patient may have a long-stay such as:

- The insertion of a tracheostomy for failure to wean from mechanical ventilation
- Still dependent on mechanical ventilation after seven days
- Still showing physiological signs of sepsis
- Greater than one body organ failing

Identifying 'the phenomenon'

According to Stake (2005) we may be more interested in the phenomena within the case, than the case itself. Anchored in real-life situations, case study allows for a rich and holistic account of a phenomenon (Merriam, 1998), which is also revealed through the use of multiple methods of data collection (Luck et al., 2006). Furthermore, the multiple perspectives of participants allows for a detailed and contextualised understanding of each case and the issue or phenomenon which impact on the case (Stake, 1995). The phenomenon of interest in this study is the **'trajectory of a prolonged critical illness in the ICU'**.

To understand the phenomenon in greater detail the use of multicase study allows researchers to examine what Stake (2006) refers to as the 'quintain' across many cases. Quintain is an object or phenomenon or condition that researchers want to understand in particular how it performs across all cases (Stake, 2006). Rather than looking at a few variables in many studies, the researcher looks for the complex interaction of many factors in a few cases (Ragin, 1992), by looking at how the 'quintain' is similar and different across cases. This allows comparison of the 'quintain' across differing contexts, for example different ICU's, structural processes or leadership approaches.

Identifying 'the context'

One of the key characteristics of case study is the exploration of a case within its 'real life' context, thus capturing the holistic and meaningful characteristics of events

(Simons, 2009). However, Yin (2009) states that the boundaries between phenomena and context are not clearly demarcated. Similarly, Stake (2006) notes all cases have an inside and outside, with a few of the outside features defining the contexts or environment of the case. All cases operate within a number of contexts, including physical, economic, ethical, historical and aesthetic (Stake, 1994). As alluded to in the previous chapter, the contexts of healthcare have been shaped by local and international historical, political and organisational issues which need to be considered within the context of the case (Strauss et al., 1985). Case study research makes the deliberate choice to not control events to ensure that the results of their work are applicable to contexts, ensuring the case is not isolated from embedded factors within the contexts that influence the case (Gilgun, 1994; Walshe et al., 2004). The overarching context of this case is **‘intensive care units within the public healthcare system of New Zealand’**.

Rationale for this approach

This study approach allows for the case of ‘the long-stay patient in the intensive care unit’ to be explored and reveals the issues or phenomena that shape the experiences for the patient, their family and healthcare professionals involved in their care throughout ‘the trajectory of a prolonged critical illness’. The use of qualitative multicase study is a comprehensive approach to describe and explore complex issues relevant to nursing (Anthony & Jack, 2009; Luck et al., 2006) and is congruent with addressing both practice issues and the environment in which practice is immersed (Walshe et al., 2004). Accordingly, it aligns with the theoretical underpinnings of the trajectory framework that considers many complex issues that shape an illness trajectory (Corbin & Strauss, 1988).

Methods

In this next section I discuss the planning, legal, ethical and cultural considerations which were addressed in this study in order to collect data within the complexities of the ICU environment and with vulnerable participants. The methods for data collection used in this case study such as interviewing, conversations, observing and document analysis are discussed, along with data analysis methods.

Justification for data collection throughout illness

This study aims to explore the case of a prolonged-stay ICU patient throughout their trajectory. As was revealed in the theoretical chapter, the illness trajectory is shaped

by the many participants and contexts. Consequently, it was imperative to collect data throughout the patients' stays in the ICU and not just retrospectively. However, collecting data in this setting raises a plethora of ethical challenges that needed to be recognised and contingencies planned for in order to maintain the principles of beneficence, respect, autonomy, justice and informed consent that are essential in all research designs.

In line with being an ethical researcher, it was important to have a clear justification why it was important to collect data throughout the patients' stay as well as after their discharge. In order to understand how the phenomenon was shaped by all the participants involved in the case I needed to collect data as it occurred, so that it could be mapped. Hence, I needed to be present in the ICU for periods of time throughout the illness, gathering data from multiple participants, within the contexts at the time. Patients frequently have poor recall of events after ICU discharge and therefore it was important to capture events as they occurred. Capturing the experiences within as they occur allowed a holistic picture of participants' experiences that is influenced and shaped by many contexts.

[Legal, Ethical, and Cultural Considerations](#)

The legal, ethical and cultural considerations when planning and conducting qualitative research in the intensive care context are complex and required careful consideration to ensure I addressed the principles as an ethical researcher. Before applying for ethical approval and locality agreements, there was a great deal of planning and discussion with various experts to ensure I had considered all potential issues and had a plan to deal with any problems that may arise during the data collection process. This plan can be seen in Figure 2.

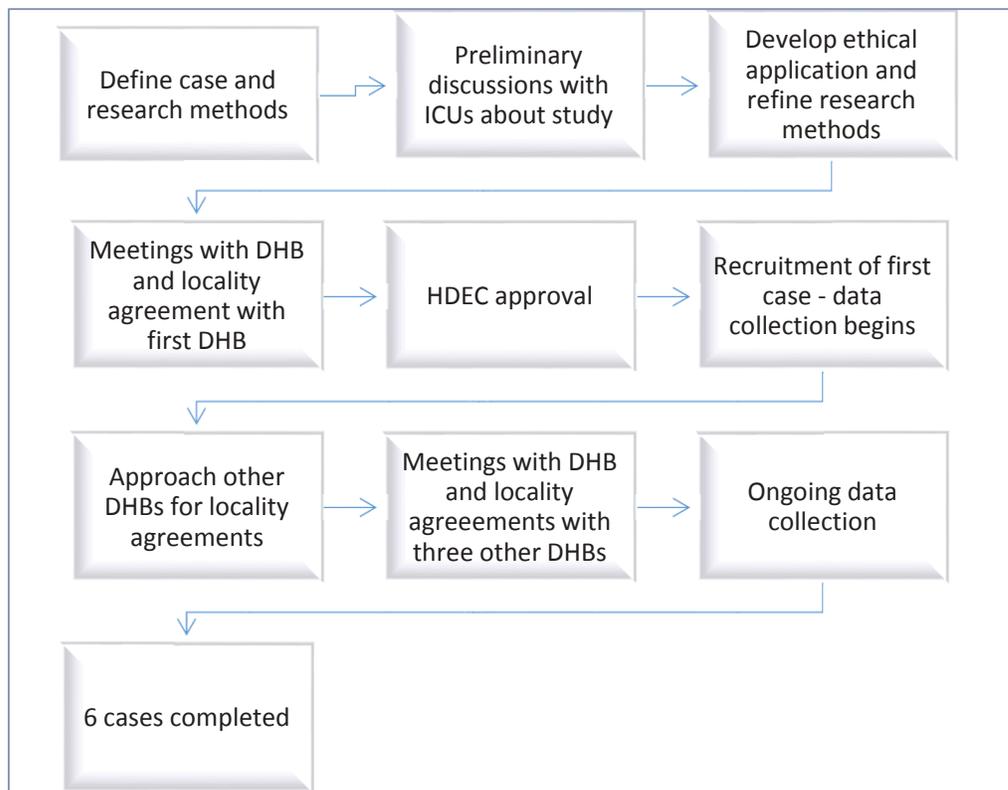


Figure 2 Order of research planning

Negotiating access

Discussions were initially held with each ICU where I planned to collect data and locality agreements were required from each one. Within New Zealand, it is acceptable to obtain locality agreements either before or after approval from the Health and Disability Ethics Committee (HDEC), because locality review should address local research governance issues, and HDEC looks at the ethics of the study as a whole. Following a meeting with senior clinical healthcare professionals and a Māori advisor to discuss how the study would proceed in their unit, locality agreement was granted in one ICU before HDEC approval. However other ICUs did not want to consider my application until I had approval from HDEC. Formal ethical approval for this study was granted from HDEC (12/NTB/3), in August 2012 as per appendix one.

Once HDEC approval was granted I made contact again with the ICUs in which I wished to collect data. After meetings with senior healthcare professionals from these ICUs, a short presentation to their senior nursing and medical staff and a meeting with Māori liaison, I was granted locality agreements. This enabled cases to be recruited from two secondary and two tertiary public hospital ICUs, which would allow

comparison of the similarities and differences within different contexts, such as level of ICU, leadership style and structural organisation within different ICUs.

Sampling choices

As the aim of case study is to fully explore and understand a particular case, the researcher selects cases that offer the opportunity to learn about the phenomenon (Stake, 1994). Participants are chosen who have key roles in the case from whom the researcher can learn most about the issue in question (Merriam, 1998; Simons, 2009; Stake, 1994). In this study purposeful sampling was used to recruit key participants: the patient with a prolonged illness, their family and significant others, healthcare professionals who were directly involved in the patient care as well as senior healthcare professionals who oversaw the management of the ICU. People are central to qualitative research, but within the boundaries of case study, so too are artefacts, policies, documents and the environment, which help the researcher understand the phenomena of interest to the case.

Recruitment of the case

Each of the four ICUs had a specific nurse I could liaise with for recruitment of participants. To identify potential participants, the nurse needed to have a daily overview of patients within the unit and to note their progress so that patients who were still dependent on life-support on day seven, could be assessed for eligibility into the study. Charge nurses or research nurses in the ICU held pivotal roles for this to occur and were the liaison nurses for recruitment of patient participants. The patient needed to have family present to provide informed consent and also be able to speak English. The process of recruitment then followed as shown in Figure 3.

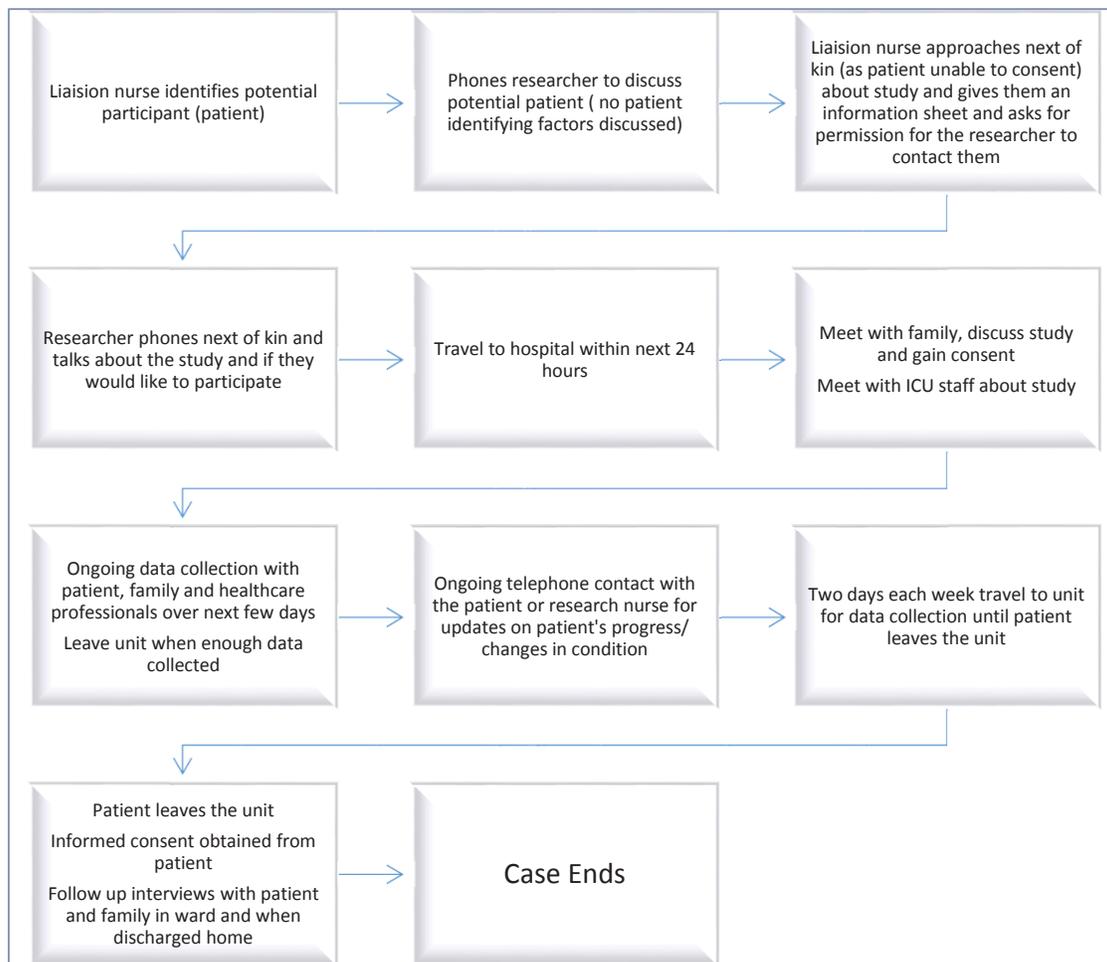


Figure 3 Recruitment and data collection procedures

Informed consent

As I wanted to investigate the experiences of participants within a real-life context, I needed to gain consent firstly to recruit the critically ill patient into this study. Research involving critically ill patients is recognised as ethically challenging due to the serious nature of their illness, being vulnerable and having cognitive impairments which can preclude obtaining their valid and informed consent (Burns, Zubrinich, Marshall, & Cook, 2009; Silverman & Lemaire, 2006). Much of the literature about involving ICU patients in research has been written by doctors in relation to gaining consent for participation in intervention studies (Chenaud, Merlani, Verdon, & Ricou, 2009; Gigon, Merlani, Chenaud, & Ricou, 2013; Rincon & Lee, 2013). As this is an observational study, the researcher is not controlling an intervention and all interventions are given to the patient regardless of participation in the study.

To be ethical, research in ICU must be designed to address significant clinical issues to ensure the advancement in practice with benefits for patients (Silverman & Lemaire, 2006) and the legal requirements within New Zealand. It is acknowledged that observational studies are designed to help people in the future, with minimal benefits to individual participants, because it is about collecting data. However, the benefits of participation in qualitative research has been demonstrated as beneficial because participants have the opportunity to talk about their experiences and make sense of how they are feeling (Gysels, Shipman, & Higginson, 2008).

Information sheets were developed for the three different participant groups and given to them to be read before any family or healthcare professionals were interviewed and observed. Patients were given an information sheet to read when it was deemed they were cognitively able to understand information. The patient's information sheet was developed into a larger font for ease of reading while in bed. All information sheets can be viewed as appendix two.

For this study, informed consent was an on-going process that occurred throughout data collection because of the continuing interactions and data collection that occurred throughout the patient's stay in the ICU and after discharge. Initially, it was deemed appropriate to ask the next of kin if they thought the patient would have chosen and consented to participate in this study if they were able to. When the patient was alert and orientated, the patient would then consent for themselves. Should they refuse to participate in this study all data on that case would be destroyed. The consent form for this process can be seen as per appendix three.

As the next of kin had already been approached about the patient's participation in the study, discussion was then extended to family members. Gaining informed consent from the next of kin, was managed as an on-going process, as data collection occurred throughout the patient's illness in the ICU and therefore family members' experiences were collected during this time. It was acknowledged that family had a number of stressors confronting them including fear of losing their family member and uncertainty of outcomes. These stressors would affect their ability to process information in relation to decision making on behalf of the patient, so I needed to ensure that participating in this study was not an added burden for them and so on-

going communication was vital to assess their needs and understanding as the study progressed. The consent form for family can be seen as per appendix three.

Informed consent was also required from healthcare professionals in this study. Healthcare professionals within the unit were informed about my study by senior nurses. On my arrival for data collection, I would inform the charge nurse and she would alert staff about my presence in the unit at shift handovers and doctor's rounds. Each day I would introduce myself and give an information sheet to healthcare professionals. Information sheets were hung within the bed space on a cork board for anyone to read as they wished. A one-page form was put in the front of the patient's clinical notes informing staff that the patient was in the study and how they could contact me if required, see appendix four.

Gaining informed consent from the patient occurred towards the end of data collection. Although I was keen to gain informed consent from the patient as soon as I thought them cognitively intact to do so, I learnt from the first patient they were not able to take in the detail of my study because they were so unwell. I have captured this in my field notes while visiting a patient in the ward:

"I asked patient if he had read the information sheet, which he said he had not and did not know where it was, I gave him another one, he did not want to read it and said he was exhausted and then talked about dreams he had in the ICU. I asked if he wanted me to come back when he was feeling a bit better which he said he did. On reflection, I am keen to get informed consent, however, this patient does not care about this at the moment. Why do I care so much? I want to ensure he understands what I am going to do with the information I have about him. I have been collecting data for 18 days and he was unaware of this, however, he knows I am doing a study about him and says it's all right to be there but at the moment he doesn't care about the rest...

Why does he not care? He is physically and emotionally drained. He is happy for me to be there with him and his [family] but really does not want to know about this study at present. He is slowly coming to terms with the ordeal he has been through and coping with his failing body. He is dependent on all physical care." (C1, Field notes)

Reflecting on this scenario I soon realised that this patient was not capable of making informed consent because he did not want to consider the information at the time. This patient, like many others, decided they would participate in this study well after their

discharge from ICU when they were well enough to process what had happened to them. It was only at this stage that they had energy to understand and consider what the study was about. My anxieties about this lessened as I collected data on other cases and I experienced how other patients felt after discharge from ICU. It did raise questions in my mind about how some ICU patients are often asked about options for future treatment toward the end of their stay. Because of their lack of ability to cognitively think beyond the moment, it raised issues how some patients could make an informed decision at this time.

Confidentiality and anonymity

Maintaining confidentiality and anonymity was important to consider in this study due to a case consisting of one patient, family members and some staff members who could be identifiable to each other. Maintaining confidentiality was important between case participants and I was aware that I may be asked for information from participants. Furthermore, there was potential for participants to be identifiable if the hospital where data was collected was known, hence it was decided that each hospital where data was collected should be kept anonymous.

I was the only person who knew who all the participants were. To ensure data were safe when out in the field, I carried all notes and my digital recorder in a shoulder bag that was always with me. Transcribers signed a confidentiality agreement for typing up interviews as per appendix five. All names and identifying information was removed from the transcripts before they were seen by my supervisors.

There were occasions when family would ask me if I had read the patient's notes and what I thought about that patient's condition. I reiterated that I could not discuss what I thought and read but that they needed to talk to the nurses and doctors. Family accepted this explanation and did not want any further information from the nurses or doctors. On reflection, this often happened when the patient had developed another complication and family were faced with uncertainty. I found that family did this not because they were concerned about care, but because they were searching for some certainty or hope when the patient's prognosis may have been poor.

During data collection within the unit, there were times when I could not help but hear information about other patients, or due to activities in the unit, had an understanding of what was occurring with other patients because of my nursing knowledge.

However, I made a point of removing myself from areas where I could hear conversations about other patients or if the patient was particularly unwell.

Presentation of data findings proved to be challenging for maintaining anonymity of all participants and the locations. Initially I had thought that single case analysis could be presented as part of the study findings, but for the cases to be presented accurately participants became identifiable if a participant from the study was to read the findings. After many drafts of single cases, I decided to present only the cross case analysis. Furthermore, presentation of some of the participant's biography was also challenging to ensure I maintained confidentiality so not all information was presented. Due to the limited number of male nurses in this study, they would be easily identifiable within cases therefore I have presented all nurse participants as female.

Researching vulnerable groups

Critically ill patients are a vulnerable group and research with this group of patients and their family's needs to be held to a high ethical standard. Vulnerability refers to the inability to protect oneself (Silverman & Lemaire, 2006). Researchers need to ensure extra efforts are made to protect individuals and families without denying them the chance to participate and potentially benefit from research.

Involvement of patients as active participants while still in the ICU could only occur if patients were deemed well enough. Generally, patients were tired, and at times slightly confused, therefore there were limited conversations with patients during this time. Most patients understood who I was and why I was there and towards the end their stay in the ICU I would have short conversations with patients or at times just sit with them if they wanted me to. There is a potential for psychological distress when patients are critically ill as they realise the extent of their illness. However, it is reported in the literature that it can be therapeutic for ICU patients to talk about their experiences and throughout this study patients often discussed how they benefited from someone to talk to who understood what they had been through. Patients stated my presence had benefits as they had someone to share their experiences and I was able to fill in some gaps in their memory or help them make sense of their dreams or hallucinations.

Family as research participants are also a vulnerable group which I needed to consider and plan for. Firstly, family members were experiencing a high level of stress due to

the family member's critical illness, furthermore the next of kin was also the person providing consent for the patient and I needed to ensure I had on-going dialogue with the family to maintain the informed consent process. The family members were also participants in this study and were asked to talk about their experiences of having a family member in intensive care. Although this had the potential to cause distress, again I found the complete opposite for most family participants, as they were keen to talk about their experiences with some family openly reporting that they felt better after an interview. However, there was an exception with one family who early in the patient's illness felt quite traumatised at the thought that their family member could have died and therefore requested not to talk about this experience. As time went on they did want to participate in interviews and shared their early experiences. Therefore, the on-going communication with the family throughout this study was fundamental to ensure there was no extra burden for them and I respected their need for privacy if they wanted it.

Participation in qualitative research has been demonstrated to have benefits. Gysels et al. (2008) conducted a descriptive qualitative study of palliative care patients and their family members which explored their perceptions of the benefits and problems associated with open interviews and attempted to understand what causes distress and what is helpful about participation in a research interview. Their participant group consisted of 76 patients and 28 family members. Participants reported positively about the interviews, with the interviewer showing an empathic interest that was non-judgemental, the opportunity to talk about their frustrations and make sense of their experiences was seen as beneficial to participants. No participants reported that the interview had caused distress (Gysels et al., 2008).

Participation also appeared to have many benefits for patient and family participants. Family members in this study openly shared that talking to me, was helpful as I was a neutral person who knew what they were going through. My ongoing presence throughout the illness in ICU, my follow-up in the ward and at home seemed to help them adjust to what they had been through and I understood their illness continuum in comparison to the nurses who cared for them for short periods of time. After data collection had concluded many family members kept in touch. One family, where the patient participant had suffered considerable disability, would ring for advice about concerns they had, in which I would refer to them to an appropriate healthcare

professional for assistance. However, other families stayed in touch often via texts to inform me of milestones and progress:

“Happy New Year Claire. [Family member] is now an outpatient at rehab, so was home for Xmas. Follow-up hospital appointment on the 6th Jan. Wishing you a fab New Year Claire. Thanks for coming into our lives, mine especially.” (C6, Wife)

Because long-term ICU patients have a high mortality rate there was the potential the patient’s treatment could change from cure to palliation. This process may be part of the trajectory for the chronically critically ill that required ongoing research. If patients in this study were to have their treatment changed to palliation, I planned to seek sensitive and ongoing communication with the family for data collection to continue. If at any time relatives or healthcare professionals showed signs of distress, a discussion about seeking the appropriate help was to occur. Each ICU where this study was conducted had a bereavement service for relatives of ICU patients, which could offer ongoing services if required. However, this never eventuated and all patients survived their ICU stay to hospital discharge.

Due to the complexity of the patient group, I also needed to consider any potential problems that could arise for healthcare professionals, as a participant group in this study. Discussing issues about patient care could surface professional issues related to this complex group. If healthcare professionals showed signs of distress during interviews this was to be addressed and, if appropriate, a recommendation would be made that they visit their employee assistance programme that is available within each District Health Board (DHB).

Conflicts of interest

I needed to consider a number of issues that may arise undertaking direct observation of the patient in the ICU, care delivered by healthcare professionals and their interactions with family. It has been acknowledged within the literature that there are difficulties nurses can encounter when conducting clinical research due to their dual role as a nurse and a researcher (Bland, 2002; Borbasi, Jackson, & Wilkes, 2005; Wilkes & Beale, 2005). In my dual role, as a nurse and researcher, there was always potential for tension when witnessing care of patients (Hay-Smith, Brown, Anderson, & Treharne, 2016). Because of the potential conflicts that could arise, I needed to anticipate what these could be and have some strategies in place. The issues I

considered and measures I planned to take are listed in Table 6. Having this plan in place ensured that if incidents did occur in the field I would be prepared to deal with these appropriately. Further issues that arose during data collection will be discussed later in this chapter

Table 6 Potential conflict problems and solutions

Potential problem	Planned solution
Practice issues in relation to unsafe practice	As a Registered Nurse, under the Health Practitioner’s Competence Assurance Act (HPCA), I needed to discuss issues with those involved and report to an appropriate person at the earliest opportunity which in this study would be the charge nurse
Patient or family member that appeared overtly distressed	Discuss this with family and assist them to seek appropriate help or with the nurse caring for patient. If issue continues I would refer to the charge nurse
Healthcare professionals who did not want to be a participant in the study, but were involved in the patient’s care	Ensure on-going communication about my presence before my arrival, so before nurse allocation they are aware of my presence
Issues that caused distress to myself	Writing up field notes to capture my thoughts. Debriefing with supervisors

Cultural considerations

Within this study there were a number of cultural considerations that need to be addressed. Firstly, all health research conducted in New Zealand is of relevance to Māori, therefore this study has possible health outcomes for Māori. The overall aim of this research is to improve health care for a very vulnerable group of long stay patients (and their families) in the ICU setting. As Māori and Pacific peoples experience higher levels of conditions that are likely to lead to the need for intensive care, they also have higher levels of co-morbid conditions that can complicate their care leading to longer stays. There is therefore the potential that this research could inform clinical developments which could work towards reducing inequalities in the future. This research will result in the development of in-depth understanding of long-term patients and their family’s experiences, which may include examples of clinical practice that resulted in cultural distress.

As there was potential for a Māori ICU patient to be a participant, consultation with a Māori health researcher was undertaken. This ensured that research practices were appropriate, acceptable and that outcomes could contribute to Māori health outcomes. Consultation was initially with Dr Maureen Holdaway, Associate Director, Te Pumanawa Hauora, Research Centre for Māori Health and Development, Massey University, Palmerston North campus. She was available to offer support throughout this research project. Consultation is a way of arriving at and sustaining research partnership with Māori communities. To build trust and a meaningful relationship I liaised with each hospital's Māori Health Unit before data collection. This ensured consultation was an ongoing process throughout the project as mutually agreed by each party if a Māori patient or family was recruited into this study.

Because of the number of participants in this study there was potential for participants from cultures different from my own. Papadopoulos and Lees (2002) argue culture-generic competence is a prerequisite to developing culture-specific competence, where one is culturally aware, knowledgeable and sensitive to permit cultural competency. Furthermore, they argue that to be culturally competent is the same whether one is a healthcare provider or a healthcare researcher, with the only difference being the application of the specific skills. In order to ensure culturally competent research practice, it was important to have on-going conversations with family throughout the data collection to ensure I understood what was important for them and that my presence was never intrusive.

Data collection methods

Multiple data collection methods are the hallmark of case study research (Creswell, 2013; Merriam, 1998; Stake, 1995; Yin, 2009). In order to achieve the aims of this study within the complex setting of the ICU, observation with field notes, in-depth interviews, conversations and clinical record reviews were employed. An overview of data collection methods is given in table 6. This approach enabled the methodological triangulation of multiple sources of data, allowing the researcher to gain in-depth knowledge of the case, phenomena and contexts (Creswell, 2013). In order to understand the case and phenomena in depth, Woodside (2010) recommends data collection methods should occur across multiple time periods, which occurred throughout this study.

Data collection methods needed to be congruent with the theoretical underpinnings of the Chronic Illness Trajectory Framework. The work needed to manage an illness leads to a sociological perspectives of the trajectory, which is different from a medical course. The trajectory was central to this study as it refers to not only the physiological unfolding, but also the total organisation of work done over the course of the illness and the impact on all involved. An inductive approach to data collection was vital to ensure the trajectory and the work involved to manage and shape the illness was accurate. Therefore, data collection methods needed to include the work and biography of key participants so that the trajectory could then be mapped retrospectively.

According to Stake (1995) data collection in case study begins when there is a commitment to do a study. This builds the background to the case and first impressions that can never be captured again. While planning this study I maintained field notes to capture discussions with colleagues and healthcare professionals. During visits to ICUs to discuss my study and liaise about locality agreements, I captured what had been discussed in these meetings. Often discussions about past or current long-term patients in the unit at the time occurred and it was important to record this information. I also made a point of noting what it was like to be a visitor in an ICU, particularly because as an ICU nurse for 15 years, I had never had to wait in an ICU waiting room. These initial experiences needed to be captured because they would never be the same again and this data informed the contexts of the ICU.

Data collection occurred over a two-year period with six cases from four different ICUs as seen in Table 7. Due to the demand of intensive fieldwork while the patient was in the ICU, data collection occurred with one case at a time until the point where the patient was transferred to the ward, at which point another case could be recruited.

Table 7 Data collection hours and methods for each case

ICU length of stay (LOS)	Interviews (Hours)	Observation (Hours)
27	10	34
24	7	15
66	23	23
37	13	18
17	10	27
51	18	42
Total	66	159
Total Data Collection Hours: 225		

Observation

Participant observation was considered imperative in this study for the researcher to acquire an understanding of the case and how the phenomenon of the trajectory was shaped over time and by the multiple participants involved within the case. Data collection using observation does not follow a detailed, predetermined study design, but is responsive to what is found in the field (Savage, 2006). Participant observation entailed talking to people about the case, directly observing the case, noting the environmental contexts, reading clinical notes and understanding the guidelines, policies and procedures which all directly or indirectly impact on the case (Thomas, 2016). Furthermore, observation consisted of noting the key concepts of the Chronic Illness Trajectory Framework of work and biography, so I was interested in observing the work participants did to manage and shape the course of the illness. Observations are fundamental to case study methods when the case is studied in the natural setting (Yin, 2009), it allows the researcher to gain a comprehensive picture of the site, provides rich description, the norms and values of the site can be discovered and importantly, observation provides a cross check on data obtained in interviews (Simons, 2009).

The use of participant observation in healthcare research has many advantages. It has been seen as a way of understanding beliefs and practices, which can be viewed in the context in which they occur to enhance understanding of behaviour surrounding health and illness. It is also useful to understand the organisation of healthcare, such as rules and structures that are in place and what that impacts on the individual (Savage, 2000a). My epistemological stance for use of participant observation was to observe and document actions, interactions and practices in all aspects of the case, as in order

to understand how the trajectory was shaped I needed to be able to observe all players involved. My involvement as an observer was never to participate in any aspect of patient care, or to offer to be involved in any decision-making or plan of care with healthcare professionals. This was to ensure I did not influence the patient's trajectory and I would be able to view the case without bias. Although I was apprehensive about how I was going to conduct observation, being present but having no involvement in patient care or decision-making was a first for me. However, being able to observe without any input I was able to see things I had never seen before as a nurse working in the ICU.

Some researchers have argued that being a nurse conducting research in a known clinical environment is easier because they understand the cultural environment, (Borbasi et al., 2005), however the opposite can also be argued, in that they are so emerged in their environment they do not see the cultural influences. The parallels between participant observation and practice professions, such as nurses, are similar as they both aim to have an understanding of another and they generate knowledge by gathering sensory data (Savage, 2000b). My identity as a nurse clearly influenced my relationships in the field and shaped my interactions with the different groups I was studying. Because of my previous work in the ICU and my knowledge of the speciality, I was easily able to speak to healthcare professionals about patient care and understood their decision making processes. This probably gave me some credibility while observing because I understood how routines operated and the plan of care for the patient. It also helped my decision-making process in terms of what to observe and when. Key events during the day were important to capture, these included the nurse handovers, morning doctors' rounds and visiting time.

From my knowledge of working as an ICU nurse, I knew I would need to position myself far enough away so as not to be in the way of healthcare professionals. In addition, I did not want to be an overbearing presence for the patient who was likely to be cognitively impaired and my presence could cause them distress. I needed to observe from a distance, and from my visits to arrange locality access, I knew work stations were far enough away from the bed area that I would not be in the way, but close enough that I could see whether sitting or standing. This worked well and during doctors' rounds or at times when I wanted to clarify what I was observing, I would go over and talk with the nurse. Being far enough away from the immediate work area, I

would also not be seen as someone who could assist with patient cares. Furthermore, in my role as a researcher, I thought it unethical to assist with care, and did not want to be part of the patients' memories of care in the ICU. The only time I would have intervened with patient care was if there had been an emergency and there was no-one else, which in an ICU setting was an extremely unlikely scenario.

My presence within the units was well tolerated and even in the large tertiary units, healthcare professionals knew who I was because of my earlier presentation about the study and at shift handover the nurse in charge would inform staff of my presence. I wore my everyday clothing with a name badge and when I went into the bed area and touched patient surroundings I wore a plastic apron as per unit policy. There were occasions when I would sense my presence made some nurses uneasy, when this occurred I would leave the area for a coffee break, or use the time to write some of my reflections. There were other times when I chose to leave the area because cares were being carried out, or I did not want to intrude on visits from family. Because I had a relationship with the family I became aware of what was acceptable to them in terms of my presence when they were visiting. Some family were fine with me observing at times, but others valued private time with the patient, particularly in the early phases of the patient's illness when there was uncertainty about outcomes. On these occasions I would leave the unit. There were times when family came together with the patient to pray or just to be close, and I left the unit out of respect for the family's privacy.

