Patients' and Families' Experiences

Following Prolonged Critical Illness

A Narrative Inquiry Spanning Intensive Care to the First Year at Home

A thesis presented in partial fulfilment of the requirements

for the degree of

Doctor of Philosophy

in

Nursing

at Massey University, Wellington,

New Zealand

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(2026)

Abstract

Aim: Explore survivors' experiences of prolonged critical illness, and their families, across the full care trajectory, from intensive care admission through the first year after returning home from hospital.

Background: Prolonged critical illness is profoundly stressful for patients and families. Despite extensive research on diagnostic outcomes following critical illness, there is limited understanding of how a prolonged critical illness influences the lives of survivors and their families.

Research Design: Narrative Inquiry was used to follow the first year of ICU survivorship, as told by five patients and five family members (10 participants).

Data Collection and Analysis: Participants were interviewed four times during the first year following hospital discharge. Transcribed data were analysed using the three-dimensional narrative inquiry framework and thematic analysis.

Findings: Through longitudinal data analysis, common themes and subthemes emerged pertaining to specific time periods and places in the participants' journeys. For patients, the first theme, *Being out of control,* portrayed their experiences of the ICU. The second theme, *Unmet needs*, revealed their experiences of the general hospital ward. The third theme, *A year of tending to the self,* captured their year-long journey. For families, the first theme, *Being on life's edges in a world of uncertainty,* portrayed their experiences of the ICU. The second theme, *Where is the care?*, revealed their experiences of the general hospital ward. The third theme, *Navigating new realities alone and in the dark*, reflected their struggles across the first year at home.

Conclusion(s): The impact of a prolonged critical illness on the patient and their family is immense and life changing. Both parties experience a continuum of

vulnerability that begins in the ICU and endures long after hospital discharge. This ongoing vulnerability reflects systemic shortcomings and exists within a fragmented healthcare system where no one fully grasps or accompanies them through the entire journey. To address these gaps a person-centred, navigated model of care is needed that includes structured ICU follow-up, dedicated post-intensive care syndrome support for both patients and families, access to a continuum of specialised rehabilitation, and dedicated nursing.

Preface

This thesis is an original work by Amy Eyre. The research project of which this thesis is a part obtained research ethics approval from the Northern B Health and Disability Ethics Committee, “A Narrative Inquiry Exploring the Experiences of Survivors and Support People of Long-term ICU”, ethics reference: 2022 EXP 12583 (Appendix A). Locality authorisation has been obtained from participating sites.

Acknowledgements

There are many people that I wish to sincerely thank whose support has been crucial in the completion of this research project.

First, I wish to express my deepest gratitude to the people who participated in this study. Being invited into your homes and hearing your story has been the greatest privilege of my career. You showed me the joy and the hardship of surviving a prolonged critical illness. There is much that nurses and other health professionals can learn from your experiences, and I am committed to disseminating the findings of this research so that your stories contribute to care being improved for future long-stay ICU patients and their families.

I also wish to thank my supervisory team. Thank you for helping to bring this narrative inquiry to life and thank you for your support.

To my husband Danny, I am so grateful for your love and support.

Finally, to my parents, especially Mum, thank you for the hours you spent looking after Rian and Conor so that I could progress this work.

PhD Thesis Declaration

Candidate's Statement

By submitting this thesis for formal examination at Massey University, I declare that it meets all requirements as outlined in the Research Higher Degree Theses Policy and Procedure.

Statement of Authorship and Originality

By submitting this thesis for formal examination at Massey University, I declare that all of the research and discussion presented in this thesis is original work performed by the Author. No content of this thesis has been submitted or considered either in whole or in part, at any tertiary institute or university for a degree or any other category of award. I also declare that any material presented in this thesis, performed by another person or institute, has been referenced and listed in the reference section.

Copyright Statement

Acknowledgement of Financial Support

This research was self-funded by the researcher; however, the completion of this study was made possible by financial support from the New Zealand Nurses Organisation McCutchan Trust, the Perpetual Guardian New Zealand Nursing Fund, the Health Research Foundation Hawke's Bay and the Barbara Wood Memorial Foundation Trust. The grants covered doctoral course fees, fieldwork expenses, and

professional transcription services. I would like to express my sincere thanks to the members of the funding committees for their generous support of this project.

Acknowledgement of Professional Services

Some interviews were transcribed by Pacific Transcription and Capital Transcription. The use of a professional transcription service was included in the Study Information Sheet and Consent Form and all participants consented to this. The use of a professional transcription service was necessary for data management. To maintain data integrity and ensure the accuracy of the raw data, the researcher meticulously checked the transcripts for accuracy and context, correcting errors or ambiguities and ensuring they accurately reflected the spoken data. Participants' names were anonymised in the transcripts to protect confidentiality, and the final transcripts were stored securely to ensure compliance with the informed consent agreements.

Statement of Contribution

See Appendix B

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List of Abbreviations

ANZICS	Australia New Zealand Intensive Care Society
ARNA	Australasian Rehabilitation Nurses' Association
CCI	Chronic critical illness
CNM	Charge Nurse Manager
CPR	Cardio-pulmonary resuscitation
ED	Emergency Department
GP	General Practitioner
ICU	Intensive Care Unit
LOS	Length of stay
NE	Nurse Educator
NOK	Next of kin
NZ	Aotearoa New Zealand
OECD	Organisation for Economic Co-operation and Development
PAR	Patient at Risk nurse
PerCI	Persistent critical illness
PI	Principal investigator
PICS	Post-intensive care syndrome
PICS-F	Post-intensive care syndrome-family
RLN	Research Liaison Nurse
RN	Registered Nurse
UK	United Kingdom
USA	United States of America
WHO	World Health Organisation

Chapter 1: Introduction to the Inquiry

1.1 Introduction

This thesis examines the lived experience of patients and families navigating prolonged critical illness in Aotearoa New Zealand, using Clandinin and Connelly's (2000) narrative inquiry approach. The study follows their trajectory from the intensive care unit (ICU) to the general ward and onwards, to capture the complexities of recovery during the first year at home. This chapter begins by introducing the research. Then, prolonged critical illness is defined and quantified, including the working definition for prolonged ICU stay utilised by this study. Next, the background to the research is presented. The research justifications are then discussed, including the personal, practical, and social justifications. Then the *research puzzle*, narrative inquiry's term for the research question, is presented, followed by the research aim and objectives, and concluding with an overview of the chapters included in this thesis. Throughout this chapter and the thesis, the use of the first-person voice is a methodological necessity and deliberate tool used to acknowledge my positionality as an ICU nurse as well as active participant in the research, thereby enhancing the trustworthiness and reflexivity of the data.

1.2 Research Focus

The purpose of this research is to explore the stories of patients and their families who have experienced a prolonged critical illness in Aotearoa New Zealand. The research focuses on their experiences during the time in the ICU and the general hospital wards as well as during the first 12 months after the patient has been discharged home from the hospital. This timeframe was chosen because evidence suggests this is a time of heightened vulnerability due to the continuing impacts of the critical illness and high levels of ongoing needs (McPeake et al., 2022;

Zare-Kaseb et al., 2026). Survivors of critical illness commonly experience new or worsened impairments in physical, cognitive, and mental health that can lead to disability, difficulties in returning to work, and impact both the patient and their family's quality of life (Alrø et al., 2026; Ayenew et al., 2025; Gerth et al., 2019; Zare-Kaseb et al., 2026); collectively these impairments have been termed post-intensive care syndrome (PICS) (Needham et al., 2012). It has been reported that PICS is present in 50-80% of ICU survivors (Zare-Kaseb et al., 2026). Prevalence is greatest following the first few months after discharge from the ICU and partially tapers off by 12 months (Marra et al., 2018) but significant, long-lasting impairments are a burden for many survivors (Hiser et al., 2023). Ayenew et al. (2025) showed that those patients who remain in the ICU for more than four days are more likely to develop PICS. Gerth et al. (2019) note that the greatest health improvements for survivors occur in the first year after discharge from hospital, with little further improvement after that. This suggests that interventions to improve health after critical illness might be most effective in the first year after hospital discharge, highlighting a critical window for recovery interventions.

McPeake et al. (2022) in a systematic review and meta-analysis, showed that pooled estimates for hospital readmission after ICU were 16.9% at 30 days, 31.0% at 90 days, 29.6% at six months, and 53.3% at 12 months. Recently, Kang and Lee (2024) reported similar findings with 40% of ICU survivors readmitted to hospital within six months of discharge, and nearly 50% within a year. McPeake et al. (2022) showed that for prolonged critical illness survivors, the hospital readmission rate at 12 months post-discharge was 51%.

The research focus in this narrative inquiry addresses the *survivorship* gap identified in the international literature, where survivors often transition from acute

dependency requiring high-tech care to a state of profound existential and physical uncertainty (Iwashyna, 2010). Following such a profoundly impactful physical and psychological experience, it might be reasonable to expect a follow-up service; however, international evidence highlights that ICU survivors do not receive the care and support they need after a critical illness due to a lack of post-ICU infrastructure (Connolly et al., 2021; Cook et al., 2020; Dafoe et al., 2026; Nakanishi et al., 2024). This is the current reality in Aotearoa New Zealand with limited specialised recovery, rehabilitation, and follow-up services for ICU survivors (Dafoe et al., 2026; Sutton et al., 2025b).

After examining the literature, this study analysed both ICU survivors' and families' stories from Aotearoa New Zealand in two phases: first, the Clandinin and Connelly (2000) three-dimensional narrative inquiry space framework was applied, and second, a Braun and Clarke (2006; 2019; 2021) thematic analysis was performed. This process enabled patterns and themes to emerge within and across participants' stories of their journeys as survivors of critical illness and illuminated the individual meanings of their experiences. Collating the stories of multiple ICU survivors and their family members revealed understanding of problems the survivors and families faced, and their health needs to be identified and understood. The researcher then developed 13 recommendations to improve quality care processes for this population, to be disseminated in the broader literature and healthcare system.

1.3 Defining and Quantifying the Long-Stay ICU Patient

Continual advancements in critical care technology and treatments have resulted in improved survival of critically ill patients in recent decades (Barisich et al., 2024). In Western countries, many critically ill patients survive to ICU and hospital

discharge. Advancements in ICU therapeutics have also resulted in the emergence of a subgroup of complex patients who have survived their acute, life-threatening event/illness but do not recover rapidly. Instead, these patients transition to a state that has been termed persistent or chronic critical illness, remaining dependent on ICU therapies for a prolonged length of time (weeks to months) due to persistent organ failure and a cascade of critical illnesses (Ohbe et al., 2024). A recent review of the literature on definition, epidemiology, and outcomes of persistent critical illness (PerCI) and chronic critical illness (CCI) identified 99 eligible studies, of which 64 used the term CCI, 18 used PerCI, and 17 used various other terms (Ohbe et al., 2024). These patients can collectively be termed *long-stay ICU patients* (Minton et al., 2021).

While different duration thresholds have been used to define long-stay ICU patients, there is consensus that an ICU patient transitions from being acutely ill to persistently critically ill around days 6-10 of the ICU stay (Iwashyna et al., 2016), thus PerCI is often defined by an ICU length of stay (LOS) greater than or equal to 10 days (Ohbe et al., 2024). Chronic critical illness on the other hand, is often defined by an ICU LOS greater than or equal to 14 days (Ohbe et al., 2024). Evidence suggests long-stay patients constitute 5-12% of the ICU patient population in developed countries, depending on definition criteria and complexities related to individual ICU resourcing (Iwashyna et al., 2016; Ohbe et al., 2024). The most recent study to examine the timing and burden of PerCI in Australia and Aotearoa New Zealand found that it occurred in 5% of ICU cases (Iwashyna et al., 2016). This population of patients was first described in the literature in 1985 as *chronically critically ill*, when Girard and Raffin (1985) posed the controversial question of whether they should be saved.

Common characteristics can be identified. Long-stay patients often appear to be at high risk of dying during the early phase of their illness, but do not die and go on to face a range of complex and multi-dimensional issues including physiological, physical, cognitive, psychological, emotional, and social problems that persist across their illness course (Minton et al., 2020; Voiriot et al., 2022). Typical clinical features of this patient group during their ICU stay include:

- higher severity of illness (Rodrigues et al., 2024)
- prolonged dependence on mechanical ventilation (Ohbe et al., 2024)
- persistent multiple organ failure (Darvall et al., 2019; Ohbe et al., 2024)
- new and recurrent complications (Darvall et al., 2019; Voiriot et al., 2022)
- recurrent episodes of sepsis (Darvall et al., 2019; Mira et al., 2017)
- critical illness weakness due to neuropathy and myopathy (Minton, 2017; Nelson et al., 2010; Voiriot et al., 2022)
- acute psychological problems, including delirium, severe stress, and anxiety (Minton, 2017; Moser et al., 2018).

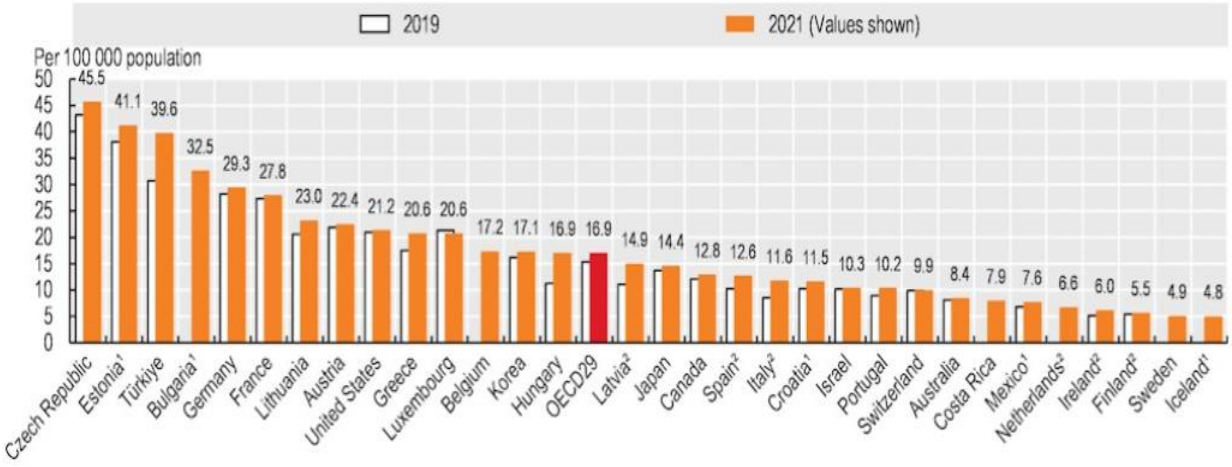
A significant challenge surrounding this group is the ongoing absence of a consensus-derived definition (Minton et al., 2021; Sterr et al., 2026). While definitions for PerCI remain relatively consistent with an ICU LOS greater than or equal to 10 days (Ohbe et al., 2024), a recent narrative review by Sterr et al. (2026) identified 12 definitions for CCI highlighting the variability in the literature. The reasons for this lack of consensus derived definition are complex, as Minton and colleagues point out.

First, the heterogeneous nature of the ICU population makes defining the long-stay patient difficult. Second, different countries have different healthcare resources and, therefore, different ICU services and varying capacity (Sen-Crow et

al., 2021), which can influence admission criteria and treatment limits. For example, Aotearoa New Zealand has one of the lowest levels of ICU beds per capita in the OECD at 5.42 beds per 100,000 of the population (Australia and New Zealand Intensive Care Society, 2025). In comparison, Australia has 8.9 beds per 100,000 of the population (Australia and New Zealand Intensive Care Society, 2025). Figure 1 highlights international differences in adult intensive care beds per 100,000 population among most OECD countries.

Figure 1

Adult Intensive Care Beds, 2019 and 2021



Note: Data for countries marked [1] include neonatal and paediatric ICU beds. Data for countries marked [2] cover critical care beds only. Source: OECD Health Statistics 2023.

Also highlighting these differences, in Aotearoa New Zealand and Australia, 5% of ICU patients have a length of stay greater than 10 days (Iwashyna et al., 2016) compared to 9% in the UK (Harrison et al., 2023) and 16% in Canada (Bagshaw et al., 2018). In the United States, nearly 8% of patients experience

prolonged ICU stays (Kahn et al., 2015). Third, there are differing thoughts on when an ICU patient is considered long-stay, with studies ranging from an ICU LOS of 72 hours to 21 days (Sterr et al., 2026).