Interviews

Qualitative research is about discovering and portraying multiple views and the interview has been viewed as the main way of doing this as the source of the most important information (Merriam, 1998; Stake, 1995; Yin, 2009). The purpose of the interview is to understand the other person's perspective and discover what cannot be directly observed such as emotions, thoughts, feelings and purpose (Merriam, 1998; Patton, 1990). Interviews are essential to case study research; however the key is to use a variety of approaches to counteract the weakness of each (Gillham, 2000; Merriam, 1998; Patton, 1990).

The most open approach to interviewing is informal conversations, which often explores the immediate context (Patton, 1990). Conversations are particularly relevant when researchers may want to know about an immediate event during an observational period and are also useful in the early stages of research when the researcher does not

know enough about the phenomena and context (Merriam, 1998). Conversations were used as a data collection method throughout this study with all participant groups and they were often used to clarify what was happening immediately. When patient participants were well enough in the ICU or ward, short conversations were useful to gather an understanding of the patient's thoughts without being too tiresome. They often wanted to tell me their immediate concerns and then wanted me to sit with them. For some of the participants my presence seemed to be of some comfort to them. Although they knew I was conducting a study they were unable to express interest at this point but were more interested in having someone sit with them.

Short conversations were also used during periods of observation when I wanted to clarify aspects of the patient condition and treatment with a nurse or doctor. At times when the patient seems agitated or had a change in their physiological parameters, short conversations were useful to clarify what the nurse was thinking in relation to the patient's condition. It was also helpful to answer questions about the day to day routines and rules that governed each ICU. Short conversations with family members often occurred when they arrived for the day, during periods in the waiting rooms or when they were with the patient. The use of text messages was also used by some family members to give me updates about the patient and how they were feeling. Often short conversations would be followed up with a sit down audio-taped interview where conversations could be explored further.

In-depth interviews, combined with periods of observation and short conversations, were inseparably linked in this study, thus enriching the data and providing an increased depth of knowledge. These processes were particularly important to understand how participant's biography informed the trajectory. To understand the world from the participant's view and unfold the meaning from their lived world the interview gives voice to participants therefore allowing them to present their life situation in their own words (Kvale, 2006). Face-to-face interviews in a quiet private room were ideal to explore participants understanding and meanings of the case. Interviews initially occurred with healthcare professionals and family members during the patients stay in the ICU and once the patient was discharged interviews were also conducted with the patient.

Semi-structured interview guides were developed for use with all three participant groups as appendix six. These guides were developed to ensure an understanding of the phenomena of the case was explored. Interviews were also an opportunity to understand what had been noted during observation and in short conversations that could be discussed in more detail. Interviews often followed periods of observation with a healthcare professional because it gave the researcher time to learn about how the interviewee worked and develop rapport, which facilitated a more in-depth interview. There were limited follow-up interviews with healthcare professionals because of changes of nurses looking after the patient as time progressed. Family members participated more often in follow-up interviews sharing their experiences in-between my site visits as the patient's illness progressed. Participants interviewed in each case can be seen in Table 8. Interviews were conducted with patients when they were well enough to cope with an interview after ICU transfer to the ward and once discharged home.

Interviews became more focused as the study progressed with issues identified in earlier cases explored in more detail. Interviews also focused on more topics to guide or test preliminary findings and began to look for commonalities and differences in participants' stories (May, 2013). However, in doing this, it was also important not to lose focus of the topic when restructuring questions to ensure consistency in data collection methods. The semi-structured interview guides ensured interview topics were consistent.

Table 8 Semi-structured interview participants excluding patient

Case	Family	Health care Professionals
1	Parent x 1	Nurses x 5 Doctors x2 Allied healthcare professional x1
2	Adult children x3	Nurses x 3 Allied healthcare professional x1
3	Adult children x2	Nurse x 4 Doctors x2
4	Spouse x1 Parents x 2 Sibling x2	Nurses x 5 Doctors x 1 Allied health care professionals x1
5	Sibling x 1 Niece x1	Nurses x2 Allied healthcare professionals x1
6	Sibling/ In-law x2 Spouse x1	Nurses x 5 Doctors x 1 Allied healthcare professionals x1

Document analysis

Document analysis is relevant in all case studies because of researching real-life contexts, it also adds depth to the study (Gillham, 2000; Simons, 2009; Stake, 1995; Yin, 2009). Documents are relevant to the case if it contains information or insights applicable to the research question (Merriam, 1998). Documents significant to this study included the patient's clinical records, observation charts and any other relevant clinical paperwork to capture the patient's care. This was important for overview the illness progression, the plan of care and clinical issues/ problems that occurred. As I was not present with the patient throughout their stay, the clinical records were reviewed as soon as I returned to the unit in order capture to what had occurred since my last visit. These data were recorded in my field notes with any identifying information about the patient, family or healthcare professionals omitted.

Recording data

Field notes were initially handwritten in the ICU, and this process was difficult at times when I did not have somewhere to sit and write. In the beginning I used loose paper but found it was difficult to file quickly to keep it safe. I soon realised that an A4 spiral bound booklet worked best to record information in chronological order and I did not have to worry about pages falling out. I also used a contact summary form that could be filed in my shoulder bag when in the ICU. I was very conscious that I

did not want to drop anything and therefore this method worked well in this environment. At the end of a data collection period, I would type my field notes into a continuous word document per case. There was a strong reflexive element to writing up these notes after I left the field I was able to add reflective sections into this writing or write a separate memo in relation to themes and research questions I wanted to follow up on.

Interviews with all participants were audio recorded and later transcribed by myself or a transcriber. Early in data collection, all the first three cases were transcribed by myself. Although this was time consuming it allowed the interviews to be re-lived and a deeper reflection occurred during the early analysis phase of the study. As more cases were recruited and due to time commitments, a transcriber was used.

Reflexivity

In qualitative research, the researcher is considered the research instrument, therefore reflexivity involves recognition of the researcher's integral part in the social world being studied. Hence the credibility of a study rests on the procedures implemented and the self-awareness of the researcher through the research process (Hand, 2003; Lipson, 2013; Pellatt, 2003). To be reflexive is to consider how one's actions, values, beliefs, preferences and biases influence the research process and outcomes. This is important in ethnographic fieldwork, which has a biographical dimension (Coffey, 1999), and particularly so in case study research because you are representing other's experiences, stories and reconstructing what you observed (Coffey, 1999; Merriam, 1998).

The researcher, as a major research instrument, needs to be aware of biography that they also bring to the study to ensure the validity of the study (Coffey, 1999). As a pākehā¹¹ middle aged nurse with many years' experience of working in the ICU and as a nurse academic, I needed to be aware of my own biography that had been shaped through caring for these patients, and working in this environment. The influence of self in fieldwork is seen as an integral process and the theoretical position that unpins self as an instrument for data collection has implications for how one might represent the work (Borbasi et al., 2005). Merriam (1998) argues the key to reflexivity is the

1. ¹¹ Pākehā a white New Zealander as opposed to a Māori.

transparency in the process which has three key advantages. Firstly, it enables the researcher to identify 'self' in any research process, secondly, by critically reflecting on actions taken throughout the research process it clearly shows how interpretations and conclusions were drawn and finally it allows the researcher to indicate their biases that emerged through the research process and what steps were taken to counteract these.

Identifying 'self' in the research process, started at the beginning of the research project as I developed knowledge on the topic through exploration of the literature and started to have conversations with various groups of people about my research ideas. To capture my thoughts, I started writing up my conversations and thoughts with ideas to reflect and explore further. Field notes throughout the research process provided me with an avenue to not only find meaning but also to identify my assumptions (Manias, 2000). Early field notes helped me remember my early understanding of the case. As I was becoming immersed in the case, and as I had new insights, it reminded me of my previous thoughts on particular matters.

Field notes were also an avenue in which I could note my emotions as this study progressed. Having considerable experience of ICU nursing assisted my knowledge of what I was observing and hearing, but it also meant I could, at times, see practice that did not follow what I thought was best practice for the patient. To deal with this when collecting data, I would remove myself from the unit, go for a walk around the hospital, then sit down and write about how I was feeling and then return to data collection. At times, witnessing the patient's deterioration, hearing the family's distress and also the opinions of the nurses caring for the patient was emotionally challenging. However, this was all relevant data to be recorded, so when leaving the field, I would go and capture my feelings so that I did not overlay my feelings to those of others. Coffey (1999) argues a strength of fieldwork is the involvement of the researcher, but failure to acknowledge and critically engage with self can result in superficial telling it as it was, instead of a deeper level of analysis.

It was also important to have an avenue to vent my emotions as I was perhaps trying to understand what was happening in the case. Case analysis meetings with my local supervisor meant I could discuss issues which were puzzling me, unexpected events, and any analysis I needed to understand the case in more depth (Miles & Huberman,

1994). These meetings were recorded and often during the meetings by talking about the issues at hand I identified an analytic moment I may have been struggling with.

My biography was captured through note taking and in case analysis meetings this was particularly relevant in relation to my pre-judgement about outcomes for patients and sometimes my nursing view. As observer in the ICU for the first time and not in my other roles as an ICU nurse or nurse educator, I needed to capture my changing view of what I was observing.

Data Analysis

Case study methods employ a number of strategies for data analysis depending on the nature of the phenomena and case. An important point is not to lose sight of the case and therefore the frameworks for analysis need to be holistic (Thomas, 2016). Stake (2005) refers to triangulation within cases and across cases and the use of constant comparisons. The use of theme mapping, vignettes developed and narrative are also common in qualitative case study research (Miles & Huberman, 1994).

Stake (1995) argues the researcher needs to find a form of analysis that works for them through experience and reflection as “this is case study not general qualitative research” (p. 77). In this study general qualitative approaches were used because of their potential to understand the case and phenomena, which Stake (1995) maintains this is particularly pertinent with instrumental case studies. However, general qualitative approaches also fit with the theoretical underpinnings of Corbin and Strauss’s (1988) trajectory framework. Creswell (2013) argues the key to case study analysis involves a description of the case, as well as themes, issues or situations specific to each case. Adequate contextual description is also important to understand the setting and contexts in which the case is revealed (Hyett et al., 2014).

Single case analysis

In the early phases of data collection there were a number of procedures used to begin early analysis. How data was organised was important to understand how the trajectory was being shaped throughout the study. The approach to analysis and interpreting data is influenced by the theoretical perspectives and in this study how the phenomenon developed throughout the patient’s stay in ICU.

Case study analysis consists of first making a detailed description of the case and its context first (Creswell, 2013). To enable this to occur, all data were formatted into

word documents, named by case number, participant type, date data were collected and patient's number of days in ICU. All data were then entered in chronological order into Dedoose Version 7.5.16,¹² a web application for managing, analysing, and presenting qualitative and mixed method research data. Entering it in chronological order facilitated changes in how the case was initially described as the illness progressed. Creswell (2013) recommends analysing multiple sources of data together in chronological order to determine the steps or phases. This was particularly pertinent to this study as I wanted to determine how the trajectory was shaped throughout the patient's illness and how that then informed the other participant group's trajectory.

All data entered into Dedoose were first coded with:

- How is this case described;
- What is typical about this case; and
- What is atypical about this case.

As each case was coded, a large word document could then be printed out in the order it was coded to maintain chronological order. Miles and Huberman (1994) view making case descriptions as making complicated things understandable by reducing them into components. Creswell (2013, p. 200) views descriptions of the case "...as a detailed view of all aspects about the case – the facts". However, it still produces a large volume of text, which alone is a weak and cumbersome form of display (Miles & Huberman, 1994). However, data that were atypical about each case did not become apparent until a number of cases had been analysed.

According to Stake (1995) the researcher is trying to pull the data apart and bring it back together in a meaningful way through analysis and interpretation so that an issue-relevant meaning will emerge. To understand each case further, the descriptive data were written up into long narratives as a way to encapsulate the essence of the case and help reveal how the trajectory was formed and shaped. Merriam (1998) and Stake (1995) both argue analysis and interpretation of data is a key component of case study analysis through the narrative structure used to present the data, as it is important for the reader to place the narrative into context, through being able to relate this to their own context, which can only occur through adequate description. Stake (1995, p. 39)

¹² <https://app.dedoose.com/App/?Version=7.5.16>

maintains that “qualitative research tries to establish an empathic understanding for the reader, through *thick description*”, so the reader understands the experience for themselves. The use of vignettes as recommended by Stake (1995) was useful to capture rich pockets of meaningful data early in the study (Miles & Huberman, 1994).

Through writing and rewriting of case descriptions, issues and themes were developed as the trajectory was evolving. Furthermore, as trajectories can only be understood retrospectively

However, because of three participant groups, there was a need to separate the description of the case into participant group case descriptions. This enabled developing issues and themes to be seen and allowed the trajectory developed for each participant group to be viewed more clearly. The trajectory was mapped chronologically for each case. Through this process the concepts from the Chronic Illness Trajectory Framework of work and biography became more apparent as was how they shaped the trajectory. Because of the length of stay for the patients in this study and wanting to see how the trajectory developed over time, large pieces of paper were used to hang on the wall and then descriptive data were hand written across for each case. Simons (2009) refers to concept mapping as a means of representing knowledge visually and mapping links between related concepts in making sense of the data. Mapping has three purposes, firstly it allows for coding and categorizing the data. Secondly it identifies themes or issues throughout the trajectory and thirdly it reveals the interrelationships and patterns between the issues, which is particularly important when there are different participant groups.

Trajectory mapping made it clearer to see issues as the similarities and differences became increasingly apparent between cases, including the concepts of work and biography and how it informed the shaping of the trajectory. The use of memos at this stage was important to ponder questions that arose from the analysis and to tie together issues that were becoming apparent for separate participant groups. Miles and Huberman (1994) suggested memos are useful to step back and make a deeper and more conceptually coherent sense of what is happening. Memos were useful to take a snapshot of my analysis, so it was captured when it was difficult to make sense of the complexity occurring between participants and I needed to understand why.

Trajectory mapping also made apparent key signposts or events that shaped the patient's trajectory and the phases that were developing within the trajectory. Apparent key events were noted across each case. Questions were developed about issues that were problematic in the trajectory such as:

- nurses' distress at certain points of the trajectory;
- uncertainty at the beginning and midpoint of the trajectory with the development of complications/ contingencies;
- a trajectory of steps forward and steps backwards - that appeared it would never end; and
- Lack of continuation of care with nursing.

Issues that were identified were then mapped against the contexts that were identified to influence each case. Some of these issues were about the ICU routine, the nurses' focus on daily tasks and lack of long-term plan for the patient. These issues were noted for cross-case analysis.

Interview data that were mapped into the trajectory were data that had been themed from reading the transcripts to identify issues for the family during this time and how they managed whatever was happening with the patient. These themes defined the major components of the trajectory for family members throughout the illness progression.

Key themes that were noted were:

- The ongoing uncertainty that consumed family;
- Physical, psychological and spiritual wear and tear for the family as the illness progressed;
- The strategies they developed to assess the patients' wellbeing for themselves; and
- The strategies they used to manage different behaviours displayed by nursing staff.

Similarly interview data from healthcare professionals, mainly nurses, were themed from reading the interview transcripts and revealed issues for nurses as the trajectory progressed. Key themes noted for nurses during the trajectory were:

- Distress at the potential for a poor outlook for the patient;
- Enduring suffering that they witness in patients;
- Frustration they could not meet their patient's needs during the later stages of the illness; and
- The unending work involved in patient care.

Underpinning this analysis was the theoretical framework, with the focus on work throughout a trajectory and the many lines of work the nurses navigated while managing patient care.

Multicase analysis

Stake (2006) argues multicase studies are so complex that it almost needs to be done by one person as it is difficult to transfer to others a full picture of what both researchers and data sources know of experience, interactivity and context. The number of cases analysed is also important as too few are chosen as it will not be possible to demonstrate the phenomenon in depth, whereas if too many cases are used they will provide more individuality than the researcher could understand. Hence it is important for the researcher to understand what connects the cases together, which in this study is the quintain as described by Stake (2006) or for simplicity the phenomenon which is: the trajectory of a prolonged critical illness in the ICU.

Once each case analysis was complete, cross case analysis was undertaken with a focus on issues related to the differences and similarities in experiences of the participant group across the six cases. Data saturation was determined to be reached during this phase of analysis as the themes with similarities were clearly identifiable and the differences were explainable. Issues and events related to similarities were mapped out from each individual case. These milestones signified events that altered the trajectory and identified different phases occurring with commonalities for all cases. These similarities included:

- The trajectory projection by all healthcare professionals;
- The slow and complicated trajectory progression;
- Similar phases for all patients while in the ICU; and
- A midway point of multiple complications or changing contingencies in relation to the course of treatment.

The patient's phases of their illness needed further analysis to identify defining features in each phase. Again large charts were used to map out the phases with supporting data from all the cases. To further validate these phases these codes were analysed through Dedoose before writing up these phases began. Data were then available in Dedoose for all participant groups to identify key issues happening as the patient's trajectory progressed.

As the trajectory of a prolonged critical illness was established, the other participant group's trajectories became clear as it was informed by the patients. Data that had been coded with the patients' phases was then used to identify the interplay between the participant groups. In keeping with the theoretical underpinnings it was important to understand how nurses managed their lines of work throughout the trajectory. Data that related to nurses and their work was coded against the phases and then matched to reveal their lines of work throughout the illness trajectory. The use of a matrix helped to display the data about the nurse's work during the different phases of the patient's trajectory.

Issues revealed throughout the cases were then compared to understand how they performed in different contexts. As a number of different units were used for data collection, the influence of unit culture became more apparent as data was further synthesised and represented within the patient phase and the nurses' lines of work. Comparing issues within different contexts aided the identifiable differences between cases and how the local contexts influenced these differences.

The use of vignettes throughout the cross case analysis helped to bring participants' groups stories together and assisted to see the generalisations that were made about a group but was read as one person's story. Vignettes allowed the storyline structure, while preserving the chronological order of issues identified through all participants (Miles & Huberman, 1994).

Triangulation and confirmability

One of the recognised strengths of case study research is a triangulated approach to data collection (Merriam, 1998; Stake, 1995) in which one source can confirm or refute evidence found from another source (Hutchinson, 1990). Stake (2006) views the purpose of triangulation as the same whether single or multicase study which consists of assuring an adequate picture of the case that is clear from biases and not

likely to mislead the reader. However triangulation involves more than this: it also encompasses data sources, different investigators and theory to provide corroborating evidence (Creswell, 2013; Lincoln & Guba, 1985; Miles & Huberman, 1994).

Stake (2005, p. 454) defines triangulation as the “process of using multiple perceptions to clarify meaning, verifying the repeatability of an observation or interpretation”. He further comments that no observations or interpretations are exactly the same and triangulation serves to clarify meaning by finding different ways to view the case. The researcher is interested in multiple realities in which people view their lives.

Analysis was confirmed in a number of ways. The most obvious was analysis of each case individually which displayed similar patterns and issues as each trajectory progressed. These cases were constructed over a two-year period of data collection and analysis. Within each case the same issues emerged as the trajectory progressed: this was profoundly clear within the trajectory phases. Initial analysis of transcripts was blindly analysed by a supervisor to confirm my findings. Further confirmation of data was clarified through debriefing with a supervisor on a regular basis as previously discussed and by the use of reflexivity to identify my thoughts throughout data collection and analysis.

Generalisations

Qualitative research focuses on the theoretical generalisability and its rich description of experiences. Although many qualitative researchers recognised the importance of dealing with the issue of generalisability, there is much debate. Within the naturalistic paradigm it is argued there can be no generalisation because no two social settings are sufficiently similar. However regardless of the surface similarities in any setting, when they consist of many complexities individual generalisation becomes difficult (Erlandson, Harris, Skipper, & Allen, 1993). Furthermore Guba and Lincoln (1982) argue that generalisations are impossible because phenomena are not time or context free, instead there is emphasis on detailing enough information about the entity studied and the setting so that an informed decision can be made if conclusions cannot be drawn from the study (Schofield, 2002) .

Simons (2009) argues that in many contexts we have an obligation not to generalise but to demonstrate how our findings can be transferred to another context and used by others. Hammersely and Gomm (2000) argue that case studies need not make any

claims about the generalisability of their findings, but what is crucial is for others to make them. It is through the use of rich, thick description that this occurs, so that the reader has the basis of information appropriate to judge (Merriam, 1998). Stake (1995, p. 86) suggests “to assist the reader in making naturalistic generalisations there needs to be the opportunity for vicarious experiences”. To do this Stake (1995, pp. 86-87) suggests:

Accounts need to be personal, describing the things of our sensory experiences not failing to attend to matters that personal curiosity dictates. A narrative account, a story, a chronological presentation, personalistic description, emphasis on time and place provide rich ingredients for vicarious experience.

Context-specific or naturalistic generalisations allow the reader’s tacit knowledge to help make connections and association with the study. Hence the way of experiencing the case is relevant for the clinical practice setting. In the contexts of this study the rich description of the participants’ experiences can be generalised to other groups of ICU patients and high acuity settings.

Trustworthiness

The steps to maintain trustworthiness of this research have been described throughout this chapter. The criteria for trustworthiness as described by Lincoln and Guba (1985) are detailed in Table 9.

Table 9 Techniques to demonstrate trustworthiness

Criteria	Techniques employed
Credibility	Prolonged engagement in the field Triangulation of data sources Triangulation of data collection methods
Transferability	A detail and rich description of the study and study sites Purposive sampling
Confirmability	Audit trail of data analysis Memoing Peer review
Dependability	Audit trail Reflective note taking

Conclusion

This chapter has drawn together the methodological and theoretical underpinnings informing this study. Case study is an approach that allows the researcher to deal with complex, context-dependent situations and clinical environments. It is highly suitable to use within the clinical setting and is flexible enough to capture multiple perspectives that inform a phenomenon. Researching within the natural setting of the ICU needs special consideration and planning and I have explained the process of ethical research in this environment. Case study is a useful approach in nursing research to understand a highly contextualised phenomenon of the trajectory of a prolonged critical illness.

The next four chapters form the cases study starting with a detailed account of the ICU environment in which the patient with a prolonged critical illness dwelled. The next three chapters provide an exploration of the trajectory of a prolonged critical illness from the experiences of each participant group – the patient, their family and healthcare professionals with a particular focus on the nurses' work.

The following conventions have been used in the presentation of the case study

...	Material edited out – part of a sentence
[...]	Material edited out – more than a sentence
[]	Editorial comments for clarity
Field notes	Case number, Field notes
Bold	Emphasis e.g. loud speech
(CM)	My initials – my questions/comments
<i>Italics, Times new roman font</i>	Participant's speech
(C, participant title, Letter)	Case, participant, identify code - i.e. A, B, C etc., times interviewed if more than once – i.e. 2 nd , 3 rd etc.
Calibri type font	Quotes from my field notes
Courier new type font	Quotes from documents

Chapter 6 - Context to the Cases

Introduction

The aim of this chapter is to provide a detailed picture of the ICU as the site where the case of the long-stay ICU patient and the phenomena of a prolonged critical illness is enacted. This chapter describes the physical environment of the ICU, the waiting area, the rules about visiting and access into the ICU through the researcher's observational data from all four ICUs where this study was conducted. It is intended to provide an in-depth description of an ICU within the New Zealand public healthcare system and to provide detail of the visitor's perspective as they arrive in the ICU for the first time.

The physical location of the ICU

The ICU is a specialised work site within the hospital with the task of saving the lives of critically ill patients. This specialised work site requires the intensive care unit to be centrally located within the main acute services building of the hospital. Other supporting worksites such as the emergency department, operating theatres, radiology services and medical and surgical wards are also within close proximity. Newcomers are guided to the ICU from the main entrance via signage along corridors and through lifts to the entranceway. Upon arrival at the entrance to the unit, newcomers are met with signs and security cameras indicating this is a serious and controlled space. The entrance into the ICU is protected by locked large double doors with the following signage:

INTENSIVE CARE UNIT

No admittance, visitors please ring for attention
(C1, 2, 3, 4, 5, 6, Field notes)

Security cameras inside the ceiling monitor activity which can be seen by healthcare professionals from within the ICU. The time of day will dictate initial responses and greetings, Monday to Friday during office hours a receptionist may be present to greet and facilitate access. Outside of office hours signage by the doorway gives instructions for access.

Visitors

Please ring the intercom and wait. Do not enter.

A staff member will be with you shortly

This applies with every visit (Thank you)

(C1, 2, 3, 4, 5, 6, Field notes)

Once the intercom has been rung, visitors wait for a response. This response may be immediate or there may be a delay, consequently the visitor often pushes the button, again waiting for a response. A voice from within greets the visitor and asks who they are and whom they would like to see. They are instructed to wait while a staff member confirms their identity and allows access. The outcome may be immediate visitation or they may have to wait in a designated waiting area.

Waiting areas

Waiting areas for visitors are within close proximity to the main entrance of the ICU. Rows of uniform seating with washable surfaces dominate the room. A large television screen is centrally located on the wall for viewing, which may or may not be switched on, with the remote control to operate it chained to a permanent fixture nearby. The walls have instructional posters, with information about the ICU and the medical equipment in the patient's bed area. Access to tea, coffee or water is not apparent and the only visible locations to get drinks are from vending machines which are located in central corridors on route to the intensive care unit. These machines generally only stock sugary drinks, bottles of water, confectionary and potato chips. Toilets and a public telephone are located near the waiting area. Security cameras in the ceiling are visible in all waiting areas. There are pamphlets placed in a prominent position which inform relatives about the aims of an ICU, amenities they may use, and the rules of visiting:

-
- Only 2 visitors at a time
 - Use the intercom or ask at reception before entering the unit
 - Avoid visiting between 8am – 11am due to doctors' rounds
 - You will be asked to leave the unit during the course of the day to allow staff to attend to patients
 - No fresh flowers in the unit

(C1, 2, 3,4,5,6, Field notes)

Access into the unit

First time visitors are greeted by a staff member who instructs them on the rules upon entry. Once inside the double doors, the visitor must wash their hands at the sink or use a hand sanitiser before proceeding. At this point there is still no view of what lies beyond. A corridor leads visitors into the main unit. Neutral coloured walls and laminated flooring dominate. The corridor is lined with an occasional framed print donated by past patients and their families.

The main unit

On entering the main unit there is an open plan large room which is segregated into 'bed areas'. The brightness in the room comes from fluorescent lighting. Some bed areas have a large window, and some have no natural light. The large room accommodates six to ten beds in a square or rectangular fashion. Located either centrally or along one wall, are staff workstations with computers, telephones, stationery supplies, an intercom system and a security monitor of the entrance to the unit. Depending on the time of day and the activity within the unit, there may be a lot of noise from healthcare professionals conversing, phones ringing and alarms from bed areas ringing out. At other times there may be a subtle noise of medical equipment working, papers being shuffled and nurses' footsteps from individual bed areas.

The physical 'bed space'

Each bed area is uniform. The bed areas are physically separated by a half wall and/or curtains. The flooring is covered with a durable linoleum and the walls are painted, and there are boards at eye level where patient's flow charts hang.

An electric hospital bed dominates the centre of the bed area which can be accessed from all sides. Above the bed a monitoring screen is positioned which can be viewed

from many angles around the bed area. Wall mounted rails or shelves support a multitude of power and medical gas outlets at the head of the bed. A mechanical ventilator is at the head of the bed and infusion pumps are located to the side of the bed. Adjacent to the bed is a work station containing frequently used supplies. Hand basins are positioned near each bed area and a large standing desk is positioned near the bed and is covered with clinical notes and charts. The daily observation chart dominates by its size, which is formatted with many tables and boxes. There may be one or two chairs in the bed area which are provided for visitors. Not all patients in each case were in a bed area that had any natural light. Everything in this bed area is set up ready for immediate use. When the bed areas are in use the patient's lighting can be intense via overhead lights and from medical technology. It is all this equipment within the bed area and how it is set uniformly and ready to use which makes this area the 'ICU patient bed space'.

Allocation of patients to a bed space

On admission to the ICU patients are generally admitted into a bed that is grouped near other patients in the main unit. This is for ease of relieving nurses for breaks and the ability for nurses to watch each other's allocated patient if the nurse needs to leave the patient for a short period of time. As the illness trajectory extends patients were often moved to quieter bed spaces within the main unit or a side room. This would generally occur when the patient became more responsive to noise and activity in the unit. However, moving to a different bed space did not always indicate that there would be a view from a window or much natural light within the room.

The presence of health care professionals

Upon entering the main ICU, the presence of a large number of health care professionals is obvious.

"It is 1515 hours on a week day. The morning staff and afternoon staff are all present at the central work station. A health care salesman is present to give an in-service tutorial on a new piece of equipment the unit is using. I count how many people are in the unit as I notice the increased activity and noise and wonder what the patient thinks about the presence of all these people. There are four patients present in the main unit. Two patients have visitors with them. There are twelve nurses, five doctors, one ward clerk, and two healthcare sales representatives present amongst the four sick patients." (C1, field notes)

At certain times of the day there seem to be large numbers of people present compared with the patient ratio. During morning doctor rounds, teams of different speciality doctors come to visit their patients, each team can be comprised of four doctors or more. Other members of the multi-disciplinary team also come throughout the day, or when required, for input into patient treatment and interventions. An increase in healthcare professionals will also correspond with a deterioration in a patient's condition or during an admission to the ICU. During an admission, which can occur at any time of the day or night, there is likely to be a multitude of people present. Shift changeover, for nurses and doctors to a lesser extent, will also see a significant increase in healthcare professionals within the unit.

The entwined physical space

This overview of the physical structure of the ICU is to prepare the reader for the place where the long-term ICU patient, their family and healthcare professionals dwell during the illness trajectory. The physical space is entwined into the lived experiences for all persons who dwell in it, as it encapsulates feelings and experiences as well as interactions with others in this space. The ICU, as a physical space, is designed to meet the goals of the hospital as a work site for efficient treatment of patients, within designated areas. ICU is one of the many workshops within the hospital where the 'arc of work' is to provide efficient care to patients with a critical illness. The goals of the environment from the architecture to the fittings in the ICU all serve the purpose of efficiency, control and safety (Almerud et al., 2007). The equipment and fittings used within the ICU make it one of the most technologically advanced place within the hospital (Almerud, Alapack, Fridlund, & Ekebergh, 2008a). The relationship between the level of acuity and a hostile environment is not new, Dyson (1999) suggests as sickness increases, the environment becomes more hostile and alien. It also makes it a very controlled and secure place in the hospital. It is controlled by the staff who work there and dominated as a place designed for staff, with limited space for anyone else (Eriksson, Lindahl, & Bergbom, 2010; Olausson et al., 2012).

The ICU physical environment is one which patients and families cannot influence, but it will affect their experiences while in the ICU. It is also an environment where healthcare professionals manage all critically ill patients throughout their stay in the ICU. As their illness trajectory progresses the environment remains static, but the phases of the patients' trajectory will be shaped and influenced by this environment.

Conclusion

The aim of this chapter was to set the scene for the reader of the physical environment where the trajectory of a prolonged critical illness is played out. It enables the reader to experience the structure and organisation of this environment and how it influences all participants throughout the trajectory. In the following three chapters, the findings generated across the cases within this setting will be presented. Although separated in chapters all participants involved are connected to each other and this environment.

Chapters 7, 8 and 9 reveal the trajectory for each participant group for clarity for the reader, but all experiences are informed by each participant group and the environment in which one dwells. Chapter 7 focuses on the patient's illness trajectory, chapter 8 portrays the family's trajectory and chapter 9 demonstrates the nurses' lines of work through the different stages of the patient trajectory.

Vignette

The Trajectory of a Prolonged Critical Illness

Doctor's project the patient's illness trajectory to be complicated. Overwhelming sepsis consumes the patient's body. All his body systems are dependent on technological and pharmacological supports to sustain his life. His family are told there is little hope of survival. His life swings in between improvement and deterioration.

Despite predictions, he survives but is left with the aftermath, a physiologically frail dependent body. This fuels a cycle of critical illness as his body has little to fight against further invasion. Infection, skin breakdown, gut dysfunction and bleeding grips his failing body. As he slowly becomes more aware, he feels trapped, confused and distressed. His family watch and wait, they face continued uncertainty as another complication sets back his illness progression. They watch him suffering and wonder what they have done to let him endure such misery.

Nurses work hard caring for his failing body, they are so busy with all the different tasks that must be completed to maintain his body. As he becomes more awake he is difficult to communicate with due to intubation and his confusion. They wonder if he is in pain as he becomes more awake and increasingly agitated. Nurses are exhausted caring for him and some request to have a break from nursing him. He has many nurses caring for him over the subsequent weeks.

He becomes more awake as physical assaults to his body lessen, and the focus of care is on 'weaning' from life supports. He is confused and has periods of agitation. He slowly becomes more aware of his failed body; he cannot lift his legs off the bed, his fatigue is unimaginable, he is constantly thirsty and the noisy environment is intolerable at times. As he is liberated from life sustaining treatment he is ready for discharge to the ward. He has no idea he has been in the ICU for over a month. His family are not with him, they have had to return home to work. He is alone, confused and scared.

“...please God never give this illness to my worst enemy”. (Case 5, patient)

Introduction

The introductory vignette introduces the trajectory of a prolonged critical illness that is presented in the following three chapters. It gives a glimpse at the complexities and uncertainties which inform the trajectory for all participant groups in this study.