Adding to this complexity, Minton et al. (2021) point out the great variability in terminology used to define this cohort in the literature. Common terms are:

- prolonged mechanical ventilation (great variation in studies with duration of ventilation ranging from 72 hours to ≥28 days)
- failure to wean from mechanical ventilation
- insertion of tracheostomy
- chronically critically ill
- persistently critically ill
- persistent inflammatory-immunosuppressive and catabolic syndrome
- frailty.

Minton et al. (2021) note that this lack of a common definition is problematic clinically as it increases the likelihood that patients' care needs go unmet, making the long-stay patient vulnerable. They argue that early identification is necessary to plan proactive, structured care that is centred around the long-stay patients' unique needs. This can prevent complications, improve outcomes, and reduce LOS. Additionally, the lack of a standardised definition presents challenges to researchers. Minton and colleagues suggest that when exploring and interpreting the literature, one must begin with a careful assessment of each study's definition of a long-stay patient.

1.3.1 Definition of Prolonged Critical Illness Used in This Study

Given the ongoing international debate regarding prolonged critical illness, as outlined above, developing a working definition for this study was challenging. The

definition developed was informed by a review of the literature, consideration of the characteristics most consistently associated with prolonged critical illness, and alignment with the study's aim and objectives. Although no universally accepted definition exists, there is consensus that prolonged ICU admission accompanied by prolonged mechanical ventilation, persistent organ dysfunction (Ohbe et al., 2024), and sepsis are key defining features of prolonged critical illness (Darvall et al., 2019). While prolonged ICU admission was considered for this study, it was felt by the research team that this alone would not necessarily distinguish prolonged critical illness, for example a patient may remain in ICU for several days due to being bed blocked. Additionally, this narrative inquiry sought to hear and give voice to those patients who did not have a voice in the ICU thus prolonged mechanical ventilation was a better fit for this study in that sense.

Also informing the study definition, drawing on the only international study to conceptualise the phases of prolonged critical illness (Minton, 2017), it was felt that prolonged mechanical ventilation, multiple organ dysfunction, and the effects of an inflammatory cascade resulting from sepsis were key characteristics that underpin the *complexity of caring for long-stay patients* and contribute to the long-term physical, cognitive, psychological, and social consequences experienced by patients and their families. Therefore, selecting participants with these characteristics ensured that the study focused on individuals most representative of the phenomenon under investigation. Accordingly, the research team defined a long-stay patient as an individual who had been mechanically ventilated in an ICU for eight days or more, had experienced dysfunction of more than one organ system, and had an episode of sepsis.

Developing inclusion and exclusion criteria is further discussed in the Chapter Four, Research Methods, Section 4.4.1. The inclusion and exclusion criteria for patient and family participants are presented in Chapter Four in Table 3 and 4, respectively.

1.4 Background of this Study

1.4.1 Rise of ICU 'Survivorship'

International evidence reveals the profound impact that critical illness has on survivors' recovery, health, disability, and quality of life (Geense et al., 2021; Gerth et al., 2019; Gravante et al., 2024; Schwitzer et al., 2023; Zare-Kaseb et al., 2026). In response to this, the last decade has seen a paradigmatic shift occur among the ICU community where greater attention is now being paid to understanding how critical illness and the ICU experience impacts people. Also, greater attention is being given to helping survivors with life after the ICU and the years-long process of healing from critical illness (Iwashyna, 2010). Paul et al. (2022) conducted a bibliometric analysis of research on health problems that remain post-ICU and showed outputs have increased from 11 articles in 2012 to 95 in 2020, highlighting the increasing attention given to this area.

The term 'survivorship' was first described in oncology literature over 40 years ago (Mullan, 1985) and was more recently adopted by intensive care scholars to encapsulate the burdens and legacies of surviving critical illness (Iwashyna, 2010). Nowadays, the term is used to refer to people with lived experience of the ICU (Kean et al., 2021; Kean et al., 2017; Page et al., 2019a). Iwashyna argues that the ICU community can learn from the oncology community which has succeeded in improving the lives of cancer survivors by making such improvements a priority across research, care, and infrastructure. He states:

> One way to begin grappling with the needs and hurts of critical illness survivors may be to learn from the experience of cancer survivors. Survivors of both critical illness and cancer emerge from a highly technical acute hospitalization… Both are discharged alive but face profound existential uncertainties and, often, an alienated relationship with their own bodies. (p. 204)

Iwashyna famously issued a call to action in 2010 when he said, “survivorship will be the defining challenge of critical care in the 21st century” (p. 204). Kean et al. (2021) map out what is known about ICU survivorship. They note that despite the term being commonly used in critical care literature, a theoretical definition is lacking, pointing out that the phrase has mostly been used in a generic way with limited understanding of what survivorship means in the context of critical illness. Kean and colleagues conclude their review by commenting that the experiences of people who have survived ICU “have been studied fractionally rather than holistically” (p. 2606). They point out that the physical and psychological dimensions of critical illness survivorship are well reported, but the social and economic consequences are not.

Current knowledge of what survivorship is and means in the context of critical illness is therefore narrow, demonstrating the need for future high-quality research to explore this phenomenon with breadth and depth. There is a growing awareness of the need for high-quality research to better understand survivorship and recovery from the perspectives of patients and families. This knowledge can then improve the quality of care and inform the development of interventions that support survivors across the spectrum of post-ICU care.

1.4.2 Post-Intensive Care Syndrome (PICS) and Post-Intensive Care Syndrome-Family (PICS-F)

In recent decades, improved survival rates of critically ill patients have brought to light the many short- and long-term health consequences of surviving critical illness and the associated challenges for both patients and their family members (Iwashyna, 2010). Studies have identified adverse outcomes in physical and mental health, cognitive functioning, and social domains (Geense et al., 2021; Gravante et al., 2024; Hiser et al., 2023; Marra et al., 2018). It is established that the longer a patient stays in the ICU, the greater their risk of developing long-term health complications (Herridge et al., 2016). Health issues and disabilities can persist for years after ICU discharge (Fan et al., 2014; Herridge et al., 2011; Marra et al., 2018; Shima et al., 2020). Patients with prolonged ICU stays tend to have worse outcomes compared to patients with shorter stays, as evidenced by higher ICU and hospital mortality rates (Damuth et al., 2015; Hermans et al., 2019; Jeffcote et al., 2019; Rodrigues et al., 2024). Rodrigues et al. (2024) reported that prolonged ICU stay is also linked to an increased risk of dying in the first two years after discharge. Patients who have experienced a prolonged ICU stay also have a higher incidence of post-critical illness sequelae and physical disabilities (Ågård et al., 2012; Davydow et al., 2008; Herridge et al., 2016; Probert et al., 2021). This may be due several factors including higher severity of illness, critical illness weakness, and the presence of sepsis (Rodrigues et al., 2024).

Post-intensive care syndrome is a term used to describe a spectrum of new or worsening impairments in three domains: physical, cognitive, and mental health, arising from critical illness and persisting beyond discharge from the ICU (Needham et al, 2012; Yuan et al., 2021). The term was formally established during a

stakeholder conference convened by the Society of Critical Care Medicine in 2010 to raise awareness of the long-term consequences of critical illness and ICU treatment (Needham et al., 2012). Common symptoms of PICS include generalised weakness, fatigue, decreased mobility, anxiety, depressed mood, sexual dysfunction, sleep disturbances, and cognitive issues (memory disturbance and/or loss, slow mental processing, poor concentration) (Rawal et al., 2017). Symptoms can last for a few months to many years after the patient has been discharged from the ICU. A recent meta-analysis of more than 10,000 cases revealed a pooled incidence of 54%, with an increased rate in patients who had longer ICU stays (Ayenew et al., 2025). The burden of PICS “creates a multifaceted struggle for ICU survivors” (Bornemann-Cimenti et al., 2025, p. 2) including, disability, reduced quality of life, increased healthcare utilisation and delayed return to work or worsened employment status (Bornemann-Cimenti et al., 2025).

The most recent systematic review evaluating return to work following critical illness (Kamdar et al., 2020) found that by 1-3, 12, and 42-60 months' follow-up, pooled return to work prevalence was 36% (23% to 49%), 60% (50% to 69%), and 68% (51% to 85%), respectively. Moreover, following return to work, 20%-36% of survivors experienced job loss, 17%-66% occupation change, and 5%-84% worsening employment status (for example, fewer work hours).

The consequences of an ICU experience are not just applicable to those with lived experience as patients, but also their family members. Post-intensive care syndrome-family (PICS-F) is a term used to describe the psychological, physical, and socioeconomic effects of critical illness on the family of the patient (Shirasaki et al., 2024). It includes symptoms that are experienced by family members during the critical illness as well as those that occur following death or discharge of a family

member from the ICU (Davidson et al., 2012). A recent systematic review found that three months after intensive care, an estimated 38% and 20% of family members of former critically ill patients had clinically important levels of anxiety and depression, respectively (Hartley et al., 2025). While these statistics quantify the burden of PICS and PICS-F, they do not capture the storied reality of living with these conditions, a gap this inquiry seeks to address.

1.4.3 Rising Cost of Care

The Iwashyna et al. (2016) study of over one million patients in Aotearoa New Zealand and Australian ICUs found that while long-stay patients constitute only 5% of the ICU patient population, this population consume a vast and disproportionate amount of resource, accounting for 32.8% of ICU bed days. Australia and New Zealand Intensive Care Society (2025) data reports that approximately 16,086 adult patients are admitted to an ICU each year in Aotearoa New Zealand[1]. With this knowledge it is possible to estimate that there are potentially 804 long-stay patients every year in Aotearoa New Zealand. However, this estimate is based on 2016 data (Iwashyna et al., 2016). It is unknown what the most recent statistics are.

Data from the ANZICS Intensive Care Resources and Activity Report 2023/24 (Bucci & Litton, 2025) reported the average annual cost of an available ICU bed was A$1,497,615, making the average daily cost per bed A$4,103; intensive care is expensive care (cost in New Zealand dollars is not available). Working with the definition of PerCI being classified from day 10 of the admission, if there are about 804 long-stay patients each year in Aotearoa New Zealand who have a minimum

[1] Around 97% (178/184) of Australian and 60% (18/30) of New Zealand ICUs contributed to the APD in 2022/23. This includes: 100.0% (40/40) of Tertiary ICUs, 97% (37/38) of Metropolitan ICUs, 84% (47/56) of Rural/Regional ICUs, and 90% (72/80) of Private Hospital ICUs.

LOS of 10 days, then the average cost of each patient's admission is a minimum NZ$41,030. The minimum annual cost of caring for this cohort is NZ$32,988,120; long-term intensive care is *very expensive care*. What is more, the cost of care is significant both during acute care and in the year following hospital discharge, with high healthcare utilisation during this time (Hill et al., 2017; McPeake et al. 2022). In the United States of America, annual hospital-related costs for this population are estimated to be US$26 billion (Kahn et al., 2015). The annual healthcare utilisation and associated costs for long-stay patients in Aotearoa New Zealand are unknown.

1.5 Research Justifications: "So What?" and "Who Cares?"

Clandinin and Connelly (2000) assert that from the outset of a narrative inquiry, addressing questions of meaning, social significance, and purpose is important for justifying the research. They explain that there are three levels of justification that inquirers must attend to: the personal, the practical, and the social. According to Clandinin and Connelly, the researcher's own personal interests and wonders are not enough; the personal sense of justification also needs to link with a larger public, social sense of significance. Each of these will now be explained.

1.5.1 Beginning with Wonder: The Personal Justification

In narrative inquiry, the researcher must situate themselves within the study by writing *narrative beginnings*: an autobiographical exploration of the researcher's relationship to the inquiry (Clandinin et al., 2007). Clandinin and Connelly (2000) argue that research interests are rooted in researchers' own narratives of experience; researchers often "choose a topic that is close to our heart" (Kanno, 1997, p. 6). My 13 years of experience as an intensive care nurse in Aotearoa New Zealand and Australia, combined with my work as a lecturer and researcher, led me to a deep *wondering* about the experiences of long-stay patients. Narrative inquiry is

a reflective and reflexive methodology; it requires me to inquire into my own stories before, during, and after the research (Clandinin & Caine, 2013). By looking inwards at who I am and who I am becoming as an inquirer, I can respond to the "so what?" and "who cares?" questions essential to social science (Clandinin, 2013).

My special interest in patients experiencing prolonged critical illness was ignited by Sam (pseudonym), a 40-year-old man paralysed by Guillain-Barré Syndrome. He was the first long-stay patient whose care I was involved with, and I remember this experience well because I spent a lot of time looking after him during his five-and-a-half-month ICU admission. Over the course of Sam's illness, I learnt how unwell and vulnerable long-stay patients are; his medical problems were complex, and the illness experience impacted him physically, psychologically, and emotionally.

Sam is considered a success story from an ICU perspective because he survived. However, after the ICU he spent a year in the rehabilitation hospital before being discharged home, unable to walk, unable to toilet himself, unable to return to his previous work and life. I wonder what his definition of success or recovery may be.

I also wonder what the ICU experience was like for his partner and their two young children. I wonder how it impacted them. I want to know whether they received the support they needed. I wonder how they coped with a partner and father who was now different from before. Sam's story was always incomplete for me because I did not know what his journey was like after the ICU, nor did I know what his long-term recovery was or how he perceived his life after the illness.

I learned more about the long-stay ICU patient through my post-graduate studies in nursing. I reflected on how patients' and families' voices were absent in

ICU nurse education. These silences created a tension for me, because they rendered patients' and families' lived experiences invisible. I began to question the ways in which nurse educators approach ICU nurse education. I had observed that education privileged developing nurses' biomedical knowledge. The unit I worked in had numerous in-house study days focused on ventilation, care of the cardiac, neurology, and trauma patient to name a few, but none on long-stay patients. Education on how to develop the therapeutic nurse-patient and nurse-family relationship was missing. So too was education on how to support conscious patients psychologically and emotionally.

My early reading around narrative inquiry allowed me to see that within these tensions were opportunities for alternative possibilities. Narrative inquiry provides unique interpretations of human experience that create a storied truth as opposed to an empirical truth (Vezeau, 1992). Experience itself is viewed as a storied phenomenon, and story is argued to be the best way in which researchers can understand experience (Clandinin & Connelly, 2000). A forward-facing story began to emerge where I imagined new ways that ICU nurses could learn and be educated on these patients and families in a way that foregrounded their storied reality. Several years ago, I instigated the first nursing study day in my unit on care of the long-stay patient and family and, unique to this day, was inviting a former patient and their family to speak to the nurses about their experience. I saw this as an opportunity for their silent stories to be heard. Attendees' feedback said this session was the most powerful learning experience of the day.

Since Sam, I have cared for many long-stay ICU patients. I remember a 60-year-old man who survived severe sepsis, multi-organ failure, and a several-week stay in the ICU, only to hear weeks later that he was going to have both his legs and

all his fingers amputated. He lived in a multi-story house. He was self-employed, a husband, father, and grandfather. I remember thinking about the difficult journey this man and his family would have ahead of them and it saddened me.

As another example, this one from my time working in Australia, I also remember a 45-year-old man who developed necrotising pancreatitis requiring a five-month stay in the ICU. He was cared for in a bedspace that had no windows or patient access to an outdoor space. This bedspace was positioned with other bedspaces next to and across from it, separated only by curtains. It lacked privacy. The noise and constant activity of the ICU could not be escaped. He was cared for in a unit without resources to shower long-stay patients. Night shift nurses would wake and wash all the patients between 4 am and 5 am, and when I questioned that practice, it was justified with the story “that is the way things are done here.” He was cared for in an ICU that did not adopt continuity of nursing care, so it was difficult for nurses to know him as a person and recognise both his physiological and psychological care needs. I reflected on how the physical environment, routines, task-oriented practice, priorities of nursing work, and culture of the unit conflicted with the needs of this patient. This in turn, conflicted with my commitment to holistic care and person-centred practice.

This patient was eventually discharged from the ICU alive but was left with new physical and mental health problems that meant his post-critical illness life would be very different to before. He would need more surgeries in the future. He was unlikely to return to full-time work as a teacher, play the guitar again, or travel the world. These were all things that gave him purpose and improved his quality of life. I wonder what his life is like now.

These patient stories are a few of so many that have remained embedded in my memories, and they have all made me realise the enormity of a prolonged critical illness. As my thinking has developed, I have ruminated over the challenges and downfalls of the current neoliberal healthcare system in which the patient with a prolonged critical illness is cared for in, both the ICU and beyond, and this has created further tensions for me. The acute care context dominated by the biomedical model, means that care is often system-centred not person-centred, a view held by others (Byrne et al., 2020). Byrne and colleagues note that this care is organised, prioritised, and funded to align with the requirements of the health system or service. When patients do not fit or when they deviate from expected care pathways, they become outliers.

Arguably, the context of the acute care system has changed considerably over the last several decades as advances in critical care mean that more people are surviving life-threatening illnesses or injury (Pilowsky et al., 2025). Hospitalised patients have become more complex over time (Naik et al., 2024). The complexity of care and patient needs has therefore, grown significantly but the system has failed to adapt to these changing requirements. Delivering safe, high-quality care to complex patients demands time, a skilled workforce, and adequate resources (Murkitos, 2023). However, hospitals are chronically understaffed with resource-constraints, and nurses are burnt out, creating a challenging dilemma without easy solutions (Rarani, 2026). As a result, the acute care system is staffed by a workforce lacking the knowledge, skills, time, and support necessary to provide high-quality care, ultimately compromising the quality of care for hospitalised patients (Murkitos, 2023). A good example of this is the 2013 Mid Staffordshire National Health Service (NHS)

Trust inquiry, known as The Francis Report, which found a systemic failure to provide fundamental care, leading to preventable patient deaths (Francis, 2013).

It is a system that is failing patients and families (Francis, 2013). These are “wicked problems” (Rittel & Webber, 1973, p.155) that are extremely problematic for patients who experience a prolonged ICU and hospital stay, because they are complex patients whose needs fall outside expected care pathways (Minton, 2017). This population are consequently not receiving the care they require, which negatively impacts on their outcomes and experiences (Minton, 2017).

It is these professional and personal experiences that led me to reflect upon this ongoing issue. I had so many questions and wanted to better understand this problem, to describe what is happening to the long-stay ICU patient and their family as they move through the health system. I shared these thoughts with a nursing mentor at the university I worked at, and she encouraged me to undertake a research doctorate to come alongside these patients and their families over time to learn about the whole journey, from the ICU to home: what problems they encountered, how they coped with their changed circumstances, and who was there to assist them in returning to life outside critical care. My research question had evolved.

In summary, my autobiographical narrative reflects my ontological stance and my journey as a narrative inquiry researcher, shaped by experiences that sparked my interest in a specific research puzzle. I have examined my past and future, as well as my inner thoughts and external influences, focusing on significant experiences and values that are important to me as a nurse. Exploring my own story has allowed me to justify this research on a personal level, with practical and social justifications expanded on below.

1.5.2 The Practical Justification

Practical justification in narrative inquiry requires demonstrating how research might shift existing practices and improve outcomes (Clandinin, 2013). This shift is increasingly urgent as ICU survival rates continue to rise due to medical and technological progress (Pilowsky et al., 2025); conditions once considered fatal are now survivable, creating a "new" patient population with unique, long-term needs that traditional acute-care models are not designed to meet (Abuhasira et al., 2022; Minton, 2017; van Breugel et al., 2020). However, the "success" of a clinical discharge often masks the complex, enduring challenges faced by those who experience prolonged critical illness. Capturing the contemporary experiences of this evolving group, this research provides the nuanced data necessary to adapt healthcare services from a focus on mere physiological survival to one of holistic quality of life.

The need for this adaptation is particularly acute within the Aotearoa New Zealand context where research on long-stay ICU survivors remains scarce. This lack of local data leads to an under-recognition of the unique challenges faced by Aotearoa New Zealand survivors and their family, who must often navigate a fragmented healthcare system without the benefit of a robust national infrastructure for post-ICU follow-up (Cook et al., 2020; Dafoe et al., 2026; Sutton et al., 2025a; Sutton et al., 2025b). Consequently, this inquiry serves as a vital tool for health service evaluation; building a local knowledge base, the study ensures that future post-ICU strategies and support services are developed to be culturally and structurally fit for New Zealanders.

As well as informing policy and infrastructure, this research aims to transform the bedside experience by humanising the clinical perspective. Narratives function

as *windows* into the lived reality of recovery, allowing health professionals to see patients and their families in a new light. As Chou et al. (2013, as cited in Wang & Gaele, 2015 p. 196) highlight, the power of a story lies in its ability to make "the implicit explicit, the hidden seen, the unformed form and the confusing clear." Sharing these stories, this research seeks to move clinical practice beyond physiological metrics toward a more person-centred care model that addresses the hidden complexities of the post-ICU journey, ultimately improving outcomes for those who have endured a prolonged ICU stay. Practical justification in this inquiry is therefore, about clinical practice: “How do health professionals treat these patients and their families better in the hospital and in the community?”

1.5.3 The Social Justification

In narrative inquiry, social justification reinforces the researcher’s responsibility to make visible the larger social and political contexts that shape individual lives (Clandinin & Caine, 2013). Attending to the stories of those who have survived prolonged critical illness, this research challenges dominant medical narratives that often equate *survival* with *success*. Instead, it seeks to address issues of power and representation, advocating for a more equitable healthcare system that recognises recovery as a social and moral imperative (Clandinin & Connelly, 2000). The urgency of this advocacy is highlighted by recent shifts in Aotearoa New Zealand’s healthcare policy. Following the COVID-19 pandemic, the Government announced a NZ$644 million investment to increase ICU capacity and support operational costs (Little, 2021). While this expansion is a necessary response to a chronically underfunded acute care system, it focuses almost exclusively on the *front end* of critical illness. Expanding ICU capacity without a concurrent investment in post-ICU recovery infrastructure represents a significant

systemic failure. Without a corresponding *back end* of support, an exponential increase in the number of survivors left to navigate the community with *ravaged* health and no specialised care is likely.

The social and economic consequences of this systemic gap are profound. As McPeake et al. (2022) identified, the lack of community-based post-ICU infrastructure contributes to a 51% hospital readmission rate at 12 months for prolonged ICU patients (defined in the study as ICU length of stay (LOS) greater than seven days), placing an avoidable and heavy burden back onto the acute care system. This cycle of readmission suggests that current policy does not yet reflect the reality of *survivorship*. Centring the experiences of survivors and their families, this research aims to influence policy by highlighting the complexities and inconsistencies inherent in these funding models. Ultimately, access to rehabilitation and support after a life-altering illness is a fundamental human right (World Health Organization, 2024). International consensus already advocates for dedicated follow-up services to ameliorate the long-term disabilities associated with ICU stays (Mikkelsen et al., 2020; NICE, 2009). This study therefore, serves as a form of social action. Bringing the *hidden* stories of Aotearoa New Zealand survivors to the attention of decision-makers, I aim to move the conversation toward a more just healthcare model; one where ICU survivors are not merely kept alive but are provided the structural support necessary to thrive.

1.6 Narrative Inquiry and the Research Puzzle

Unlike most other research methodologies, narrative inquiry does not have a traditional research question. Rather, the quest for knowledge is framed as a *research puzzle*. The research puzzle is the central question that guides the investigation of lived experience through storytelling (Clandinin, 2013). The shift to a

research puzzle reflects the focus of a narrative inquiry, which is to explore personal stories and understand the complexities of lived experiences, instead of seeking definitive answers to specific questions. The inquiry is collaborative, allowing participants to guide the conversation, thereby sharing what matters to them without the rigidity and constraints of a pre-determined research question (Clandinin & Connelly, 2000).

It is important to note that as the inquiry progresses and more information is gathered the inquiry can change, reflecting the fluid nature of narrative inquiry (Clandinin, 2013; Clandinin & Connelly, 2000). This was the case for this study. The research puzzle initially sought to address how prolonged critical illness survivors and their families experience life *after* a critical illness. However, during the first interviews, all the participants demonstrated a need to first talk in depth about their illness experience itself, re-storying their memories of becoming unwell, the ICU admission, and the ICU experience. I collected significantly more data than expected about the time both in the ICU and in the hospital. I felt ethically obligated to include this in the research. Hence, while the primary research puzzle was to understand how survivors and their families experience life after critical illness, I expanded the puzzle to include this other important aspect realising then that those survivors' present reality continued to be deeply influenced and framed by the illness, ICU, and hospital experience; their present was not something that could be understood without first understanding their illness experience.

1.7 Research Puzzle, Aims, and Objectives

The aim and objectives of this study and the overarching research puzzle were developed through identifying a knowledge gap based on the researcher's own professional experience as an ICU nurse (detailed above), conversations with a local

nurse academic who is an international research expert on the study population, and a review of the literature.

Research Puzzle (Research Question). My research puzzle sought to explore: What are the experiences of former long-stay ICU patients and their families during the first year following a critical illness in Aotearoa New Zealand?

Research Aim. In unpacking my research puzzle, I focused on the following aim: To gain a holistic understanding of patients' and families' experiences and journeys following a prolonged critical illness (from the ICU to home), to understand how to best support this group of survivors during recovery.

Research Objectives.

1. To explore the reality of a prolonged critical illness from the survivor's and family's point of view and what matters to them
2. To shed light on former long-stay ICU patients' and their families' experiences about their lives after a prolonged critical illness
3. To explore how the experiences of patients and family are related to the healthcare system and the health services within it and, ultimately, to understand what is happening in the system in relation to the care provision of ICU survivors.

1.8 Chapter Summary

This chapter introduced the background to this inquiry, the research topic, and the focus of the study. It presented the personal, practical, and social justifications for the study and outlined the study's significance. Following this, it explained the research puzzle, aim, and objectives. This chapter concludes with an overview of the thesis chapters presented in Table 1.

Table 1

Overview of Thesis Chapters

Chapter	Title	Main Content Focus
1	Introduction to the Inquiry	Research focus, definition, prevalence, and economic impact of prolonged critical illness in Aotearoa New Zealand, justifications for this research, research puzzle, aims, and objectives
2	Background and Literature Review	Review of the literature on both patients' and families' experiences following prolonged critical illness
3	Methodology	Narrative inquiry, positionality of the researcher, research paradigm, research philosophy, theoretical framework
4	Research Methods	Narrative inquiry as a research method, research ethics, research participants and timeline, data sources, data collection and analysis, rigour and trustworthiness, reflexivity, data management
5	Findings of Patients' Experiences Following a Prolonged Critical Illness	Themes, illustrative quotes
6	Findings of Families' Experiences Following a Prolonged Critical Illness	Themes, illustrative quotes
7	Discussion of the Research Findings	Discussion of the inquiry and the findings in the context of existing literature, theory and the theoretical framework, critical discussion of the key findings that shape the experiences for the participants across the illness and recovery trajectory, theoretical and practical implications
8	Conclusions and Recommendations	Strengths, limitations, recommendations, future research

Chapter 2: Literature Review

2.1 Introduction

This chapter provides the foundational context for the inquiry by examining the existing evidence regarding ICU survivorship after a prolonged stay. The structure of this chapter comprises firstly, an unpublished systematic integrative review of the literature following Whittemore and Knafl's (2005) approach examining patients' experiences once discharged home from hospital following a prolonged critical illness. This is followed by the formal integration of the published systematic integrative review on families' experiences once discharged home from hospital following a prolonged critical illness. Then, because the families' experiences literature review was published in 2023, an additional manual review of literature between 2023 and 2026 that was conducted to capture more recent developments is presented. The chapter concludes with a synthesis of these perspectives that identifies the limited evidence base on this topic and systemic gaps in aftercare that this thesis seeks to address. Collectively, these components provide the foundation and justification for this narrative inquiry.

2.2 Patients' Experiences Following Prolonged Critical Illness

A systematic integrative review of the literature using the Whittemore and Knafl (2005) framework was undertaken to critically examine research related to former long-stay ICU patients' experiences once discharged home by answering the specific question: *What are the experiences of survivors of prolonged critical illness during the first year following discharge home?* The PICo (**p**opulation, phenomenon of **i**nterest**, co**ntext) format was used to frame the research question. The definition of prolonged critical illness was an ICU LOS greater than or equal to seven days. The review specifically focused on narratives related to survivorship.

A literature search was conducted using the electronic databases of Web of Science, CINHAL, Scopus, and PubMed for English language studies published between January 2002 and January 2026. Search terms used: “intensive care” OR “critical care” OR “critical* ill*” OR "chronic* critical* ill*" OR "persistent* critical* ill*" OR "prolonged critical* ill*" OR "catastrophic ill*" **AND** survivor* OR patient **AND** experience* OR attitude* OR “post intensive care syndrome” OR PICS OR outcome* OR mortality.

Article titles and abstracts were screened in view of finding a selection of articles that focussed on the experiences of survivors of prolonged critical illness that are discharged home. Inclusion criteria included the review of articles concerning the adult population (over the age of 18 years) published in English and published in peer-reviewed journals. Articles also had to be of relevance to a prolonged ICU stay, which for this search, included any article listed as an ICU admission for seven days or more as this is still considered prolonged when one considers the median LOS being two days.

Data analysis of four peer-reviewed articles was informed by the Braun and Clarke (2006; 2019; 2021) approach to thematic analysis. The most significant finding from the review is the scarcity of research on this topic, identifying a critical gap. Only four studies – Ågård et al. (2012), Alexandersen et al. (2021), Ruch et al. (2026), and Sutton et al. (2025a) – explored long-stay ICU survivors’ lived experiences, defined here as those admitted to the ICU for seven days or more. Notably, Sutton et al. used a broader definition of long-stay, including patients who were mechanically ventilated for three days or more or had an ICU LOS greater than seven days. Although this study did not exclusively examine long-stay patients, it was included in the review due to the limited evidence available on this population

and its contextual relevance, given that it was conducted in Aotearoa New Zealand. While there is a considerable body of literature exploring the post-intensive care experiences of ICU survivors (Kean et al., 2021; King et al., 2019; Marra et al., 2018), the review reveals that long-stay patients, a distinctive and extremely ill population, have been missed. Given the increasing prevalence of long-stay patients, future trend predictions, and the global COVID-19 pandemic that resulted in an unprecedented number of this cohort, building knowledge of their experiences is the first step in understanding how to support survivors and families.

Furthermore, the literature review highlighted there is very little information on outcomes of long-stay ICU patients in Aotearoa New Zealand. The need to further investigate the experiences of people after ICU in Aotearoa New Zealand is, therefore, essential.

Three major themes emerged in the data from these studies: 1. the multi-dimensional burden of survival, 2. the relational transition: navigating dependency and the burden of care and, 3. recovery optimism. The themes are presented below.

2.2.1 Theme 1: The Multi-dimensional Burden of Survival

Once discharged home after a long stay in the ICU, survivors describe a protracted and arduous journey towards recovery, marked by the multi-dimensional burden of ICU survivorship spanning physical, cognitive, psychological, and social dimensions, known as PICS. Physically, survivors face the enduring legacies of ICU-acquired weakness that manifests as muscle loss, weakness, fatigue, reduced mobility, functional limitations, and disability. Also commonly reported are symptoms such as pain, breathless, and nerve issues that further compound these struggles. Because of these problems, basic everyday activities are difficult tasks. For instance,

“Then I had to try and get up with a walker and I just couldn’t. I couldn’t even hold my head. I wasn’t able to do anything” (Ågård et al., 2012, p. 109).

Survivors commonly report struggling with cognitive dysfunction during recovery, which is often persistent, lingering for many months. Difficulties related to short-term memory, having trouble findings words, and forgetting to take medications are commonly described. Memory gaps of the time in the ICU are widely reported and *not knowing what happened* is a particular burden during the recovery process:

> It really weighs on me. I usually say I don’t know anything. What I know came from others. But not remembering, that weighs heavily because I know there’ll be an outburst, and it won’t be easy. (Ruch et al., 2026, p. 5)

After discharge from the ICU, survivors experience what Sutton et al. (2025a) term the “psychological fallout” (p. 65) of what they had been through; anxiety, depression, and symptoms of post-traumatic stress disorder that are often rooted in negative ICU experiences. Of particular significance is the lived experience of delirium. Their fragmented, nightmarish memories of the ICU provoke confusion and strong emotional responses. Months later once home from hospital, some have recurring dreams:

> I dream I’m in the ICU. Or, for me, it’s not the ICU, it’s like a machine room on a ship. I’m in a corner, surrounded by machines that hum and beep. There are people, but I can’t talk to them. I keep having that dream. And each time I wake up and realise I can move, I’m free, but they’re like nightmares. (Ruch et al., 2026, p. 5)

Even after patients have been discharged home from hospital, studies show that they appear to be particularly troubled by their memories of delirium and inability to piece together what happened to them as well as differentiate reality from hallucination. They experience unresolved confusion and an absence of professional support to unpack their delirium and distinguish between the real and unreal.