This chapter presents the findings that emerged from cross case analysis of the six cases to reveal the trajectory of a prolonged critical illness. Analysis of data from interviews, observation and clinical notes led to the emergence of the phases of a prolonged critical illness in the ICU. Although this chapter presents phases for the patient, not all data come directly from the patients themselves, as they were unconscious or too unwell to partake in communication during many phases of their illness. All six cases in this study progressed through these distinctive phases described which was not only measured in days or time but by physiological and psychological characteristics.

Aligning the Corbin and Strauss Trajectory Framework

Corbin and Strauss (1988) have applied the trajectory concept to chronic illness acknowledging the path varies and changes over time. The trajectory framework includes phases that reflect fluctuations in the illness. The phases in this chapter are based on the six cases in this study and only capture their trajectory within the context of their ICU experiences. However, the phases identified when mapped retrospectively, are similar to Corbin and Strauss’s (1988) framework of chronicity, which will be revisited at the end of this chapter.

Before critical illness

For all patients in this study their critical illnesses were sudden and unexpected. Mostly these patients knew very little about intensive care and how an illness can take hold so quickly and change their lives forever. They were all admitted to an ICU with different medical diagnoses, as seen in Table 10, but all share common phases that

reflect the shape of their illness trajectory while in the ICU. Without intensive care services it is highly likely that these patients would have died early in their illness.

The Cases

Table 10 Demographic overview of cases

All cases	
Admitting diagnoses	Abdominal sepsis; Multiple trauma; Respiratory failure;
Gender	3 Males 3 females
Age range	40s – 70s
ICU level	3 cases in level 2 units 3 cases in level 3 units
Days in ICU	17 -66
Days in hospital before ICU admission	0-19
Days in hospital post ICU discharge	3- 240
Total hospital days	20 – 278
Day tracheostomy inserted	1 participant no tracheostomy 9 -17
Days on mechanical ventilation	2 - 59
CCRT due to AKI¹³	3 patients

Phase 1 – An overwhelming pre-set trajectory

Becoming overwhelmed describes all patients’ experiences of an admission to ICU due to a critical illness which in turn started a cascade of physiological events which required life sustaining interventions. Trauma and abdominal sepsis saw patients arrive from the emergency department or operating theatre in the ICU totally dependent on life-saving interventions and treatment. Patients had minimal, if any time to realise how sick they had become. Patients who were developing severe respiratory failure as either their primary illness or secondary to sepsis, had time to

¹³ (CCRT) Continuous renal replacement therapy for acute kidney injury (AKI)

realise their body was failing and they needed life-sustaining interventions to support them. Patients were confronted with an illness so severe they knew they had little control:

I said 'I am going to die', the feeling was I was going to die. My mum died [patient's mother previously died in ICU]...I was going to die, I was losing my will power because of that. (C5, Patient)

Realising they are in crisis, patients' work focuses on what they have to do to maintain life. Their respiratory system has to work hard to get enough oxygen. Their breathing increases and they struggle to maintain respiratory function. They are closely monitored by nursing and medical staff, who are ready to intervene when required. As they deteriorate nursing staff note their struggle:

She looked awful. I wondered if she was going to make it, she was quite restless and her respiratory rate was over 40 and really shallow breathing and she looked uncomfortable with it. Intubation was the right thing. (C3, Nurse A)

As their respiratory system becomes overwhelmed they need to be intubated and placed on mechanical ventilation. Patients realised they had reached a point where they could no longer maintain their own breathing. They succumb to life-sustaining inventions, there is no other way:

He was struggling to breathe, all his energy was getting air into his lungs...he said 'I can't handle this much longer...I can't do this anymore'. (C6, Wife).

It is not long before patients are totally dependent on life-sustaining technology and interventions. Their mind is overwhelmed with sedative medication and disappears to a place unknown to us all, as their body works harder to sustain life. The physiological failings become evident in their body appearance. Their body swells as sepsis and organ failure occupy their 'failing body'.

Due to the patient's physiological presentation and their continual deterioration, it became clear to experienced healthcare professions, such as the admitting consultant, the trajectory projection was going to be long and complex.

There are some patients who have disease you know are going to be long, guaranteed to be long as soon as you heard the story. So I would have thought of him as a long-term patient right from day one and there are some other diseases where you can make the same

kind of prediction, so that's one group, and then there the others who present with an acute problem and you're not quite sure if it's going to be sorted out quickly or not and you have to wait for the trajectory to become clearer. Most patients, the long versus the short nature of it [will be] clear within three or four days. (C4, ICU consultant C)

Apart from the presenting disease, the severity of symptoms, age and comorbidities present upon admission also indicated to healthcare professionals that patients had a complex and long trajectory set for them.

She was on 100 percent oxygen for many days and we couldn't move her or do many things and she had multi-organ failure and was on dialysis...she clinically appeared quite sick. You didn't know where she would end up but amazingly she is coming out all right. (C3, Nurse B)

There is growing concern by healthcare professionals that patients may not survive their illness. The continual deterioration of body systems over the first seven to ten days results in some patients being on maximum life supporting treatments with the anticipation that they may die. This is documented in the clinical notes:

After considerable discussion and examination [the patient is] not suitable for ECMO¹⁴...we would be very gloomy with patient's family about prognosis of good outcome. There may be more episodes of deterioration and improvement or may see her improve or there may be inexorable decline in her condition. At any stage may decide to stop or withdraw treatment. In summary feel patient unlikely to survive this illness. (C3, ICU consultant, clinical notes)

However, these patients did not die but the consequences of survival on their physical body has left them severely debilitated. Due to their condition, there are still doubts by healthcare professionals that survival is possible. The uncertainty about their trajectory projections results in some patients having limits put on options or offers of further treatment.

¹⁴ ECMO -extracorporeal membrane oxygenation is an extracorporeal technique of providing both cardiac and respiratory support to persons whose heart and lungs are unable to provide an adequate amount of gas exchange to sustain life.

Phase 2 – A long wavering trajectory

This phase is marked by a number of defining moments in the illness trajectory. Firstly, patients have reached a point of tentative stability. With stability comes the demarcation point of being able to have a tracheostomy¹⁵ performed because the trajectory projections indicated a prolonged stay. Insertion of a tracheostomy was seen by healthcare professionals as a common characteristic of a long-term patient, whereas other patients would have shown a reduction in dependency on mechanical ventilation. As they are showing signs of physiological stability, sedation is reduced and patients begin to show signs of waking up. Secondly, in this phase, there are periods of physiological improvement but equally periods of deterioration, making for a wavering phase of their illness.

The consequences of survival have come at a physiological cost. The initial illness deconditions patients to the extent that they are unrecognisable. They are still displaying signs of physiological stress and dependence on machinery and pharmacological life-sustaining support:

It is day ten, temperature 38.5° Celsius, heart rate 90 bpm, mean arterial pressure maintained at 60 with noradrenaline infusion, on full mechanical ventilation, continuous hemofiltration in progress, fentanyl bolus just given, supine in bed with head slightly elevated, unable to move limbs to command / attempted to poke out tongue slightly to command, eyes open slightly. (C6, Field notes).

Despite the admitting diagnosis at this stage of their illness, all patients have common clinical characteristics at this illness stage as shown in Table 11.

¹⁵ A tracheostomy is performed for long-term airway management and to facilitate an anticipated slow wean from mechanical ventilation and for patient comfort.

Table 11 Common Clinical Characteristics

Clinical Characteristics
Mechanical ventilation dependency (C 1, 3 ,4 ,5 ,6)
Extreme generalised oedema (C1, 2, 3, 4, 5, 6)
Acute kidney injury (C3, 4, 6)
Critical illness myopathy ¹⁶ (C1, 3, 4, 6)
Multiple organ failure (C1, 2, 3, 4, 5, 6)
Decreased level of consciousness (C1, 3, 4, 5, 6)
Malnutrition (C1, 3, 4, 5, 6)

These characteristics distinguish them as patients who have survived a sustained physiological assault that was potentially fatal. These clinical features are similar to those reported in the literature about CCI patients, with the hallmark feature being prolonged dependence on mechanical ventilation as described in chapter three. CCI is a syndrome of alteration in body composition, generalised oedema, neuroendocrine changes, brain dysfunction manifesting as coma or delirium, increased vulnerability to infections and skin breakdown (Carson & Bach, 2002; Hollander & Mechanick, 2006; Mechanick & Brett, 2002; Nelson et al., 2010; Vanhorebeek & Van Den Berghe, 2004).

These physiological complications make for a wavering phase as their illness progresses. With signs of physiological stabilisation the medical plan is to start to reduce some of the life supporting treatments. However, with the body so deconditioned and weak, physiological assaults still threaten and hit. There is a fine line before instability occurs again as shown below from the beginning of the day when there appeared to be improvement but by evening there was clinical deterioration and the need to increase life-sustaining supports:

Day eleven, in the morning, improving neurological status, respiratory wean. 1330 hours decreasing blood pressure, decreasing urine output, pH down¹⁷, 1800 hours - septic shock, renal failure from intra-abdominal sepsis. (C4, Field notes)

¹⁶ Critical illness myopathy – is a syndrome of diffuse, symmetric, flaccid muscle weakness occurring in critically ill patients and involving all extremities and the diaphragm with relative sparing of the cranial nerves.

¹⁷ Indicating acidosis from septic shock

Although still very dependent on life-sustaining interventions, with increasing stability and the insertion of a tracheostomy there is the expectation of reducing sedation and allowing these patients to become more awake:

The physical assaults the patient has endured dominate her existence. Every system in her failing body is supported by technology. Her respiratory function is supported by a ventilator; her cardiac system still requires medication to support an adequate blood pressure. Her renal function is supported by a dialysis machine...Her tracheostomy continues to ooze blood. She is swollen and a maze of tubes overwhelm her body. Her mouth has multiple ulcerations. She has frequent diarrhoea. Critical illness myopathy means she cannot move any of her limbs except her head from side to side. She cannot maintain her body temperature and a blanket blows [warm] air around her...the patient starts to rouse. (C3, Field notes)

Due to organ dysfunction the waking up process is not straight forward and is slow. If there were periods of hypoxaemia or hypotension there are also concerns these patients could be neurologically compromised. As the patient starts to wake they may appear uncomfortable or anxious, exhibiting behaviours including grimacing or breathing against the mechanical ventilator causing it to alarm. This can result in nurses administering a bolus of sedation, which further delays waking. As patients wake they appear confused, agitated and/or delirious. Their faces look troubled and fearful. Often there was no response to the nurse or family when they talk to them:

She lies in the bed with her eyes open. At times she looks around and grimaces. She moves her head from side to side. (C3, Field notes)

The nurse comments: *I swear she was giving me a filthy look and even the other nurses said the same.* (C3, Nurse C,)

The patient is in a delusional state and retrospective tells that she thought the nurses and doctors were monkeys: *There was a gang of monkeys, there were grey ones, huge big ones and baby one, standing in the corner and staring at me...* [She could not understand why they were there and why they would] *come and stare.* (C3, Patient interview).

Unreal experiences such as unpleasant dreams and hallucinations have been reported in numerous studies on ICU patient experiences (Karlsson & Forsberg, 2008; Lof et al., 2006; Magarey & McCutcheon, 2005; Samuelson, 2011). Dreams and

hallucinations appear to dominate during this phase of their trajectory. Experiences such as abandonment, being trapped or left to die were described:

I thought that no-one was there for me, that was the worst part. I thought they dumped me and I was crying and I was thinking about my two daughters and I was wondering what is going to happen to them. I thought one of the doctors was trying to kill me and I was just begging them to leave me alone. (C5, Patient interview)

Experiences also included being in strange places that made no sense:

I'm convinced what scrambled my thinking, my sense of time and location, where I was, because I completely lost track of where I was. I imagined at one point that the ICU was in a building away up in the far North West of England, near the Nuclear power station and another time I thought it was in the southwest of Lands' End. Another time it was near the Gulf of...coz when I was lying there I was sure I could see outside and see a windsock, like on an airstrip and also at least on one occasion I thought I heard an aircraft taking off, so I thought I was in some station where they have air ambulances. It looked like there was a ramp where they took off into the sea as if on the edge of the sea. (C1, Patient interview)

Because of the potential for many unpleasant experiences with this group of patients it is important to balance pleasant experiences for patients (Samuelson, 2011). This became increasingly more important as the trajectory progresses and patients become more aware of their surroundings and their 'failing body' making them totally dependent. Yang (2016) defines dependency in critically ill patients as a powerless and vulnerable state, characterised by losing 'self', causing feelings of shame, fear and distrust. Fear and anxiety potentiate further unpleasant experiences. Consequently, long periods of dependence with unpleasant experiences can potentiate a complex trajectory in this group of patients.

The use of music near one patient meant she reported many pleasant dreams that were triggered by her family's presence as well as familiar music she enjoyed at home. This patient had great delight as she retold her stories:

Little bits here and there, not together and I'm trying to make sense ...but I didn't want to, I just loved to be there and not interacting with the world, my daughter's voice comes to me and called out. The sleep was very comfortable and I rather liked sleeping, no worries and stuff like that and one little thing would trigger another dream so it was easy for me to keep dreaming. I had a dream my daughter

was very famous, I thought she was playing the music I could hear on a CD. (C3, Patient interview)

These pleasant experiences could be disturbed when the patient was touched by a nurse who may have been checking or performing an intervention:

You withdraw from the rush of activities. I suppose that's natural, the feelings depended on who the person was and if they are being kind or not. Sometimes I open my eyes and I see someone touching me and I go all hot and get a lot of concern and I become cross. Some people haven't the patience and they say this is the road and we have to abide by that and I thought some people are not kind. Sometimes they can be mean I think and I go back to my thoughts and I know that there are different types of people. (C3, Patient interview)

The ability to withdraw from the rush of ICU activities to her dreams gave this patient strength to be able to cope with her illness. But she could also feel invaded by a nurse touching her, something which she had no control over. The only control she had of the situation was to withdraw herself back to her dreams and this appears to be an important defence mechanism for this patient.

The patients' debilitated physiological state with little reserves, makes this phase of their illness particularly long and arduous. The emphasis on medical care during this phase is to reduce life supporting interventions as tolerated. However, because of their frailty this needs to occur slowly. Their psychological anxiety related to their delirium and/or dependence, can also produce a physiological response. Therefore, a high respiratory rate could mean they are struggling to breathe as mechanical ventilation is reduced, or indicate other physiological problems such as infection, cardiac problems, or a psychological issue such as anxiety.

He has high fevers and tachycardia...he was tachypnoeic ...so that's been an ongoing thing...are we giving him enough pressure support on the ventilator ...has he got a fast heart rate because his lungs are stiff so it's difficult to breathe or has he got a chest infection or is it just due to his general ill health? The patient looks uncomfortable breathing at a rate of 36 breaths per minute. (C1, Nurse, E).

Both physiological and psychological stimuli activate equally the hypothalamic-pituitary-adrenal (HPA) axis and therefore stimulate comparable bodily responses (Papathanassoglou & Mpouzika, 2012). Ongoing stress caused by a prolonged critical illness has been theorised to further shape the trajectory of the illness through the development of multi-organ failure (Bellar et al., 2009; Brame & Singer, 2010;

Papathanassoglou et al., 2010). Based on this theory excessive unrelieved stress will potentiate complications and increase length of ICU stay. Hence nursing interventions to alleviate stress are vital during this phase of their illness.

Complications related to being critically ill were common during this phase of the illness as shown in Table 12.

Table 12 Complications developed through critical illness

	Case 1	Case 2	Case 3	Case 4	Case 5	Case 6
Acute kidney injury			√	√		√
Hospital acquired pneumonia		√	√			
Sepsis of unknown origin	√		√			√
Skin rash	√			√		√
Pressure ulcer	√		√			
Diarrhoea		√	√			√
Myopathy	√		√	√		√
Delirium	√	√	√	√	√	√
GI bleeding			√			√
Mouth ulcers			√			

Physiological frailty makes patients prone to complications and creates the waving phase of the trajectory during patients’ progress. Complications can occur simultaneously making the assault more violent and increasing the risk of death. The following excerpt from my field notes demonstrates the patient participant’s on-going complications:

It is day 25 and he has now developed an increase in his temperature overnight, he is more tachycardic and tachypnoeic with increasing need for vasopressors to maintain an adequate blood pressure. He is still on mechanical ventilation and has started to ooze blood around his tracheostomy site. The doctor this morning has written in his notes: “appears to be developing new sepsis. Over the next 24 hours the patient starts to have malena¹⁸,

¹⁸ Bleed in oesophagus, stomach or first part of small bowel

which increases in frequency and amount to the point he requires a blood transfusion of four units of red blood cells and other blood products. As I leave the hospital I write in my field notes: “I think this man may die from all this. (C6, Field notes)

One complication increased the risk of another and progress is so slow it appears to standstill. With every new complication comes the risk that their physiological reserves will become depleted and there is nothing left to utilise. The following excerpt from my field notes demonstrates the on-going complications:

Day 21 on life support, her body is so debilitated her mouth bleeds with open ulcers which look infected. Her haemoglobin is 65 grams/litre ¹⁹ from bone marrow failure due to the severity of her illness. She has become “tachycardic, tachypneic and febrile”. She has now developed a hospital acquired pneumonia. Day 26 it is noted she has stage 1 pressure ulcer in her sacral cleft, day 27 she is finally able to move her toes, fingers and shoulders only, day 28 she has spiked a temperature with a query it is from line²⁰ sepsis, day 38 febrile again, day 42 starting having malena, day 44 gastroscopy show marked erosion involving D1-D3²¹. (C3, Field notes)

Ongoing complications made for a mid-point trajectory crisis. The multiple complications make surviving look less likely.

“Oh he was looking terrible, and he had made a millimetre of improvement every day until yesterday...and he’s probably got about hundred metres for the race and he’s only made a small amount and yesterday he’s gone back quite a lot...he has regrouped but at a lower level...he still has an extremely high mortality.” (C6, ICU consultant U)

Continuing complications limit treatment options and result in some patients having limitations put on treatment and interventions, and a ‘Not for Resuscitation’ (NFR) form completed. On day seventeen as a patient develops another septic episode the doctor comments and then writes the following in excerpt into his clinical notes:

This is a man that is now two months into it that failed to thrive, that had all these treatments that failed...if he deteriorated from that point that it would be time to approach him and the surgeons about limiting treatment. (C1, ICU consultant V)

There are no further surgical options that they can offer, not for inotropes or

¹⁹ Normal haemoglobin in female is 120 – 151 g/L

²⁰ Introduction of infection through invasive lines

²¹ Duodenum composed of four distinct parts: D1-D4

*vasopressors if develops septic shock, NFR
sheet done. (C1, Clinical notes)*

Complications add to patients' suffering through the physiological discomforts and pain they produce. Throughout most of these complications patients were conscious, although drowsy. Their discomfort was evident from facial grimacing and their body becoming stiff when touched or moved. Agitation was also evident from constantly being touched and disturbed from nurses working around the bed.

The clinical characteristics of this phase of the illness are similar to those described within the literature in relation to CCI patients. Progress is described as slow periods of improvement with frequent interruptions caused by acute events such as sepsis or heart failure (MacIntyre, 2012; Nelson et al., 2010). These complications are attributed to the cumulative damage this syndrome produces making patients prone to infection from the multiple threats such as: indwelling lines and skin breakdown, exposure to virulent and resistant pathogens and an exhausted immune system from the initial critical illness (Bellar et al., 2009; Nelson et al., 2010; Wiencek & Winkelman, 2010). Hence the longer the illness progresses slowly the higher the threat of mortality for the patient.

Phase 3 – Emerging with a failed body

This phase of the illness trajectory is marked by patients becoming more aware of their body, which does not do what it should, which in turn produces feelings of anxiety and fear. The total dependence on the nurse has the potential to create a sense of powerlessness throughout this phase for the patient. There is a gradual realisation that something unspeakable has happened to them as this patient portrayed when describing what he thinks happened in the ICU while he was unconscious.

*Well I reckon they drug you, they starve you, you know they do
something to you. It's a bit like in the [Armed] forces as they have
to tear you down before they can build you up. (C4, Patient)*

The aftermath of the physiological and psychological effects of critical illness are major for the patient. Feelings of being drugged, starved and torn down sounds similar to being tortured. There are numerous reports in the literature of patients describing being in the ICU as being kept a prisoner, in a war-zone or being tortured (Clukey, Weyant, Roberts, & Henderson, 2014; Hov, Hedelin, & Athlin, 2007; Meriläinen et al., 2013; Russell, 1999; Schelling & Kapfhammer, 2013). Most of these reports are

related to psychological trauma. The physiological effects of muscle wasting, weakness and fatigue equates to the fact that intensive care therapy saves lives but cannot prevent the development of the chronic phase of critical illness, when nutritional and vital organ function are pushed beyond their limits (Van den Berghe, 1999), hence patients are waking to find a body that no longer functions as they would expect. A study of patients' pathway from critical illness to recovery found patients' described their body as disobedient, weak upon waking, producing fear and anxiety (Palesjö et al., 2015). The more severe and prolonged the period of critical illness, the greater physiological effect one could anticipate. Hence the role of the nurses in this phase of providing psychological support is vital, which will be discussed in chapter nine.

As patients become more aware they were troubled with physiological discomforts as shown in Table 13.

Table 13 Physiological discomforts

Discomforts	Supporting data
Aches from being on prolonged bed rest	...day 20...has sore tailbone +++ (C1, Field notes)
Immobility	<i>...it's the hardness thing because overnight you lose the use of your limbs (C3, Patient)</i>
Persistent thirst	<i>"thirsty...I could drink a bucket of water (C3, Clinical notes)</i>
Dry mouth	<i>I had a very dry mouth...the mouth gets dry like sandpaper and my lips got very dry and start to crack up...so periodically they would apply some moisture with these little green sponges...they only gave a very temporary relief (C1, Patient)</i>
Fatigue	It's late afternoon...the patient is exhausted, physiotherapy has finished...he begs the nurse to turn the overhead lights off and let him sleep. the nurse will not let him go to sleep...she tells him he must adjust to a day/night routine...the patient shuts his eyes...the nurse tells him to open them...he is beside himself with fatigue (C4, Field notes)

Physiological symptoms from prolonged critical illness went beyond discomfort for some patients with episodes of severe abdominal pain or breathlessness.

His pain is relentless, it comes without warning...it is crampy and spasmodic...it totally consumes ...distress is all over his face. He grabs his abdomen as the pain takes over his whole being. He cannot yell out, he has no voice. He bears the pain alone. It drains him. (C4, Field notes).

Multiple episodes of pain as described above occurred during the patient's illness. Often he could not communicate when the pain was happening and therefore this would go unnoticed by clinicians if they are not directly watching him. Many of these on-going symptoms produce anxiety and fear. However, patients were unable to communicate their needs due to difficulties associated with intubation, or myopathies which meant they could not write. Many of these symptoms were not recognised by their frequency or intensity, resulting in much suffering for the patient.

Fear of the physiological effects produced from critical illness caused patients to be fearful and confused. Patients had trouble understanding what was happening to them. They just knew something dreadful was happening. As I sat with a patient during this phase of his illness, I asked him if he knew why he was in the ICU. He did not know, he just knew he was in a state of being constantly frightened about what was happening to his body. All he could tell me was... *"I am very scared of what is happening to my body"* (C4, Patient). Although he could not say much to describe to me how he felt, his behaviour of heightened response, alertness, and constantly looking around indicated he was afraid. These physiological symptoms produce anxiety; it adds to an increased physiological and psychological burden through activation of a stress response.

Discomforts quickly become hard to endure, and patients need their discomforts rectified immediately, but this did not always happen. A common occurrence would involve the patient wanting to go back to bed from a reclining chair and having to wait for long periods before this would happen. An example of this is described from my field notes:

It is late morning...the patient has been in the lazy-boy chair for four hours. The nurse has been waiting for the physiotherapist to arrive so they can help get the patient back to bed. The physiotherapist is running late and the patient wants to go back to bed. He is

complaining of being tired and is pleading with the nurse to go back to bed. She makes him wait until the physiotherapist arrives. The patient has been having abdominal pain all morning and looks fatigued and generally uncomfortable. He has a tracheostomy, so cannot communicate easily. There is nothing he can do but wait. (C4, Field notes)

The patient seemed powerless to do anything but to wait. The nurse seemed sure the physiotherapist would arrive soon, but it was probably another hour before the patient got back to bed. The time the patient had to wait is not only measurable in clock hours or minutes, but what that experience of having to wait meant to him while feeling fatigued. He was not well enough to appreciate the nurse's time. Nursing care is often delivered in chronological time, measured by the clock (Caldas & Berterö, 2012). Bodily changes from illness alter a person's relationship to time (Jowsey, 2015), the passage of time is individualised and so each patient will experience time in association with their existence and not the schedule of the nurse (Ellingsen, Roxberg, Kristoffersen, Rosland, & Alvsvag, 2014a).

A number of studies have demonstrated the high burden of symptoms critically ill patients endure. These include pain, dyspnoea, fatigue, anxiety, depression, thirst, hunger and sleep disturbances (Curtis, 2014; Li & Puntillo, 2006; Tate et al., 2012). Some studies have further demonstrated the high burden of symptoms in the CCI patient group (Campbell & Happ, 2010; Nelson et al., 2004). These findings suggest that symptom management remains a significant unrecognised problem and is particularly more troublesome for patients with a prolonged stay. An important finding from one study demonstrated how 'knowing the patient' in relation to continuation of nursing care prevented the burden of many of these symptoms (Tate et al., 2012). 'Knowing the patient' within the ICU context has been seen as relevant for nurses, enabling them to make therapeutic decisions, because they treat the patient as an individual (Wilkin & Slevin, 2004).

Because patients could not verbally report their discomforts, it made them dependent on the nurse to recognise their needs. When patients were not understood it produces frustration, agitation and a sense of hopelessness. Due to their critical illness myopathy they could not write and nurses had difficulty lip reading. Fundamental fears and discomforts could not be conveyed:

I was very conscious of the fact that when I was trying to speak I wasn't speaking very clearly and I think some of the nurses couldn't understand meunderstand what I was saying so it got to the stage they would sort of give me a whiteboard and a marker pen and try and get me to write down but I think another consequence of the prolonged inactivity in the ICU was that I couldn't write properly and I couldn't write clearly so what I wrote down just looked like scribble and they'd say 'I'm sorry I can't understand you'...and I tried to write it down and it just came out as an illegible scribble and they'd say I can't understand you and they'd go away again...so communication was a problem. (C1, Patient interview)

As patients were physiologically more stable during this phase of their illness the nurse was not always in the immediate view of the patient to be able to get their attention. However, during this phase of their illness, their psychological needs were greater and they were dependent on nurses for support. Being alone produced further feelings of anxiety:

It really sort of pissed me off, I was that reliant on the nursing staff to come and help me and it seemed like ages for them to arrive. The thing was, I didn't know how many other people were in ICU with me...because they [the nurse] seemed to disappear down one side, I couldn't sort of lift my head and turn around to see what was going on, so I lay there hour after hour, day after day, and I couldn't sort of read, listen to a radio. I got a bit bored with all that inactivity. (C1, Patient interview)

Some patients found this particularly distressing and some patients did resort to banging on the bedrails to get the nurses attention:

[The nurse said] you are in HDU²² now, I have another patient to look after and I will get to you.

[When the patient's wife arrives]: he grabs my hand and breaks down...and said he was scared [he said] I don't understand what is going on. (C6, wife interview)

Patients needed psychological support during this phase of their illness and lack of support could result in patients becoming more anxious. Anxiety and stress can precede periods of confusion. However, family presence provides the link back to reality and helps alleviate the stress. Many studies have found how family presence grounds patients back to reality and links to the future (Egerod et al., 2015b; McAdam, Arai, & Puntillo, 2008; Storli et al., 2008).

²² HDU - High dependency unit – step down unit with 1:2 nurse: patient ratio

The patients' anxiety, fear and behaviour was not always recognised as part of the illness trajectory and impacted on their ability to control their behaviour with all needs being perceived as urgent. If their behaviour was perceived as inappropriate by clinicians it was because they were too sick to control it for themselves. This is an example of a patient who remembered the lack of compassion shown by a senior doctor during a line change. The patient retold this story with tears in his eyes:

Patient: I remember doctor putting the line into my neck...that was quite horrific...I remember that because he is quite rude...no bedside manner...and it was quite a while and it was very uncomfortable...

Family member: ...the nurse said he was brutal but it needed to be done...

Patient: I reacted to that brutality and he just mocked me 'stop acting like a three-year-old', I remember him saying that, just felt like he didn't understand what I was going through. What I was saying wasn't me, you know, it did a lot of harm and you know...every time they did something I didn't like, I told them...I didn't deserve to be put down like that. I am a [age] year old man, as good as he might have been you don't treat your patients like that, even if I was acting like a three-year-old, which I probably was. I don't deny that, I didn't have control you know. I was in continual pain, continual and there are periods of time when I was conscious of things. (C6, patient interview)

The complete lack of control the patient had over his body and behaviour did not appear to be recognised by the doctor. There is no mention of where the nurse was during this incident. The lack of compassion shown to the patient leads to dehumanising experiences and feelings of vulnerability, helplessness and suffering (Berglund, Westin, Svanström, & Sundler, 2012; Johansson, 2014; Piredda et al., 2015; Yang, 2016). Care that is perceived by patients as poor involves healthcare professionals' who are deemed to lack empathy, are impersonal and rush care which lacks a holistic and patient-centred approach (Berglund et al., 2012; Piredda et al., 2015). The need to create an atmosphere where healthcare professionals' attitudes are encouraging and respectful has been found to increase patients' autonomy during critical illness, which in turn, influences recovery (Lindberg et al., 2015).

The need for support from nurses varied depending on patients' needs. However, when nurses knew the patient at an individual level this meant that as their illness progressed the nurses could recognise their personalities and their coping strategies during this

‘comeback’. As their illness improved and they are becoming less dependent on life-sustaining intervention, patients start to show their personalities and coping strategies. Their personalities became apparent and showed them how they could get through their illness:

She’s got quite a lot of spunk...she is quite a character...she has been calling out this morning, she wants to go home...so she has got a bit of get up and go...yeah she might get there...and with her family support there is hope there. (C2, Nurse E)

The personality of the patient and her desire to go home, along with support of many family members, was seen as positive indicators that this patient could survive her illness. The nurse’s ability to know the patient as an individual facilitated further relationship development with the family and together they could maintain a positive outlook for the patient in her recovery. For patients their family provide a sense of security and a reminder of life outside of hospital (Cutler et al., 2013).

Patients started to make light of their plight which helped to normalise and gain some control of their situation:

His sense of humour has come in quite a bit...you know if the nurse turns around he will poke his tongue out and now we have a laugh. (C6, Wife interview)

Nurses could be seen as assisting in this ‘comeback’ process as they got to know the patients’ likes and dislikes. Family members would bring in items from home that would also be of interest to patients. Simple things such as a hair shampoo and body wash, as well as some nail polish helped bring back the patient’s identity:

Mum always wants to look pretty and take good care of herself and I noticed the nurses had washed her hair and painted her toe nails and I made a comment about it and she was smiling away. (C3, Daughter 2)

Only one of the ICU’s had a comprehensive form that had information about the family and the patient’s likes and dislikes. These were personalised into the daily routine. A white board at the foot of the bed ensured the patient knew what the plan for the day was as seen in Table 14

Table 14 Example of white board

Place: ICU at [name] hospital	Orientate at least 3 times day
Assist bed wash, sit in chair, brush own teeth	Nurse: _____
8am-10am: Rounds	Number of days in ICU
10am-12pm: Physiotherapy	_____
12pm- 2pm: Visitors/ rest	
2pm – 4pm Watch TV/ Listen to music	
4-6pm: Visitors	GOAL: sit in the chair / look
6-8pm: Watch TV: Channel one plus - Who wants	out the window
to be a millionaire; One News	
9pm: Back wash, settle to sleep with own music	
	(C5, Field notes)

As patients are weaned off all life-sustaining interventions they are then ready for ICU discharge. This is met with apprehension and fear by some. Some are still confused and unsure of what is happening to them. Others are happy as it marks their regaining control of their body and therefore their life:

I was going toward the exit...I was happy and I was going to the ward and from there I was going home and that made me feel proud.
(C5, patient)

As the long-stay in ICU is over, the trajectory of a prolonged critical illness continues for the patient as they are transferred to a ward.

Phase 4 – Working to piece it together

As patients are transferred to a step-down ward they gradually learn about the illness that has consumed their body. Time had stood still for the patients; it is not measured by days. They are in a temporal place of past, present while trying to make sense of

the future and their lost time. Through the trajectory the shape of time was altered by suffering, confusion, anxiety, hallucinations pain and discomforts.

Their journey of piecing it all together began when patients became physically and mentally well enough to process the information told to them by family and healthcare professionals. Because patients feel so physically unwell initially, their attention is fully focused on dealing with their immediate physical problems including fatigue, pain or a dry mouth.

I didn't actually realise....it was sometime afterward...I think after I came to [the ward] and on several occasions they [healthcare professionals] said when I was over there [in ICU] I was a very sick man...but I don't think I was conscious of that aspect...my main concern was ... I was conscious I was kept so long nil by mouth and not allowed to eat or drink...my main concern on being nil by mouth was the dry mouth, the roof of my mouth and the dry lips which seemed to be cracking up but I'd completely lost any appetite. (C1, Patient interview)

Apart from the immediate physical needs that prevented patients realising how sick they had been, patients could also choose to psychologically separate themselves from needing to understand their illness or the consequences of it. They waited until they were well enough to cope. Firstly, they need to put all their energy into healing. For a patient who had a relative die in the car accident, which caused her admission to the ICU, she explains how she had to try and not think about the death of her relative:

I was surprised I didn't get more badly injured [in the accident] ...but I think I put it behind me until I'm out of hospital...I put the fact that [relative] died behind me so I don't worry all the time...because... [you have to concentrate on getting better]...that takes all my energy. (C2, Patient interview)

It's like journeying through uncharted territory as patients try to comprehend what family tell them about their illness. Discovering how sick they were and what the family have experienced gives them a sense of concern in terms of what family have endured:

The children...they kept telling these things and I couldn't take it in because I have never been a sick woman...and these experiences and they said "Mum we nearly said goodbye to you" ...it was a difficult time for my children. (C3, Patient interview)

Making meaning of being critically ill occurs through the recovery process. Patients try to discover the gap of weeks to months which is missing from their memory. As they recover they learn about their illness. These stories are intertwined with the distorted experiences they have of their critical illness. This can mean patients are reluctant to learn about what has happened in the ICU and avoid some conversation about it.

Patient: *I begin to wonder whether some of the images I have in my mind are true or not because I lost all track of where I was so if the surrounds are true ...I somehow doubt it...*

CM: *You should go back to ICU to have a look where you were.*

Patient: *No – I don't think so...no...I don't want to remind myself... that part is over and done. (C1, Patient interview)*

The distorted memories patients have after a critical illness are well described in the literature (Palesjö et al., 2015; Rattray, Crocker, Jones, & Connaghan, 2010). Without acknowledgement of these distorted experiences, patients have difficulty dealing with this phenomenon (Rattray & Hull, 2008). The need to debrief and support patients post-ICU to deal with these memories improves their psychological wellbeing (Harvey & Davidson, 2016). In a study of patients four to six weeks after ICU discharge, predictors for post-traumatic stress symptoms were found to be memories about pain, lack of control and the inability to express needs (Myhren et al., 2009).

As patients become well enough to understand their illness in enough detail there was a realisation they could have died from their illness. This intensified their emotional burden and they needed a lot of time to process and come to terms with this new knowledge:

I have figured out my illness enough to know that I am still here [starts to cry]...my wife has told me the stuff I need to know...how bad I really was, which is probably a good thing, I can't remember, and how it affected my family, that was bad [becoming tearful]...my niece nearly passed out...my brother choked every time. (C6, Patient interview)

As they comprehend what has occurred, this is marked with profound sadness at the thought that they nearly died, what their family has endured and the aftermath it has taken on their body:

Family member: *We've done a lot of talking about it [being sick] ...it was quite emotional and raw...but we have moved on a lot...I*

took photos...once a week and over time I've shown him those photos and explained what part of his journey he was at, at the time...so yeah we relived all that...

Patient: *...it's like six months of my life that's been taken from me.*
(C6, Patient interview)

Coming to terms with the possibility of dying during the person's critical illness brings sadness and distress. It changes who they are with the realisation they have faced death and survived. It is a difficult and painful process that is experienced during this time. ICU has been described as the 'holy ground' where people's experiences of ICU are carried with them and have a crucial significance in how their lives are shaped thereafter (Egerod et al., 2015b; Papathanassoglou & Patiraki, 2003). As the patients' illness trajectory progressed their physiological functioning was greatly affected afterwards and, for most participants, they were not able to go home for up to six months after their discharge from the ICU. Physical, mental and social problems after ICU are well documented in the literature, with recovery being long (Rattray, 2014; Rattray & Hull, 2008; Storli et al., 2008; Svenningsen et al., 2015). Although the case of a prolonged critical illness comes to an end for this study, patients' work continues as they attempt to rebuild their bodies and lives beyond the confines of the ICU.

[Aligning to the Corbin and Strauss Trajectory Framework](#)

The trajectory of the case of a prolonged critical illness demonstrates similarities to the Corbin and Straus (1988) chronic illness model as seen in Table 15. Corbin and Strauss argue that through new research a greater understanding of a particular disease, new emergent diseases or particular phases could occur. The phases of a prolonged critical illness set the ground work for further work into the complexity of illness as technological advances change the course of an illness with critically ill patients.

The course of a prolonged critical illness does not end with an inevitable downward trajectory. Although at times throughout the illness course, it appeared that this could be a possibility. The possibilities of these patients returning to their pre-critical illness health status was not studied, but it appeared to be unlikely that this was going to occur. Corbin and Strauss (1992a) emphasise that with any chronic illness, people have to come to terms with the illness and symptoms, regimes and side effects. But the trajectory model reminds us of how healthcare professionals, family and the patient themselves work to manage and lessen the impact of symptoms, side effects and the impact on their identities and future well-being.

Table 15 Comparison of Corbin and Strauss phases and prolonged critical illness

Corbin and Strauss Trajectory Framework		Trajectory of a Prolonged Critical Illness	
Corbin and Strauss Phase	Corbin and Strauss Definition	Prolonged critical illness	Phases presented within this chapter
1. Pre-trajectory	Before the illness course begins, the preventive phase, no signs and symptoms present	Co-morbid conditions; severity of physiological assault	
2. Trajectory onset	Signs and symptoms present	Severe signs and symptoms	
3. Crisis	Life-threatening situation	Sudden admission to ICU	1. An overwhelming pre-set trajectory
4. Acute	Active illness or complications that require hospitalisation	Illness progression in the ICU	2. A long wavering trajectory
5. Stable	Illness course/ symptoms controlled by regimen	Weaning from life-sustaining treatment Transfer to ward Rehabilitation	3. Emerging with a failed body 4. Working to piece it together
6. Unstable	Illness course/ symptoms not controlled by regimen		

Conclusion

This chapter has presented the four phases of a trajectory of a prolonged critical illness as experienced by patients in the ICU with the New Zealand public health system. Common to all patients were these four phases that defined their illness. Each phase was defined by common physiological and psychological characteristics and issues that shaped the trajectory for the patient. These four phases have been aligned with the Corbin and Strauss illness trajectory framework.

The following chapter presents the trajectory which the family endured throughout their family member's critical illness. Their trajectory is shaped by the patient's physiological and psychological condition.

Chapter 8 – Relentless Uncertainty – The Family

Introduction

The previous chapter presented the experiences of the patients throughout the trajectory of a prolonged critical illness. This chapter presents the cross-case analysis to illustrate the phases that family endured in relation to the physiological status of their critically ill family member. Trajectory refers to not only the physical unfolding of an illness, but the total organisation of work done over the course of the illness and the work for all involved, which in this chapter focuses on the family. During a prolonged critical illness family transition through being overwhelmed with a sudden critical illness to enduring ongoing uncertainty. The overarching theme of uncertainty captures the family members' trajectory experience which relates to the severity of the patient's illness, compounded with multiple complications, a slow recovery and uncertainties about the future. The findings presented in this chapter were derived mostly from interviews with family, but occasional information from the patients and healthcare professionals, short conversations and observations throughout their journey in the ICU and beyond.

Penrod (2001, p. 241) defines uncertainty as:

a dynamic state in which there is a perception of being unable to assign probabilities for outcomes that prompts a discomfiting, uneasy sensation that may be affected (reduced or escalated) through cognitive, emotive, or behavioural reactions, or by the passage of time and changes in the perception of circumstances. The experience of uncertainty is pervasive in human existence and is mediated by feelings of confidence and control.

Being overwhelmed

Everyday life suddenly stops for the family when their relative is admitted to an ICU and their world shrinks to concern for their sick family member. The course of the day and the daily focus instantly become so different. As family travel to the hospital the shock and reality of what has happened become real:

It was a shock obviously when he came in...getting the text on Saturday morning to say that they'd put him into intensive care and you know nobody wants to hear that because you obviously worry when it's intensive care. (C6, Sister).

Seeing their relative for the first time all attention is on them, that is all that matters.

Reality is confronted:

The first day is unbelievable, seeing her for the first time, it was a real shock, I think she was awake that day and not wanting to talk to her about the accident because we didn't know at that stage how much she had remembered...she was in a bad way. (C2, Daughter)

With little understanding of what is happening they watch in fear as they see their family member's physiological struggle:

It was quite traumatic, it was quite scary seeing her gasping for breath, she was aware of what was going on and I said "they want to intubate you and put you in an induced coma and is that ok with you" and she nodded...that was the only thing that kept her alive at the time. (C3, Daughter)

As patients deteriorate with minimal knowledge of what is happening some family think it is the beginning of the end and their family member will die:

I got pretty upset at the time [when they decided to intubate] ...to me that was the beginning of the end...I thought that was the last resort...they would call the family up and turn it off [the ventilator]. (C6, sister).

How the life situation of relatives changes suddenly when a family member is admitted to the ICU is well documented in the literature. Relationships change and everyday routine is suddenly severed as they are overwhelmed with uncertainty (Ågård & Harder, 2007; Johansson, 2014; Johansson, Fridlund, & Hildingh, 2005; Paul & Rattray, 2007). The uncertainty critical illness brings to relatives is persistent and at times could consume relatives as they began to appreciate the seriousness of a prolonged illness.

Family members are informed by an ICU consultant that their family member has the possibility of dying. For some it is difficult to accept it could be that bad but, as time progresses, the reality of the seriousness of the illness is realised. As the patient continues to deteriorate, family are faced with the prospect of death. It was described as raw and traumatic and unbearable to talk about at times. I noted in my field notes of one family's trauma during the first week in the ICU:

The family are happy for the patient to be recruited into this study, but following the events of the previous week and the traumatic information that their family received [that their family member could have died] they are still struggling to deal with it, they do not want to talk with me at this stage...they feel raw and traumatised...and can't bear to talk about it at the moment and resurface that grief. (C3, Field notes)

The extreme uncertainty of relatives' experience has been reported within the literature. Feelings of chaos, helplessness and being out of control are common place (Ågård & Harder, 2007; Blom et al., 2013; Eggenberger & Nelms, 2007). Further to these feelings are the overwhelming experiences when they see the physical transformation the patient has undergone and this exacerbates the situation (Olausson et al., 2012; Page, 2015). Shock affects their ability to comprehend and leaves them feeling numb (Eggenberger & Nelms, 2007; Soderstrom et al., 2006).

How some doctors deliver news to family in the initial meeting was a particularly traumatic event for some family members:

That was a horrible experience...we were the only two family members there which was unfortunate because I am emotional and the wife and sister ...he [doctor] didn't come across with any compassion and I was shocked at that because I thought people in intensive care are normally so kind and you know he just laid it on the floor...he said...this is what the disease does and this is the situation and it's serious and you need know and it's life threatening and it was stunning enough to get...that we didn't know that it was that bad, but the way he delivered it and portrayed it. He didn't give us any sort of ... I mean he didn't give us any kind of encouragement or hope...it was all the negatives...we just thought 'this is it', 'the end', which is never nice. (C6, Sister)

The ongoing updates about the patients' conditions are dreaded because information always seems to be negative and compounds their feelings of uncertainty:

They give the worst case scenario all the time so sometimes you dread talking to the doctor...they want to cover all bases and give you the worst case scenario and so don't get your hopes up. (C3, Daughter 1)

The initial meetings with doctors established the precedence for further interactions. Negativity has a propensity to underpin the ongoing meetings about the prognosis for a poor patient outcome. This sets the tone and therefore family dread talking with the doctors. Previous research on family satisfaction in the ICU has shown the

dissatisfaction with the way in which news is delivered (Azoulay et al., 2000; Fumis, Nishimoto, & Deheinzelin, 2008). Effective sensitive communication is vital to help family cope with a critical illness throughout the trajectory. Although family need honest information about the patient's prognosis, there was also a need for a balance between realistic information and hope within these interactions (Bernacki & Block, 2014; Eggenberger & Nelms, 2007). Support from the nurse has been found to be crucial in assisting family to cope with frightening experiences and the ability to absorb and understand the given information (Frivold et al., 2015). Families become overwhelmed with uncertainty and the thought of more distressing news.

Living in an uncertain world

During this trajectory phase the family experiences correlate with the patient's condition. In this phase patients' progress is slow and does not follow any linear course. A new sense of hope emerges as patients show signs of improvement. This quickly changes as the patients' physiological condition is prone to a multitude of complications causing the family ongoing emotional upheaval, leaving them with immense uncertainty. Family do not know if the patient will survive their illness. Family have no idea of how the trajectory will progress; they live in a state of constant uncertainty.

They wait and hope with great anticipation as the sedation is reduced. Because of their physiological instability the patient will have been heavily sedated in the initial phase of their illness. It can therefore be a few weeks before the family have any two-way communication with the patient. As the sedation is reduced they wait...and they wait...and they are anxious about how long it takes their family member to wake. There is a glimmer of hope when they do finally open their eyes when the family are present. However, this can be a very upsetting experience:

When she did wake up and she had this look of...it was almost panic she didn't know where she was...she didn't know who we were... we thought [patient] hated us...'why did you bring me back'...you should have let me go. (C3, Daughter 2)

The anguish family endured during the difficult waking period was due to a number of factors. Firstly, it relates to the suffering they see in the patient during various interventions such as tracheal suctioning and the associated physical discomforts.

Secondly, seeing their badly injured family member every day does not get any easier. Thirdly, they wonder if their family member will be thankful to be saved due to the potential physiological impairments that could occur. Finally, they are waiting for them to wake and show signs of improvement because they are living in state of uncertainty and they are looking for signs to lessen the feelings of uncertainty. Penrod (2007) views uncertainty as a conclusion of doubt reached after the family has assessed all available cognitive forms of evidence. This is then perceived as objective reality and is highly independent of awareness, acceptance and trust at that point in time.

Family see the placement of the tracheostomy tube as another marker of progress and hope. To them it meant they had transitioned from the stage of being critically ill with the potential of not surviving to a period of stability and moving forward. It is another indicator that can lessen the uncertainty for them.

It's been a bit of a waiting game and waiting on him really...putting that trachy²³ in was huge for us, it was definitely a step forward we felt and so did they...just little bumps in the road like that, but positive bumps. (C6, wife 2nd)

The recognition of the placement of a tracheostomy tube as a marker of progress contrasts to the view of healthcare professionals. They view it as an indication of a patient who is going to require prolonged mechanical ventilation and transitioning to CCI. This differing opinion has been previously noted within the literature indicating the misunderstanding about the full implications of the patient's condition and the prolonged trajectory they have ahead (Leung et al., 2016; Nelson et al., 2005).

Hope quickly vanishes at any stage as the patient's fragile physiological condition can suddenly change and again uncertainty increases about how the trajectory will progress:

We go through stages where we think he is on the improve, he will be right. First of all we thought no he won't come out of this we were facing that reality and now we think, oh he improved, and then you see him again and you think no he is not going to. (C4, father 2nd)

Their world is an emotional roller coaster due to constant physiological instability and ongoing complications that occur with the patient. They never know what will happen next. They do not know if their family member will live or die:

²³ Trachy [insertion of tracheostomy tube instead of oral endotracheal tube]

She was coming right and then she went downhill again. She was actually quite good and then she started to have a few complications and we thought we were going to lose her. I was quite worried, one doctor had mentioned they didn't want to operate because they thought it would be too much on her and then next time, they said "there is something going on inside and we are taking her down to theatre". You put your trust in them, I was quite worried that whatever was going on could kill her, it's just like you kind of think I wonder if she is ever going to get out of here. (C2, son 2nd)

Ongoing complications add to their ongoing anxiety:

She is still getting temperatures, which is a bit of a shock to the system, especially at a point when your nerves are just shot because you know we just get or we are used to getting bad news and then the slightest temperature just shocks you. It's not good for her to get a temperature because she is trying to recover and that just sets her back again, so it's still hard and we just hoping she is on an upward trend and then every time we hear about a temperature it's just a like, what's that going to cause. (C3, Daughter 1)

Uncertainty has been described as a discomforting state that is mediated by feelings of confidence and control (Penrod, 2007). With little control over the patients' on-going instability and uncertainty from complications comes the fear of death. Some families come together and pray, they believe that "...almighty God can heal beyond what we humans can do" (C3, family). Some who have never previously prayed go and pray due to the seriousness of the situation:

I went down to the chapel one day ...I had been holding off going...because to me, going in there I'm signing my life over to God...and I'm not ready to that. I went down there one morning and I said " you can't have him, he's mine....I'm not ready to give him to you, I'm going to make him fight this and ...you know ...it's not time and I want to make that quite clear to whoever is listening ...it's not time, his time is with me. (C6, Wife 2nd)

Living in a world threatened with the potential for on-going complications means family are confined in a world of uncertainty. The impact of this constant threat that family endure has not been described within the literature in relation to a prolonged ICU stay. However the degree and length of time uncertainty is endured during any illness potentially adds to the complexity and negativity of the situation (McCormick, 2002; Neville, 2000). Penrod (2007) argues that time alone does not alter uncertainty, however prolonged uncertainty provides extended opportunities to misread the situation, to gain cues and clues that mould the sense of confidence and control, thereby shifting the state of uncertainty.

The constant worry and uncertainty about the patient developing more complications makes family vigilant when visiting. They are continually looking for signs of deterioration and improvement as it is the only control they have to relieve their feelings of uncertainty. They watch during visits and they have their routine questions they ask the nurse:

Table 16 Strategies during family surveillance

Strategies during surveillance	Supporting data
<i>Looking at patient's colour</i>	<i>...when I come in I just look at her colour and the colour is going to make you think she hasn't got failing kidneys or liver or something...you see all the physical healing...let's hope it's healing inside (C2, Son 1st)</i>
<i>Questioning nurse</i>	<i>...first I ask the nurse how he has been and then I gauge it (C6, Wife 3rd)</i>
<i>Conversation with patient</i>	<i>...it's a bit hard when you come in and [patient] is asleep... you can't talk to her...you just worry like anything [that something is wrong] (C2, Daughter)</i>

The daily surveillance is similar to Plakas's et al. (2014) study of relatives' attendance during a critical illness where they found relatives conducted a personal daily assessment of their family member. This was seen as vital by the family and could replace the need to ask a doctor for information. Others use surveillance with doctor's information because of mistrust they had experienced with some healthcare professionals in terms of telling them the truth. Surveillance by family has been reported in the literature as them exercising their protective duty, however this activity was often interpreted by healthcare professionals as family 'anxiety' or 'being difficult' (Happ, Swigart, Tate, Arnold, et al., 2007).

The need for honest information about a patient's condition has been acknowledged in the literature since Molter's (1979) descriptive study of relatives' needs during critical illness (Al-Mutair et al., 2013; Jacob et al., 2016; Khalaila, 2013; Verhaeghe et al., 2005; Wong et al., 2015). Relatives look for any reaction or signs when patients are asleep. They are looking for any sign of hope (Eriksson et al., 2011) and so when patients were asleep, as described by a number of participants they often worry more because they cannot put their mind at ease. When they could not interact with the

patient as part of their surveillance they needed to look for other signs of improvements which was a way to try and relieve some of their uncertainty.

Knowing their family member so well they would notice subtle cues in the patients' behaviour. They also notice changes in physiological appearance during their daily surveillance:

She is a little bit pale, I noticed her tummy's a bit...rounder...than it's been...she had a bit of trauma in there...I suppose there's swelling. (C2, Son 1st)

They are always watch for signs of an increase in body temperature because they know that indicates infection and, from previous complications the patients have had family know this could be detrimental to progress:

It's a bit of a worry when I saw the flannel on her head and I thought she was getting a temperature or something...they said it was up a little but not too bad so... (C2, Daughter)

The need for relatives to make on-going assessments about their family member's condition is a fundamental desire and an understandable one. These actions have been discussed in the literature as something relatives need to do to assess for signs of improvement (Ågård & Harder, 2007; McKiernan & McCarthy, 2010). The opportunity to share their thoughts about the patient's condition has been found to increase a sense of control and facilitates an opportunity for relatives to follow up on information (Johansson et al., 2005). If the opportunity to share information is not facilitated by the nurse there is potential for relatives to come to the wrong conclusions (Ågård & Harder, 2007).

Family also had the ability to notice something was wrong prior to a severe complication. The wife of a patient noticed increased agitation the day before her husband had a dramatic deterioration with sepsis. She knew something was wrong, but did not know what:

On Monday he was out of sorts, definitely out of sorts...bleeding...he was definitely out of sorts. You know he was agitated: wouldn't settle, he was asleep but when he did open his eyes, he was off, the temperature was up. I questioned the temperature all day because I know temperature means fever and I did again on Monday ...so I was not surprised what happened yesterday because something had to break. (C6, Wife 3rd)

It is difficult to know if healthcare professionals had noticed the change in the patient's condition before the deterioration occurred. But it is an important finding in relation to family noting a potential deterioration before it occurred. This demonstrates the importance of open communication with family in regard to daily feedback about the patient. It has been reported that family obtain information about the patient by using a number of strategies including asking questions, and less obvious techniques such as, listening in to conversations and piecing together bits of information (Wong et al., 2015). This has been referred to as 'vigilant attentiveness' as part of a process to detect deterioration in ICU patients at the end of life by family members. They noticed deterioration from monitors, the sounds patients made and changes in treatment (Coombs, Tang, & Long-Sutehall, 2016). The strong need for the relative to be constantly monitoring the patient for signs of improvement or deterioration forms part of the on-going daily ritual that relatives use to help them relieve some of their uncertainty and gain a sense of control over this situation which they perceive as out of control. This monitoring process is long, arduous and tiring and so when they have difficulties obtaining this information it reinforces their lack of control and uncertainty.

Despite significant literature about the need for knowledge and honest information about the patient's condition, obtaining this information was still problematic for family at times. Family mostly dreaded updates from doctors because they felt they always delivered the worst case scenario. So getting an update from the nurse on a daily basis was often the family's first point of contact, and nurses tended to be more positive about the patient condition. However, not all nurses would meet this need for information, which increased the burden of the family in 'the work' they did to alleviate their uncertainty:

Some nurses are a bit cagey and some are primed not to give too much information away. Some will give you the bare minimum...so I have my days where I have to ask all the questions. (C6, Wife 2nd)

For some relatives if the nurse is not forthcoming with information they do not push for it; if they upset the nurse it may take the focus off the patient:

All the doctors and nurses you really have got to let them do their job so you don't want to get in their way... so you just say your hellos and that...just when you can...you know doctors and nurses come first...that's the most important thing because they are going to get

*your mother well again. So I just let them do what they have to do
 ...I don't want to get in their way. (C2, Son 1st)*

The power relationship between the nurse and family means relatives do not push for information. At times it appeared the nurse would put up barriers to prevent having to converse with the family, going about their work and not talking with the family or giving minimal interaction. The problems with communication between nurses and family within the ICU context are not new. Previous research has identified the negative experiences family can have connecting with the nurse. Conversely, there are many positive reports of nurses-family communication (Eggenberger & Nelms, 2007). The reason for these barriers is discussed in further detail in the data chapter on the nurses' work, however the impact on family is substantial and these consequences need to be considered.

Their exhaustion and worry consumes family as they try to manage their other essential daily activities:

Table 17 Examples of exhaustion

Examples of exhaustion	Supporting data
Falling asleep during the day at hospital	<i>A couple of times I've fallen asleep next to him holding his hand and I know...ok it is time to go and that's fine. I have definitely...I can feel it...I haven't felt it before...there is a lot going on. (C6, Wife 2nd)</i>
Fatigued	<i>I am at this stage...I've gone through the crying, laughing, angry and now I'm sort of exhausted...and I'm trying to sort things out at home. (C4, Wife 2nd)</i>
Unable to concentrate and sleep	<i>When [patient] health starts to improve, so will mine. I will sleep better...I can't read...I'm not interested...I'm not interested in television. (C1, Father 2nd)</i>
Daily exhaustion	<i>It's very wearing...come in and go out...but we are exhausted and that's the interesting thing we found...so exhausted at night ...it's just emotional...emotional stress...that's what it is. (C4, Father 1st)</i>

As the illness has become so protracted, family need to carry on with other aspects of their everyday life. Many family members need to return to other commitments such as employment, and /or care for dependent family members. Their work involves setting up a routine to meet their commitments around hospital visiting. They report

symptoms of being exhausted, having trouble sleeping, difficulty concentrating and eating poorly, the constant uncertainty they endure leaves them emotionally and physically exhausted. The numerous complications this group of patients has and its effects on the family's trajectory over a prolonged period has not been specifically reported within the literature. However researchers have reported much of the uncertainty and anxiety experienced by family was connected to the patient's condition and prognosis (Frivold et al., 2015), and family move between a state of despair and the need to maintain hope (McKiernan & McCarthy, 2010). Celik et al. (2016) argued that family members of ICU patients experienced symptoms of fatigue, anxiety, depression and sleep problems, furthermore another study found the higher the APACHE II score²⁴ the greater the correlation with family anxiety, fatigue and difficulty sleeping (Day, Haj-Bakri, Lubchansky, & Mehta, 2013). Excessive daytime sleepiness was found to be common in family members of the critically ill with associated functional impairment and decreased quality of life. This resulted in difficulties completing many everyday tasks (Verceles et al., 2014). Hence one can speculate that the cumulative effects of a prolonged critical illness on the family is going to be profound.

Family spend a lot of time waiting. They often have to wait before they can see their relative. They understand this as it means that the nurses and doctors are caring for the patient. Sometimes the wait is perceived as excessive and especially when there is other essential work some families need to complete outside of their hospital visiting responsibilities. A daughter arrives at the hospital at the same time every day to see her mother. She has limited time to visit as she needs to get home to her father who has dementia and is immobile. He is left at home alone while she is visiting. The nursing staff seem to be unaware of this situation despite her previously telling them. Her mother has been a patient within the ICU for over a month at this stage. One particular day she has to wait for over an hour (after being told her initial wait would be 20 minutes) and then still did not get to visit before she had to leave:

I went up there and I was told they were changing her and they won't be long. I ended up waiting, waiting, waiting and I came back and asked the receptionist what was happening. "Oh they will come and get you when they are ready" ...the third time...after waiting an hour

²⁴ APACHE II score – abbreviation for acute physiology and chronic health evaluation, a system for classifying severity of illnesses in ICU patients.

she said “we were busy and they hadn’t changed her yet because they were very busy” ...I had to explain to her I had to get home to let in my father’s carers and if I am not going to be able to see her to just tell me...that was not a good day...I was in tears That’s the straw that broke the camel’s back...also I was annoyed because they said she had an accident [diarrhoea] ...and I’m thinking has she been left in her own mess for over an hour? The next day I had thought I would ring up the charge nurse and speak to her and then the next day she was bleeding and having a [endo]scope...so that was the priority and by then I was over the fiasco. (C3, Daughter 2).

There are a number of problematic factors in this excerpt that can be acknowledged. Firstly, there is the lack of appreciation by healthcare professionals about the length of time family had to wait to see a patient with a prolonged critical illness. Secondly, there was a delay to attend to her personal cares. Thirdly this patient had been in the ICU for over a month so why the daughter could not visit during care or even help if it was appropriate was never explained. Lastly, the reasons why this relative chose not to complain was because the priority at the time was to support her mother in her illness. The complexity of daily life for this daughter meant waiting for long periods of time was impractical and caused considerable disruption to her daily routines as she tried to manage her multiple responsibilities. Family understood they had to wait and expected this. However, this situation could have been prevented if nursing staff had gained an understanding of the needs of her father regarding his dementia. A structured process to understand family needs was only undertaken by nurses in one of the ICUs.

The circumstances that surrounded the daughter’s decision not to complain the next day is similar to why many other family member participants within this study chose not to speak up about incidents that caused them distress. This daughter, as with many other family members, felt they did not have the energy to complain about the distress for the family as a whole. It would also take the focus off care of the patient. The family needed all their energy to cope with the enduring illness. It has been recognised within the literature that family have specific needs during a prolonged critical illness (Hickman, 2008; Hickman & Douglas, 2010; Nelson et al., 2005). To be able to meet these needs, effective communication between family and healthcare professionals is vital especially when critical illness enters the chronic phase (Camhi & Nelson, 2007; Nelson et al., 2005; Roulin & Spring, 2006). To achieve this the family must be recognised as an extension of the critically ill patient who also needs care (Hickman & Douglas, 2010) and individualised care is important.

Experiences such as this highlight the vulnerability for family during a prolonged critical illness. Because of their dependency on healthcare professionals to provide care for their family member, they are less likely to express problems that occur unless they think there is going to be a direct impact on the patients' outcomes. Being dependent can be associated with negative feelings and powerlessness (Lykkegaard & Delmar, 2013).

An altering uncertainty

As the patient improves there is less uncertainty for the family as they can see the patient has improved to the point of stability and there is now hope of recovery. Their unending work continues as the patient requires their presence now more than ever. Patients emerge from the confused state that has consumed them for a prolonged period of time. As life-sustaining treatments are discontinued and the patient becomes more aware the family finally feel they have hope:

I think she is doing brilliantly, she has really picked up in terms of being off the ventilator...she is off the dialysis and her kidneys are working...she is more awake and more alert and trying to mouth words to us... ...there are goals we are heading to...like she is eating now, she had yoghurt yesterday and kept it down...so just little things like that and they will do it slowly as today they said she was tired ...so all those little signs are very encouraging for us that she is eating, trying to mouth words, understands who we are and understands everything we say to her. (C3, Daughter 2).

As the patient improves enough to become liberated from life-sustaining technologies, family can see these as positive and encouraging signs. Their level of uncertainty starts to lessen. There is scant evidence within the ICU literature about how family members' emotional states change as the patient's condition improves throughout their trajectory. It has been reported how relatives feel good when the patient is more awake during their visits, this may correlate with the family seeing positive signs of improvement and therefore decreasing their uncertainty (Karlsson et al., 2010).

However, for some family they wonder how the patient will cope with the impact of the complications from the illness has had on their body. The personality of the patient and previous life events cause family worry about the long-term implications of this illness for the patient, as revealed by separate family members at separate intervals:

I guess the temperament of the patient and the temperament of his family have quite a bearing on how you deal with this. (C4, Mother 1st)

I don't know how [patient] will handle the road ahead...I don't know how...I don't know if [family] will look after him...I don't know what life holds. (C4, Sibling)

The ongoing uncertainty shifts to how the patient is going to deal with the physical disfigurement and dependency and these feelings consumed this family's thoughts. However, in all cases family wondered if patients would be able to return to their former lives in relation to being physically well enough to maintain their previous everyday life and work before their illness.

As patients become more aware, they wanted their family in close proximity. Family need to undertake a constant balancing act between everyday life and their personal responsibilities while the patient is trying to make sense of what is happening to them:

He keeps saying "I'm really, really sick aren't I?"... and yesterday I said "...you have been really sick but you are on the right road to recovery now". When I would arrive he would grab my hand..."you're not leaving"...and a couple of times he has broken down in front of me. (C6, Wife 4th)

As the patient improves, there is suggestion from some nurses that family members do not need as much contact time with them. The family should rest or spend time with other family members:

The nurse was on my case that I should rest...as [patient] is getting better...so I did and took my daughter out for lunch...then the next day she did the same thing...why don't you go out...it's a beautiful day...and so I said okay... and when I came back she was still there...so before she left she came over to me and gave me a big hug and said I am really proud of you for listening to me and taking my advice...but you know I could have happily sat beside him all day...so it's a big juggling act...but that's what I mean by strong nurses and strong with [patient]. [Meaning - does as nurse says] (C6, Wife 4th)

At a stage when the patient is awake and in greatest need for support, the nurse was trying to encourage the family to leave. The overarching need for the patient at this point in their trajectory is to feel safe, and to achieve this family presence is now of great importance (Azoulay et al., 2003; Blom et al., 2013; Engstrom & Söderberg, 2007; Magnus & Turkington, 2006). Furthermore, it is important for family to have a sense that they can support and be with the patient - this is the work they want to be

there for (Al-Mutair et al., 2013; Eriksson et al., 2010; Olding et al., 2015). So the nurse's intention for the family to go out for the day may not have been entirely in the family or patient's best interest.

Patients' needs are not synonymous with the family's needs (Blom et al., 2013), and nurses should balance the needs of the patient and family. In addition, the lack of continuity of carer with many different nurses caring for the same patient and interacting with family created the potential for problems. This has been referred to as mutual misunderstanding, when family and nurses do not understand the information or message being given (Soderstrom et al., 2006). When this occurs during a critical illness there is potential for suffering for both family and the patient (Blom et al., 2013; Soderstrom et al., 2006).

The patient being transferred out of the ICU is a huge milestone for the family and they know the next stage of the journey is going to begin:

It was a relief, a big relief to see that she was out of the ICU, it meant that the worst of it was over and now she was going to be going through rehab and recovering. (C2, Son 2nd interview)

Transfer from ICU is generally recognised as a positive step, but it is well documented that the transition period can create a lot of anxiety due to the change in the level of care and the amount of information provided (Bench & Day, 2010; Chaboyer, Kendall, Kendall, & Foster, 2005; Cullinane & Plowright, 2013; Verhaeghe et al., 2005).