In survivors of long-stay intensive care, symptoms of PICS appear to be particularly prevalent and managing PICS is challenging. Also, recovery is a slow process, and survivors face uncertainty regarding recovery outcomes. Complicating recovery is the reality that there is little targeted post-ICU support from the health system once the patient has left the hospital. For this reason, patients are highly dependent on family for care and support.

Furthermore, because of the lack of post-ICU support, both patients and their families are left to navigate what is an incredibly complex recovery on their own:

> So, ICU was ok. It was the minute I left the doors of the hospital that really let me down. And I do feel quite bitter about that… It would have been nice to have had support, because I didn't get anything at the time. It was just me and my husband. (Sutton et al., 2025a, p. 64)

Across all studies, the experience of prolonged critical illness resulted in profound transformations across physical, cognitive, psychological, emotional, and social domains. Consequently, survivors often experience fundamental changes in their daily lives and sense of self. Ruch et al. (2026) described this transformation as "no longer being the same person" (p. 4), highlighting the existential dimensions of survivorship following a prolonged critical illness.

2.2.2 Theme 2: The Relational Transition: Navigating Dependency and the Burden of Care

Because of the post-critical illness complications, survivors of long-stay ICU generally still need care when they return home from the hospital, making them dependent on others: “My balance was destroyed; I lost the ability to walk. I did not see much; my sight returned later; I was 100% in need of care” (Alexandersen et al., 2021, p. 3027).

However, this new dependency brings forth a relational paradox – support as a source of burden. Both Ågård et al. (2012) and Alexandersen et al. (2021) described how many survivors develop an awareness and understanding of what their family have been through and the ongoing impact of their protracted recovery on the family unit and primary caregivers. This can be associated with guilt. Also, many survivors have high levels of dependency on family, and it is spouses who often provide this care and support. Spouses assist with practical tasks including activities of daily living such as personal hygiene needs, meals, medications, transport to healthcare-associated appointments, social activities, as well as provide ongoing emotional support. Ruch et al. (2026) describe the social environment at home as both a help and a burden. Feeling misunderstood by others is common, especially when there is a mismatch between physical appearance (what others see) and the contrasting internal experiences of the patient that others cannot see:

> What I find hard to deal with is when people say, ‘You look good’. Everyone thinks I’m fine, but how I feel inside doesn’t match how I look on the outside, and that’s not very helpful in daily life. (Ruch et al, 2026, p. 4)

Survivors do not want to be a burden to family, and so, some survivors try to conceal their suffering, putting up a façade, internalising physical pain, and choosing to suffer in silence to protect others. The fact that survivors *conceal suffering* is a direct result of the *high dependency* on social support and not wanting to be a burden: “It is painful as I try to conceal that my whole-body shakes. I don’t want my family and friends to see this” (Alexandersen et al., 2021, p. 3030).

2.2.3 Theme 3: Recovery Optimism

‘Recovery optimism’ encapsulates long-stay ICU survivors' expressed hope as a form of optimism linked to tangible recovery milestones such as physical rehabilitation, restored independence, workforce re-entry, and family participation, despite PICS symptoms. This optimism motivated and sustained their rehabilitation efforts. Survivors saw physical gains as being prerequisites for restoring autonomy and independence, as illustrated by one survivor's determination, “I wanted to be independent, so I keep doing things all the time. To do some exercising” (Alexandersen et al., 2021, p. 3027). It further correlates with personal motivators, evident in aspirations like, “I don’t want to end up in a nursery and whittle away. I just want to get back to work and start to live again” (Alexandersen et al., 2021, p. 3027), or “if I manage to cycle to the store then I will be happy” (Alexandersen et al., 2021, p. 3027). There appeared to be a relationship between survivors’ optimism about their recovery and individual factors. Those whose recovery was grounded in purpose and goals demonstrated inner drive regarding their rehabilitation. Ruch et al. (2026) identified how survivors face challenges proactively through overlapping coping strategies including problem-focused coping, emotion-focused coping, and cognitive reappraisal. Their findings show that recovery is therefore, not only about physical healing but also psychological adaptation.

This review of the literature provides insight into the wide-ranging and multi-dimensional challenges survivors of long-term ICU experience once they return home from the hospital. It also sheds light on the persistent nature of critical illness sequelae and the slow pace of recovery, supporting the view held by Kang and Jeong (2018) that the recovery process following critical illness must be viewed as a continuum.

Both Morgan (2021) and Sevin et al. (2018) identified key areas of need for patients' post-ICU discharge including mental health, cognitive impairment, and physical disability with problems in these areas leading to reduced quality of life, increased dependence on interventional care, and reduced capacity to return to work. Long term morbidity therefore adds to the burden of disease for the patient, the family, and the health service. Morgan noted that because of this, collection of data from PICS should focus not only on the crude survival, but also on quality of life and the impact the extended illness has on the family and even the community. Sevin et al. found that most ICU patients leave hospital without any formal support or ongoing programme for return to previous health status. Morgan argues that an individualised rehabilitation programme should be planned and initiated prior to discharge, so that patients and families are supported during this time.

2.3 Families' Experiences Following Prolonged Critical Illness

This section incorporates material from the following peer-reviewed publication: Best, A., Harvey, C., & Minton, C. (2023). The experiences of families of former long-term ICU patients after the patient has been discharged home: An integrative review of the literature. Nursing In Critical Care, 28(4), 596-607. DOI: 10.1111/nicc.12886 (Appendix C). In accordance with Massey University regulations for a Doctorate by Monograph, the candidate was responsible for the purpose, data

collection, analysis, and drafting of the manuscript (80% contribution). The text in this section has been adapted to ensure narrative consistency with the surrounding thesis. The Statement of Contribution (DRC 16) is in Appendix B.

The aim of this review was to examine research related to the experiences of families of survivors of prolonged critical illness who are discharged home by answering the specific question: *What are the experiences of families of former prolonged critically ill patients that have been discharged home?* The PICo (**p**opulation, phenomenon of **i**nterest**, co**ntext) format was used to frame the research question. Originally, the definition of prolonged critical illness was an ICU LOS greater than or equal to seven days, however this yielded few studies and so the threshold of more than five days was chosen.

This review was conducted using the Whittemore and Knafl (2005) framework for integrated literature reviews. A literature search was conducted using the electronic databases of Web of Science, Cumulative Index to Nursing and Allied Health (CINAHL), Scopus, and PubMed for English language studies published between January 2002 and October 2022. The keywords and Boolean operators used for this search were combined as follows: (*"chronic* critical* ill*"* OR *"long-term ICU patient"* OR *"long-term intensive care"* OR *"long-term critical* ill*"* OR *"prolonged mechanical ventilation"* OR *"persistent* critical* ill*"* OR *"prolonged critical* ill*"*) AND (*family* OR *carer* OR *caregiver** OR *relative**) AND (*experience** OR *attitude** OR *survivorship* OR *discharge* OR *home*).

Article titles and abstracts were screened in view of finding a selection of articles that focused on the experiences of families of people who have survived a prolonged intensive care stay that are discharged home. Study quality was assessed using the CASP (Critical Appraisal Skills Programme) tool. Data analysis of nine peer-

reviewed articles was informed by the Braun and Clarke (2006; 2019; 2021) approach to thematic analysis. The Preferred Reporting Items for Systematic Review and Meta-Analyses (PRISMA) guidelines were used to report the review process.

The review identified nine studies across the USA, Canada, Denmark, and the Netherlands. No studies were identified from Aotearoa New Zealand, highlighting that little is known about the experiences of families of prolonged critical illness survivors in this context.

The review revealed that families face a trajectory defined by significant health deterioration and a lack of recognised support for them as both a carer of an ICU survivor but also, themselves being a survivor of a long stay in the ICU. Three major themes were identified: 1. the negative impact on family caregiver health and well-being, 2. caregiver burden, and 3. unmet support needs.

This article was published in 2023. A manual search was conducted in 2026 and there has been nothing published on this topic since.

2.3.1 Theme 1: The Negative Impact on Family Carer Health and Well-being

The first theme concerns the profound and negative impact of the caregiving role on family carers' health and well-being, which persists well beyond the patient's hospital discharge. In the research, relatives report a range of symptoms consistent with PICS-F; anxiety, depression, and even post-traumatic stress are common. The research emphasises that these psychological legacies are not temporary; they often persist for years and are compounded by significant physical health deterioration. Also, family carers frequently report fatigue, significant energy loss, sleep disturbances, and a reduced appetite, often described as being *mentally and emotionally exhausted*. This state is further exacerbated by a constant sense of worry about the patient, where family carers adopt a heightened state of awareness

and continuous observational behaviour due to fears of the patient's health suddenly deteriorating. Furthermore, the family carer's social health suffers as the demands of caregiving lead to social isolation and the loss of personal friendships, creating a *dualistic world* where the caregiver's life becomes consumed by the patient's needs and they have significantly less time for themselves.

2.3.2 Theme 2: The Caregiver Burden

The second theme, caregiver burden, explores the complex and demanding transition from a familial role, such as a spouse or child, to that of a primary caregiver. Prolonged critical illness is a significant life event that thrusts families into an uncertain and slow recovery pathway, where they must manage intensive physical and psychosocial care alongside practical daily support for the patient. The burden is particularly heavy because recovery from prolonged critical illness is often non-linear and requires the management of complex medical equipment and intensive therapy with little to no formal training or preparation. This leads to a subjective *caregiver overload* that can actually worsen in the six months following discharge, suggesting a cumulative and exhausting effect of the caregiving role. This burden is further exacerbated by the fragmented nature of the healthcare system, where the lack of a seamless transition between hospital services and community-based primary care leaves families navigating a *cliff-edge*. In this environment, family caregivers must struggle to balance intense medical duties with existing *role complexities*, such as raising children, caring for elderly parents, or maintaining paid employment, often leading to a total role transformation that is both stressful and overwhelming.

2.3.3 Theme 3: Unmet Support Needs

Finally, the review identified a critical gap in support, categorised as unmet needs that often remain unrecognised by the healthcare system. A consistent finding across the international literature was the overwhelming feeling for families of being *abandoned* by the health system upon discharge. Families report that the initial transition from the hospital to home is characterised by feelings of overwhelm and underprepardness due to a lack of structured hospital discharge preparation and a distinct absence of information regarding the expected trajectory of recovery for the patient. This lack of a roadmap fuels families' anxiety and induces a constant state of hyper-vigilance. There is a strong expressed desire for a *navigated* model of care involving a dedicated coordinator who can bridge the gap between medical specialties and connect families to necessary psychological and rehabilitative support for them and the patient. The research indicates that support requirements mirror the survivor's recovery; while initial needs are often physical and practical, they shift over time toward a need for professional mental health support to manage the survivor's fragile emotional state. While strong social support from friends and family is associated with more positive experiences, many caregivers find themselves navigating recovery from prolonged critical illness alone, struggling to provide care while their own needs for professional guidance and support remain unaddressed.

2.3.4 Conclusions about Families' Experiences

In conclusion, families of prolonged critical illness survivors who are discharged home face complex challenges that make their experience exceptionally difficult and demanding. The early returning home period is often marked with anxiety and stress. Families' support needs after hospital discharge are largely

unrecognised and unmet within the current healthcare framework. Best et al. (2023) highlighted the urgent need to further investigate the experiences of these families through qualitative research. Such insights are essential to inform better service provision, create more robust discharge structures, and ensure that both the prolonged critical illness survivor and their family caregivers receive the long-term support necessary for a sustainable recovery.

2.4 Recent Research and Newly Emerging Themes

Since Best et al. (2023), it is understood that no further studies specifically exploring families' experiences following a prolonged critical illness have emerged. However, a manual search revealed that several new lines of evidence relating to families' experiences following critical illness have emerged and these are worth acknowledging. These can be grouped into the themes 'from hospital to home: the heightened window of vulnerability' (Howard et al., 2025a), 'the emotional labour of caregiving' (Arlo et al., 2025; Howard et al., 2025b), 'existential navigation' (Danielis et al., 2024a), and 'fragmented realities' (Major et al. 2019).

Howard et al. (2025a) identified the transition from hospital to home after critical illness as a "heightened window of vulnerability" (p. 10). Families described feeling that patients were "being pushed without a plan" (p. 10), perceiving them as too unwell for discharge and lacking clear guidance for managing illness and recovery at home:

> They were ready to discharge him. And I was like, 'What are you talking about? He still is not that mobile'. And actually, it got quite ugly with them back and forth. I said, 'I'm not bringing him home. He's in no condition to be home.' I did everything I could. I spoke up… In the end, they just said, 'He's coming home.' They arranged a [public disability

> transport], and he got dropped off at home… It was on Tuesday, I was at work. (44-year-old-woman caring for her 80-year-old father admitted to ICU with hospital-acquired pneumonia). (Howard et al., 2025a, p. 11)

Families describe the transition home as being challenging. Rather than marking a period of recovery for the patient, the return home is frequently experienced as a time of deteriorating health, with further physical and emotional decline. Families described this phase as one of extreme vulnerability, compounded by the absence of a reliable safety net.

Families are now described as having to show optimism to counter the patient's exhaustion, poor mental health, and lack of motivation, a burden that leads to a conflicting sense of hopelessness for the caregiver (Howard et al., 2025b). Also, the continuous heavy load of responsibility and emotional labour that family carers shoulder leaves little time for them to process their experiences and trauma (Arlo et al., 2025). Danielis et al. (2024a) highlight the *existential navigation* that family members face; with time, their focus shifts from daily survival to reflecting on the philosophical implications of the illness and their new reality: finding purpose, acceptance, and new trajectories amid ongoing uncertainty.

Fragmented realities have been described by Major et al. (2019), for instance during discussions related to hospital discharge planning where patients often overestimate their own physical abilities and the caregiving capability of their family. Major and colleagues also described fragmented realities related to discharge where patients often put on a facade or perform, such as pretending to be stronger than they are, to prove they are ready to go home, leading to a dangerous misalignment between caregiver expectations and patient abilities. Also, the notion of fragmented realities applies to current post-ICU support; existing models of post-ICU support

remain fragmented and system centred, rather than person-centred (Dimopoulos et al., 2024; Stewart et al., 2025).

2.5 Overall Synthesis: The Systemic Gap

The identification of only a limited number of relevant papers is, in itself, a significant finding that suggests a notable gap in the evidence base both locally in Aotearoa New Zealand and internationally, justifying this inquiry. Moreover, when the patient literature (Section 2.2 ‘Patients’ Experiences Following Prolonged Critical Illness’) is synthesised with the family literature (Section 2.3 ‘Families’ Experiences Following Prolonged Critical Illness’), a significant *storied gap* is exposed. The institutional medical narrative defines hospital discharge as a success, yet for both the patient and the family unit, the reality of the first year is a *continuum of vulnerability*. This continuum of vulnerability is marked by persisting sequelae of PICS and PICS-F which are unrecognised, the burden of care experienced by both patient and family, and a lack of care and support for both patients and families once they leave the hospital. In Aotearoa New Zealand, there is a catastrophic lack of post-ICU infrastructure, leaving survivors and families to figure out recovery and because of this, they feel alone, let down, and abandoned by the health system. This synthesis justifies the current research puzzle: if the system spends millions on acute survival but fails to provide comprehensive care after discharge, it creates a *wicked problem* that requires the deep, longitudinal exploration offered by this inquiry.

2.6 Chapter Summary

This chapter has presented the background and literature review and grounded the inquiry in the realities of prolonged critical illness survival. By weaving together patient-survivorship literature and research on family experiences, it has demonstrated that recovery is a temporal process that fundamentally alters the

social place of the family unit. Critically, it has shown that patients' and families' experiences following a prolonged critical illness have not been extensively studied. Furthermore, it has shown that there is limited research into outcomes and experiences of this cohort within Aotearoa New Zealand, highlighting the need for further research and the gap this thesis helps to fill.