These positive feelings were not there for all family. For one family who knew that their hospital journey was going to be particularly long, with a high possibility of severe disability for their relative, ICU transfer just meant a change in location:

It's a long road...no doubt. (C4, Father 2nd)

Transfer out of the ICU for patients with a poor outcome is distressing, with much uncertainty about the future. The emotional responses of relatives are likely to be influenced by the patient's positive outcome and recovery. Hence a prognosis of a poor quality of life when leaving the ICU is going to be very different. The problems the relatives face on discharge mirror the problems of the patient and so the need for support for the family and patient is vital (Bench & Day, 2010; Paul & Rattray, 2007). The lack of support for family to deal with the aftermath of a prolonged illness meant

some family found it particularly difficult to get information from health care professionals about a future plan of care.

Uncertainty in a different location

Uncertainty again resurfaces for family on transfer to the ward from the ICU. This uncertainty relates to: firstly, the long journey ahead of them in terms of the patient's physiological deconditioning; secondly, if the patient will return to their previous everyday life, work and health status; and thirdly, how the patient will deal with the knowledge of their critical illness.

Upon transfer out of the ICU the family know they have a long journey ahead of them, due to the physiological deconditioning of the patient. They wonder if the patient will ever return to their pre-illness status:

...but she wasn't really through the worst of it, but there was nothing she needed to be in ICU for even though when she came to the ward she got pneumonia...we were hoping she can get back home, but I don't feel like she is going to because of her age and her injuries. I don't feel she is ever going to get back to where she was because when you are that age you are on a backward hill aren't you. So to get back to where she was probably is not real and I don't think she ever thinks she is going to get back to where she was...she doesn't think she will walk again. (C2, Son 2nd)

The uncertainty of the future is still present for many families. Many patients are still physiologically dependent from critical illness myopathy and have on-going complications. They worry about the final physiological and psychological outcomes for the patient as the illness trajectory seems to go forever. They are emotionally shattered and they just want their family member home without necessarily understanding what challenges that would bring. When I visited an older man whose son had been in hospital for a number of months, he opened the door for me and said:

I'm worn out...I feel terrible and I have had enough of [son's] illness...it goes on and on and on...how will [son] work in the future and when he gets home, how will we cope? (C1, Field notes)

The ongoing stress this illness had placed on his father became more apparent every time I saw him. He was tired of coping alone, had minimal social support and saw no end in-sight. As his son was slowly starting to get better he commented to me during a follow-up interview how he had "*noticed how his father had aged*" while he was in hospital. The cumulative effect of such prolonged stress for this man and many other

of the primary family support was evident. The family serve as a buffer for emotional stress for the patient, as caregiver, and decision-maker (Chui & Chan, 2007; Pang & Suen, 2009). This burden on family over a prolonged critical illness was considerable and there was minimal, if any, support offered for families.

After transfer to the ward, the patient's condition improves to the point they want information about their illness:

She is now realising that she was really sick and she was crying a lot we were just telling her "don't worry its good and you're getting better. (C5, Sister)

Family need to spend a lot of time telling the patient about their illness, which requires a great deal of emotional work as they have to relive the experience themselves and deal with the emotions of the patient as they learn about how sick they have been:

So the brother comes in when [patient] is at his most vulnerable and starts talking about how he nearly died, and he had been to visit their father's grave, and he just burst into tears...and the brother can't stand seeing him crying and walks away and I am left there. (C6, Wife 5th)

Slowly they fill in the gaps, give the patient time to think and deal with the ongoing emotions as the patient comes to terms with the fact that they could have died:

We've done a lot of talking about it...in the early days...it was quite raw and emotional... (C6, Wife 6th)

The only person who can fill in all the gaps when the patient is ready is the family. Some family members had kept a running record about their family member's illness taking weekly photos, so they could show the patient as they explained their illness at a later date. Photos give factual information to the family member which helps them realise how seriously ill they have been and helps them understand memories and sensations (Combe, 2005; Storli & Lind, 2009). Family have been found to be important mediators of information to the patient after transfer from the ICU, which is psychologically demanding (Söderström et al., 2009).

The on-going burden and work of a critical illness on the family has been highlighted throughout its trajectory. As patients were transferred to the ward the case of their prolonged critical illness comes to an end in respect of data collection. The aftermath of the illness continues for an extended period of time as the patient continues to deal with the physiological and psychological impact. Although data collection was limited

after transfer from the ICU, through ongoing follow up it was clearly evident that family were contending with daily stress and anxiety. The burden of a critical illness on caregivers has been documented in research and a high incidence of depression has been reported in a number of studies (Choi et al., 2012; Foster & Chaboyer, 2003; Haines, Denehy, Skinner, Warrillow, & Berney, 2015; van Beusekom, Bakhshi-Raiez, de Keizer, Dongelmans, & van der Schaaf, 2016). Douglas and Daly (2003) found that family caregivers of CCI patients have a higher incidence of depression than in any other caregiver groups. A decrease in their physical health has also been reported. The diverse types of burden reported by caregivers after discharge from the ICU include: anxiety, depression, post-traumatic stress disorder, change in employment status, health-related quality of life issues and interference with social activities (van Beusekom et al., 2016). The ongoing burdens that caregivers' face have been linked to patients not returning to previous functional status or being institutionalised. These had negative emotional effects with ongoing pain, restrictions placed on family's daily routines, particularly in terms of their social and personal outings (Choi, Donahoe, Zullo, & Hoffman, 2011).

Moving on

Family moved on with their recovery from a prolonged critical illness with differing thoughts about their future as seen in Table 18.

Table 18 Moving on

As they move forward...
<i>I never lost faith that he would survive...I always felt myself on my own, I never felt that I would lose him even though we had those horrendous days...I never lost the faith that he would fight it. I always felt confident that he was in the right place...I am confident that he will be home by Christmas...I can feel it. (C6, Wife 6th interview)</i>
<i>We can't make definite plans – it depends on his recovery and mine. We look to a better future. We are lucky we have people like you. (C1, Father 3rd interview)</i>
<i>On bad days I wonder why ICU saved him...he is just an invalid and all the family are suffering because of it. (C4, Mother 3rd interview)</i>

The significance of family by the patient's side throughout a prolonged critical illness cannot be overestimated:

I couldn't believe that I was in ICU... my family have stories to tell me but I can't remember...and I'm glad I can't remember...but all these stories to tell that I can't relate to...but one thing I know is my children have been there...standing by me with their love and prayers and cares. (C3, Patient)

Patients well-being and recovery is positively influenced by the presence of relatives (Obringer et al., 2012). Therefore, family-centred care needs to be an integral part of patient care within the ICU during a prolonged critical illness.

Conclusion

Relentless uncertainty dominates all phases of the trajectory for family during a relative's prolonged critical illness in the ICU. When faced with a family member's critical illness, family shift rapidly into a world of many unknowns. Families were totally unfamiliar with all aspects of the ICU and they worked hard to navigate a complex situation, this, coupled with the on-going uncertainty throughout the trajectory resulted in prolonged psychosocial stress for immediate family members. Assessment and interventions by nurses are crucial to lessen the burden and work for family as they journey through a prolonged trajectory in the ICU and beyond. A greater understanding by nurses, of the needs for family through a prolonged critical illness is crucial to improve outcomes for patients and their family.

The following chapter presents the findings that demonstrate nurses' and other healthcare professionals' experiences of caring for patients through a prolonged critical illness. It will focus on the complexities of caring for this group of patients with the focus on nurses and the many lines of work they manage.

Chapter 9 – The arc of work

Introduction

The previous findings chapters presented the context of ICU, the phases of patients' prolonged critical illness and the ongoing uncertainty endured by the family. Chapter nine shifts the focus to the experiences of healthcare professionals caring for long-term ICU patients and their family across all the six cases. This chapter will illustrate the complexities of caring for these patients with the focus on nurses and their work. Their work, and that of other clinicians, while separate, is also intertwined and these experiences will be integrated throughout the chapter.

The overarching focus when caring for this cohort is 'work', defined by Corbin and Strauss (1988, p. 9) as “ a set of tasks performed by an individual, alone or in conjunction with others, to carry out a plan of action designed to manage one or more aspects of the illness”. Corbin and Strauss (1988) argue that illness brings with it 'a failed body' and the body is the foundation of one's existence and, unless care is taken to support and repair that foundation, the whole structure can fall. According to Strauss et al. (1985) there are many different types of work, including comfort, safety, machine, patient and sentimental work. All work occurs through the coordination of the many lines of work, which nurses manage constantly and simultaneously, although these lines of work are described separately for simplicity. The priorities for completion of all work dominates within the arc of work for the ICU (Fagerhaugh et al., 1987; Strauss et al., 1985). As reminded by Strauss (1985) the hospital is viewed as a large work site with an assortment of workshops/wards organised around similar trajectories or specific phases, hence nurses will manage their lines of work within the arc of work of their workshop/ ward.

The arc of work – this is intensive care

The arc of work within the ICU is to perform life-saving interventions on critically ill patients. The arc of work dominates how the work is organised with mitigation of safety and identification of risk prioritised. It has controlled how the work is done for so long that it is embedded in practice of staff and the power it has can be invisible. “*This is intensive care*” (C4, conversation), said by a senior nurse, as a passing comment, encapsulates this arc of ICU work, but it is also the place where the long-term patient dwells throughout their stay. 'Intensive care' means that the arc of work is first prioritised around the intense, immediate, urgent and unexpected that can occur

at any time and nurses must be ready for whatever happens next. Consequently, this directly impacts the delivery of patient care and ultimately on the well-being of the long-term patient who dwells there.

The nurse allocated to the patient is responsible for maintaining the many aspects of patient care, with the arc of work, throughout their shift. Nurses have a particular way they work in a uniform work area. Failing bodies are stripped of any identity and connected to a multitude of machines, nothing in the bed space identifies the patient as a person. The failing body takes precedence in the nurses' work to prioritise of what is necessary and vital for survival. The routine of hourly recording the patients' measurable physiological parameters onto large charts allows the patient's condition to become readable to doctors and nurses. There are many lines of work that nurses need to manage in their daily care of critically ill patients. Safety maintenance and risk identification must be maintained at all costs, machinery must be operated, cares to the body undertaken, comfort care is needed, and as the patient wakes, their psychological well-being requires the nurses' attention.

An ICU by its own definition, manages patients with life-threatening conditions that are compatible with recovery (Joint Faculty of Intensive Care Medicine, 1997), the emphasis of care is on effectiveness, technology and intensiveness (Merilainen et al., 2010). Hence the definition of intensive care describes how nurses work and how their lines of work must be prioritised. As nurses manage critically ill patients often with rapidly changing conditions, their work focuses on clinical decision making and skills required in order to prevent further complications. Nurses need to respond promptly and appropriately to their patient's changing condition (Storesund & McMurray, 2009). As the long-term ICU patient progresses through their illness trajectory, so the nurses' lines of work change as the phases change. These phases which influence the nurses' work are similar to the Corbin and Strauss (1988) phases in their Chronic Illness Model as shown in Table 19 and align with the patients' phases discussed in chapter 7.

Table 19 Phases and overarching themes

Corbin and Strauss phases	Phases of patients in this study	Overarching lines of work presented in this chapter
Crisis	An overwhelming pre-set trajectory	Lifesaving work
Acute	A long wavering trajectory	Multiple contingencies
Stable	Emerging with a failed body Working to piece it together	Just weaning

Phase 1 – Crisis – Lifesaving Work

In this study all patients were critically ill on admission to ICU. Without intensive care therapies these patients would probably have died early in their illness course. On ICU admission, they needed maximum therapy to maintain their life and, during this crisis phase, there was uncertainty whether the patient would survive. A great deal of work needed to be done to maintain the failing body. The focus of the nurses' lines of work involved the vigilant assessment and management of the patients' physiological condition and life-saving interventions. During this phase, patients are critically ill and have a decreased level of consciousness, often due to sedation. At this time there is, therefore, limited need for nurses to consider what Strauss et al. (1985) called the sentimental²⁵ aspects within their lines of work.

Mitigation of Safety and Recognition of Risk

Mitigation of safety and recognition of risk are paramount in all aspects of nursing care; actions are prioritised before any other lines of work. During this phase nurses focused on monitoring physiological parameters and adjusting the myriad of machinery keeping the patient alive.

He was in multi-organ failure, so very sick. The first night he was dialysed, the challenges were to keep him stable as he was just quite unstable and very septic. I like patients like him that are challenging, there are lots of things wrong with him. (C4, Nurse L)

During this early phase of the patients' illness, the nurse works to maintain physiological parameters within an acceptable range. The patient is critically ill and could die, their body is failing, and therefore vigilance of the unconscious patient must be maintained. Safety within the bed space is maintained with tightly controlled parameters, rules and guidelines. The environment is controlled, visitors are

²⁵ Work done on or with a patient by a healthcare professional, but it is the psychological effect on the patient that is central to the work.

controlled, the focus is on the failing body in the bed, and nothing can disrupt this process. The nurse must study the failing body as an object to make sense of all the data that is presented to her via the machinery that has become an extension of the failing body. The nurse acknowledged her sense of fulfilment in successfully caring for this critically ill patient whose condition constantly challenged her knowledge base and skills to keep him stable.

As the failing body declines further, there are more lines of work the nurse needs to consider to support and repair:

[He's] been quite unstable, his lungs have been quite good. He has a lot of cardiovascular problems, they are a big issue, because he's been peripherally cool, his feet in fact, we scanned to make sure he had a decent perfusion because his feet have been mottled, slightly dusky, cool and it's been frightening to try and ensure he doesn't get any pressure areas because he's just been a sitting duck. So it's been a real nursing focus to make sure they don't break down because they will never heal because his perfusion is just not right, he's so oedematous, and you know his fluid balance, because of what is coming out the drains, so that's always a nursing challenge to make sure that he doesn't get an infection, he has always been spiking temperatures. (C4, Nurse L)

As time progresses, there is increased risk of further complications which the nurse needs to monitor for. Within the lines of work through the mitigation of risk, safety and comfort, the nurse assesses and manages the fundamental and essential cares of a critically ill patient. Meticulous care is needed to manage the failing body's skin for signs of inadequate perfusion, infection and pressure points. As the nurse manages the many interventions and monitors the patient's vital functions, she is applying this knowledge to the essential nursing care. She knows that the patient's failing cardiovascular system is going to impact on how she will manage this patient's potential for skin breakdown due to third spacing from his septic response and his poor peripheral perfusion, as a result of sepsis and the side effects of high doses of vasopressors²⁶.

The intense focus on the failing body is similar to the findings of McLean, Coombs and Gobbi (2016) who found nurses concentrated on patients as a 'medical case' as they considered physiological changes, so they could comprehend how the disease

²⁶ High dosage of vasopressor to maintain an adequate blood pressure causes vasoconstriction of the systemic and peripheral circulation with the potential for peripheral ischemia

was impacting on the physiological body. The way the nurse manages the lines of work during a period of physiological instability is therefore a process to ensure the patient's physiological needs are met at a crucial time.

Mitigation of Safety and Recognition of Risk at the Expense of Other Work

As physiological instability dominates the patients failing body, nurses need to concentrate their lines of work in relation to risk and safety with minimal time for any of the other lines of work such as comfort and sentimental work²⁷.

The nurse reports to me "I am very busy, I have the sickest patient in the unit and I have so much to do". Throughout the morning I watch her work, most of her work involves recording observations, numbers and more numbers go in the flow chart, pushing the drip pumps' flow rate up or down, drawing up more medication. Any contact with the patient to communicate is to see if he follows her command. She has minimal contact with the patient throughout her shift. (C6, field notes)

The failing body dominates the nurse's work with every monitoring device that enters the patient's body continually checked and recorded. The patient, as a person, appears invisible as the nurse went about her many tasks with minimal communication or explanation. The patient was semi-conscious, and the nurse's voice became loud as she commanded him to move his arm or poke out his tongue, there was no other communication with the patient. Her constant touching of his body and devices was not acknowledged by her as a disruption to the patient, instead, the body was an object that the nurse studied for signs of physiological improvement or deterioration. Everything had to be measured, recorded, and documented, every hour on the hour, clock time ruled all the recording of measurable parameters.

White (2008) describes how the work within the ICU can make the body invisible and reduced to numbers for the requirements of the nurse's practice at a given time. This entails the body being primed in a way that can be physiologically read. Upon admission, this process begins with the insertion of lines and attachment of monitoring devices. The sicker the patient, the more monitoring and technological machinery visible within the bed space. It has been noted how nurses and other healthcare professionals can read monitoring devices carefully but, at times, ignored patient

²⁷ Any work that is done with or on a patient, by a healthcare professional, and it is that effect on the patient which is central to the work.

attempts to communicate (Almerud et al., 2007). As the failing body becomes an object of treatment and assessment, the body is breached by many monitoring devices, but also extended into the technologies that have overtaken the body (White, 2008). A number of researchers have found that the more technology the nurse needs to monitor, the more it impedes her time for other work (Almerud et al., 2008b; Kongsuwan & Locsin, 2011; Price, 2013).

The nurse's ability to concentrate on the mitigation of safety and identification of risk as important priorities is evident as a patient began to have an unstable heart rhythm. To reduce distractions, the nurse keeps the patient's wife outside in the waiting room.

The patient is being given an amiodarone infusion for runs of atrial fibrillation²⁸. His wife is outside and wants to visit. The nurse has told her she is busy and will get her in 30 minutes. The family eventually are allowed into visit. The nurse tells his wife "he has had a heart rhythm" Confused his wife asks, "is this a heart attack or stroke?" the nurse replies, "No". His wife then asks "what do you call what he has?" the nurse responds, "AF- atrial fibrillation". That was the end of any attempt to explain about the patient's new rhythm and she went back to her documentation. Later in the day when I asked this nurse if she had much to do with the family her response was 'I am too busy for the family'. (C6, Field notes)

The nurse views the patient as still critically ill and potentially unstable and therefore concentrates her thought processes on continually looking for signs of instability. This intense concentration in her work was noted in an ethnographic study of nurses in the ICU regarding the practice and dialogue that accompanied their work. When caring for unstable patients, the nurses needed to focus on maintaining their physiological targets to ensure safety, and risks to the patient were mitigated (McLean et al., 2016). Soderstrom and colleagues (2003) found that nurses perceived that medical and technical tasks with patients were of highest importance and that family members should not disturb their work. However it has been observed that this can also be the individual nurse's preference, but this can vary considerably (Agard & Maindal, 2009).

The interaction between the nurse and the patient's wife was minimal and it appeared as if the nurse did not want to enter into a conversation with the wife about what was happening with the patient. This behaviour has been recognised previously in ICUs,

²⁸ Amiodarone is a class III antiarrhythmic drug used to treat his atrial fibrillation (heart rhythm disorder, in which the heart rhythm becomes fast and irregular)

the nurses could radiate a coldness during emergency situations due to their level of concentration (Engstrom & Soderberg, 2007). These interactions have the potential to influence further interactions between family and healthcare professionals (Soderstrom et al., 2003).

Phase 2 – Acute - Multiple Contingencies

During the trajectory uncertainty of a positive outcome can overshadow the patient, as was revealed in the previous data chapters. As the patient's trajectory progresses, they enter a phase that is highly unpredictable, problematic and long in duration. The multitude of contingencies²⁹ occurring throughout this phase means progress is slow and there are many episodes of regression along with periods of such gradual, slow improvement that it is difficult to notice these on a daily basis. As many contingencies occur throughout this phase there are many factors that cause distress for healthcare professionals, especially in regard to management of immediate problems and the long-term outcomes for these patients. To further complicate the complexity of care, these patients are becoming more conscious, which increases the work required to care for these patients as their illness course progresses.

Mitigation of Safety, Recognition of Risk and Sentimental Work – The Waking Patient
It was evident through all cases that as patients started to become more conscious the nurses' lines of work increased. As the patient started to wake, the nurses needed to increase their vigilance to maintain safety and minimise risk. They also had to consider the sentimental effects of their work on the patient, which meant tasks could take longer because they would need to explain what they were doing:

I think it's probably easier if you have a patient who is not conscious [laughs] because they are almost not human...well they are human.
(C3, Nurse C)

The reluctance to have an awake patient was evident in the data at many points throughout the trajectory, there was a latent perception that patients were easier to care for when sedated. The reason for this, at first glance, may be from the perspective that it is just easier for the nurse to manage her lines of work in relation to safety and risk, but as the nurse above acknowledges, in an embarrassed fashion, they can suppress the human side of the patient more easily if they do not have to interact with them. If

²⁹ Unexpected events that may arise in the course of an individual's trajectory that may affect work and the course of the illness (Corbin & Strauss, 1988)

the patient is unresponsive, the nurse can concentrate solely on the illness which is a distraction.

As patients became more responsive to the environment and aware of discomforts from their condition, such as the many invasive lines, devices and therapies that occupy their body, there were occasions when nurses would try and delay their waking. They would want to give a bolus of narcotics to settle the patient back to sleep:

The patient is looking fairly sedated and opening his eyes to command, or when the nurse is doing a task directly on him. He is stable and on pressure support ventilation with good oxygen saturations, which would indicate that he should be more awake. As the patient is becoming more awake over the morning the patient is coughing against the ventilator, but appears to have no detrimental physiological effects from this. However, the nurse does not like seeing him cough and he is triggering the alarms on the ventilator. She talks to another nurse about giving him a drug to stop him coughing. The other nurse comments “they [Doctors] won’t give you anything”. (C6, field notes)

At first glance, it would appear the nurse wanted the patient to remain heavily sedated because it would be easier to care for him as alarms demand attention, however there are other factors involved. As the patient slowly becomes more awake, the nurse’s work can become bewildering as she manages an increase in her workload. As patients woke they could be delirious, agitated and physiologically unstable. Her work is going to become increasingly more complicated as she manages a waking patient’s psychological needs along with safety and risk. It is acknowledged within the literature that nurses prefer to care for deeply sedated patients compared with lightly sedated patients (Karlsson & Forsberg, 2008; Sneyers et al., 2014; Tingsvik, Bexell, Andersson, & Henricson, 2013). Adding to the complexity is the assumption by the doctors of how the nurse will talk the patient through their current situation.

Medication is just one component of it... the other thing is communication, just talking with the patient. One is the nurse at the bedside, that’s always there, but they go together...the medication with the reassuring part. Because if you keep them light [sedation] to the point of them communicating with you...and you’re there at the bedside to reassure them and talk to them and explain to them what happening...and that is important. (C1, ICU consultant V)

Although nurses are at the bedside, talking and reassuring patients as they begin to awaken, the comments made this sound so easy, however, the work involved in communicating with patients at this stage of their illness was not straightforward. Patients were often confused, it was difficult for the nurse to lip read, and they were too weak to write. The time it took for nurses to find out what patients wanted was considerable, and often they did not find out what the problem was. The lack of insight into the complexity of the nurses' work resulted in tension for some nurses, this lack of acknowledgement of nurses' experiences and knowledge by doctors can create dissatisfaction and conflict (Coombs, 2003; Storesund & McMurray, 2009).

Comfort work within the lines of work

As patients become more awake the nurse knows her work will take longer because she will need to explain what she is doing to the patient, who may not be able to understand what is happening:

When he was asleep...you would say the care, it was less complex because you don't have him needing you as well. Because he was just asleep you had to make sure he was comfortable.... when he was sedated ...makes care less complex because you can do things like there are still tons you have to do but you have to worry about that response because it's not going to be an appropriate response.(C1, Nurse D)

As the patient wakes, the nurses consider comfort within her lines of work. This involves assessing whether the patient is comfortable and pain free.

In the few times that he has tried to communicate...he gives little feedback...so it's hard to work out...he grimaces a lot...so it's hard to work out...is he in pain...is he anxious...is he finding it hard to breathe...is he in agony.... or is he just confused and disorientated and that's why he grimaces...so it makes it hard to look after him because you can never fix the problems. (C1, Nurse E)

Concerned that some patients may have pain or discomfort that they cannot communicate, nurses would give a bolus of pain relief medication, often a narcotic. This could result in the patient going back to sleep for an hour or so until they would wake again often in a confused state with grimacing. This cycle of waking, grimacing and looking agitated could occur over a few days and often as a result of medication being administered. This process seemed to delay the patient's progress and, at times, although unsubstantiated, may increase the length of stay unnecessarily. These contingencies may have been avoidable if an assessment scale that could measure

delirium was used, such as the ICU-CAM³⁰, however this was only used in one of the four ICUs in the study. Earlier detection and treatment of delirium may be an important measure that decreases stay for this group of patients.

Some nurses' inability to detect delirium in their waking patients was noted as problematic. As the patients started to wake, nurses would assess them for signs of orientation and the ability to follow simple commands. When patients have their eyes open, but do not respond to the nurse, there was concern that the patient may have sustained some neurological damage as a result of sustained hypoxia or hypotension. This could increase the nurses' level of distress, and on occasion, they misdiagnosed hypoactive delirium³¹.

I still think she is pretty gone... I could be wrong but I wonder neurologically the impact because there's some attempt to communicate but then she doesn't recognise her family at all which is a bit of a worry...she is quite sensitive to the noise, she gets restless when she hears the alarms going off.

CM: *So she reacts to the alarms....*

Yeah I think... it is quite odd she reacts to that and I swear sometimes she is giving me a filthy look.

CM: *You don't think she is confused... you know having dreams, hallucinations?*

No – I don't get that impression. (C3, Nurse C)

Delirium has been reported within the literature as being under-recognised and under-diagnosed with prevalence from 40% to 80% (Belanger & Ducharme, 2011; Glynn & Corry, 2015; Speed, 2015; Svenningsen & Tonnesen, 2011; Wells, 2012). Within the CCI group of patients, it is reported as a common problem (Bellar et al., 2009; Happ, Swigart, Tate, Hoffman, et al., 2007). Delirium is also associated with increased length of stay, mortality and morbidity all adding to increased healthcare costs (Glynn & Corry, 2015). Despite the outcome for patients with delirium, it was clear that this group of patients did have periods of delirium that some nurses were not able to identify. They could see that their patients were not resting comfortably and they did

³⁰ The ICU-CAM (confusion assessment method) is a screening tool to improve early recognition of delirium (van Eijk et al., 2011)

³¹ In hypo-active delirium the patient is apathetic, lethargic, has slow psychomotor responses, with depressive features and extended responses (Svenningsen & Tonnesen, 2011)

not know what the cause of this discomfort was. This is yet another component that added distress to the nurse within her lines of work.

Having feelings of apprehension that patients may have pain during the waking process was concerning for nurses and especially hard to assess when patients had a degree of confusion.

Pain was hard because they stopped the fentanyl infusion he was on which I thought was a bit abrupt and he had nothing regular [for pain] ...because of his confusion or drowsiness or inability to communicate...it was hard to get him to tell if he was sore, or when he was sore, or what kind of sore...but with an open abdomen and stuff you've got to expect him to be sore... and just with conflict with differing opinions that you have from medical teams...because the doctors are quite reluctant to give him the pain relief because it sedates him and because they are not sure he is clearly communicating he is sore. (C1, Nurse Q)

The difficulties ICU nurses have with assessment of pain, sedation levels and confusion have been previously reported in the literature. Pain has been reported as particularly difficult to assess because of problems with patient communication, especially when there is a lack of the use of pain assessment tools (Louise Rose et al., 2012; Woien & Bjork, 2013). The increase in the time it takes a nurse to assess pain added to the nurses' lines of work and so if the nurse had any doubt she would give a bolus of analgesia. This resulted in the patient becoming sleepy. Consequently, at times this created conflict when doctors wanted to reduce or stop the analgesia because they believed the patient's pain to stem from generalised discomfort/ pain meaning therefore a narcotic was not required. When nurses are uncertain about whether a patient is suffering from pain this undoubtedly adds to the nurses' burden. Being witness to stress and suffering has been acknowledged within the literature as distressing, leading to ethical conflicts and feelings of powerlessness for nurses (Karlsson & Bergbom, 2015).

Communication within the lines of work

As patients became more aware there were attempts at communication. Establishing communication was a complex activity for nurses for a number of reasons, firstly, patients had a tracheostomy for long-term mechanical ventilation³², therefore nurses

³² People who have a tracheostomy and are mechanically ventilated cannot speak as air no longer passes through the vocal folds so the person cannot produce sounds.

had to try to lip read what patients were saying. Secondly, they were also physiologically frail, combined with some degree of myopathy, meaning they could not write on a board. Periods of delirium could also make communication difficult as nurses often did not know if patients were cognitively orientated.

I guess with [patient] as with any long term patient...it's a bit of a hard slog...he is difficult to communicate with and that makes the job harder. (C1, Nurse E)

Once the patient is awake the nurses' work alters. Her work can become increasingly complex, as she communicates to the patient what is happening whilst she performs the multitude of tasks that need to be done throughout the shift.

You've got to do more of it [communication] and you need to prepare her more and take time...you can't do anything without telling her whereas other patients who are tubed...that are asleep or sedated you can fiddle around and do a lot of stuff but everything with her you have to communicate. (C2, Nurse F)

During a shift there were many tasks nurses needed to complete to manage the patients physiological deconditioning. Compared to the care of an unconscious patient, the awake patient requires more of the nurses' attention, this creates tension for the nurse as she tries to balance her work and now has to consider the impact of sentimental work upon the patient.

If I had to continue like the other day with the frustration and anxiety that he had and the way I was feeling about not being able to understand what was wrong...I really couldn't have done too many days like that...quite often long term patients can be quite...not demanding but they are used to having someone there all the time...it's more draining I think. (C1, Nurse D).

Frustration and stress felt by nurses about communication difficulties with ICU patients is well documented (Alasad & Ahmad, 2005; Dithole et al., 2015; Happ et al., 2011). Additionally communication problems have been found to be more problematic in patients with a more severe illness (Happ et al., 2011), resulting in this cohort being particularly vulnerable. The frustration felt by the nurses during mid-trajectory is linked to the amount of safety, risk and machine work that are required. The nurse was unable to focus purely on specific tasks which in turn threaten her lines of work and the safety of how she practices, as she tried to manage communication with the patient as well.

Uncertainty through the lines of work

Another prominent issue during this phase is uncertainty for many nurses and other healthcare professionals about a positive outcome, due to the multiple complications and contingencies that arise for patients throughout this phase. The suffering and disfigurement that critical illness had on patients caused conflict and distress for nurses and doctors as they cared for patients. As intensive care therapies constantly advance, it is perceived that what is acceptable and what was not is continually changing. This culminated in frequently calling into question what is ethically and morally right. This is portrayed by an ICU consultant as he reflects about the dilemmas long-term patients create:

The burden of treatment has to be balanced by an acceptable outcome and sometimes it's a real challenge to try and philosophically and intellectually balance those two things together and say... "Yes this is the path we should go down". And I think as gatekeepers we often find ourselves talking to people about things like limitations and ceilings of treatment and alternative objectives and I often say to people "well we'll try this...if we're not winning then we may have to re-orientate the focus of that care". (C1, ICU consultant W)

The advances of contemporary intensive care have changed the work and continue to change the landscape. It is becoming more difficult to know how long is acceptable to continue with treatment for certain patients, there are no clear boundaries as to what is acceptable about when and who to treat with intensive care.

In times gone by it seemed to be much more black and white... I'm sure it wasn't but it appeared to be much more black and white – yes to you, no to you... now it's more of we could...sort of The grey zone has got broader... between the black and white. (C1, ICU consultant W)

As time passes and treatment for this group of patients has not progressed well, a positive outcome can look unlikely. There is an ever increasing uncertainty about what is an acceptable approach to take as reflected during an interview with another ICU consultant.

The NFR [not for resuscitation] is one thing...is part of it...it's almost like the NFR is the easy bit...it's what happens if he develops sepsis again and requires inotropes support or he get another pneumonia and requires mechanical ventilation...I mean...how far do you go with this? When you know you've got this man who failed everything

so far...that's the heart of it...the NFR is easy. (C1, ICU Consultant V)

As medical staff pondered about an appropriate treatment and outcomes for this group of patients, the nurse at the bed side is managing the work required to sustain life. As she goes about her work she has uncertainties related to the prognosis and suffering she sees for the patient and their family.

You can see that a patient's not going to get better and yeah, and you wonder if all you are doing is delaying the inevitable and they might be suffering in that time. So that's one issue, another is, sometimes I've seen patients who are really, really sick and they come right. Whereas, other staff might not see any hope there and... they speak these negatives that the patient is going to die and I think 'No, they're not'... so we all have different views. (C1, Nurse E)

The many different views reflected in this senior nurse's comments show the complexities and uncertainties faced by nurses and doctors. They do not know the outcome due to the many factors that make this cohort so complex. The uncertain outcome for these patients can be accepted by some nurses, as reflected by this nurse with over ten years' experience of working in the ICU:

She's got a Not for Resus order on her so there's a limit to what we would do... which I think's appropriate because I think she's got a lot of guts and courage and I think there's no reason why she won't survive but viewing statistically a little old lady, who is all smashed up, with injuries that will limit her and possibly a chest that will end up with pneumonia or something that she might not recover from and now two, three lots of bowel surgeries ... all those things are against her and it's just whether she has the mental fortitude to make herself physically do the work to recover and then it's not guaranteed... that's what... it's just reality... that's life... it doesn't distress me because...possibly... because I've learnt to manage that sort of grief and stress because if I took it on board I'd be a blithering mess .. I'm a bit of a soft-hearted sod really but...yeah, I don't take it on board now. Once upon a time I might have. I hope she survives... but who knows." (C2, Nurse F)

For a nurse with less experience her level of distress about a good outcome for a patient was more obvious. This is reflected during an interview when asked what she thought about the treatment course and final outcome for the patient.