Chapter 3: Methodology

3.1 Introduction

This chapter introduces the methodology of this study. It explains the history of narrative inquiry, why narrative inquiry has been chosen for this research project, and why it suits exploring the research question and aim. I present my positionality as a researcher in this inquiry and discuss the philosophical underpinnings of the study, including the research paradigm and ontological and epistemological assumptions. Next, I set out the theoretical framework informing this study: the three-dimensional narrative inquiry space framework developed by Clandinin and Connelly (2000), including an overview of its development and explanation of key concepts. Additionally, I address how I applied the framework to this study, that is, how ICU survivors' and their families' narratives of experience were explored through the three dimensions of experience: temporality, sociality, and place. Lastly, I set out a justification for this theoretical framework, which informs how I managed, structured, and analysed the data.

3.2 Narrative Inquiry: History and Choice

3.2.1 History

Clandinin and Connelly's (2000) narrative inquiry has been used as a research methodology since the late 1980s (Clandinin et al., 2007; Connelly & Clandinin, 1990). It emerged from the belief that humans are inherently storytelling beings (Bruner, 2002). In Bruner's (1987) narrative theory, life is viewed as a story. That is, people interpret and understand their lives through stories; people actively construct narratives to process, make sense of, and organise their experiences, events, memories, and the world around them. They attribute meaning to those experiences and effectively story their lives into a meaningful and coherent narrative.

Bruner (1987) emphasises that these narratives shape people's identities and understanding of reality. Polkinghorne (1995) also speaks of narrative ways of knowing, highlighting the importance of stories as powerful and rich sources of information, arguing that stories are a crucial tool for understanding human experience because stories are how people construct meaning and make sense of their lives.

While narrative inquiry is a relatively new method of qualitative research, having only emerged in the late 20th century, the use of narratives in social science research has a "long intellectual history" (Connelly & Clandinin, 1990, p. 2). The early 1900s saw both sociologists from the Chicago School gather life histories to study social change and anthropologists collect narratives as a way of preserving cultural data (Kim, 2016; Raine, 2013).

Greater interest in narrative research methods began in the 1960s (Pinnegar & Daynes, 2007) and gained momentum in the 70s and 80s (Czarniawska, 2004). It signalled the beginnings of what came to be known as the *narrative turn*, where a shift occurred in research and social sciences (Czarniawska, 2004) that challenged the dominant positivistic, scientific approaches that valued "abstract experimentation and generality toward a narrative paradigm which gives primacy to human experience and subjectivity to studying" (Raine, 2013, p. 64). The narrative turn focused on lived experiences, exploring personal accounts of research topics to gain in-depth insights into human experiences and social phenomena. The narrative turn also validated the value of individual stories as rich sources of knowledge (Czarniawska, 2004). Narrative and stories were thus established as legitimate sources of knowledge challenging the traditional dominance of quantitative methods.

Kim (2016) notes that the beginning of the narrative turn was signalled with two issues of the journal *Critical Inquiry* published in 1980 and 1981, which later became a book titled *On Narrative* (Mitchell, 1981). It compiled essays examining the nature and value of narrative written by prominent thinkers from disciplines including literary theory, philosophy, anthropology, psychology, theology, and art history that show how the study of narrative has become a valuable source of insight for research in various fields of social, human, and natural sciences (Kim, 2016). Thomas Mitchell, editor of *Critical Inquiry*, proclaimed,

> The study of narrative is no longer the province of literary specialists or folklorists borrowing their terms from psychology and linguistics but has now become a positive source of insight for all the branches of human and natural science. (Mitchell, 1981, p. ix)

In the late 1980s and early 1990s, Jean Clandinin and Michael Connelly pioneered narrative inquiry as a research methodology in the seminal text *Stories of Experience and Narrative Inquiry* (Connelly & Clandinin, 1990). Published in *Educational Researcher* (Clandinin et al., 2007), the article introduced the term *narrative inquiry* and set out their approach, including how it drew on Dewey's (1938/1963) idea that "life is education" (Clandinin et al., 2007, p. 22). Clandinin and Connelly are interested in "lived experience – that is, in lives and how they are lived" (Clandinin & Connelly, 2000, p. xxii).

Clandinin and Connelly were teachers who at the time, were working as educational researchers. They applied the approach in the field of education to study what and how teachers come to know through narrative analysis of the personal stories and experiences of teachers (Connelly & Clandinin, 1990). Their innovative research programme marked the inception of narrative inquiry as a storytelling

methodology through which inquirers study narratives and stories of experience to understand a phenomenon of interest (Kim, 2016).

Beyond its influence and contribution in education research, narrative inquiry has been used in disciplines including anthropology, linguistics, philosophy, theology, women's studies, law, medicine, geography, psychotherapy (Craig, 2007), and nursing (Foxall et al., 2021; Haydon et al., 2018; Haydon & van der Riet, 2016; Puplampu et al., 2020; Wang & Geale, 2015).

According to Connelly and Clandinin (1990), "(t)he study of narrative […] is the study of the ways humans experience the world" (p. 2). Narrative inquiry focuses on understanding human experience, or more precisely, thinking narratively about human experience (Connelly & Clandinin, 1990). Clandinin and Connelly (2000) argue that a narrative is "the ideal way to organise, give meaning to, understand and represent experience" (p. 18). Their approach focuses on exploring and understanding lived experience by interpreting and analysing the stories people tell about their lives.

3.2.2 Choice

The Clandinin and Connelly (2000) narrative inquiry was chosen for several reasons. Firstly, during the early design process, I saw that it fitted well with my research puzzle. Engaging in narrative inquiry by coming alongside former long-stay ICU patients and their families and following their journeys closely over the first year following discharge from hospital, offered the potential to develop new knowledge about the complex and evolving nature of navigating post critical illness life for these groups. I had learnt from an early review of the literature that many survivors of critical illness experience long-lasting physical, cognitive, and psychological

impairments. Narrative inquiry with its attention to temporality and change over time thus aligns with this longitudinal nature of recovery.

Secondly, narrative inquiry was appropriate because its theoretical underpinning, specifically the three-dimensional space framework that specifies a multifaceted exploration of experience, allowed for a holistic understanding of the participants' experiences. The framework also allowed the study to go beyond mere individual outcomes to examining the systemic and structural factors that shaped the participants' experiences, recovery, and outcomes. This would increase the potential for the study to impact both healthcare practice and policy.

Thirdly, the ethical and relational commitments of narrative inquiry align with my nursing philosophy. I was drawn to how narrative inquiry is a way of thinking about people's experiences and of thinking about how researchers engage in research. Narrative inquiry considers the researcher as not an objective inquirer, but rather, a relational inquirer (Clandinin & Caine, 2013; Connelly & Clandinin, 1990). As Clandinin (2013) explains, in a narrative inquiry, "We [the researcher] do not stand metaphorically outside the inquiry but are part of the phenomenon under study" (p. 24). Being acknowledged and valued as a visible participant and not an observer was important to me. I hoped to have many conversations with participants and find out how they experienced their critical illness and the time afterwards. I anticipated these conversations to be personal and that discussing topics like closeness to death and dying, health/illness, and trauma could potentially be emotional work for the participants. Hence, I felt the need to establish rapport and have a trusting professional relationship with each person, which the narrative inquiry methodology accepts (Clandinin & Connelly, 2000; Clandinin & Caine, 2013; Connelly & Clandinin, 1990).

Furthermore, in my initial exploration of the methodology, I discovered that narrative inquirers find ways to be helpful to participants, often needing to "live out professional responsibilities and express personal practical knowledge" (Clandinin, 2013, p. 51). As a Registered Nurse (RN) with a duty of care, this was ethically significant to me; I recognised the possibility that during the interviews I would observe health issues in participants that required medical attention. In such cases, I would need to direct them to appropriate professional support. Also, given my role as an ICU nurse and the expertise participants might perceive I possess, I anticipated they could approach me with unresolved questions about their ICU experiences, treatments, recovery, and potential complications. It was crucial for me to share my knowledge as a RN and subject matter expert in these discussions, which the narrative inquiry methodology supports.

Finally, narrative inquiry was chosen because narrative inquiry researchers are attentive to the audience when writing final research texts, aiming to create texts that allow the reader to engage (Clandinin, 2013). At the outset, I thought about who this research was intended for and the impact I wanted it to have. I did this by reflecting on the practical and social justifications (Clandinin & Caine, 2013). The audience that I anticipate reading these texts is potentially wide, including nurses and other health professionals involved in the clinical care of long-stay ICU patients and families across the continuum of care, as well as policy and decision makers. It is these points that collectively made the case for adopting narrative inquiry most appropriate and compelling.

Alternative qualitative methodologies were considered but ultimately not selected, for instance, grounded theory, phenomenology, ethnography, and interpretive description. While these other approaches may identify common

experiences, perspectives, and themes across participants, narrative inquiry was determined to be the best fit for this research due to its multi-dimensional exploration of experience at both a personal and social level. The longitudinal perspective that narrative inquiry allows for was considered to best capture the whole trajectory of critical illness and recovery and in doing so, provide understanding of the entire care journey for patients and their family across the full trajectory and multiple healthcare settings. This would identify important areas for practice development across the continuum of hospital and community care, something this research sought to do. It was determined that such valuable insights may be lost if experiences were examined at a single point in time, through a single interview. This is particularly relevant for long-stay ICU survivors, because their recovery trajectories are often prolonged, uncertain, and identity-altering.

Another consideration for this study was the appropriateness and applicability of Indigenous methodological approaches given the anticipated inclusion of Māori participants. I addressed this through an ongoing practice of reflexivity, with particular attention to my own cultural background and position. Integral to this reflexive process was engaging with literature on Indigenous methodologies (Geia et al., 2013; Smith, 1999; Ware et al., 2018). I concluded that as a New Zealand European researcher, applying a Māori methodology without the appropriate cultural positioning and knowledge would be inappropriate.

Engaging with literature on Indigenous methodologies, it was apparent that the underpinning principles of narrative inquiry including, giving voice to research participants, valuing storytelling, prioritising relationship, and a commitment to relational ethics all resonate with Indigenous methodologies, for example Kaupapa Kōrero, (Ware et al., 2018) and yarning (Geia et al., 2013) (Smith, 1999). These

shared principles provided a foundation for conducting this narrative inquiry in a way that was respectful and accommodating of Māori participants. Further discussion on cultural safety, its relevance to the research, and specific examples of how culturally safe practices are embedded in the research is presented in Section 4.3.6.

3.3 Positionality of the Researcher

Positionality describes a researcher's worldview and where they stand in relation to the research (Holmes, 2020). In any research, the researcher's position needs to be considered in terms of how it may influence the research process through biases, prejudices, and beliefs (Mills & Birks, 2014). Kennedy et al. (2024) describe how examining positionality is a personal process that involves identifying and exploring one's "social identities, personal histories and philosophical assumptions" (p. 1) followed by consideration of the potential impact of these aspects on the research process and outcomes.

I now present my positionality statement. I have chosen to undertake qualitative research precisely because, being an ICU nurse, I am drawn to understanding patients' and families' lived experiences of health, illness, and care and the meanings they ascribe to those experiences. My position as an ICU nurse shapes what I see as a qualitative researcher; in the case of this study, my clinical experience attunes me to the lived, relational, and often marginalised aspects of ICU survivorship. Also, my clinical background has taught me that personal, social, and political contexts shape how people experience healthcare and how they fare in terms of health outcomes. This leads me to view research questions through the lens of care, context, and relationship and I see *truth* regarding an experience or reality as being subjective: whatever the person says it is. As a qualitative researcher, I am therefore drawn to approaches that foreground participants' own words and

interpretations, such as in-depth interviews and narrative analysis, alongside interpretivist and critical-constructivist frameworks that recognise reality as co-constructed through language, relationships, and social power. What this means for this study is that I seek to understand the true human journey of ICU survivorship and then take this to help me understand as a RN what I can do to better help survivors as well as their family on both a practical level and social justice level.

As an ICU nurse, I also experience the emotional and moral weight of the study participants' stories in ways that someone outside the profession may not; I have stood with families when they are told "he is still alive, but he is not going to be how he was," and I have watched patients who leave the ICU only to move along a care system that has no clear pathway or recovery infrastructure for them. This has made me attuned to moments in clinical practice and the literature where the humanity of ICU survivorship is not acknowledged; when success is defined as discharged alive, when outcomes are reduced to mortality statistics or functional scores. This is because I know how much is lost when context and meaning are stripped away. In other words, my position as an ICU nurse does not only give me privileged observational access; it also shapes what I see and what I care about finding out as a researcher.

This brings me to the tension at the heart of my positionality: I am both an Insider and an Outsider in this research (Goundar, 2025). As an ICU nurse, I hold an insider perspective on prolonged critical illness and ICU culture. I understand the routines, the medical jargon, the power dynamics, and the expectations that shape how patients and families are treated. This insider knowledge has helped me frame the research problem, particularly my concern that, in Aotearoa New Zealand, there is little specialised recovery infrastructure for long-stay ICU patients and their

families. Yet, that very same insider position means I bring assumptions – about what "good" ICU and post-ICU care looks like, about what patients and families need, and about what counts as a meaningful outcome – that may not align with the participants' own views and experiences.

At the same time, when I sit opposite a participant as an interviewer, I am an outsider to their unique lived experience. I have not experienced their experience. Their stories are their own, and no amount of clinical experience can fully bridge that gap. Goundar (2025) describes this dual position as both Insider and Outsider: I am part of the culture that produces the phenomena I study, yet I must remain open to perspectives that challenge what I think I already know. This insider/outsider tension requires ongoing reflection and reflexivity, noticing where my assumptions and expectations may shape how I listen, interpret, and frame findings. I must constantly ask myself if I am interpreting study participants' narrated experiences through the lens of my nursing expertise and assumptions. I must also ask myself if the findings reflect what the participants said, as opposed to what I expected to find based on my clinical knowledge. Furthermore, I must position my clinical experience as a resource rather than a substitute for participants' truths, using it to deepen, rather than diminish, the stories of ICU survivors and their families.

3.4 Research Paradigm

Qualitative research is a type of inquiry that aims to explore and understand social phenomena (Busetto et al., 2020; Creswell, 1994). This approach assumes that truth is a relative concept co-constructed by the researcher and participant (Curtis & Keeler, 2022). Selecting a qualitative methodology made sense to me because the approach resonated with the research question, aim, and objectives. I intended to investigate and gain rich, in-depth insight into the human experience of

ICU survivorship by exploring participants' thoughts, feelings and experiences, which would be possible through a qualitative approach (Tenny et al., 2024). Furthermore, qualitative research recognises the relationship between the researcher and what is being studied, accepting the researcher's position and perspective as being necessary and important to the research process (Clandinin & Caine, 2013).

Qualitative research is embedded in the interpretivist and constructivist paradigms. Schwandt (1994) writes that advocates of these paradigms ultimately seek to understand the complexity of "lived experience from the point of view of those who live it" (p. 221). Schwandt's words highlight the importance of understanding experiences through the subjective perspective of the individuals who have them, including the meanings and interpretations that individuals attach to their experiences. Narrative inquiry as methodology, has its roots in both the interpretivist research paradigm and constructivist research paradigm. Definitions and the technicalities of these will now be outlined.

Interpretivist and constructivist paradigms do not have fixed rules, for instance, a laboratory protocol, because they emphasise understanding human experiences, meanings, and social contexts rather than testing phenomena under controlled conditions. Instead, they follow shared assumptions about how knowledge is created and understood. The interpretivist paradigm assumes that truth and knowledge is subjective, multiple, and socially constructed (Ryan, 2018). This means that concerning the questions 'what is reality?' (Creswell, 2007, p. 16) or 'what is there that can be known?' (Lincoln & Guba, 1985, p. 200) the interpretivist believes reality is socially constructed and, that there are multiple realities. Interpretivism rejects the notion that there is a single, objective truth, instead arguing that multiple and varied perspectives and interpretations of what may be real are possible (Ryan,

2018). Research that is rooted in interpretivism focuses on gaining understanding of the subjective meanings and interpretations that individuals assign to their experiences. Subjectivism asserts that reality is “our own perception, experiences and feelings” (Ryan, 2018, p. 14). Interpretivist research lends itself to qualitative data collection methods to gather thick, rich data to generate an in-depth understanding of the phenomenon under investigation.