I think it's cruel ... that's the hard thing and I do understand from the doctor's point of view...I think it is cruel for her, it's like she is locked in. Do you know what I mean and what are we doing? She got all this... kidneys are fairly well stuffed she been on the prisma [dialysis machine] for how long now. And she is still not doing

anything. And then she has now got all these other things happening. Her mouth is breaking down. What more is going to happen? (C3, Nurse C)

This internal tension felt by nurses and doctors when caring for this cohort has been reported in the literature (Leung et al., 2015; Roulin & Spring, 2006; Williams, 2007) and there are a number of factors related to these tensions. Firstly, because the outcome for the patient is unpredictable it causes unease. As the patient is severely debilitated after their initial physiological assault, they now have ongoing complications, which prolongs their illness further. The nurse sees the ongoing suffering the patient must tolerate, which has been reported in the literature as the biggest challenge for nurses caring for this cohort (Bellar et al., 2009). Furthermore, caring for patients with the realisation that they may never recover, adds to the complexity for the nurse (Meadors & Lamson, 2008; Sibbald et al., 2007; Wilkin & Slevin, 2004).

The thought of what the patient and family have endured, coupled with the potential for further complications, and possibly death is distressing for some of the nurses as they care for the patient:

I feel sad in the last couple of days, just grappling with his prognosis...I guess it's his journey more than anything...that everything that could have gone wrong has gone wrong and more and just sort of coping with that because I know he doesn't know what is happening...it makes me sad because he probably won't leave ICU; it makes me sad because his Dad probably isn't aware how sick he is. (C1, Nurse Q)

Caring for a patient who may die is not as distressing for all nurses as further discussed by a more experienced nurse:

Well for me...I'm not...it might sound harsh, it doesn't distress me as it might some others because you've got to separate yourself, it's their grief, it's their family, it's their pain, and as an observer it's distressing to know and it's sad and it's a terrible thing but it's not anything that I can change...it's part of my job...people come and people go and you know, you do your best for them but I'm not in control of what the future is really, it doesn't upset me so much that I would go home and worry about it or anything. (C2, Nurse F)

The nurse see herself as dispassionate because she is able to separate herself from the family because of her many years of experience, she has learnt to contain her emotions. Scholtz, Nel, Poggenpoel and Myburg's (2016) ethnographic study of ICU nurses' culture describes how nurses may seem distance, but they have become emotionally

disconnected from situations as a self-protective mechanism a skill they had developed over time. It was seen as the only way to continue to work in such an environment. Similarly, Stayt (2009) found nurses experienced many emotions when caring for ICU patients and their family, but these emotions were frequently suppressed, and over time this can have a cumulative effect. Distress relating to a poor outcome was not the only issue that nurses needed to deal with while caring for this group of patients.

Caring for patients who have been left with a major body disfigurement and the potential for a poor quality of life is particularly challenging and distressing for nurses.

I knew there were complications internally but ...its way more complicated...I worry about how the patient [will cope]...it just doesn't seem right to have that bowel leakage coming through the wound...it just feels wrong and he's awake...and we are doing these things to him ... I find it hard that we are continually doing things for somebody whose prognosis doesn't look good... (C4, Nurse I).

There are a number of factors that cause distress in these situations. The disfigurement that has occurred and major complications to this patient's gastro-intestinal tract indicate he will have a poor quality of life, furthermore, there are doubts whether this patient may even survive this illness. Finally, this patient was awake, as many are, with a partial open abdomen with faecal material oozing through his wound, which was very confronting to the nurses. Distress caused by caring for patients who have to endure treatment when they have a potential poor prognosis, is commonly reported within the ICU literature (Choe et al., 2015; Fridh, 2014; Meadors & Lamson, 2008; Sibbald et al., 2007; Wilkin & Slevin, 2004). To add to the nurses' distress, the change in sedation practices has resulted in lighter sedation meaning patients are more aware of what is happening to them (Fridh, 2014; O'Connor et al., 2010; Salgado, Favory, Goulart, Brimiouille, & Vincent, 2011). Hence it may become increasingly more difficult for nurses to detach themselves from challenging situations because they are more likely to develop a relationship with a patient who is awake.

In this study it was evident that nurses had some degree of distress when caring for this cohort, however it was more pronounced during the mid-phase of the patients' ICU trajectory. Nevertheless, the cumulative effects of distress from caring for these patients over time can potentially impact on the patients' trajectory due to avoidance strategies used by nurses. As noted by Strauss et al. (1985) from his field work in

hospitals, nurses faced with the emotional strain and the intensity of the work, are candidates for, as he termed it, the technologically related work hazard, burn-out.

The family within the lines of work

When family come to visit, the nurses' lines of work can potentially become disrupted and unfocussed as they need to consider family presence and their needs. Some work cannot be undertaken or nurses may not want to complete it with family in close proximity. The nurse will also have to be more prepared to explain what she is doing. At certain times it is easier for her when there is limited family presence as described:

It's better for me [when family are absent] because I can get on with what I'm doing but now he's more awake he might want a bit more stimulation...does that sound awful...you can just get on with what you need to do. (C1, Nurse R).

At times nurses would carry on with their work as family members watched. Nurses could mentally block out family and work with little interaction when they were concentrating, resulting in increased anxiety for the family.

They are quite hyper-vigilant when they come to visit, you know the monitor alarms or the prisma they will inquire ...why is that flashing... I took bloods off the A-line³³ yesterday which mucks up all your trace [on the monitor] and starts screaming at you and she turned around and said 'that's not a good blood pressure' and I said "it's okay" I should have explained to her before knowing how hyper-vigilant they are. (C3, Nurse C)

If the nurse was busy and wanted to concentrate she may choose to leave the relatives in the waiting room until she has all aspects of patient care organised and tasks completed. The nurse then does not have to work around visiting family. At times this could result in a long wait.

The patient is taken for a CT scan and arrived back in the unit at 1700 hours. His wife has stayed in the ICU waiting room while he was at CT. Once back from CT scan two nurses tidy away all the equipment and change the patient's sheets and then the nurse prepares her final documentation and prepares for handover at 1900 hours. The wife is still waiting outside to come in. After handover, the departing nurse says the wife may come and visit, but the nurse about to start her shift says "no wait". She has no idea how long his wife has already been waiting. The nurse has handover and then spends approximately one hour reviewing

³³ A-line: arterial line – for continuous monitoring of blood pressure

notes and orders before she allows his wife to visit. It is now three hours since he arrived back from CT scan. (C6, Field Notes)

Family presence when nurses are busy increases their work and could result in a mistake or in tasks taking longer than usual, because they cannot concentrate or work as quickly. Some nurses choose not to have family visit when they had tasks to perform or direct patient care so they could concentrate and, if relatives are present, this has the potential to be disruptive. Similarly, Scholtz, Nel, Poggenpoel and Myburgh (2016) found nurses accommodated family into their care, but always put patients' needs first. Therefore, during periods of instability or concentration, nurses would ask the family to leave in order for them to have control of the situation. The nurse who kept the wife waiting had never looked after the patient before despite him being in the unit for a number of weeks. The lack of a clear documented plan meant it took a long time for the nurse to have sufficient information about the patient before she was confident to have the family visit. The need to concentrate on tasks as part of safety and risk management may be interpreted as unfriendly by family having to wait outside. Conversely, the need for nurses to practice safely may see them implement practices that may seem inappropriate at first glance (McLean et al., 2016).

Phase 3 – Stable – 'Just Weaning'

The final phase of the patients' trajectory involved weaning from life sustaining supports which had been maintaining the physiologically failed body, however during this phase there was an increasing need for psychological support. The complexities involved in weaning patients was often not recognised by nurses, however one senior nurse did notice the intricacies of care:

Weaning from the ventilator is a terrifying business for patients...but for us 'oh they are just weaning', you know, and you know staying with a patient because their breathing is changing, they're terrified...and everything...for a man to tell me that after going through a [big natural disaster] and being dug out, the most terrifying thing for him was being weaned from the ventilator...you know, that's a huge impact statement. But once again, it's a relatively simple thing that we can fix, if we keep our mind on what we're about and make it easier for the patient, then there's less trauma, then there are less repercussions. (C4, Nurse S)

Weaning for this group of patients was lengthy and complex. Within the arc of work of all that is 'intensive care', the focus on the work is no-longer fast-paced life-saving interventions. As the weaning process is protracted with limited signs of improvement

on a daily basis, who do not fit with the arc of work of what ‘intensive care’ is about. The assumption by many nurses that their patients are ‘just weaning’ does not acknowledge the needs and complex care required. Descriptions used by nurses during this phase can be seen in Table 20. These labels given to describe the patient do not acknowledge any of the complexity in the care needs. Patients may have had a reduced need for life-sustaining supports, but their care needs were still high, particularly their psychological care.

Table 20 Terminology to describe weaning

Terminology to describe ‘weaning’ patients	
<i>Awake and weaning patient</i>	(C1, Nurse E),
<i>The slow patient</i>	(C3, Dr A; C4, Nurse K; C6, Nurse O; C5, Nurse M),
<i>The less stimulating patient</i>	(C4, Nurse K)
<i>Good patient for a junior nurse</i>	(C6, Nurse P)
<i>Difficult patient</i>	(C1, Nurse A; Nurse D; C6, Nurse P)

The classification of long-term ICU patients as ‘just weaning’, and the view that they were unchallenging or stimulating for the nurses to care for, results in nurses asking not to care for these patients:

If someone was allocated a slower patient consistently they do say...” hey, I’m ready for something a bit more interesting”. (C4, Nurse K)

Within the arc of work, these patients are not the standard ICU patients and so nurses could view them as needing minimal care and not as interesting, despite their psychological needs. This resulted in patients having a different nurse caring for them on every shift every few days, which was particularly evident in units where nurses worked 12 hour shifts. The nurse may care for the patient for two to three days in a row and, on her return to work, may then ask not to care for them again because she may have found them difficult to care for.

Safety and Identification of Risk Work During the Wean

Although the patient is less dependent on physiological supports the nurse must still consider safety and risk first. The focus of treatment is on weaning from all life-sustaining supports, establishing a night/ day routine and rebuilding body strength and mobilisation. However, as the patient has limited physiological reserves, nurses need to carefully manage activities and weaning from life-supports. The nurse plans her tasks and activities with this at the forefront:

He's been slow to recover so he's had multiple trips to the operating theatre... he's had multiple anaesthetics, he has fevers despite antibiotics, he's weak so he can't turn himself over or move very much, he's doesn't sort of wriggle around or anything... so he's very weak. He's slow to recover you've got to try and think is it time to get him in a chair which would improve his mood and help him think that he's getting better or is he too sick to get up in a chair...I didn't think that he looked well enough but the consultant wanted him in a chair. I'm reluctant because he's still got an open abdomen and he just looks unwell. (C1, Nurse E)

The nurse must also consider that if she gets the patient out of bed, it may affect his respiratory wean from mechanical ventilation because of over exertion:

The other issue with [patient] is he's tachypneic... so that's been an ongoing thing because ... are we giving him enough pressure support on the ventilator... I think we're not giving him enough but then I'm old school and my thinking is he might be needing more support. He's got a fast heart rate because his lungs are stiff so it's difficult to breathe and hard to ventilate ...or has he got a chest infection brewing or is it just due to his general ill health. None of us like to see people breathing really fast... chugging along on a ventilator...and we don't want him suffering ... we want to make him comfortable. (C1, Nurse E)

It is a fine balance between ventilatory weaning, mobilising and psychological well-being for the patient. The nurse needs to constantly consider these factors:

It's taken quite a lot out of him [weaning from the ventilator] we use to alternate the trachy mask for four hours and then try CPAP, but he has had a huge stretch so he's exhausted...you know...but his saturations are staying up...his respiratory rate is high though...but then it's always high...he gets anxious about coughing because he has a lot of sputum and so that puts it up. (C1, Nurse R)

Because patients have been in the ICU for such a prolonged period there is a lot of information exchange required at change of shift handover. Because of the lack of any long-term documented plan of care, nurses would spend a considerable amount of time

at the beginning of their shift trying to understand the patient's course of illness and plan of care to date. Because of the lack of documentation, there was a potential for nurses not to fully comprehend all aspects of care and they could potentially miss something:

I made a mistake that morning... he had all these interventions ... the dialysis and he was very dependent at that stage but they didn't want him sedated which added a complication...plus a new nurse that he hadn't met before and I had to get the history...plus he was on a research trial...that's where I made my mistake. That's a lot for a nurse taking over a long term patient. If you had a continuing team or a 'care leader' or something like that or 'primary nursing' those patients do well. Some think that you should be able to chop and change and take over everything but that's kind of looking at it from a department point of view and not always from a patient's point of view nor the staff point of view. (C6, Nurse S).

The lack of documentation for a long-term plan and current interventions meant some nursing treatment plans could be changed or omitted because they had been missed at the nursing handover. Due to the lack of continuity of nursing care, any particular plan of care instigated on one shift may not follow through to the next because it is forgotten at the handover:

I find that quite hard because depending on the nurse, because it is good if you get the nurse who looked after him previously or the night before, but if you get a brand new nurse who hasn't had them for a couple of weeks and everything has changed it's quite hard to continue their care that we have been doing. It's quite hard because nurses all want to do different things and all have their own different opinions of things. Because I am so junior I always ask my senior nurses when I am not sure about something because that's my safety net for myself. You've got a senior nurse they just do their own things and could do it completely differently (C1, Nurse D).

For some nurses the lack of a nursing care plan was not seen as a problem, as they practised within the arc of work of intensive care and usual routines:

No. It's not anything that is major, it's more things like long-term patient things like giving enemas in the morning and doing this and physio at this time and physio might need to come regularly. Might actually be quite good for him, getting out in the chair or this is a period or this is when he has a bath... just a rough guide... you know what happens in ICU ...they change all the time. (C6, Nurse P).

Comfort Work during the Wean

Comfort work during the weaning process was a fundamental element through the nurses' lines of work because their patient needed considerable attention to their failed body which was overwhelmed with discomforts. Nurses felt it was hard to meet all the patients' comfort needs over the shift:

I found it a little bit frustrating in the sense that I really wanted to help ...but a lot of the things that I did...it didn't matter what I did, it didn't seem to make it better for him. He was quite restless and he couldn't find a comfortable spot. So every sort of 10 minutes to half an hour, turning, and repositioning trying to find a comfortable stretch for him but it just seemed impossible. There's just nowhere, it wasn't a pain relief issue, he had pain relief but it didn't seem to help. It's not because he was sore, just couldn't find a comfortable place to sit still. We did things like slide him in to a chair which he was able to tolerate for a while, but again starts to get really uncomfortable. (C6, Nurse O)

The demands of trying to find comfort for the patient are relentless; often the nurse can feel she can never achieve adequate comfort and manage all her lines of work:

In the ICU we find with patients that five minutes to them is a couple of hours. It is really such a long time so forever he was asking me "Can I get out of the chair can I get out of the chair?" But because of physio ... and some other procedures ...and he had to stay in the bed until we could get that done. And then the physio was late ... so he's getting grumpy and then he says "Out in the chair, out in the chair" and were also pushed [for staff]. So finally I got him out to the chair about five o'clock and he sat there and sat there for ten minutes and then goes "I want to go back to bed". I just about banged my head against the wall...like come on! He wanted to go back to bed and was uncomfortable in the chair which is fair enough but it's just like you've spent all day telling me that you want to get out into the chair and then ten minutes later I want to go back to bed. Again it was insistent it was just ...so that was probably the hardest thing over the day, it was just trying to keep him calm, me calm, everyone in the bed space calm because he was... if you're not careful you do end up feeding off on these patients and you end up rarking yourself up if you don't deal with it. (C6, Nurse P)

There is great frustration expressed by nurses who felt they could not meet the patient's needs. It was as if they had personally failed in their ability to deliver good nursing care:

Nothing is good enough...everything is more noticeable...it's like every sense is heightened...Like that bit of secretion in the mouth is like a massive thing for them...it's like I need this and I need it

NOW...and it doesn't matter what you explain...they want...they don't seem to realise that you haven't got eight arms. (C4, Nurse I)

When the nurse spent a long time trying to comfort the patient it meant other tasks could not be achieved and this caused frustration:

In our ICU role, we have to do all these things [lists many tasks] ...there's a hundred things to do on a shift and sometimes the long term patient doesn't know all the things we need to do and they might be very demanding of our time for certain things but they just don't understand the workload we have sometimes. So that can make your shift quite difficult or hard going. So you do your best for your patient to make them feel comfortable and cared for but sometimes they get frustrated with you and you get frustrated with them because you have such a big workload. (C1, Nurse E).

Frustration, from needing to concentrate, creates an inner tension for the nurse. She knows the patient is uncomfortable but no number of interventions keep the patient comfortable for long and there are certain tasks that must be done as a priority. Hence it creates an interplay of tension for the nurse and patient. This has been previously reported in the literature regarding the inability to meet patients' needs within the confines of intensive care, cause conflict in relation to prioritising nursing tasks over promoting patients' well-being (Olausson et al., 2014; Price, 2004).

Differing interpretations of time for the nurse and patient cause further conflict. For the nurse, her lines of work are done around the clock, and within the routine of the ICU. The patient who knows they are uncomfortable and their whole being is focused on their physical and psychological needs, so time means now, they cannot wait! The experience of time is uniquely individualised, and we can never be sure how the other person feels, thinks or means (Ellingsen, Roxberg, Kristoffersen, Rosland, & Alvsvag, 2014b). As the patient is cared for in organisational time by the nurse, the patient's mind is still in a temporal place (Egerod et al., 2015b), it could be argued that this is how the conflict arises. Due to the irreversible and linear movement of time, each situation and each of us are unique and singular like no one else. The challenge for the nurse, and the culture within the ICU is to work in clock time and understand the patient's perception as associated with their existence (Ellingsen et al., 2014b).

The need to provide comfort to patients amidst the numerous unpleasant interventions during the day and to relieve their discomfort even if only temporarily, was recognised as a fundamental aspect of care for this group of patient. Nurses used an opportunity

for providing comfort as a way to connect with the patient and alleviate their discomforts and the complications of being bed bound for such a prolonged period of time. An example of this was the nurse who used the bed bath as a task which would relieve some of the patient's discomforts.

Nurse: This week I really wanted to get her going a bit more and like get her skin sorted out and give her a massage and moisture and her rash sorted ...so I have spent about an hour in the morning washing and moisturising and massaging her and trying to get her happy.

CM: Does she like that?

Nurse: I think so. Its seems to be – it's quite hard because you spend the first four hours of shift going flat out being super chatty with her and like trying to get her to communicate a bit more and she does seem to open up or she will start smiling and opening her eyes and looking at you. (Case 3, Nurse G)

The bed bath was one way the nurse could give comfort amongst the complexity of other interventions that potentially caused pain and discomfort for the patient. The time devoted to caring for the body and connecting with the patient during personal care was a way to give hope and encouragement to the patient. It was a way of ensuring that the patient could receive a pleasant experience amid the unpleasantness of the daily routine. Moments of care such as these articulated by the nurse, show how some nurses recognise the importance of time to provide some comfort back to the patient. By the time she has completed her care, the patient is opening her eyes and smiling.

The ritual of the bed bath has been associated with attentive, caring nursing care and was viewed as central to the role of the nurse when caring for CCI patients (Happ, Tate, Swigart, DiVirgilio-Thomas, & Hoffman, 2010). Within the demands of trying to comfort their patient, the bed bath was one intervention with which the nurses could feel a sense of accomplishment. The sense of failure at not being able to meet the patients' needs can make caring for this group of patients difficult. Current research in the care of awake ventilated patients has revealed nurses needed positive feedback when caring for patients they found demanding. This was achieved when they could provide empathy, touch and communication with their patient (Acebedo-Urdiales et al., 2016; Laerkner, Egerod, & Hansen, 2015). It also promoted a closer relationship between nurse and patient, allowing them to get to know their personality and hear their personal history, instead of a viewing them as a patient with a critical illness,

organ failure who may be technologically dependant (Laerkner et al., 2015; Tingsvik et al., 2013).

The continuation of care by the nurse was important as it consolidated to nurses what they perceived as comfort for individual patients. This was particularly obvious in the ICU where nurses worked eight hour shifts and generally went back to the patient they had cared for the day before. This created a group of nurses who would mostly look after the same patient:

I like long-term patients because you get to know what they like and don't like. It's quite nice having people for a few days in a row and you can do things they enjoy and you feel you can do things properly. (C3, Nurse G).

Nurses got to know how to comfort patients and the patients' behaviours:

I like that continuation because you get to know things, even though she can't communicate she has her own little quirks about how she likes things, like the blanket, I think she is more settled with the blanket. She doesn't like being exposed, she gets cold or it's a comfort thing. I did wonder about that if people in ICU, if anyone else has noticed it, because a lot of our patients do get unsettled and a lot it is about security. (C1, Nurse C)

Sentimental work during the wean

The subtle and complex nature of sentimental work is often invisible to many onlookers, but is vital for the psychological well-being of the patient during this phase of their illness. Healthcare professionals' acknowledgement of the devastating effects of a prolonged critical illness was vital for them to appreciate how they could best manage the patients through this protracted and difficult phase of their trajectory. Sentimental work during this phase focuses the need to give the patient back some control, as well as encouraging and instilling hope that they can get through their difficult illness. It involves recognising the cumulative effects of being a patient in ICU for such a prolonged time, and the devastating impacts the illness has on the patient.

As the patients' trajectory progresses, regardless of the admission diagnosis, all patients had similar clinical features in the latent phase of their illness (as described in chapter seven, such as muscle wasting and weakness). Therefore, care needed to be

planned to prevent feelings of helplessness and the loss of control that was common in this cohort.

Yeah I think it's mainly the physical deterioration that they become aware of the weakness, their limited self-caring ability... being aware of their dependence on other people. Forgetting that they may be attached to a machine. I think being on a ventilator or dialysis machine, that's taking care of them.... It's when they realise they can't even lift their hand to wipe their nose or feed themselves, have a drink when they want to, lift the cup, even tell someone they want a drink, all those things must be quite frightening and I think bringing to them how unwell they have been or how unwell they are. I think that's a reasonably common thing for people who have been seriously ill. Once they have the mental capacity there to appreciate all of that. (C3, ICU consultant X)

Once the patient realises the devastating effects their illness has had on their body and the total dependence they have on the nurse, it is a crucial time for the nurse to support the patient through this phase of their trajectory:

Their needs are different...it doesn't mean that there is no care that needs to be given...they're just different...and some of that is talking to him...finding out what's going on in his mind, helping him do things by himself...which takes longer than just doing it yourself...and you will find the experienced nurses will pick that up. Someone who's not experienced and doesn't see all that ...and would do what they need to do... and then sit outside [the patient's room] and reading their book, which is really sad...you know that's reflective of their experience. So it makes me a bit sad seeing a nurse sitting outside reading a magazine when a patient is inside, sitting there on his own, not talking to anyone.” (C4, Nurse K)

The nurses' work is still influenced by the total arc of work of “*this is intensive care*” and all it encompasses, meaning that many nurses do not recognise the impact this has on patient care in this phase of the illness trajectory. As the patient becomes physiologically more stable and needs fewer intensive care interventions, the patients were viewed as stable and slow. The nurses who recognised this as problematic were senior nurses with many years of experience who had reflected on the many aspects of care for this cohort:

It is done this way...it's what we do...rather than what the person needs....it's across the board...and that is sad. (C4, Nurse, S)

The domination of the arc of work within intensive care can denote how this group of patients are viewed and cared for by many nurses. The biomedical ‘cure-orientated’ model within the ICU can result in nurses focusing on the physical well-being of their

patient (Jakimowicz & Perry, 2015; Mazzotta, 2016). This model of care has been emphasised as problematic for nurses when caring for the long-term patients who have different needs than the usual ICU patient (Bellar et al., 2009; Roulin & Spring, 2006).

At an individual level, there were some nurses who seemed to cope better with caring for the long-term patient, and this was noted by senior nurses who would oversee all patient care:

There are always certain nurses in ICU who are going to have more empathy for looking after those long-term patients and I think if they want to, they should be encouraged to take those patients because they will do that little bit more. Whereas other nurses, it's not their fault, it's just not their makeup. They are going to be more geared towards high-tech, acute stage, but it is also mindful too that if a patient is long-term they do become...it becomes quite draining on the staff...it becomes about relieving and sharing the load. (C1, Nurse A).

These nurses, individually recognised the effects of being in the ICU for a prolonged period of time and tried to encourage the patient:

Anyone in intensive care that's here for longer than a week or so I think we start to feel a bit discouraged that you really want them to get better, if progress is really, really slow. Yet as the nurse in the bed space for 12 hours a day ... if your patient's conscious as well you start to think okay stay positive, encourage them, tell them things are going okay but when things are going okay at a very slow pace, I think it becomes harder to do that, positive encouragement is part of your job, I find that anyway. (C6, Nurse O)

Encouragement can be difficult when patients are withdrawn and there is little or limited positive feedback from them. Additionally, there are cares that need to be carried out to promote recovery which patients find hard to tolerate:

Nurse: I find it really tiring to look after her because you are trying so hard to make her happy [laughs] and to do the right thing that she is going to be happy and not hate you at the end of the shift. Like everyone seems to go through that phase that they just like not give up but they are so sick of it and they just don't care.

CM: Do you do some things to her and you feel like you are the big meany?

Nurse: Yeah and if you feel like – like that look she gives you when she has had a enough and you are doing things to her and she looks at you and it's just like “leave me alone” and you know that [laughs]. (C3, Nurse G)

The need to give some control to patients was recognised by some of the nurses. This was viewed as a vital intervention during this phase of the illness trajectory.

Nurse: it's the weaning bit I find them very tired, like when you try and wean them off they quite often go back and it takes a long time and they get depressed and withdrawn. They get very angry and get to the point when they say "back off".

CM: How do you handle that for nursing them?

Nurse: I just first explain things to them and go over it again and sometimes I just give them the time to think and just come back to them. I just go away and come back later because if you try and do something you are just forcing things and they don't like you and won't cooperate so if you give them the time and they can just relax back and come back to you. It's just you are losing their trust if you don't. (C3, Nurse B)

Control for the patient was recognised as dependent on who the nurse was for the shift and each nurse may have a different way of working:

Once you get his confidence you almost feel guilty leaving him because it's a new personality and it doesn't matter how wonderful they are it's still a new relationship for that patient to build which is really hard. Hard to be left I am sure...it's hard to be left with a whole new focus on the person that you are most dependant on for 12 hours. 12 hours can be a long, long time....I was anxious taking over [his care] because nurses get anxious. The nurse before you has done her thing and it doesn't matter what, but that's what the patient has got used to...The negative ... of course if you've somebody that doesn't suit a patient then they are stuck and could be thinking "here comes Jo Blogs and I am in for this for 12 hours" and they could get quite depressed....so there is an awful lot of skill....ok I will put it out there...I don't think ICU's are very good at it. (C6, Nurse S).

The recognition of the complexity that needs to be considered during the care of a long-term weaning patient is a critical reflection noticed by this senior nurse, was not noticed by others. The cumulative sentimental effects on the patients' well-being during the weaning phase can result in patients becoming increasingly withdrawn. However, the constant small gestures during the weaning process of giving some control and encouragement to patients is vital for patients' long-term well-being.

[The end of the wean](#)

As patients were weaned off all life sustaining treatment they were generally ready for transfer to the ward with or without their tracheostomy depending on local hospital practice. As the patients' journey came to an end in the ICU, the work for the ICU

nurses has ended. As patients are transferred to the ward, the patient and their family's work to manage the devastating effects this illness has had on their body and mind just begins.

I feel very sorry for him and I hope that I will always feel very sorry for those patients. I hope that I always get anxious about patients. This is only the beginning of his journey. It's going to be a good two years before he is somewhere near where he was before. Little wins, you know ...to be able to turn on your right side instead of your left and knowing that you have called the shots. (C6, Nurse S)

Conclusion

This chapter has presented nurses' lines of work throughout the patients' different phases of a prolonged critical illness that resulted in a long-stay in an ICU. The findings presented in this chapter suggest that at each phase of the patients' illness, nurses are challenged by an array of complex clinical issues that impact on their work. When analysed through the theoretical underpinnings of Strauss et al.'s (1985) and the lines of work, the challenges presented to nurses caring for this group of patients became more apparent.

The following vignette completes these four data chapters and portrays my reflections as the researcher. It reveals the impact of illness on patients and their family which I witnessed for the first time, as a nurse researcher within the ICU. The themes I portray in this vignette, were common in all cases in this study.

Final Vignette

I documented this patient's journey for the last 27 days. He has no idea what has happened to his body. He just knows he has pain, discomfort, weakness, tiredness, confusion and a body with limbs that are too weak to move. He can see a large dressing covering his abdomen, but he has no idea his abdomen is still partially open and he has drainage bags everywhere. He has limited family support. He is alone and about to be transferred to a ward where no one will really understand the complex nature of his illness and what he has suffered. I wonder how he will be in a few days' time as he realises how sick he has been and the complications he has suffered. His ICU care has ended, but he has such a long road ahead of him.

With all my years of being an ICU nurse and an educator, I stood in ICU and looked at this patient and I was struck with an overwhelming feeling that the case of a prolonged critical illness does not end here. No healthcare professionals have witnessed his journey as I had. I felt a great sadness because no one really understood what he had been through and what he had to go through. This was reconfirmed to me when I visited him on the ward for the first time. He has just returned to bed after being out in the chair, in which he had been left in a position that was uncomfortable for him and due to his weakness he could not ring the call bell to get anyone to help him. His bottom was sore and he was exhausted.

When I returned a few days later I was greeted by the charge nurse, who, in a joking way suggested that perhaps I could get him to change his colostomy bag, obviously because they could not. While I was there he needed to write something down on a piece of paper, however I noted the poor fine motor strength he had in fingers, which caused him difficulties to write. Upon seeing this, I did wonder how he would be able to change a colostomy bag and again I noted the lack of understanding at what this man had been through and the lack of individualised care to consider why he could not change his colostomy bag after he had been in ICU for about a month.

As his illness trajectory continued and I followed him up at home, again I was struck how no one understood his journey or had been there with him. He had been reading his discharge letter from hospital at home and discovered that while in ICU he had been to the operating theatre 7 times, and was struggling to understand his illness

trajectory and make sense of his distorted experiences that he remembered while in ICU.

The extent of his suffering continued at home as he coped with pain, fatigue, drains and poor mobility. His immediate family worried about him at home. He was exhausted and found managing his abdominal dressings difficult, as they were prone to leaking. This made leaving the house difficult and he was fearful they may leak so he stayed at home. When his family went out and left him, he became anxious by himself and worried they will not be home in a hurry. His family were exhausted from stress, running the household and caring for him.

Throughout my interactions with this man, it was clear the prolonged critical illness does not end when he was transferred out of the ICU. For him, as he tried to rebuild his life, it was the beginning. The complexities for this man and other participants continued for many months after they were transferred from the ICU, however there was lack of any follow-up service that provided care to some of these patients.

Seeing this man's illness experiences and all others involved in his trajectory and the influences that impacted on this case, I was able to see what no-one else had. Uncertainty dominated throughout all the trajectory phases for all participants, including healthcare professionals in this study. However, my overview of the trajectory demonstrates there were many opportunities to improve care for these patients and their family.

Chapter 10 – Discussion

Introduction

This chapter presents the research findings in the context of existing literature and the theoretical framework and critically discusses the key findings that shape the experiences for the participants throughout the trajectory of a prolonged critical illness that necessitates a prolonged stay in the ICU. These critical elements are presented as: the consequences of advancement in healthcare; working within the biomedical model; the multiple layers of distress that emerged for all participants and finally biographical re-casting following a prolonged critical illness.

Navigating the Grey Zone

A key factor in the survival of most patients who develop CCI, as seen in this study, is related to advancements in technology and medicine within the ICU and other areas of healthcare. The devastating physiological assault of the initial critical illness on the patient and the consequence of surviving, informs the patient's trajectory as well as that of their family and the healthcare professionals involved in their care. Despite ongoing debate within the literature about a definition for this group of patients and what causes CCI syndrome, there is no doubt that survival is a direct result of advancements in intensive care therapies.

Intensive care is positioned as part of a continuum of a healthcare system, which is influenced by global and local contexts. As healthcare continues to advance, it impacts on intensive care and creates an interplay that affects healthcare professionals, patients and their families. Previous generations of patients experienced acute diseases that were often rapidly lethal because there were less effective treatments, however for this cohort of patients without continuing advancements, they probably would have died early in their illness. As was demonstrated throughout the trajectories in this study, and the literature, advancement creates new groups of patients with impending problems which may not initially be recognised and therefore not addressed.

Eventually the consequences of these advancements, which creates new groups of patients, cannot be ignored because it creates novel issues in practice. This was demonstrated by Mesman's (2008) exploration of technological developments within neonatal intensive care, who noted with new therapy options, come new questions, new dilemmas and much suffering. This is applicable in any intensive care treatment,

because advancement equates to improvement in medical process but also to complexity by giving rise to new uncertainties about symptoms and expectations involving treatment. Mesman (2008) argues uncertainties have contributed to the emergence of the 'grey zone' referring to patients who do not clearly fit the criteria of patients who should be treated and others who should not. Similarly, as was highlighted in this study, the boundaries between the 'white and black zone' were noted to be expanding, which were identified during the multiple contingencies phase of the trajectory. For healthcare professionals the uncertainties of a good outcome, during a phase that was dominated by complications with minimal forward progress for the patient, created moral and ethical distress and clinicians questioned whether it was right to continue with treatment.

Uncertainties created by progress have been challenging for healthcare professionals since the early development of ICUs (Le Fanu, 2001; Mesman, 2008; Reiser, 2009). The earliest documented dilemma related to a patient in a vegetative state who was kept alive by mechanical ventilation and the debate amongst healthcare professionals as to whether this should be discontinued (Reiser, 2009). Complex ethical dilemmas, brought about by a new treatment, such as the development of positive pressure ventilation, were easily recognisable because they were seen as a technological breakthrough. However, the insidious advancements in therapies now, such as a new drug for sepsis and improved ventilation modes of mechanical ventilation all cumulate to advance therapy on a day to day basis so that the complexities this creates are not easily recognisable. However, it creates tension for healthcare professionals as they find themselves in a situation that causes them to question the treatment the patient is receiving or creates a feeling of unease which they may not be able to articulate. Failure to recognise and then acknowledge the changing landscape in which care is provided results in distress for many. Mesman (2008) refers to working in the in-between zone as creating tension between the familiar and unusual, control and contingency, certainty and doubt, cohesion and conflict. These factors are related to the known and unknown, and the risk and responsibility of caring for this group of patients.

Despite their admission diagnosis, all patients in this study had similar physiological characteristics as their illness progressed. Identification of similar physiological characteristics between geriatric and critically ill patients has seen the concept of

'frailty' used to describe patients who have survived their initial critical illness regardless of their age (McDermid, Stelfox, & Bagshaw, 2011). This phenomenon is seen as a direct unintended consequence of the capacity to prolong life in increasing numbers of critically ill patients (McDermid & Bagshaw, 2011). Frailty has been defined as a "multidimensional syndrome characterised by the loss of physical and cognitive reserve that leads to increased vulnerability to adverse events" (McDermid et al., 2011, p. 301) with "decreased reserve and resistance to stressors" (Cohen et al., 2016, p. 12). Frailty shares many features with the syndrome of CCI (McDermid & Bagshaw, 2011). These conditions share similar pathological pathways of an ineffective and prolonged stress response resulting in an exhausted compensatory inflammatory system which results in a vicious cycle of decreasing muscle mass, malnutrition and susceptibility to infection (Bellar et al., 2009; McDermid et al., 2011; Vanhorebeek & Van Den Berghe, 2004). The physiological deficits produced from surviving the initial critical illness causes patients to be vulnerable to adverse outcomes and complications as evidenced by the number of severe deteriorations during the patients' trajectory in this study. It is these characteristics caused from the effects of the initial critical illness that caused the prolonged critical illness that necessitated a prolonged stay in the ICU.

Advancement equates to new consequences, but with anything new there is the unknown. With any new technological or medical advancement, diagnosis and prognosis becomes more complex due to more options, other risks, different decisions to be made and more dilemmas for all concerned (Mesman, 2008). Healthcare professionals are therefore working in uncharted territory with a complicated interplay of potential problems and dilemmas associated with day to day practice. In this study there were many occasions when it was looking increasingly likely that patients would not survive their critical illness, especially at the mid-way point of the patients' trajectory and limits were put on increasing life supporting treatment. Hence the work of healthcare professionals during this phase of the trajectory was not routine as first may appear, with existing rules and routines not always effective in addressing new and unexpected situations. Riemann and Schutze (1991, p. 333) argued Strauss noted the most sophisticated organisation of work is in fact very fragile due to the multitude of contingencies (unexpected events that may arise in the course of a trajectory) arising from many sources, such as the illness itself, therapeutic interventions, the

organisation and the many participants involved. A critical factor that influences this is increasing medical knowledge and technology that combines to create increased risk and unforeseen consequences, making an unavoidable conflict of control and new contingencies in patients' trajectories (Fagerhaugh et al., 1987).

May et al. (2014) argue that advancement has resulted in an increased emergence of the symptom burden for patients and the burden of treatment for patients and their family with many chronic conditions as was seen with patients and their family in this study. These burdens accumulate for patients and their families resulting in poor health outcomes. These factors together with social and environmental factors add to the complexity for this group of patients. The notion of studying patient complexity has been suggested as a way to understand the many dilemmas that present in patient groups. Shippee et al. (2012, p. 1041) define patient complexity "as a dynamic state in which the personal, social and clinical aspects of the patients' experience operate as complicating factors". It is these factors which accumulate over time, interacting with each other and causing on-going problems. To complicate this, Manning and Gagnon (2017) argue the concept of the complex patient is widely used in clinical practice, yet is rarely called in to question in nursing, meaning the situational, relational, temporal, sociocultural and clinical contexts are not being critically examined. Hence Manning and Gagnon argue how the complex patient informs practice and shapes attitudes, behaviours and relationships is not fully understood.

Uncertainty was a consequence of advancement which influenced the trajectories of all participants throughout the course of a prolonged illness in ICU. The everyday practice of treating this group of patients with their many complexities was complicated by the fact that the answer to all their problems cannot be found in one recommended guideline or study creating complexity and uncertainty. This produces distress for all participant groups, but for a multitude of differing reasons, and creating an interplay of distress simultaneously. The concept of uncertainty has been studied by a number of related disciplines with differing definitions, these include medicine, nursing, psychology and anthropology (Cranley, Doran, Tourangeau, Kushniruk, & Nagle, 2012; Penrod, 2001). The significance of uncertainty was highlighted by Morse and Penrod (1999) who used the concepts of enduring, suffering and hope in a cyclic relationship, demonstrating how a person moves from one state to another. Importantly this reveals a state of uncertainty which is characterised by emotional

instability, with individuals enduring the present whilst suffering the inability to envision a way forward and this is suspended until hope is foreseen.

Uncertainty was evident in all participant groups within this study, although reasons differed. In her theory of uncertainty in illness, Mishel (1988) argues that complex diseases, poor information, and the unpredictability of events interfere with a patient's ability to understand, sequentially causing uncertainty. Uncertainty in illness is recognised as being poorly addressed and managed which results in negative experiences for patients (Etkind, Bristowe, Bailey, Selman, & Murtagh, 2016). Cranley et al. (2012) demonstrated nurses experienced and responded to uncertainty in practice in relation to patient care situations that were unexpected, unpredictable, unfamiliar, challenging and/or complex. Importantly of note from this study was that one of the main issues that caused uncertainty was navigating the ethical 'grey zone' of practice that was 'not clear-cut'. The significance of understanding uncertainty in relation to advancement in healthcare is to be able to acknowledge it. Acknowledgement and recognition of uncertainty are seen as a precursor to acceptance and a way forward (Morse & Penrod, 1999). Enhanced awareness and increased understanding regarding uncertainty can be important factors for navigating the 'grey zone' in an attempt to improve the experiences of uncertainty for all through an illness trajectory.

[Working within a biomedical model of care](#)

In this study, I used Strauss's 'lines of work' to understand how nurses manage their work within the ICU. Through Strauss's understanding of the hospital as a work site, the 'arc of work' within the ICU focusses on performing life-saving interventions on critically ill patients, which is dominated by rules, routines and medical control. These rules and restrictions exert power and control over all aspects of practice. Within the arc of work, care focuses on physiological restoration of the 'failing body'. The biomedical model dominates all clinical practice within the ICU with the preservation of physiological parameters as paramount, therefore maintaining safety and mitigation of risk govern all aspects of care. The environment, the rules, routines and the work of healthcare professionals are all underpinned by the biomedical model. The biomedical model is explicit and implicit in all aspects of practice within the arc of intensive care work.

Dehumanised care

The domination of the biomedical approach to patient care is logical during a life-threatening acute event, it guides healthcare professionals' assessment, diagnosis, treatment, critical thinking and decision making to ensure the best physiological outcome and during the initial phase of a patient's critical illness trajectory it ensures efficient treatment. It makes sense that nurses use these skills from a biomedical model for aspects of their patient care in the ICU, but there is potential for it to dominate nursing practice. Nurses in this study expressed a sense of accomplishment that they could manage profoundly physiologically unstable patients during their initial illness. Scholtz et al.'s (2016) study of ICU nurses' culture found they had a sense of pride in their ability to be able to utilise and display knowledge and practical skills while providing care. As demonstrated in this study, when nurses have difficulty meeting the needs of their patients or they are not working in the manner that they are accustomed to, a degree of distress was experienced by a number of participants.

Knowledge of disease processes and how they affect the physiological body is vital in intensive care to be able to treat patients effectively, nevertheless, this knowledge on its own is incomplete as it allows the understanding of the physical body only and it disregards the person. Sunvisson et al. (2009) refer to the mechanistic physiology that makes nurses assume that it is all about the disease, causing them to overlook the lived experience for the patient. Because of this lack of dialogue between the two discourses, patients can suffer. Within the context of intensive care, the physiological body is in much need of 'fixing', however the patient experiences can go unrecognised as nurses spend a lot of their time focusing on 'body work'. A potential consequence over time could be that nursing work becomes conceptualised solely as technical and physical work, resulting in care that is depersonalised and mechanistic. Marchetti, Piredda and Marinis (2016) refer to body care and attention to embodiment as a fundamental focus of nursing practice, but these concepts have not been overtly accepted into the theoretical foundations of nursing.

Nurses need to appreciate the duality of scientific knowledge which informs how the body works and the experiences of what it means and feels like to live through the body. They also need to be aware of how their body and embodiment impact on their patient's and family's care. Draper (2014) refers to nurses and their bodies, as the primary instruments of our practice and so the way our bodies are used is crucial in

our practice. Nurses carry out most of their work in the ICU by touching patients and entering into their personal space (Marchetti et al., 2016; Merilainen et al., 2010) and in this study there were times when nurses constantly touched patients as they performed tasks with little consideration of the ‘sentimental’ impact. It is our bodies and their actions that will have the ‘sentimental’ effect on the patient and their family, referring to the way in which we make the patient feel by our actions (Strauss et al., 1985). When the body is ill, relationships between the body and environment become altered and complex (Marchetti et al., 2016) and nurses need to consider the ‘failing body’ and how their practice impacts on embodiment for the patient. When nurses do not recognise this, there is a power imbalance during interactions with patients which occurs during nursing work that involves doing a task that is absolutely necessary for the patient at the time, or nursing routines that attract only a scientific interest to the point where it becomes sole focus of attention and other aspects of nursing care are not considered (Delmar, 2012).

In this study during the ‘weaning’ phase of the patient’s trajectory there was an overt notion that care was not so complex. As the physiological body was less dependent on life-saving interventions, they were viewed by many nurses as a ‘slow’ patient for a junior nurse. This embedded mindset shows the nurses’ understanding of the patient’s body only, with a lack of acknowledgment of embodiment as weaning this group of patients is complicated due to many physiological and psychological factors (Chlan & Savik, 2011; Delmore, 2006; Kydonaki, 2010). The need to understand the patients’ experiences during the weaning phase is vital to progress weaning without other contingencies occurring. Without this perspective, patient care becomes dominated by a narrow biomedical and technical view and the central importance of the person becomes overlooked. This is at a time when patient input can actively reduce the weaning time when supported adequately by nurses and their family.

Recognition of embodiment facilitates ‘knowing the patient’, which in the ICU context has been demonstrated as relevant for nurses, enabling them to make therapeutic decisions, whilst treating the patient as an individual (Wilkin & Slevin, 2004). ‘Knowing the patient’ has been acknowledged as vital in successfully managing the weaning patient (Crocker & Scholes, 2009; Logan & Jenny, 1997; Tingsvik et al., 2013). Jenny and Logan (1992) describe the process of ‘knowing the patient’ as a cognitive and relational process, by which nurses identified salient aspects of the

patient and situation, while establishing their professional credibility, which was vital for positive patient outcomes.

To 'know the patient' involves a relationship process that occurs over time. This involves getting to know the patient as a person and then creating a foundation for deeper understanding and sustaining that connection (Zolnierek, 2013). Maintaining continuity of nurses caring for the same patient is vital to 'knowing the patient' (Crocker, 2006, 2009; Wilkin & Slevin, 2004; Williams, 2003). In this study some nurses worked twelve hour shifts and often only ever cared for the same patient on two consecutive days. As these patients were often perceived as unchallenging, nurses would request not to care for the patient when next on shift. Other studies have identified patients who were being weaned as unpopular and nurses requested not to care for them (Crocker, 2006; Williams, 2007). It seems nurses treated the patients as recipients of care with minimal partnership (Crocker, 2006). Despite the benefits of 'knowing the patient' being discussed within the nursing literature, it was occasionally undervalued by some nurses in this study and of concern was that many of these nurses were senior nurses, who allocated junior nurses to care for these patients. The concept of 'knowing the patient' requires commitment, continued contact with both patient and their family and support from senior nurses (Whittemore, 2000).

Not 'knowing the patient' creates potential consequences for patient outcomes. These include late or delayed detection of deterioration, and depersonalised care because patients are objectified (Whittemore, 2000). 'Knowing a patient' has been correlated with patient centred care, which has gained increasing interest and is part of the World Health Organisation global strategy for healthcare that is 'people-centred and not 'disease-centred' (World Health Organization, 2015). Three core elements fundamental to patient-centred care are: patient participation and involvement, the relationship between patients and healthcare professionals and consideration of the context in which care is delivered (Kitson, Marshall, Bassett, & Zeitz, 2013). The concept of patient-centred care is difficult to define across various settings and within the ICU context (Jakimowicz & Perry, 2015; van Mol et al., 2016). The attributes of patient-centred nursing in the ICU include maintenance of patient identity; biomedical nursing practice, referring to expertise and a high level of clinical skills and knowledge; and compassionate and professional presence (Jakimowicz & Perry, 2015). Regardless, it has been argued that patient-centred care is difficult to instigate

within an acute care environment due to the dominance of the biomedical model, and the devaluing of fundamental care (Feo et al., 2016; Feo & Kitson, 2016; Galvin, 2010).

Core components of patient-centred care include patient identity and relational factors within the contexts of ICU, therefore family inclusion in all aspects of care which is key. Recent literature refers to patient-family-centred-care (PFCC) as vital the ICU context, making it clear that patients are embedded within a family and therefore care should be inclusive for both (Mitchell et al., 2016). Within this study only one unit appeared to be working towards the concept of PFCC and was actively looking for initiatives to involve this aspect of care. Other units lacked common knowledge of family dynamics with limited documentation about family details. Lack of understanding about family was seen to directly influence the family's trajectory and added to family burdens in terms of anxiety and time, because nurses did not consider family needs when planning daily patient care.

Within this study, there were some significant findings that need consideration in relation to family presence and their monitoring of the patient. Firstly, a number of family participants noted a patient's early deterioration, in the context that they knew something was wrong, but they could not articulate what it was. Because of the retrospective nature of this data it could not be followed up to determine if healthcare professionals had the warning at the same time, however, it is important to note that families are becoming increasingly recognised as vital in patient safety with it now acknowledged that family can recognise and respond to patient deterioration (Gill, Leslie, & Marshall, 2016). Family were often reluctant to question nurses about the patient during daily visits when the nurse did not seem open to communication. PFCC requires a partnership between healthcare professionals, the patient and their family to plan and deliver care. This clearly needs development within units where this study was undertaken.

[Safety and risk mitigation rule the environment](#)

The relationship between the hospital environment and the biomedical approach to care within the ICU is the predominant focus on life-saving care, hence the work site is designed to meet this need, where the focus is on technology, work flow and unit design. This emphasises the management of disordered physiology at the expense of an individualised approach to creating a healing environment. The role of the physical

environment, within the acute care context on patients' well-being, is a growing field of research (Edvardsson, Sandman, & Rasmussen, 2005; Minton & Batten, 2016; Timmermann & Uhrenfeldt, 2014), and as patients are now treated with less sedation, the negative impact of the environment becomes more problematic (O'Connor et al., 2010; Salgado et al., 2011; Sneyers et al., 2014). Throughout the ICU patient's trajectory, the negative impact of the environment on their well-being became increasingly more apparent as their illness progressed and they became more awake.

Safety, rules and policies are paramount in maintaining order in this intense, technologically demanding environment. Rules must be adhered to, ensuring safety and control, they dictate how the environment is maintained and are there to control the risk of creating another danger. For example, having lights on when patients are mechanically ventilated ensures nurses can quickly notice a potential disconnection or hypoxia, but for patients who are awake and mechanically ventilated for a prolonged period of time, artificial lighting in the ICU becomes hard to tolerate and adds to their stress level. This caused tension for nurses, as they would often override the 'light on' rule and choose to dim the lights for patient comfort. At times, they could be challenged by senior doctors and nursing management about their decision.

Excessive sound within the unit was an on-going issue which frequently impacted on patients' well-being. Noise produced by machinery, telephones and healthcare professionals' activity and conversations had a detrimental effect, in terms of overstimulation and disruption from rest and sleep. One unit had the sound from the cardiac monitor turned on resulting in constant beeps that coincided with every beat of the patient's heart rhythm, unfortunately, most nurses did not appear to notice the excessive noise. Studies have shown how excessive noise has physiological and psychological effects and causes sleep disturbances (Konkani & Oakley, 2012; Memoli et al., 2014). A result of excessive noise and sleep deprivation is delirium (Figueroa- Ramos, Arroya-Novoa, Lee, Padilla, & Puntillo, 2009; Glynn & Corry, 2015; Zaal et al., 2013) which all patients in this study experienced during their trajectory and which is a serious unexpected contingency culminating in an increased length of stay with poor outcomes. The effects of excessive noise on a 'failing body' becomes complex (Marchetti et al., 2016), and so the subjective experience of sound can be distressing as sounds can become part of patients' dreams and unreal experiences. These unfamiliar sounds cause anxiety as the patient never knows what

sound will occur next (Johansson, Bergbom, & Lindahl, 2012). Unable to recognise the sounds, patients wonder where they are (Storli et al., 2007). Excessive noise and anxiety produces a hyperactive state leading to further problems of sleep deprivation (Tembo & Parker, 2009), another contingency complicating a patient's trajectory.

According to Strauss et al. (1985) managing and shaping a trajectory involves numerous lines of work that need to be coordinated. To ensure all work is completed within the work site (hospital) requires articulation of tasks from all workers when they are scheduled. Tasks are performed at the convenience of doctors and nurses even though the timing may not be appropriate for the patient's comfort level at that particular time. Work during the morning shift was seen to be particularly task orientated and patients endured many activities and interventions that they found exhausting. There were also times when patients were constantly interrupted, woken from sleep and touched during nursing tasks and their bed space was regularly encroached by numerous healthcare professionals. The relentless proximity of the nurse to the patient during care invades their personal space (Merilainen et al., 2010) and I observed during the morning shifts, patients being touched by the nurse approximately every five minutes, over a two to three hour period. The patient is often powerless to do anything about this, which causes stress, anxiety, anger, interrupts rest and sleep (Edvardsson et al., 2005; Fredriksen et al., 2008; Johansson, Bergbom, & Lindahl, 2012; Merilainen et al., 2010; Timmermann, Uhrenfeldt, & Birkelund, 2014).

Identification of the nurse's role in creating a healing environment dates back to the era of Florence Nightingale who emphasised that the room is not merely for sleep but a place that should promote healing and wellbeing, including having a view to the outside (Nightingale, 1860). The predominant focus of the ICU to efficiently treat and cure physiologic disorders, is evident with technology, work flow and unit design which all emphasise therapies to treat patients at the expense of individual and holistic care. The open plan design of ICUs is not conducive for the care of patients with a prolonged stay. Although patients were often moved to a quieter area of the ICU it was still noisy; some lacked views to the outside and access to natural light, and the bed area lacked space and comfort for family to spend long periods of time with the patient. Environments that promote healing should be welcoming, be able to maintain social relations and have space for adding personal artefacts (Edvardsson et al., 2005). As ICUs are re-designed these factors need to be considered.

Emotional disruption from nurses' work

Strauss et al. (1985) argued the complexity of any situation needs to be analysed through the macro-micro relations to comprehend the influence on the present. How the nurses work within the ICU is related to the macro relations that have influenced their practice since the inception of the ICU. Hence, advancements in healthcare, and the domination of the biomedical model all influence how nurses work within the ICU, which in-turn impacts on patients and their families. Working in the 'grey zone' under the domination of a biomedical model, while caring for patients who had a prolonged and complex critical illness, subjected nurses to varying levels of emotional disruption. The interplay between nurses' emotional disruption related to their personal interpretation of events and therefore varied accordingly, but distress affected all nurses in different ways.

Working under the domination of the medical model of care, nurses were accustomed to the acute context of care in the early phases of the patients' illness. Their practice was unchallenged as these patients met the nurses' view of a typical ICU patient. The dominant focus of care was on the physiological aspects of the failing body, and so this was their priority. As this was the nurses' typical work there was minimal emotional disruption. Nurses felt a sense of achievement and satisfaction because they could use their skills and knowledge of the patient's physiological systems, maintaining parameters set by doctors. This mind set required concentration and meant nurses responded to the patients' physiological needs as the primary focus of care, ensuring safe practice. The ability of nurses to tune into the physiological needs of their patients reflects the findings of McLean, Coombs and Gobbi (2016) who found that for safe practice, nurses must adopt this mode of working to suit the context at the time. When a patient is unstable, as patients often were when first admitted to the ICU, nurses think and converse about patients from a physiological perspective in order to manage their care effectively.

Because nurses are accustomed to working in a particular way, a patient with a prolonged illness can be particularly confronting to them. The sense of achievement and satisfaction nurses experienced with short-term acutely unwell patients, because they improve quickly, did not occur with the prolonged illness patients. As this cohort consists of only five to ten percent of ICU patients, they are not the usual ICU patient. Nurses in this study were challenged to meet patient needs due to patient complexity,

but when this is unrecognised it resulted in frustration and distress for nurses. Weiss (2007, p. 375) suggests a complex patient “is one for whom clinical decision-making and required care processes are not routine or standard...with many recommendations from evidence-based medicine unlikely to apply in a straightforward manner”. When complexity is recognised, nurses and other healthcare professionals can incorporate complexity-linked interventions in the patient care plan (Peek, Baird, & Coleman, 2009).

The complexity of the patients’ initial illnesses increases the likelihood of nurses witnessing prolonged suffering for the patients for whom they provide care. To deal with this distress there were a number of strategies nurses utilised, some nurses focused on the physiological aspects care, so when the patient was semi-conscious they could choose to have minimal interactions with them. At times nurses appeared to have a low threshold for giving patients pain relief, when they were perceived to be uncomfortable, which resulted in patients becoming drowsy, rather than trying non-pharmacological comfort measures, which resulted in nurses being able to focus on other tasks. While lessening the burden for the nurses, these strategies are detrimental to patient outcomes. These strategies used by nurses created a short reprieve from a patient who showed signs of distress and they could relieve the patient’s suffering intermittently.

At times nurses felt care was aggressive and inappropriate, and some struggled with the control of the medical team who decided treatment. A lone nurse at the bedside would find it hard to openly question care or the value of the suffering they observed. In many studies, power status differentials and inadequate interdisciplinary collaboration have been reported as factors that cause distress for nurses (De Villers & DeVon, 2012; McAndrew et al., 2011; Papathanassoglou et al., 2012; Pavlish, Brown-Saltzman, Fine, & Jakel, 2015). Aggressive care, when deemed inappropriate, has been previously reported as one of the greatest sources of moral distress for ICU nurses (De Villers & DeVon, 2012; McAndrew et al., 2011).

Moral distress is defined as stress experienced when a nurse cannot take a moral action that they perceive to be correct (Dodek et al., 2016; Henrich et al., 2016; McAndrew et al., 2011). The effects of moral distress on nurses include emotions such as anger, anxiety, sadness, powerlessness and helplessness (De Villers & DeVon, 2012; Henrich

et al., 2016). In this study during the mid-phase of the patients' trajectories, nurses displayed signs of moral distress in relation to on-going complications and a poor prognosis, NFR orders, and suffering they witnessed in patients. Moral distress is not only a situational phenomenon, but has a long-term effect when sustained for an extended period (De Villers & DeVon, 2012), for example caring for a long-term patient. A mechanism nurses in this study would use to protect themselves would be to request not to care for the patient again. It has also been reported nurses have limited interactions with patients and their family when they are distressed about their care (Wiegand & Funk, 2012). The complexities of caring for this cohort was acknowledged by senior nursing staff, however, their strategies to deal with these problems were to allow nurses to request not to care for particular patients or to alternatively limit days in which they would be allocated to care for them, resulting in lack of continuation of carer for the patient.

The feelings of moral distress passed as patients began to improve, but nurses still found this cohort emotionally exhausting as nurses felt they could never meet the patient's demands. Their usual mode of work was influenced by the acute care/medical model of care and nurses struggled to meet the requirements of working within the lines of safety and risk first meeting the psychological needs of the patients. The negative feelings nurses have experienced previously overshadowed future care, because of tension felt during the mid-trajectory phase. Vouzavali et al. (2011) recognise the process of empathising with patients experiencing intense suffering results in hurtful imprints on nurses, and those authors characterise it as a 'soul-wrecking' process.

The progressive and cumulative effect of caring for these patients on a daily basis was emotionally exhausting for many nurses in this study. After the initial phase of critical illness, patients in the ICU continued to have multiple contingencies/complications that challenged nurses due to the potential for a poor outcome. Nurses started to feel uneasy about treatment and some questioned care as the patients' illness progressed. Caring for patients, with the realisation that they may never fully recover, is extremely challenging and has been associated with distress (Meadors & Lamson, 2008). As the patient's illness progressed and they became more alert, nurses were challenged to meet the patients' psychological needs amidst the many cares to address physiological needs. Nurses' overall impression of patients with a prolonged illness has been

informed by the moral distress and feelings of emotional exhaustion from caring for this group of patients. As many nurses found this cohort difficult to deal with many did not care for them often, hindering the development of a relationship with the patient. This resulted in many nurses never gaining satisfaction that they had been able to meet patients' needs.

Compassion satisfaction, which is defined as positive feelings from caring for others through difficult situations, is thought to counteract distress nurses can experience (Sacco, Ciurzynski, Harvey, & Ingersoll, 2015; Stamm, 2010). Compassion satisfaction occurs when nurses feel they can do their work well (Stamm, 2010). However, the nurses in this study who were caring for this group of patients for only one to two days at a time were unlikely to experience satisfaction as they did not see the progress the patient made or get to know the patient and family well enough to meet their individual needs.

Compassion is fundamental for the provision of good nursing care and is at the core of all nursing work (Winch, Henderson, & Jones, 2015). Compassionate care is also essential for the delivery of patient-centred care as the nurse's actions are based on their understanding of patients' needs and their willingness to reduce patient difficulties (Lee & Seomun, 2016). However, it is clear there are many barriers for nurses working within the intensive care context caring for patients with a prolonged illness, to deliver the care that is appropriate. The interplay of tensions for nurses to deliver compassionate care is related to the awareness of the conflicts of providing care within the complexity of the ICU (Jones, Winch, Strube, Mitchell, & Henderson, 2016; Winch et al., 2014). Jones et al. (2016) found a number of barriers to providing compassionate care in the ICU, which have also been identified in this study. These are: firstly, the overall team culture, in particularly the importance of supportive relationships; secondly, the lack of a clear and concise care plan for patients; thirdly, a strong emphasis on procedural work with compassionate care not seen as 'real work'; fourthly, lack of continuation of care and finally, lack of 'knowing the patient'.

It has been well articulated within contemporary healthcare literature that the power of working conditions and poor workplace culture, results in the essence of nursing becoming eroded and therefore compassionate care is not easily recognised (Freshwater & Cahill, 2010; Jones et al., 2016). Furthermore, compassionate care is

actively devalued due to the focus on risk and safety management (Winch et al., 2015). If nurses feel overwhelmed while trying to manage their work and feel they can never meet all the needs for the patient, there is also going to be a reduction in time for nurses to attend to their own emotional needs (Freshwater & Cahill, 2010). Nurses need to become attuned to the impact of elements that hinder compassionate care.

Jones et al. (2016) argue for nurses to become 'compassionate literate' which involves the recognition of influences that promote or hinder their abilities to provide appropriate care. Delivery of compassionate care occurs when there is a relationship between the nurses and patient and is determined by two conditions, the presence of suffering in one player and the desire by another player to relieve the suffering (Sinclair et al., 2016). The question then arises how can nurses care for others without support and education to deal with the complexities of suffering and emotional disruption they see in this group of patients? Incidences as described in the Francis report³⁴ have caused alarm internationally about the state of compassion in hospitals (Dewar, Adamson, Smith, Surfleet, & King, 2014; Lee & Seomun, 2016; Sinclair et al., 2016), however the process of how compassionate care can be achieved in everyday practice remains unclear at an individual, team and organisational level (Dewar et al., 2014). International policy initiatives are focusing on two related areas which link directly with compassion which are promoting person-centered care and fundamentals of care (Care Quality Commission, 2010; Feo et al., 2016; World Health Organization, 2015). The concept fundamentals of care reflects the centrality of activities to reduce harm, optimise recovery and ensure positive patient experiences (Feo & Kitson, 2016).

Nurses within the ICU setting have been educated within the acute, curative model and within an institution designed for acutely unwell patients needing highly technological care. Much of nurses' specialty education focuses on a body systems approach with only one out of nine core systems including psychosocial aspects of care (New Zealand Nurses Organisation, 2012). Therefore, if nurses are educated under this model, they are then going to be judged on their nursing care within the domains of this model. The importance of ICU nurses having their knowledge recognised by other nurses and doctors has been reported. This recognition enables

³⁴ Severe compromised patient care at Stafford Hospital in the UK, run by the Mid-Staffordshire NHS Foundation Trust, result in a public inquiry led by **Robert Francis QC**

them to care for the sickest patients, perform highly technical tasks and educate other nurses (Copnell, 2008). These attributes are then pursued in order to be a ‘good nurse’, and this has been reinforced by doctors in arenas such as the ward round (Coombs, 2003; Coombs & Ersser, 2004; Manias & Street, 2001). Furthermore, this has been found to be reinforced by other nurses who make the assumption they are unknowledgeable until they can prove themselves otherwise (Copnell, 2008). Research has also demonstrated nurses will modify what they do within a framework of what is acceptable practice on the particular ward they are working in (Mantzoukas & Jasper, 2008; Skår, 2010), so within the domain of the ICU, nurses are likely to be influenced by the dominant force of body work first, which becomes problematic as the complexity of the patient increases.

Understanding how ICU nurses manage the care throughout the patients’ trajectory is the first step in facilitating an understanding of the influences that impact on their practice. Nurses need supportive environments to facilitate reflection on their emotions toward promoting new ways of understanding clinical care with the group of patients. Lack of understanding regarding behaviors and psychological needs for these patients hinders effective care and, in turn, nurses’ responses to patients.

Biographical re-casting following a prolonged critical illness

Understanding the process of work for patients during the trajectory phases of a prolonged critical illness allows for those who support them to be better prepared to deal with the complexity of the illness. Corbin and Strauss (1988, p. 49) argue that as “illness comes crashing into someone’s life, it separates the person from the present, and shatters images of self for the future.” Within this study, patients and their family’s existences were threatened in many ways. Uncertainty throughout their trajectory in the ICU threatened their perception of who they were previously, as certain points of the trajectory, such as transfer to the ward and discharge home. For patients waking to find a ‘failed body’, compounded with the realisation they had lost a significant period of time, and then wondering if they would be able to return to their previous existence, caused distress and uncertainty. Corbin and Strauss (1988, p. 52) argue that when “illness brings a failed body, the foundation of one’s existence is shaken”, and without support and assistance it “can bring down the whole self-structure it supports”. In this study viewing cases retrospectively, patients’ past and present situations presented clues determining how they would cope with their illness, and shape their future.

Knowing the patient's past through the family and also seeing how the family coped with this critical illness, indicated aspects of the patient's biography that would facilitate or hamper their ability to cope with such an illness. When nurses did know about the patient's personality and coping strategies during the later stages of their trajectory, they could plan interventions and activities that supported them. The importance of nurses, with the assistance of family, to find ways to encourage patients has been linked to maintaining hope, an important coping mechanism, which serves as an essential psychological function (Wiles, Cott, & Gibson, 2008). This forms part of the biographical work which is important for maintaining their identity and self-concept through an illness trajectory.

The illness trajectory framework describes biographical work involved within an illness as contextualising, coming to terms, reconstituting identity and recasting biography. During the patient's illness in the ICU, they were too unwell to be able to make sense of their illness, it was only through their failed body that they knew something dreadful had happened to them. Although patients' illness trajectories in the ICU were prolonged, the patients' perceptions of time or temporality are different to that of their families and healthcare professionals. According to Corbin and Strauss (1988) time perceptions imply a consciousness but time conceptions are expressed in terms of temporal perceptions and clock time. Seymour (2002) argues time is a medium in which patients experience illness, but this only occurs when patients can reconceptualise their illness in terms of its temporal implications. In this study patients were not able to do this until they were well, which was after transfer from ICU, however this is part of their illness experience. It has become increasingly acknowledged within the literature that critical care services should have responsibility to care for patients post – ICU and to identify and treat the consequences of critical illness for their patients and family (Haraldsson, Christensson, Conlon, & Henricson, 2015; Harvey & Davidson, 2016; Svenningsen et al., 2015; Tilburgs, Nijkamp, Bakker, & van der Hoeven, 2015). Patients and their families in this study received minimal, if any, follow-up by ICU healthcare professionals about their experiences, physical problems and how to deal with these issues. This is particularly important for patients with a prolonged critical illness who have a number of complex issues after transfer from ICU and discharge from hospital.