The ontological perspective underpinning interpretivism is relativism (Ryan, 2018). Relativism claims that truth, knowledge, and ethical standards such as right and wrong are not fixed and universal but rather, are relative to, and products of a specific context (social, historical, cultural), perspective, or framework of assessment (Siegel, 2004). From a relativist perspective, there is no absolute or objective truth; what is true or right can vary depending on the context in which it is situated (Ryan, 2018). Narrative inquiry with its attention to context, time, and place is therefore well suited to this relativist ontological position.

Selecting a research methodology such as narrative inquiry that is grounded in the interpretivist paradigm resonated with me as a nurse because as Ryan (2018) writes, the principles and values of interpretivism align with many of nursing’s approaches, principles, and values such as person-centred care and holistic care.

The constructivist paradigm ontologically emphasises that reality is subjective, multiple, and actively constructed by individuals through social interaction, experiences, and interpretation (Lincoln & Guba, 1985; Schwandt, 1994). It rejects the idea that one ultimate truth exists (Schwandt, 1994). It is often used to explore in-depth, subjective experiences and meanings as well as how people make sense of their lives and social contexts. Epistemologically, constructivism emphasises that knowledge generation is a collaborative process where researchers and study

participants co-construct understanding (Schwandt, 1994). Constructivism dictates using data collection methods such as interviews, focus groups, and participant observation (Tanlaka & Aryal, 2025).

3.5 Research Philosophy

In the article *Putting Philosophy into PhD*, Baldwin (2014) asserts that "philosophy is undeniably a central pillar underpinning research design" (p. 3) and argues that philosophy needs to be at the forefront of the research for a Doctor of Philosophy, emphasising that it is a Doctor of Philosophy after all. Kim (2016) also speaks of the same necessity of doctoral students "doing" (p. 28) philosophy, writing that it is essential students interrogate themselves, critically examine their thinking, and challenge taken for granted ideas and what they have known as *truth*. Kim argues that when students do philosophy in this way, their discussions become deeper, more engaging, and more complex. Kim draws on Foucault's words (1984):

> The displacement and transformation of frameworks of thinking, the changing of received values and all the work that has been done to think otherwise, to do something else, to become other than what one is – that too, is philosophy… it is a way of interrogating ourselves. (p. 329)

Research philosophy refers to the researcher's beliefs and assumptions regarding reality, knowledge, and values, that inform a researcher's worldview and guide a researcher's approach to understanding and generating knowledge (Baldwin, 2014; Mills & Birks, 2014). Philosophy forms the foundation of a study and influences all aspects of the research process, underpinning research design and methodological choices. It also guides data collection and analysis methods as well as interpretation of findings (Ryan, 2018). Baldwin (2014) states that engaging in personal philosophical exploration is essential in "the building of a doctoral identity"

(p. 1) and is fundamental to one's doctoral journey with the researcher selecting research methods that are congruent with their philosophical viewpoint (Ryan, 2018).

Mills and Birks (2014) describe philosophy as the lens through which a person views the world, and define it as, "a view of the world encompassing the questions and mechanisms for finding answers that inform that view" (p. 18). As a lens through which a person views the world, philosophical questioning allows researchers to identify knowledge gaps and thus the research problem to be addressed as well as selection of research methods with which the gaps are filled (Mills & Birks, 2014).

Philosophy includes both ontological and epistemological elements (Baldwin, 2014). According to Crotty (1988) "ontology is the study of being" (p.10). It refers to an individual's existing assumptions about existence and being and how that individual views the world; in essence, what is real (Denzin & Lincoln, 2005). Epistemology on the other hand refers to how an individual believes that knowledge is generated including what is considered valid and acceptable knowledge (Crotty, 1988). Put simply, ontology and epistemology can be understood as what the researcher knows to be true and how they come to know it (Baldwin, 2015; Denzin & Lincoln, 2005). The philosophical underpinnings for this research are pragmatism (ontology), social constructivism, and interpretivism (epistemology).

Clandinin and Connelly (2000) elucidate that what differentiates narrative inquiry from other narrative methodologies is its philosophical underpinnings, specifically the way in which experience is viewed. A narrative view of experience is central; experience is understood as being narratively constructed reflecting the underlying assumption that humans organise their experiences, memories, life situations, and events in narrative form. Czarniawska (2004) also describes this process of how humans use narrative to create coherent stories to understand life,

themselves, and others, “in order to understand their own lives people put them into narrative form – and they do the same when they try to understand the lives of others” (p. 7). Consequently, narrative inquiry’s ontological position is that the nature of reality is constructed and storied (Clandinin & Connelly, 2000). Story is viewed as a portal through which a person enters into a world, where he or she interprets and makes personal meaning from their experiences (Clandinin, 2013; Connelly & Clandinin, 2006). Furthermore, narrative inquiry’s ontological belief supports the view that multiple realities exist because people construct meaning in different ways (Crotty, 1998). To make universal claims about the nature of personal experience is therefore impossible because such experiences differ in historical, cultural, and practical contexts (Crossley, 2007).

Clandinin and Connelly (2000) also explain that narrative inquiry has a pragmatic and relational ontology and this is due to the methodology’s Deweyan view of experience. Dewey (1938/1963) claimed that there are two principles (or criteria) fundamental to experience: the principles of interaction and continuity. Interaction refers to the notion that human experience is both personal and social. Drawing on this, Clandinin & Connelly (2000) wrote, “People are individuals and need to be understood as such, but they cannot be understood only as individuals. They are always in relation, always in a social context” (p. 2). Clandinin and Rosiek (2007) expanded on this, writing that while a narrative inquiry begins by inquiring into an individual’s experience, it is also:

> an exploration of the social, cultural and institutional narratives within which individual’s experiences are constituted, shaped, expressed and enacted – but in a way that begins and ends that inquiry in the storied

> lives of the people involved. Narrative inquirers study and individual's experience in the world. (p. 42)

This is the premise for narrative inquiry's relational ontology (Clandinin & Connelly, 2000).

Continuity refers to the notion that experience is a continuous process (Dewey, 1938/1963). Dewey wrote that "Every experience lives on in further experiences" (p. 27). What he means by this is that every experience builds up from previous experiences and modifies in some way the quality of the experiences that come after (Kim, 2016). Drawing on this, Clandinin and Connelly (2000) wrote:

> Experiences grow out of other experiences, and experiences lead to further experiences. Wherever one positions oneself in that continuum – the imagined now, some imagined past, or some imagined future – each point has a past experiential base and leads to an experiential future. (p. 2)

This is the premise for narrative inquiry's pragmatic ontology. This Deweyan view, which emphasises the interconnectedness of continuity, interaction, and situation as understanding key aspects of human experience, is central to Clandinin and Connelly's narrative inquiry; it is these three elements of experience (continuity, interaction, situation) that informed Clandinin and Connelly's conceptualisation of a metaphorical three-dimensional inquiry space (Clandinin, 2006). (The three-dimensional inquiry space is covered in detail in Section 3.7).

Narrative inquiry's epistemology rooted in interpretivism and social constructivism, views knowledge as socially constructed through relational interactions and experiences, rather than objectively discovered. It emphasises

understanding lived experiences and the meaning people make of them within specific contexts (Clandinin, 2013; Clandinin & Connelly, 2000). Narrative inquiry is transactional; therefore, a transactional view of experience is central epistemologically (Clandinin & Rosiek, 2007). Knowledge is created through a collaborative process, a co-construction between researcher and participant (Connelly & Clandinin, 1990). Knowledge is viewed as embedded in lived and told stories and (Clandinin & Connelly, 2000; Connelly & Clandinin, 1990) embodied in lived or living stories (Downey & Clandinin, 2010).

Narrative inquiry then can be understood as the study of experience as story (Clandinin & Connelly, 2000; Connelly & Clandinin, 1990). Connelly and Clandinin (1990) believe that “Humans are storytelling organisms who, individually and collectively, lead storied lives” (p. 2). Grounded in philosophical traditions that value the importance of stories and the construction of meaning through narrative, the approach recognises that stories are fundamental to how people understand the world and make meaning of their experiences (Caine et al., 2013; Clandinin & Connelly, 2000). As Clandinin (2006) states, “human beings both live and tell stories about their living. These lived and told stories and talk about these stories are ways we create meaning in our lives” (p. 44).

Understood this way, stories are viewed as a rich source of knowledge. Connelly and Clandinin (1990) write that it is equally correct to say, "inquiry into narrative" as it is "narrative inquiry" (p. 2), meaning that narrative is both phenomenon and method. They point out that ‘narrative’ names the structured quality of experience to be studied, and it names the patterns of inquiry for its study. Connelly and Clandinin (2006) define their approach to narrative inquiry accordingly:

> People shape their daily lives by stories of who they and others are and as they interpret their past in terms of these stories. Story, in the current idiom, is a portal through which a person enters the world and by which their experience of the world is interpreted and made personally meaningful. Narrative inquiry, the study of experience as story, then, is first and foremost a way of thinking about experience. Narrative inquiry as a methodology entails a view of the phenomenon. To use narrative inquiry methodology is to adopt a particular view of experience as phenomenon under study. (p. 477)

Narrative inquirers, therefore, engage with storytelling, specifically the stories lived and told by study participants, to explore and understand peoples' individual experiences across time, places, and situations (Clandinin, 2007).

A key term in narrative inquiry is *relational*. The concept of relationship is applied in several ways. First, narrative inquiry is characterised by "people in relation studying people in relation" (Clandinin, 2013, p. 23). This refers to the relationship between researcher and participants. Second, narrative inquiry attends to the relationships between the three dimensions, for instance, the research participant and his/her world (sociality); between past, present, and future (temporality); between person and place; between events and feelings; and the physical world and people (Clandinin, 2013). (These terms are covered in detail in Section 3.7). Via a process of interaction, participants in a narrative inquiry provide the researcher with their life experiences through rich stories, from which an understanding of patterns within and across individuals can then be found.

3.6 Examining the 'Expert versus Learner' Tension

In undertaking this doctoral research, the *expert-learner* tension arises from the dual pull between my clinical identity as an expert ICU RN and my methodological role as a curious, not-knowing novice qualitative researcher. In other words, I am an *expert* in ICU practice, but a deliberate *learner* regarding patients' and families' lived experiences – their unique meanings, sense-making, and interpretations of those realities. While my clinical background allows me to "world travel" (Lugones, 1987, p. 3) into the ICU bedspace with participants giving me a deep contextual understanding, – I understand the environment, technology, routines, illness trajectories – and to *get ICU*, which will help to gain the participants' trust, it also poses several risks. Such risks include, letting my expertise close-down rather than open-up what counts as knowledge in the study; and, imposing a biomedical lens on the data, that is patients' *narrative lived truth*.

To reduce these risks, throughout this study, I needed to ensure that I handled my ICU expertise reflexively to ensure that the voices of the study participants – what they actually said – shaped the findings, rather than my prior clinical knowledge and assumptions. I did this by adopting several strategies to *de-centre* my nursing expertise and privilege the study participants' experiential truths as the primary data. Central to this was the systematic use of a reflexive journal throughout data collection and analysis.

For instance, I prioritised participants' *hallucinatory truths* over my clinical framing of delirium as a pathophysiological state. To achieve this, I used a Double-Entry Reflexive Log that contrasted my clinical observations (Expert) with the *narrative lived truths* (Learner) from participants' accounts, plus included a reflexive

action column. An example from my journal, Appendix D, illustrates this process, titled: The Clinical Observation (Expert) and The Narrative “Lived Truth” (Learner).

Returning to these entries during analysis allowed me to see patterns in when and how my clinical lens was activated and to consciously set it aside while working closely with the transcripts. In writing up the findings, I continued to prioritise participants’ language and narrative structure before offering any secondary, clinically informed commentary. Quotes were selected and presented to preserve the sense of the participants’ lived realities. In this study where I am a researcher-insider, by making the expert–learner tension explicit, and by documenting how reflexive journaling was used to de-centre my professional expertise, I reduced the risk of *finding what I expected to find* based on prior clinical knowledge.

3.7 Theoretical Framework: The Three-Dimensional Narrative Inquiry Space

Patients’ and their families’ narratives were explored by myself as the researcher using Clandinin and Connelly’s (2000) three-dimensional narrative inquiry space framework – the theoretical framework underpinning this study. In this section I present the framework including an overview about its development, key concepts, and explain how it has been used in this study to explore participant experience. Lastly, a justification for use of this framework in the research project is provided.

The narrative inquiry three-dimensional space framework is a conceptual framework developed by Jean Clandinin and Michael Connelly in the late 1980s and first described in their work in 1990 (Clandinin & Connelly, 2000; Connelly & Clandinin, 1990). They used the framework to explore the educational experiences of teachers (Connelly & Clandinin, 1990).

Teacher and curriculum theorist Joseph Schwab’s term *commonplaces* is key to narrative inquiry and the three-dimensional space framework. Schwab, in his

writing on curriculum, developed four commonplaces – teacher, learner, subject matter and milieu – to deal with the complexity of curriculum. He claimed that an adequate curriculum argument needed to address all four of these elements (Clandinin et al., 2007). Clandinin and Connelly adopted the term to create a metaphor of a three-dimensional place, comprising three commonplaces of "temporality, sociality and place – which specify dimensions of an inquiry space" (Connelly & Clandinin, 2006, p. 479) and serve as a conceptual framework for analysing and interpreting narratives, providing a structured way to explore research participants' stories (Clandinin & Connelly, 2000). According to Connelly and Clandinin (2006), the three commonplaces are interconnected and must be explored simultaneously when undertaking a narrative inquiry to understand human experiences through stories. The commonplaces are crucial elements in narrative inquiry and exploring experience through these is partly what differentiates narrative inquiry from other narrative research methods (Clandinin & Huber, 2010).

Attending to these commonplaces is, therefore, imperative throughout the inquiry; it is a defining feature of the narrative inquiry methodology (Clandinin & Connelly, 2000). Additionally, thinking about participants' stories and narrative accounts in terms of the three commonplaces provides a structure to the analysis, helping the researcher to organise what can be a huge amount of data. Clandinin et al. (2007) note that commonplaces are an important scaffold for analysis and interpretation of data.

Applying the three-dimensional space framework involves viewing experience through four specific directions of inquiry – inward, outward, backward, and forward – which facilitates a multi-faceted exploration of the commonplaces of temporality, sociality, and place, detailed in the following sections (Clandinin & Connelly, 2000).

The framework is outlined in Table 2. Its application during the analysis phase of the research is expanded on in Chapter 4: Research Methods, section 4.6.1.

Table 2

The Three-Dimensional Narrative Inquiry Space Framework

Interaction		*Continuity*			
Personal	*Social*	*Past*	*Present*	*Future*	*Situation/Place*
Look inward to internal conditions, feelings, hopes, aesthetic reactions, moral dispositions	Look outward to existential conditions in the environment with other people and their intentions, purposes, assumptions, and points of view	Look backward to remembered experiences, feelings, and stories from earlier times	Look at current experiences, feelings, and stories relating to actions of an event	Look forward to implied and possible experiences and plot lines	Look at context, time, and place situation in a physical landscape or setting with topological and spatial boundaries with characters' intentions, purposes and different points of view

Note. From Wang and Gaele, 2015, p. 197.

3.7.1 The Temporality Commonplace

Temporality is one of the three commonplaces central to narrative inquiry (Clandinin & Connelly, 2000). Narrative inquiry assumes that there is a temporal flow to experience and its meaning: experiences grow out of other experiences, and these experiences lead to further experiences (Connelly & Clandinin, 2006). When analysing a story, the narrative inquiry researcher holds the view that "events under study are in temporal transition" (Clandinin, 2006, p. 479), a concept that Clandinin and Connelly (2000) describe as being "in the midst" (p. 144). Narrative inquirers

understand that they enter into the midst of ongoing experiences in the participants' lives, lives in motion. The temporality commonplace emphasises the ongoing nature of life and how experiences change and evolve over time, therefore, "in narrative inquiry, it is important to always try to understand people, places, and events as in process, as always in transition" (Clandinin et al., 2007, p. 23).

Narrative inquirers attend to the temporal reality of experience by focusing on the temporal aspects of the story including the past, present, and future and, how storied experiences unfold over time. This means that the researcher considers experiences and stories as situated in the past, present, and future. These can be thought of as backward, current, and forward-facing stories respectively, stories that the researcher constantly moves between. As such, both storyteller and researcher can be positioned in different places on a continuum – whether it is an imagined past, present, or future (Clandinin & Connelly, 2000).

The notion that experience is continuous and a person's present and future experiences come out of their past experiences helped me to see critical illness as an experience that was ongoing after the ICU admission, one marked with uncertainty and struggle, and because of this, the patient was always positioned somewhere along a continuum of vulnerability. This unfolding of experiences looked different depending on where the patient was at in their journey. Participants' stories of being critically ill, an event that was in the past, continued to shape their present situation and influence their futures. This led me to see that for the long-stay patient and their family, the experience of being critically ill, and the ICU experience does not end at ICU discharge; the experience is ongoing. Because none of the participants had experienced anything like this before, they had no previous

knowledge or experience to draw on to help them with adjusting to the challenges they faced post critical illness.

3.7.2 Application of Temporality to the Inquiry

In this study, the dimension of temporality is operationalised through a longitudinal design that tracks the first year of recovery. Data analysis is structured in relation to *time*. This approach is essential for capturing the *change* over time as well as the *fragmented boundaries* often experienced by survivors of prolonged critical illness. Because critical illness often involves periods of sedation and delirium, participants' narratives are not always linear; they frequently involve *lost time* or blurring of real and delusional memories. By attending to the backwards-looking stories (the ICU experience) and forward-facing aspirations (the recovery journey), this framework allows the researcher to document how the *midst* of the illness continues to shape participants' evolving self-identity and everyday life over a year.

3.7.3 Temporal Ordering of Events

Clandinin and Connelly (2000) emphasise the importance of temporal ordering of events – the sequencing of events across a continuum of time – as a core feature of narrative construction. Their approach underscores the way in which stories unfold in time, and how this temporal ordering helps people organise and interpret events in their life.

The temporal ordering of events acts as a conceptual framework that helps narrative inquiry researchers organise and structure the data in a way that is meaningful and interpretable. When conducting narrative inquiry, researchers look at how participants structure their stories across time: what they emphasise from the past, how they describe their present, and how they envision the future. They argue that temporal aspects of narrative, such as recalling past experiences, considering

present situations, and imagining future possibilities, are crucial for understanding identity and continuity. Attending to temporal ordering within participants' stories can provide a deeper understanding of the person's lived experience of the phenomenon under investigation (Connelly & Clandinin, 2006).

All participants in this inquiry narrated their experiences following the timeline of the critical illness and recovery, beginning with participants' experiences of becoming critically unwell and being admitted to the ICU to one year post hospital discharge. Weaved within participants' stories are narratives of their life before the critical illness. These narratives of life before the event are important for several reasons. First, because they highlight how the critical illness has changed their lives, and second, because they contextualise the three-dimensions of narrative inquiry, highlighting how time, place, and sociality are intertwined in the participants' continued experience of surviving a critical illness. Ultimately, the findings tell the story of survivors of prolonged critical illness. These experiences were central to them making sense of their new reality and moving on with life after critical illness.

Additionally, temporal ordering in narrative inquiry highlights the role of change over time and this is something that this inquiry sought to capture; how participants experiences changed over the year following the critical illness. The way stories are sequenced reveals how individuals experience progress and setbacks. Therefore, in this inquiry attending to participants temporal ordering, allowed me to capture how participants experienced the change that the critical illness and its aftermath had caused to their lives. The changes that participants have experienced post critical illness became more meaningful when their stories of change unfolded in relation to the broader narrative of their life which this research captured.

During the interview process, all participants outlined their past, present, and future experiences related to the critical illness, and these narratives were situated within a broader narrative of their life. Specifically, participants travelled back in time and place to the time of becoming unwell and being admitted to hospital. They also travelled back in time and retold stories of their experiences being critically unwell and being cared for in the ICU. They described their present situation, how their lives had changed because of the critical illness, and outlined their futures.

3.7.4 The Sociality Commonplace

In Clandinin and Connelly's (2000) three-dimensional narrative inquiry space, the sociality commonplace encompasses both the personal and social aspects of the storied experience. They write, "People are individuals and need to be understood as such, but they cannot be understood only as individuals. They are always in relation, always in a social context" (p. 2).

For Clandinin and Connelly (2000), attending to sociality requires the researcher to explore and then describe the internal conditions and external conditions of participants under study. Looking inward, the researcher explores the personal conditions of the participant such as "the feelings, hopes, desires, aesthetic reactions, and moral dispositions" (Connelly & Clandinin, 2006, p. 480) that shape their ways of framing experience and then explore how those conditions may have been shaped by larger narratives (e.g. social, cultural, institutional) (Clandinin & Rosiek, 2007). Looking outward, the researcher attends to the social conditions under which participants' experiences are unfolding such as "the existential conditions, the environment, surrounding factors and forces, people and otherwise, that form each individual's context" (Clandinin et al., 2007, p. 23) and ultimately

analyses how experience is shaped by and embedded in particular contexts (Clandinin & Rosiek, 2007).

The sociality commonplace also includes paying attention to the researcher-participant relationship. Narrative inquiry is a collaborative mode of research and requires both researcher and participant to engage in a relationship (Clandinin & Connelly, 2000). The relationship is important; to quote Kanno (1997):

> Study participants have a way of knowing if researchers are truly interested in their stories. They adjust the extent of disclosure accordingly. Stories cannot be told when they are not heard. That is why story-telling is a collaborative endeavour between teller and listener. (p. 6)

The commitment on the part of the researcher creates a safe place where the participants' stories can unfold fully. My own role and close connection with participants was a relationship that was negotiated and considered throughout the research process.

3.7.5 Application of Sociality to the Inquiry

For sociality, I explored external factors that influenced the participants' experiences such as the context of care including the hospital (institutional) and the political landscape of the time and its impact on the healthcare system. Sociality provided the lens through which to examine the impact of the broader neoliberal healthcare environment. It allowed the study to move beyond individual clinical outcomes to examine how social and institutional narratives, such as the pressure for "efficiency" in the general ward, shape patients' and their families' personal interactions and recovery.

The sociality commonplace in this research also specifically addresses the notion of relationship, that is, the relationship participants have with themselves as well as their interactions with others, self-identity, and participants psychological and emotional recovery. I paid attention to the people participants spoke of such as healthcare professionals and family members and their experiences of interactions with these people. I attended to the thoughts, feelings, emotions, and desires that participants shared.

This dimension also addresses the relational ethics between the researcher and the participants. Given my background as an ICU nurse, the *inward* and *outward* directions of this inquiry allow for an exploration of the nurse-researcher dynamic and how this shared professional context influences the depth of storytelling.

3.7.6 The Place Commonplace

Place, the third commonplace in the three-dimensional narrative inquiry space framework, refers to the physical location of the experiences under study (Clandinin & Connelly, 2000). For Clandinin and Connelly, participants' stories, or life narratives, are situated in places that become the contextual landscape. Those places impact the experience and in turn impact the meaning individuals make of such experiences and their lives. Furthermore, "Place may change as the inquiry delves into temporality" (Connelly & Clandinin, 2006, p. 480) and a narrative inquirer needs to "think through the impact of each place on the experience" (Clandinin et al., 2007, p. 23). Connelly and Clandinin (2006) define place as "the specific, concrete, physical, and topological boundaries where the inquiry and events take place, recognising that all events occur somewhere" (p. 480).

Attending to place requires narrative inquirers to explore and examine the specificity of the location where storied events take place (Wei, 2023). Connelly and

Clandinin (2006) suggest that when analysing a story, the researcher considers place in terms of physical landscape, including, the storyteller's location, and the places, and spaces where storied events take place. The researcher needs to ask: what are these places and how are peoples' stories nested within these spaces?

Additionally, place includes attending to the place where the inquiry takes place. Clandinin and Connelly (2000) argue that this is an important consideration as the place where a story is told, can influence how it is told. For example, a story told by a former long-stay ICU patient in their own home may be different to one told in a hospital room. Home can offer greater comfort and a more personal environment whereas hospital settings can be stressful, overwhelming, and lack privacy.

3.7.7 Application of Place to the Inquiry

In this study, *place* is understood as more than a static backdrop; it is a series of topological boundaries that significantly alter the patients' and families' experience. The framework is applied to explore both experiences within, and the transition between, distinct landscapes: the ICU, which many families described as a *sanctuary* of high-intensity care; the general ward, which often presents a *shocking reality* due to reduced monitoring and nursing presence; and finally, the home environment, a place of comfort, but also a transition described as *terrifying* where both patients and families felt *alone and abandoned*. By attending to place, the inquiry examines how each of these physical spaces influences the meaning patient participants make of their recovery. This allows the researcher to ask how the specific *where* of the story, such as the transition from a hospital bed to the family lounge, impacts the *how* and *why* of the participant's narrative.

Ultimately, this three-dimensional framework serves as a portal through which the researcher and participant enter the story together (Connelly & Clandinin, 2006).

From my position as researcher, I realised that by attending simultaneously to time, relationship, and place, the research process acts as a form of *narrative repair*; it provides the structure necessary to re-stitch the severed selfhood of the patient participant, turning fragmented memories of critical illness into a coherent life narrative.

3.8 Chapter Summary

This chapter introduced Clandinin and Connelly's narrative inquiry. Narrative inquiry and the three-dimensional narrative inquiry space framework were chosen for this study as they allowed the researcher and participants to explore the phenomenon of interest in its context and across time: ICU survivorship from the perspective of patients and their family across the continuum of care, and the complex and evolving nature of these peoples' experiences over a given period of time. Narrative inquiry allowed the patients' and their family members' voices and their stories to be heard, which facilitated deeper insight and understanding of their experiences of ICU survivorship. This chapter also presented the background to narrative inquiry and the philosophical underpinnings that informed the research.

Chapter 4: Research Methods

4.1 Introduction

Chapter Three established the philosophical commitment to Deweyan continuity. This chapter details the longitudinal narrative design required to capture that continuity over a 12-month period. To operationalise the three-dimensional inquiry space, the data collection methods were designed to be sensitive to the shifting landscapes of place (from hospital to home) and the evolving sociality of the participant-researcher relationship across four distinct points in time (temporality). Following Dewey's principle that every experience lives on in further experiences, a longitudinal approach was essential. This chapter describes how the three month interview intervals allowed for the nesting of stories, ensuring the inquiry remained attentive to the unfolding nature of recovery rather than capturing a static snapshot. Building on the relational ontology established in the previous chapter, the ethical procedures described here move beyond institutional requirements to address the relational ethics of entering the participants' private lives as both a nurse and a researcher. The analysis process outlined in this chapter uses (a) 'Messy Mapping' not merely as a coding tool, but as a way to visualise the intersections of the three-dimensional commonplaces within each unique story, and (b) thematic analysis to gain deeper insight into the systemic failures within the healthcare system. Also discussed is rigour, trustworthiness, reflexivity, and data management.

4.2 Narrative Inquiry as Longitudinal Research Method

Data were collected at multiple time points as part of the longitudinal design including the initial interview for both patient and family participants that occurred about 6-12 weeks post-hospital discharge, and three additional interviews for each patient and family participant (occurring every three months) over a 12-month period.

This longitudinal approach, and the interview schedule were chosen to help me with the three-dimensional space as I explored how participants' social and place *changed over time.* Within the three-dimensional inquiry space, temporality functioned as the analytical axis. I tracked the transitions in sociality and place by anchoring the inquiry to distinct moments in the continuum of the participants' recovery.

4.2.1 Research Timeline

Each patient and family participant's first interview occurred about 6-12 weeks after the patient had been discharged home from hospital. This period was chosen to allow the patients time to settle into their home environment after an extended stay in hospital, thereby minimising the burden on them. Iwashyna's (2010) powerful description that survivors of critical illness discharge from hospital ravaged, unable to walk and think clearly, alongside the broader literature on PICS that reports symptoms of PICS are most prevalent during the first few months following hospital discharge (Alrø et al., 2026; Ayenew et al., 2025; Gerth et al., 2019; Zare-Kaseb et al., 2026), provided the justification for giving all of the participants 6-12 weeks to adjust to being at home before meeting with me.

The 12-month period of data collection was chosen to capture the evolving lived experiences of patients and families during the first year following prolonged critical illness and importantly, the change over time. Three-month intervals were chosen because this frequency was thought to capture the *rhythm* of prolonged critical illness recovery better than, say, a single interview at 12 months. I was able to interpret the patients' and families' journey as it unfolded across shifting contexts – from the ICU and the general ward to the home – while exploring how their past illness continued to shape their present and future. This enabled me to gain a deeper

understanding of their experiences including how, when, where, and why they struggled, and how they navigated the pathway after critical illness.

4.3 Conducting an Ethical Inquiry

Before commencing the inquiry, this study sought ethics approval from the New Zealand Health and Disability Ethics Committee (NZHDEC), and ethics was approved on 9 September 2022 (number 12583, Appendix A). NZHDEC guidelines were complied with as per ethical approval.

Being constantly attentive to ethical issues was central throughout the inquiry. The ethical issues concerning this research are centred on: relational ethics; vulnerability of participants; informed consent; confidentiality and anonymity; and harm or benefit to participants. These will now be explained.

4.3.1 Relational Ethical Considerations

Narrative inquirers have a commitment to working within ethical frameworks that reflect the relational responsibilities researchers have toward their study participants (Clandinin, 2013). In the following quote, Clandinin and Connelly (2000) highlight the changing nature of ethical matters as a narrative inquiry progresses and the need for the researcher to attend to these matters throughout the entirety of the inquiry, which this study was committed to:

> Ethical matters need to be narrated over the entire narrative inquiry process. They are not dealt with once and for all, as might seem to happen, when ethical review forms are filled out and university approval is sought for our inquiries. Ethical matters shift and change as we move through an inquiry. They are never far from the heart of our inquiries no matter where we are in the inquiry process. (p. 170)

Participants in a narrative inquiry must trust the researcher to safeguard their stories and to represent them with integrity, sensitivity, and fairness (Josselson, 2007). With this understanding, I ensured that trust was the foundation of my relationship with each participant. I drew on culturally safe, theoretical frameworks as appropriate to establish a positive, trusting professional relationship with the study participants. I utilised excellent verbal and non-verbal communication skills to ensure participants felt safe and listened to. Also, I ensured that I treated participants stories with high levels of respect, care, empathy, and sensitivity.

I also recognised the importance of being ethically aware of the impact I had and would continue to have in relationships with participants and furthermore, to ensuring the wellbeing of participants through carrying out this research in an ethical manner as described by the Research Ethics Guidelines (Health Research Council of New Zealand, 2021) and Te Ara Tika Guidelines for Māori Research Ethics: A framework for researchers and ethics committee members (Hudson et al., 2010).

Importantly, given the nature of the study, attention was paid to considering the vulnerability of both the participants and researcher. Research involving former ICU patients and family presents important ethical challenges, due predominantly to the severity of the patients' illness which can result in cognitive impairment impacting on the patient's ability to comprehend information and their decision-making capacity. Also, recovery after prolonged critical illness is often protracted and non-linear, where patients can be psychologically and emotionally vulnerable. This makes them a vulnerable group.

This vulnerability informed the process and timing regarding approaching eligible patients and their family about participating in the study. Prior to being approached about the study, I ensured that all patient participants were assessed for

capacity to participate in these conversations. This involved the Research Liaison Nurses (RLNs) speaking with the patient's primary ward nurse and ascertaining information about the patient's clinical state and cognitive functioning including whether the patient had been diagnosed with acute delirium. If it was considered inappropriate to speak to the patient due to illness, cognitive impairment, or delirium, the RLN would try again in a few days, ultimately engaging with the patient when they were well.

Additionally, it was anticipated that during the data collection period, patient participants may have ongoing health issues and require ongoing management from their health provider (General Practitioner (GP)). As a RN, I have a duty of care, and so a plan was put in place to manage this whereby if a patient was found to be experiencing concerning health problems, I would support them with contacting the GP. Furthermore, if the patient was found to be in distress with unmanageable symptoms, I would collaborate with them and/or their family member/carer to call an ambulance. The same process was to be followed for family participating in the study who exhibit distress or concerning health problems. No adverse events or safety issues to the participants occurred during the research process.