With advances in healthcare more patients survive their stay in the ICU, but the implications of this are that patients face challenges during the recovery phase when they may receive little support for (Ullman et al., 2015). It is suggested ICU staff should collaborate more with ward staff to support this cohort in order to reduce suffering (Haraldsson et al., 2015). Within this study it was noted that when patients were transferred out of the ICU, this was perceived as the ICU nurses' work being done. However care is on a continuum for patients and their family, and the sudden withdrawal of intensive care input was notable, particularly in the regional hospitals that did not have an outreach service³⁵. The impact of critical illness is now recognised as highly problematic, for both patients and their family, being termed post-intensive care syndrome (PICS). PICS is defined as impairments in physical, cognitive or mental health arising and persisting after the ICU for patients. It is also recognised as problematic in families with issues consisting of psychologic, physical and social consequences (Harvey & Davidson, 2016; Jensen et al., 2015; Svenningsen et al., 2015). Furthermore a prolonged stay is associated with potential for long-term consequences for poor quality of life (Myhren, Ekeberg, & Stokland, 2010). Overseas literature suggests that the use of follow-up and patient diaries is becoming more common to assist patients and their families in dealing with the aftermath of a critical illness (Aitken et al., 2013; Svenningsen et al., 2015; Ullman et al., 2015).

After a prolonged critical illness, the patients' understanding of the illness needs to be established through experience. This is a complex process that can only be done when the patient is well enough, which is often not on transfer to the ward. Their biographical work involves reconstructing their identity and self-concept as a survivor of a prolonged critical illness. To contextualise the ICU experiences into one's life, patients first need to understand it; without adequate support they are unable to do this. In this study, family were able to assist patients with this process, but family could not fill in all the gaps; assistance was needed from someone with expert knowledge who understood their illness and what was normal in respect to distorted experiences and explanations of the illness progression. When this is not available it is an added burden that family needed to endure. One intervention that may have assisted patients to

³⁵ Outreach services is generally a nurse-led service that respond to patient deterioration, expedites early interventions. It also provides education and support to ward staff as well as supporting patients and their family after transfer from the ICU (Pedersen, Psirides, & Coombs, 2016).

understand their illness could have been a patient diary. Intensive care diaries can provide a written and/ or pictorial account of the patients' illness experience, as a means of improving communication and promoting psychological recovery (Aitken et al., 2017). However, the diary cannot replace the humanistic attributes of a healthcare professional who understands their experience and facilitates acceptance and adjustments to life after a prolonged critical illness. The degree to which a patient and their family can integrate the consequences of a prolonged critical illness to recast biography may determine the success with which that they can move on with their lives and grow as a survivor. This biographical work should not have to be faced alone, after such 'intensive care' in the ICU, healthcare professionals need to ensure they assist in the biographical re-casting.

Conclusion

This chapter aimed to bring together the findings from this study, and through analysis of literature and the theoretical framework, demonstrate what factors influence the trajectory of a prolonged critical illness with the context of ICUs in New Zealand. Understanding of the macro to micro factors that inform a trajectory is the first step in influencing practice to improve outcomes for patients, and their families, as well as decreasing the burden healthcare professionals' face in providing complex care to these patients. In the next final chapter, I conclude this study and make recommendations for practice, education and research.

Chapter 11 – Conclusion and Recommendations

Introduction

This chapter draws together conclusions from this study, from the overarching themes, and highlights the recommendations for clinical practice, education and research. The theoretical foundations from this study are three concepts: trajectory, work and biography. The recommendations are discussed within the components of the Chronic Illness Trajectory Framework. It is anticipated that these findings can inform future care practices for patients in intensive care units in New Zealand and internationally.

Summarising the study

The objective of this research was to:

Examine the experiences of the patient, their family and the healthcare professionals during the trajectory of a prolonged illness in the intensive care unit.

The research aims for this study related, to the ICU context, were to:

- Examine the patient’s perspective of the trajectory of the prolonged critical illness;
- Investigate how families experience a family member’s prolonged critical illness;
- Explore how healthcare professionals experience the daily care of patients with a prolonged illness; and
- Explore the interplay that occurs throughout the prolonged critical illness between the patient, their family and healthcare professionals.

The case

Analysis of the case of **the patient with a prolonged stay in ICU**, with the phenomena of interest being **the trajectory of a prolonged critical illness in ICU** has resulted in the identification of a number of key findings.

Firstly, this study has revealed that the trajectory of a prolonged critical illness has specific sub-phases regardless of the patient’s admitting diagnosis. Each sub-phase was determined by the patients’ physiological condition, however all sub-phases also represented different psychosocial needs. The patients’ debilitated state made them prone to complications and added to the complexity of their trajectory and their care.

Secondly, the families' trajectories were informed by patients' trajectories and were dominated by uncertainty. Families worked hard to relieve the uncertainty by looking for signs of improvement. They were very conscious that they did not want to interfere with nurses' work as it could take the attention off their family member. As their trajectory progressed the ongoing stress from prolonged uncertainty became more evident.

The nurses' experiences of caring for this cohort was informed by the patients' trajectory and each sub-phase represented different challenges. There was distress during the mid-phase because of uncertainty about positive outcomes for the patient and the suffering they witnessed. During the emerging with a failed body sub-phase nurses were challenged to meet all the patients' needs because of the many tasks they needed to complete over their shift. The model of care they worked with caused conflict at times, and lack of continuity of carer meant there was difficulty knowing the patient as a person.

This study has highlighted the changing trajectories the need to recognise the on-going impact these changes have on everyday practice. These findings contribute to theory development of the trajectory framework as it aligns with Corbin and Strauss's (1988) recommendation to concentrate more directly on the nature of the trajectories and sub-phases typically characteristic of an illness and the patterns of work in each illness.

Within these cases it was apparent the physical ICU environment, which is designed to safely enable intense observation and prompt intervention had detrimental effects on patients' and families' well-being during a prolonged stay when a different focus of care and environment was needed. Furthermore, the acute care/biomedical model of care dominated how nurses delivered care to this group of patients. However, some nurses were able to navigate this and provide patient-centred care were others were not. This study draws attention to the constantly shifting boundaries of intensive care therapies as technology and interventions continually advance, saving patients who may have previously died. This produces a trajectory of uncertainty and distress for families and healthcare professionals who provide care to the patient with a prolonged critical illness. It illustrates the complexities of a prolonged critical illness, and the devastating impacts this illness can have on all participants. This study has highlighted

the need for care that is both patient and family centred to ensure individualised care and improved outcomes.

The longitudinal nature of data collection with the three participant groups gave a comprehensive view of the trajectory of a prolonged critical illness. This view would not have been captured with only one participant group or if data were collected retrospectively. This research has highlighted how trajectories were interlinked for all participant groups. If this study had only focused on one participant group and one point of time this new knowledge would not have emerged.

Limitations of this study

The limitations of this study relate firstly, as discussed in chapter five, that the findings of qualitative case studies are not generalisable because no two social settings are sufficiently similar to those of other patients, families and healthcare professionals. However, rich descriptions and contexts can offer insights to inform practice. Although this study may be viewed as small due to the number of cases, with only one patient per case, there were 60 participants, with some participants interviewed multiple times, which added to the richness of data gathered.

The need to maintain confidentiality and anonymity within each case and each District Health Board has meant that some findings have been withheld. This mainly related to the presentation of biographical information which may have made people and places identifiable.

Key research findings and recommendations for practice, education and research

The key research findings in this study and recommendations are discussed under the following themes:

- The sub-phases of a prolonged critical illness
- The contexts of care
- Patient complexity

The sub-phases of a prolonged critical illness

This study has revealed that all patients, regardless of admitting diagnosis, transitioned through specific sub-phases of a prolonged critical illness trajectory, which was dominated by complexity. The implications for improving practice from this study are

significant, given the identification of sub-phases in the illness trajectory. Work is central to illness management therefore in each sub-phase it is important to examine the types of work and the way it is performed to improve experiences and outcomes for all participants, including medical, biographical and psychosocial within a particular phase. Patients had many physiological and psychological symptoms during differing sub-phases of their illness, and the severity of discomfort these caused was not always considered. Patients and their families faced many challenges adjusting to life after a prolonged critical illness, a particular challenge was one of feeling unsupported.

Knowledge of the work through each sub-phase of a prolonged critical illness sets the ground work for future practice, education and research into the complexities of this illness. Identification of contingencies, and understanding the consequences of illness and its management is crucial to improve outcomes and experiences for patients and their families. In this study, there were many issues identified that were problematic and difficult during the mid and end-phases of the trajectory. Therefore, as each sub-phase of the trajectory has identified issues that need further investigation, there is a need for inventional and evaluative research that targets specific issues and sub-phases.

Recommendations

- There needs to be a heightened awareness of CCI/ prolonged stay patients as a unique cohort, through post-graduate and ward based education
- Based on the findings from this study education and raised awareness of the sub-phases of a prolonged critical illness and the physiological and psychological problems that patients and their families' encounter is essential for healthcare professionals in the ICU, but also in step-down wards. Hence this knowledge and awareness will facilitate an increased understanding of why this cohort is complex and the holistic care priorities in each sub-phase. This knowledge can enable nurses to re-examine their models of care for these patients to best meet their needs. It could also support nurses to better manage the emotional disruption that can often occur when caring for this patient group, who do not reflect the typical characteristics of an ICU patient.
- As patients transitioned to a step down ward they needed to work hard to understand their illness, which was difficult given the prolonged period of

serious illness, and then to make sense of it as part of their biography. The use of techniques such as patient diaries for this patient cohort may be a way to capture their illness journey. Those tools can be useful for patients to know about their illness progression and why they, when alert, find themselves in such a debilitated state. An intervention study on ways to help patients integrate their ICU experience effectively into their biography with interventions such as the use of patient diaries is worthy of further investigation.

- Within each sub-phase assessment and management of delirium, sleep deprivation and relief from bothersome physical symptoms such as thirst and fatigue and psychological problems such as anxiety need targeted research. Findings then need to be used to develop evidence-based guidelines to address these common physiological and psychological symptoms through the differing sub-phases.

Contexts of care

Within this study, healthcare professionals managed illness work and prioritised the types of work. Based on the findings from this study the biomedical model of care, the routines and priorities of work in the technological-medical environment was in conflict with the needs of patients and their families. Routines and task-orientated practice during the day shift, particularly during the weaning sub-phase, left patients feeling exhausted, powerless and anxious. Within each sub-phase of the illness, care planning needed to reflect the individual needs of the patient and their family.

The contexts in which patients are cared for in this study, such as the physical environment, was problematic to patients and their family's needs as the trajectory progressed. As patients became more awake and aware the open plan of the ICU, with the presence of many people, noise and constant interventions, was not conducive for healing. The unpredictable levels of noise, constant touching by nurses as they carried out their interventions and intervals of numerous people near the patients bed area caused disruption, resulting in over stimulation and interruptions to their sleep. At times this increased patients' anxiety level, and appeared to be a precursor for delirium.

The context of the ICU was not always conducive to family's needs as the trajectory progressed. In some units the lack of patient-family centred approach to care resulted

in the needs of the family not being overtly obvious and so often not met. As the illness progressed and family needed to manage hospital visits, other family and work responsibilities there was lack of consideration to their needs. This resulted in family, at times, waiting for excessive periods to visit, which was often problematic for family.

At various points throughout the trajectory some nurses' experienced considerable distress from witnessing what they viewed as patient suffering and a poor prognosis. As the patient progressed to the weaning phase of their trajectory, nurses were challenged to meet their psychological needs, compounded with difficulties in nurse-patient communication, which could result in nurses requesting not to care for patients again. Lack of the use of nursing care plans resulted in a lack of short and long-term goals that were patient and family centred. However, 'knowing the patient' as an individual resulted in some nurses individualising care and working with patient's strengths. The lack of appreciation of the complex psychological needs of patients during the weaning phase resulted in the view by some senior nurses that junior nurses were able to provide care to this cohort.

The importance of family to the patients' well-being and recovery was underestimated and family experienced extreme prolonged stress and fatigue throughout the illness which impacted on their own well-being.

Recommendations

- Based on these findings a new model of care needs to be developed and evaluated for this patient cohort. It needs to include consideration of the physical ICU environment and the management of that environment that is most appropriate for this patient cohort. The environment should promote privacy, quietness, adjustable lighting, enable family presence and provide aesthetic surroundings such as a window with a view. Care routines should be cognisant of the specific patient needs for this cohort that are additional to those of most short-stay ICU patients. This would include cares being clustered when patients are awake, periods of the day when patients are left undisturbed, and short sleep periods during the day, when patients are fatigued. In addition, the night-time routines should facilitate as much undisturbed patient sleep as possible.
- As ICUs are re-designed, nurses and healthcare professionals have an important role in advocating for architectural and environmental design that

includes the principles of healing environments such as sunlight, natural views and noise reduction.

- The philosophy of patient-family-centred-care needs to be integrated into all aspects of care. Care planning should incorporate patient-family centred goals to meet short and long-term needs facilitated by a nurse specialist/senior nurse coordinator of care. A new model of care should be consistent with the changes needed to meet needs during different sub-phases. Evaluation of the new model and its implementation as stated is important.

Patient complexity

Interaction is crucial to carrying out illness work, as work is relationship work, meaning one person does work for another. Therefore, it is important to understand the role of interactions in carrying out this work. Understanding collaboration, cooperation and conflict when dealing with complex clinical situations and patient groups is the first step to improve experiences for all.

This study highlighted the emotional disruption nurses experienced at sub-phases of the trajectory caring for this complex patient group. As the patient progressed to the weaning phase of their trajectory, nurses were challenged to meet their psychological needs, compounded by difficulties in nurse-patient communication, which could result in nurses requesting not to care for patients again. The lack of appreciation of the complex psychological needs of patients during the weaning phase resulted in the view by some senior nurses that junior nurses were able to provide care to this cohort.

The findings from this study are informative for nurse educators in a number of ways. This study, as have many others, highlighted the emotional needs for critically ill patients and their families. Critical care education tends to focus on the pathophysiology, and technical aspects of care for patients, with minimal attention on the relationship needs. Postgraduate education for ICU nurses should focus on helping nurses to understand the illness experience and also to be able to critically reflect on aspects of patient care that are particularly challenging for them. On-going education and professional development needs to be targeted to all nursing levels, with on-going evaluation.

Recommendations:

- Education on patient experiences needs to be a regular part of ward in-service as well as post-graduate education for nurses, so they can then best address how to provide patient-family-centred care to this unique cohort. This approach may help nurses to form more effective relationships and partnerships with patients and their families to improve the experiences for all participant groups.
- Good mentorship and nursing leadership will assist all nurses to understand why they find care challenging at certain times throughout the patient illness trajectory. Regular case reviews should include all health professionals involved in the care of patients who have the clinical characteristics of CCI. On-going small group reflection will assist nurses to discuss frustrations, disappointments and distress encountered after caring for complex patients over a prolonged period of time and to plan future care with the support of others.
- Good mentorship and nursing leadership with help support and develop nurses within the ICU to deal with emotional disruption and build resilience to cope with the complexities in practice.
- Nursing leadership needs to consider the breadth of patient complexity in the allocation of staff with different levels of expertise to care for this cohort and consider the skills and support nurses need to improve patient outcomes during particular sub-phases of the trajectory, particularly during the emerging with a failed body sub-phase.

Concluding statement

During my years of working as a nurse in the ICU, long-term patients had always been a noticeable and memorable group of patients because of the challenges and complexities involved in their care. This study has revealed the complexities and the multitude of issues as patients' progress through their illness trajectory in the ICU. This study was developed because I wanted to highlight complexities I saw in practice, however this study has revealed more than I ever anticipated and it has answered many questions about why their care can be so challenging at times. This study has highlighted the enduring burden for patients and their families as they cope with a

devastating illness, but it has also revealed the strategies nurses use to assist patients to get through their illness experiences.

The study highlighted to me the enormous burden that not only the patients endure, but their families as well. Although the literature highlights the burden on family, witnessing the uncertainty and stress they live with for extended periods of time has been enlightening and New Zealand ICU services clearly need to implement a more family-centred approach to care.

This study acknowledges that an inevitable consequence from the advances in healthcare is that the complexities of care for patients who survive their initial critical illness will continue as healthcare pushes new boundaries. As nurses and healthcare professionals we must be prepared to constantly question, reflect and evaluate our care for patients and families to ensure they are at the forefront of these advancements.

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Appendices

Appendix 1 Ethical approval



Health and Disability Ethics Committees
Ministry of Health
1 the Terrace
PO Box 5013
Wellington
6011
0800 4 ETHICS
hdecs@moh.govt.nz

03 August 2012

Ms Claire Minton
School of Health and Social Services
Massey University
Private Bag 11222
Palmerston North 4442

Dear Ms Minton

Re: Ethics ref:	12/NTB/3
Study title:	When the closest thing to home is an intensive care bed: a long stay in intensive care from multiple perspectives.

I am pleased to advise that this application has been *approved* by the Northern B Health and Disability Ethics Committee. This decision was made through the HDEC-Full Review pathway.

The main issues considered by the HDEC in giving approval were as follows.

- The Committee noted the potential value of research such as this for people in intensive care, and considered that it was likely that participation rates would be high.

Covered as identifies data collection sites

- The Committee asked that "ICU" be spelled out in full in information to be provided to participants, and that the time commitment be more clearly explained. The researcher explained that the precise time commitment would depend on participant and family availability, and that it was important not to intrude during this time.
- The Committee noted the difficulty of obtaining informed consent in the ICU. The researcher agreed, noting that the timing of approach would be important. The researcher's experience working in ICU would make this more straightforward.
- The Committee discussed the availability of the Vidatak EZ boards in ICUs nationwide.
- The Committee queried whether data from patients who did not wake up would be used. The researcher explained that the family would be asked to consent to information being used in the study, as this would be important in building a full picture of long stays in ICUs, to capture the experience of as broad a range of families as possible. The Committee agreed that these cases should remain in the study where appropriate.

- The researcher clarified that "key participants" would include clinical staff and close relatives identified by the researcher by observation and asking clinical staff.

Conditions of HDEC approval

HDEC approval for this study is subject to the following conditions being met prior to the commencement of the study in New Zealand. It is your responsibility, and that of the study's sponsor, to ensure that these conditions are met. No further review by the Northern B Health and Disability Ethics Committee is required.

Standard conditions:

1. Before the study commences at *any* locality in New Zealand, all relevant regulatory approvals must be obtained.
2. Before the study commences at a *given* locality in New Zealand, it must be authorised by that locality in Online Forms. Locality authorisation confirms that the locality is suitable for the safe and effective conduct of the study, and that local research governance issues have been addressed.

Non-standard conditions:

3. Please correct the name of the HDEC in the information to be provided to participants.
4. Please replace "ICU" with "intensive care unit" in the information to be provided to participants.

After HDEC review

Please refer to the *Standard Operating Procedures for Health and Disability Ethics Committees* (available on www.ethics.health.govt.nz) for HDEC requirements relating to amendments and other post-approval processes.

Participant access to ACC

The Northern B Health and Disability Ethics Committee is satisfied that your study is not a clinical trial that is to be conducted principally for the benefit of the manufacturer or distributor of the medicine or item being trialled. Participants injured as a result of treatment received as part of your study may therefore be eligible for publicly-funded compensation through the Accident Compensation Corporation (ACC).

Please don't hesitate to contact the HDEC secretariat for further information. We wish you all the best for your study.

Yours sincerely,



Mrs Raewyn Sporle
Chairperson
Northern B Health and Disability Ethics Committee

Encl: appendix A: documents submitted
appendix B: statement of compliance and list of members



MASSEY UNIVERSITY
COLLEGE OF HEALTH
TE KURA HAUORA TANGATA

This study has ethical approval from the Northern B Health and Disability Ethics Committee (12/NTB/3)

Please feel free to contact the researcher for any other information about this study

Researcher's contact details:
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A Long-Stay in Intensive Care

Healthcare Professionals' Information Sheet

My name is Claire Minton and I am a nursing lecturer at Massey University in Palmerston North. My clinical background is intensive care nursing. I am undertaking research for my doctorate and would like to invite you to participate in this research. Before you decide it is important for you to understand why the research is being done and what it will involve.

What is the purpose of this study?

I am using case study research to investigate the experiences for the patient, their family and the healthcare professionals of the long-term stay in ICU. The aims of the research are to understand the differing experiences for all the participants and explore the interchange that occurs throughout the patient's stay in ICU.

How will this study proceed?

A patient has been identified as a long-term ICU patient in the unit you work in. Their family has given proxy consent for the patient and themselves to take part in this study. You are also invited to be part of this study. Data collection will occur at varying times throughout the patient's stay in ICU. It will consist of:

- Interviewing participants on several occasions (patient, family, and healthcare professionals from the ICU)
- Observation within the ICU of daily events such as family meetings, ward rounds and nursing care of the long-term ICU patient
- Reviewing relevant documents such as patient notes and policies

Why I am inviting you to participate in this study?

The patient who you have provided care to is part of my study. To understand the complexity involved in the care of this group of patients it is important to know the healthcare professional's experiences during the patient stay in the ICU.

Do I have to take part in this study?

Participation is voluntary. All research findings reported will be anonymous and will not be associated with the names of participants or hospitals where this research is conducted. If you decided to take part in this study you are free to withdraw at any stage.

What will happen if you take part?

You will be asked to talk with me over the course of the patient's stay and after discharge about your experiences of caring for the patient and their family. With your permission I would like to sound record the discussion and take notes. This may require an interview of 30 – 60 minutes and at other times just short conversation will occur.

I would also like to observe staff caring for the long-term patient, having discussions with the multidisciplinary team and the patient's family. I may ask if I can record some discussions, such as family meetings.

What are the benefits and risks of taking part?

This research is the first New Zealand investigation of experiences of the long-term stay to ICU from multiple perspectives. It is driven by the lack of information about the complexities of care for this group of patients and their families. It will highlight areas of practice that need improvement for the patient and their family, as well as identify areas of education and support that healthcare professionals need when caring for these patients and their families.

This study has ethical approval from the Northern B Health and Disability Ethics Committee (12/NTB/3)

Please feel free to contact the researcher for any other information about this study

Researcher's contact details:

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MASSEY UNIVERSITY
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A Stay in Intensive Care

Patient Information Sheet

My name is Claire Minton and I am a nursing lecturer at Massey University in Palmerston North. I am also an intensive care nurse. I am undertaking research for my doctorate and would like to invite you to take part in this research. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information and carefully discuss it with friends and family

saying or else I will use cards for you to communicate on. I will also review your clinical notes and listen to nursing and medical handovers about your treatment so that I understand the care you have been receiving.

I will ask your family and friends as well as the nurses and doctors involved in your care if they want to talk to me about their experiences while you have been a patient in the intensive care unit.

What are the benefits and disadvantages of taking part?

There are no specific benefits in taking part in this research, but you might find it helpful to talk about your experiences and to know that your recommendations will contribute to future improvements in care.

What is the purpose of this study?

This study aims to understand the experiences for the patients and their families of being in an intensive care unit.

Why are you being invited to participate?

You have been invited to participate in this research because you are a patient in an intensive care unit.

Do you have to take part?

Your participation in this study is entirely up to you. You are free to withdraw from this study at any time. All research findings will not identify you or any other participants. There will be no change in your treatment whether or not you take part in this study.

What will happen if you take part?

When you feel able I will talk you about what it is like to be a patient in the intensive care unit. It is all right if you can't speak because I will try to lip read what you are

This study has ethical approval from the Northern B Health and Disability Ethics Committee (12/NTB/3)

Please feel free to contact the researcher for any other information about this study

Researcher's contact details:

Claire Minton
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A Stay in Intensive Care

Family's Information Sheet

My name is Claire Minton and I am a nursing lecturer at Massey University in Palmerston North. My background is intensive care nursing. I am undertaking research for my doctorate and would like to invite you and your family member who is a patient in the ICU to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information and carefully discuss it with friends and family

What is the purpose of this study?

This study aims to understand the experiences for the patient, their family and the healthcare professionals of a stay in the intensive care unit.

Why you are being invited to participate?

Your relative has been identified as a potential participant in this study. If they are unable to consent their next of kin will need to consider whether to provide proxy consent. When the patient is awake I will ask their permission to use the data that I have gathered in my study. If they do not want to be in this study, all data will be destroyed and not used.

I would also like you and other members of your family or close friends to take part in this study as it is important to know how the patient's illness also affects others.

What participation will involve?

The patient: I will gather information about their illness from the clinical notes. I will also observe nursing and medical handovers about the patient. This information will help me to understand the plan of care for the patient. When the patient is awake I will ask them questions about what it's like to be in the intensive care unit

Family members: I will ask you to talk to me about your experiences of having a family member/ close friend in the intensive care unit. You will do this over a period of time as it is important to capture the experiences you have over the entire period of the patient's stay in the intensive care

unit. With your permission I would like to sound record the discussion and take notes. I will remove all identify personal details from the transcript of the recording and your name or any of your relative's and friend's names will not be used in any of the reports from the study.

Do you have to take part?

Participation is entirely up to you. You are free to withdraw from the study at anytime. Your relatives treatment will be the same whether you participant or not. All research findings reported will be anonymous and will not be associated with anyone's name.

What are the benefits and disadvantages of taking part?

The information gained from this research will be used to improve care in the intensive care unit. I hope you will gain something from the research too, by talking about your experiences and knowing that your recommendations will contribute to future improvements in care.

You may find that you become upset talking about your family member's illness. This is a difficult time for you and I will be as sensitive as possible about this. Sometimes people find that it makes them feel better being able to talk about their experiences. If you want a support person with you at the interviews you are welcome.

Appendix 3 Consent forms



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A Stay in Intensive Care

STATEMENT BY RELATIVE/FRIEND/ WHANAU

Lay title: A Stay in Intensive Care

Principal investigator: Claire Minton

Participant's name: _____

I have read and understand the information sheet dated 2012 for people taking part in this study designed to understand the experiences of a long-term ICU admission. I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.

I believe that _____ would have chosen and consented to participate in this study if he/she had been able to understand the information that I have received and understood.

I understand that taking part in this study is voluntary and that my relative/friend may withdraw from the study at any time if he/she wishes. This will not affect his/her continuing healthcare.

I understand that his/her participation in this study is confidential and that no material which could identify him/her will be used in any reports on this study.

I know whom to contact if anything occurs which I think he/she would consider a reason to withdraw from the study.

This study has been given ethical approval by the Health and Disability Ethics Committee. This means that the Committee may check at any time that the study is following appropriate ethical procedures.

I/my relative/friend would like a copy of the results of the study Yes/No

Signed _____ Date _____

Printed name: _____

Relationship to participant: _____

Address for results: _____

STATEMENT BY PRINCIPAL INVESTIGATOR

I Claire Minton declare that this study is the potential health interest of the group of patients which _____ is a member and that participation in this study is not adverse to _____ interests.

I confirm that if the participant becomes competent to make an informed choice and give an informed consent, full information will be given to him/her as soon as possible, and his/her participation will be explained. If the participant makes an informed choice to choice to continue in the study, written consent will be requested and if the participant does not wish to continue in the study, he/she will be withdrawn.

Signed: _____ Principal Investigator Date: _____

(If applicable at a later stage)

I _____ having been fully informed about this study agree to continue taking part in it.

Signed: _____ Participant Date: _____

STATEMENT BY INDEPENDENT CLINICIAN

I confirm that participation in the study is not adverse to _____ interests.

Signed: _____ Clinician Date: _____

Printed name: _____



MASSEY UNIVERSITY
COLLEGE OF HEALTH
TE KURA HAUORA TANGATA

Consent Form - Family/ Friend Participant's

Study Title: A Stay in Intensive Care

1. I have read the Information Sheet for this study and have had details of the study explained to me.
2. My questions about the study have been answered to my satisfaction, and I understand that I may ask further questions at any time.
3. I also understand that I am free to withdraw from the study at any time, or to decline to answer any particular questions in the study.
4. I agree to provide information to the researcher under the conditions of confidentiality set out on the information sheet.
5. I wish to participate in this study under the conditions set out in the Information Sheet.
6. I would like a recording of my interviews returned to me Yes/ No

Participant's Name: _____

Participant's Signature: _____

Date: / /

Contact details: _____

Researcher's Name: _____

Researcher's Signature: _____



MASSEY UNIVERSITY
COLLEGE OF HEALTH
TE KURA HAUORA TANGATA

Consent Form - Healthcare Participant's

Study Title: A Long-Stay in Intensive Care

1. I have read the Information Sheet for this study and have had details of the study explained to me.
2. My questions about the study have been answered to my satisfaction, and I understand that I may ask further questions at any time.
3. I also understand that I am free to withdraw from the study at any time, or to decline to answer any particular questions in the study.
4. I agree to provide information to the researcher under the conditions of confidentiality set out on the information sheet.
5. I wish to participate in this study under the conditions set out in the Information Sheet.
6. I would like a recording of my interviews returned to me Yes/ No

Participant's Name: _____

Participant's Signature: _____

Date: / /

Contact details: _____

Researcher's Name: _____

Researcher's Signature: _____

Appendix 4 Information sheet for patients clinical notes



MASSEY UNIVERSITY
COLLEGE OF HEALTH
TE KURA HAUORA TANGATA

Study Title: A Stay in Intensive Care

Insert patient bradma

I am a nursing lecturer at Massey University in Palmerston North. My clinical background is intensive care nursing. I am undertaking research for my doctorate. My study investigates the experiences for the patient, their family and the healthcare professionals of the long-term stay in ICU.

This patient has been identified as a long-term ICU patient. Their family has given proxy consent for the patient and themselves to take part in this study.

Please be aware that while I am not on site:

- I will ring the bedside nurse for a daily clinical update.
- If there are any changes to the patient condition, if able, please contact the researcher.

Researcher's contact details:

Claire Minton
School of Nursing
Private Bag 11 222
Palmerston North 4442
Phone: 06 3569099 ext 7039
Cell phone: 0273727593
Email: C.Minton@massey.ac.nz

This study has ethical approval from the Northern B Health and Disability Ethics Committee (12/NTB/3)

Thank you for your assistance

A Long Stay in Intensive Care

TRANSCRIBER'S CONFIDENTIALITY AGREEMENT

I (Full Name - printed) agree to transcribe the recordings provided to me.

I agree to keep confidential all the information provided to me.

I will not make any copies of the transcripts or keep any record of them, other than those required for the project.

Signature: _____ **Date:** _____

Semi-Structured Interview Guide – Family Members

Prompts may include:

First interview

1. Tell me about when _____ was first admitted to intensive care and what has happened up until now.
2. Now that your relative has been here for _____ length of time; how has this altered your experience?
3. Is there anything that you find has helped you during this time?
4. Describe to me the meetings and information you have had from the nurses and doctors in ICU?
5. Do you feel you understand what is happening to _____ in relation to their treatment and plan of care?
6. Have you been asked to make decisions about _____ care? How did you feel about this?
7. Have you been asked to participate in _____ care?
8. What would be helpful to you during your time in ICU in way of making this ordeal easier?

Subsequent interviews

1. Since we last talked can you tell me what has been happening with _____ and yourself?
2. Then similar questions as above from question 5

Semi-Structured Interview Guide – Healthcare Professionals

Prompts may include:

First interview

1. Can you tell me about caring for _____ since they were admitted to the ICU?
2. Can you tell me about any clinical/personal/ ethical dilemmas while caring for this patient?
3. Have you participated in any family meetings or discussions with the family?
4. How do you think the family are coping with the patient's illness?

Subsequent interviews

1. Since I last talked to you about _____ what has occurred in their treatment?
2. Can you tell me about your experiences of caring for _____ since we last talked?
3. What would make it easier to care for _____ (the patient)?

Questions relating to care of long-term ICU patients to be asked at a later stage of interviewing

4. Do you think this patient is typical of other long-term patients you have cared for?
5. What are the general problems they encounter? (physical and mental/ what about families)
6. How is the continuation of care and coordination of these patients managed in the unit?
7. How does a long-term patient fit into the fast-paced environment of ICU?

If patient is awake:

8. What is it like to care for _____ now they are awake?
9. Do you think they (patient) understands what is happening to them?
10. Do you care for them often?

Semi-Structured Interview/ Conversation Guide – Patient

Prompts may include:

1. Do you understand that I am here to interview you for my study?
2. Are you happy to talk with me now?
3. Do you understand why you are in ICU?
4. Can you tell me how you are feeling today?
5. Can you tell me any physical symptoms you have had in the last 24 hours?
6. What about emotional feelings you have had?
7. Are you having any difficulties with communicating?
8. What is it like to be on mechanical ventilation?
9. Tell me about what it is like when you family/ friends come to visit?