I was also cognisant of the power dynamic of a nurse interviewing a vulnerable patient in their home and considered how I would navigate this, particularly during home visits. To ensure that participants felt like partners in the inquiry rather than research subjects, I was committed to taking a person-centred and partnership-based approach. Specifically, the interview process was designed to support comfort (being in the participants own home and at a time of their choosing), trust, and shared dialogue. I told participants that I saw them as being experts in their own experiences and I was here to learn from them. Participants were

reminded they may pause or stop the interview at any time and decline to answer any questions without consequence. I aimed to create a respectful conversational environment in which participants felt seen, heard, valued, and able to speak freely, and on their own terms.

Maintaining my own personal safety in these environments was essential. A comprehensive plan was developed and is provided in Appendix J.

4.3.2 Informed Consent

In inviting participants to be part of the study, I ensured that they were given both verbal and written information about the study (Study Information Sheet Appendix E and F). This included the nature and purpose of the study, what it will involve, possible risks and benefits from participating, as well as stating that interviews will be audio recorded, and the participant may always have a support person present if that is their wish (note, with the exception of one patient's first interview, all participants chose to be interviewed on their own, declining the offer of a support person). Other details included that the participant is willing to take part in the study, and that participants could withdraw their consent at any time, and they could request withdrawal of their story at any time, that is prior to publication or any public presentation of the study.

Participants were offered time (several days or more if requested) to think about participating in the study and encouraged to talk about it with friends and family. None of the participants requested further time to think about their participation; all expressed that participating in the study was something they would like to do. At the commencement of the first interview, participants signed an informed consent form (Appendix G). Due to the long collection time of field text, I re-assessed consent orally (Appendix G) at the beginning of each participant's

subsequent interview, ensuring that they were still comfortable taking part in the research.

When undertaking research involving survivors of prolonged critical illness, there are important ethical considerations concerning the consent process that must be acknowledged. Survivors of long-stay ICU may have cognitive impairment and ongoing physical or mental health issues, and this makes them a vulnerable group. Assessing the patient's capacity to consent began prior to the informed consent conversation. Firstly, before meeting each person, I had spoken with them on the phone and from this conversation they appeared of sound mind. This is subjective, and so I also asked their family member about the patient's cognition and their view on the patient's capacity to consent. I also asked the family whether participating in this study was something they felt the patient was up to and whether they had any concerns. Then, on the day of each participant's first interview, I asked the patient how they were currently in regard to their physical and mental health and cognition. As a RN I determined that all were alert and orientated and able to converse normally. I did not detect any reg flags such as inability to process and retain information, think clearly or make decisions. Thus, from my position as a RN, I was able to use my clinical judgement to assess capacity to consent prior to gaining informed consent.

4.3.3 Confidentiality

To maintain confidentiality and preserve anonymity, participants' names and all other identifying information (e.g., names of family members; names of health professionals involved in their care; geographic location; and other unique aspects of their experience that could be used to identify them) were removed or anonymised from interview transcripts and narrative accounts by assigning a random letter.

I transcribed some of the interviews and a number were transcribed by a professional transcription company who signed a confidentiality agreement (Appendix H and I). Given the huge number of interviews – 40 in total – and long duration of each interview, I made the decision to outsource the transcription of some interviews. Practically, the huge volume of data and project timeline meant that if I had personally transcribed every interview, my time and cognitive capacity for careful narrative analysis and reflexive thinking would have been significantly reduced.

I recognise that this sits in some tension with narrative inquiry's emphasis on the researcher's direct involvement with participants words, pauses, and silences during transcription to capture nuances. Therefore, I engaged in several deliberate practices to ensure deep immersion in the participants' voices. I listened to the audio recordings of each interview at least once on its own and then again while reading along with the transcript, making notes on tone, emphasis, and significant pauses, silences, and emotions. I kept a reflexive journal in which I recorded my reactions to emotions and silences, responses to participants' stories, and how my own positionality influenced what I noticed and how I made sense of it.

I provided clear guidance to the transcriber to ensure that the transcripts supported narrative inquiry principles, for example, guidance on verbatim transcription, the marking of pauses, and the inclusion of emotions. I also conducted systematic accuracy checks of each transcript. Outsourcing was not a way of distancing myself from the data, but a strategic redistribution of labour to support depth rather than breadth in my analytic work.

Only I, the researcher, read the transcripts. Members of my supervisory team had access to the narrative accounts once they had been anonymised. The audio-

recordings of the conversations and the transcribed interviews have been saved as password protected documents on my university's cloud storage service 'OneDrive'. All paper documents have been stored in a locked filing cabinet to ensure security of the data. The signed consent forms and identifiers are stored for 5 years as per the ethics approval guidelines

4.3.4 Other Ethical Considerations/Risks and Benefits to Participants

The potential risks and benefits of participating in the study were explained to participants. Such risks included uncomfortable or distressing emotions that might arise in recounting one's experiences. Each participant was informed that if they became upset or emotionally distressed during the conversation, they had the option of pausing the conversation until they were ready to resume or withdrawing from the research without any questions being asked.

Corbin and Morse (2003) write that there is evidence that qualitative interviews may cause some emotional distress but, "there is no indication that this distress is any greater than in everyday life or that it requires follow-up counselling" (p. 335). Most participants cried during conversations. During these moments, I recognised that participants displaying emotion and talking about difficult experiences in their lives was a sign of them feeling safe and comfortable in my presence. I ensured that I demonstrated appropriate empathic listening and responded sensitively to the emotional experiences being narrated and expressed (Corbin & Morse, 2003; Josselson, 2007). At the outset of the study, participants were provided with details of counselling and mental health support services in their local area. Māori and Pacific participants were provided with details of Māori and Pacific support services. While I was prepared with a procedure in place should a

participant become so upset or distressed that I needed to intervene and make a referral for them to get professional help, this did not occur.

Corbin and Morse (2003) posit that when qualitative research is conducted with sensitivity and guided by a code of ethics, “it becomes a process with benefits to both participants and researchers” (p. 335). This study offered several potential benefits to participants. Participants may find it beneficial to discuss their experiences with someone who understands the ICU environment and has expertise in post-ICU complications. Also, participating in this study might help participants develop a sense of coherence of their experiences by telling their stories. Additionally, participants might benefit from knowing that their stories would help further the advancement of knowledge on approaches to caring for future long-stay ICU patients and family both in and beyond the hospital setting, as well as contribute to the education of nurses and other health professionals who work with long-stay ICU patients.

The following reflection, which I wrote after completing the final interview, reflects the benefits participants described from participating in this study:

> *Knowing that I am an intensive care nurse, both groups of participants would ask me questions. Questions were often about their own health or their relative’s health; especially new or worsening symptoms post critical illness that confused and worried them. Family participants additionally asked questions about their own struggles as a family member walking alongside the patient. I delivered a lot of education during our conversations on common ICU complications to help the participants understand the patient’s conditions better, manage recovery expectations, and generally provide reassurance.*

I became aware that both groups of participants greatly appreciated the opportunity to tell their personal stories, including their innermost thoughts and feelings, many of which had not been verbalised before, to someone who could relate to their experience. Participants also expressed gratitude to have someone present who listened to them empathically, who validated their experiences and their ongoing difficulties. Several articulated how therapeutic the process of periodically having these conversations was, stating that my presence was helpful in making them reflect on and express their unfolding experiences and furthermore, see how far they had traversed. All perceived the research as being useful and wanted the knowledge from their stories to help others by making their experiences better.

4.3.5 Risk Management

Survivors of prolonged critical illness and their family are a vulnerable population and there are complex issues that need to be addressed when undertaking qualitative research of this population. A substantial amount of planning and discussion had occurred with the research project's team and various experts to ensure that all potential risks to the study, participants, and the researcher were identified and that a plan was developed to mitigate and potentially deal with such risks. This was presented in the research proposal. Examples include budgetary constraints, ethics approval, access to participants, materials or equipment, COVID-19 factors, as well as specific procedures for managing emotional safety, potential suicidal ideation, and health concerns of the participant. Appendix J presents the

Study Risk Management Plan that was reviewed and approved by HDEC as part of obtaining ethics approval.

4.3.6 Cultural Considerations

The concept of cultural safety underpinned all interactions with participants. Several participants were Māori. Researchers engaging with Indigenous people have a professional responsibility to ensure that the behaviours, processes, and methodologies used in research are culturally safe and respectful, and that tangible benefits for these groups are realised (Hudson et al., 2010). As stated in Te Ara Tika Guidelines for Māori Research Ethics: A framework for researchers and ethics committee members (Hudson et al., 2010, p.1): “All research in New Zealand is of interest to Māori, and research which includes Māori is of paramount importance to Māori.”

To ensure culturally safe interactions with Māori participants, I grounded my approach in tikanga Māori practices, recognising the cultural and relational responsibilities inherent in qualitative research within Aotearoa New Zealand. Prior to each interview, I sought participant’s guidance on process by asking: “How would you like our interview to be conducted today?”, “Would you like a whānau support person present?” and “How would you like your information to be managed and protected?” This conversation allowed participants to set the tone, pace, and protocols, whether that meant karakia (prayer) to open and close or pauses for wairua (spirituality).

Kanohi ki te kanohi (face to face) interviews were conducted, with the exception of four that were online. My way of being with Māori participants was grounded in a desire to uphold the mana of tangata whenua (Indigenous Māori population or the local people of a specific area) and whānau (family). I also brought

kai (shared food such as biscuits) as a customary gesture of manaakitanga (hospitality and care), offered respectfully outside the formal interview to foster whakawhānaungatanga (relationship-building). Many participants requested that the interviews were paused for a shared lunch, again to foster whakawhānaungatanga.

The current study demonstrated a commitment to Te Tiriti and its principles. Dr Bevan Eruiti, Kaiarataki Māori/Associate Dean Māori, Pūkenga Matua/Senior Lecturer, Te Kura Hauora/College of Health, Massey University provided Māori cultural advice for this study. Dr Hana Tuisano (RN, PhD) provided Pacific cultural advice for this study.

4.4 Research Participants

4.4.1 Participant Sample

Participants in a narrative inquiry study are selected by the researcher based on their suitability to meet the aim as well as the purpose and objective of the study. Because this study sought to find meaning from a targeted population, that is people who experienced a prolonged critical illness and the family of these people, the selection methods were intentional. The criteria were developed to ensure individuals were selected who would have the ability to provide meaningful and relevant stories – rich data – to the research questions; individuals whose narratives could provide the most valuable insights (Merriam, 2002).

The inclusion criteria for patient participants are presented in Table 3 and the inclusion criteria for family participants are presented in Table 4.

Table 3

Inclusion and Exclusion Criteria for Patient Participants

Inclusion Criteria	Exclusion Criteria
Adults (people aged over 18 years old)	Presented to the ICU with brain injury including stroke, traumatic brain injury, hypoxic or ischaemic brain injury, encephalopathy, or status epilepticus
Mechanically ventilated for ≥8 days	People who have pre-existing cognitive impairment (as recorded in the patient's medical notes)
More than one organ system failure	Intellectual disability in which patients are already mentally, cognitively, or functionally impaired before the ICU admission (identified from the patient's health history)
Sepsis	People who have pre-existing neurological condition including Guillain barre syndrome, myasthenia gravis, spinal cord injury resulting in paralysis
English speakers	People not expected to survive their hospital stay as identified by a senior medical officer once the inclusion criteria are met.

Table 4

Inclusion and Exclusion Criteria for Family Participants

Inclusion Criteria	Exclusion Criteria
Adults (people aged over 18 years old)	People who have cognitive impairment
Family members who are the primary support person for a survivor of prolonged mechanical ventilation (mechanically ventilated for ≥8 days)	
English speakers	

4.4.2 Sample Size

Clandinin and Connelly's (2000) narrative inquiry emphasises a deep and intimate engagement with participants' lived experiences, and because of this, common practice is to have small, purposive samples. As narrative inquiry captures

a holistic and deep understanding of participants' experiences as they unfold over time, data are thick and rich with description (Kim, 2016).

Ten participants were invited to participate, which included five patients and five family members of these patients. The family members were all spouses. All invited participants consented to participate. A total of 40 interviews were completed (four with each patient and family participant) – a massive dataset and strength of the study. The research explored complex phenomena and furthermore, thoroughly explored the interaction (personal and social), continuity (past, present and future) and situation (place) dimensions of each participants' storied experience, justifying the small sample size (Kim, 2016).

Unlike many other qualitative research methodologies, achieving data saturation is not a goal in Clandinin and Connelly's (2000) narrative inquiry. Underpinning this position is the belief that human beings are unique and so too are experiences under study (Kim, 2016). Kim asserts because of this, "there will always be new things that unfold, depending on the research topic. Hence, data can sometimes never be fully saturated" (p.161). Narrative inquiry therefore, emphasises the depth and uniqueness of each participant's story. Specificity and complexity of individual experiences is the focus rather than generalisability across participants, further supporting this study's small sample size.

4.4.3 Context/Access to Participants

This was a multi-centre study. Two ICUs were chosen to recruit participants from. Inclusion of both a tertiary and regional hospital increased the likelihood that the study would be inclusive of a broad range of participants and representative of the Aotearoa New Zealand healthcare system. A locality agreement was obtained from each hospital. Given that I am a staff nurse at one of the recruitment sites,

during the recruitment phase I ensured that I did my best to not care for any long-stay patients or patients who were predicted to progress to a trajectory of prolonged critical illness to avoid a conflict of interest.

4.4.4 Inviting Participants

The recruitment process is summarised in Table 5. First, each of the recruitment sites had an ICU RLN who I could liaise with and so these nurses were used as a recruitment channel. During the recruitment period, RLNs who worked in each of the ICUs screened patients for eligibility based on the study inclusion and exclusion criteria. The criteria were developed to ensure individuals were selected who would have the capacity to provide meaningful and relevant stories to the research questions; “information rich” individuals whose narratives could provide depth and valuable insights.

The following details were collected by the identified screener from potentially eligible patient’s medical records and notes:

- ICU admission and discharge dates
- diagnosis
- contact details for patient and support person
- demographic data.

Demographic data for patients included gender, age, ethnicity, duration of invasive mechanical ventilation, tracheostomy weaning duration, time to extubation, time to tracheostomy decannulation, and the ICU LOS. For family, this included gender, age, ethnicity, and relationship to the patient.

Table 5

Recruitment Process

Eligibility Screening	Approaching Participants	Consent
ICU Research Liaison Nurse (RLN), or CNM, or NE, or physiotherapist (all dependant on context) screens patient-family dyads for eligibility in the ICU or rehabilitation hospital	Once eligibility agreed, the screener follows-up the patient and their NOK/family on the ward (within one week after the ICU discharge) and approaches them about the study. Screeners are aware that the patient may have cognitive impairment and so discusses their current state with the primary RN on the ward. Patient is included in the research conversation if screener deems it appropriate.	When patient discharged from hospital, PI phones patient and family, discusses study, provides information sheet (via email) and asks whether they would be interested in participating. Makes a plan to follow-up decision in coming days.
If a participant dyad is deemed eligible for recruitment, individual conducting the screener phones primary investigator (PI) to discuss potential participant.	Approaching NOK/family involves: 1. briefly explaining the study 2. providing information sheets 3. seeking permission for the researcher to contact them once discharged from hospital if they are interested in participating.	Telephone follow-up to confirm patients' decision regarding participation. Makes arrangements for first patient and family member interview if interested in participating.
	RLN or other screener contacts PI and communicates outcome of the conversation with the patient and NOK/family. If prospective participants agree to take part in this first instance, researcher gets a handover of details including ICU admitting diagnosis and length of stay.	Patient and family participant consent obtained on day of each person's first interview (scheduled for approximately 6-12 weeks post hospital discharge).

Once a participant dyad was deemed eligible for recruitment, the RLN called me to discuss the potential participants. If it was agreed they were eligible, once the patient was discharged from the ICU to the ward, and within 1 week of this ICU discharge, the RLN followed up the patient and next of kin (NOK)/family together, and after gaining verbal consent to speak with them, provided information about the study including the nature of the study and requirements for participation. This process involved, (a) approaching the patient and NOK/family about the study; (b) providing them with the Study Information Sheet; and (c) if they expressed an interest in taking part in the study, asking the NOK/family member for permission for myself to contact them both to discuss the study further. If they did not give permission for me to contact them, they were told to make contact themselves if they would like to discuss the study further. All potentially eligible participants who were approached about the study consented to me contacting them.

I recognised that it was possible that patient participants may struggle to process information about the study at the time the RLN approached them due to still being unwell, but it was important to me that they be included in the conversation. In such instance, the NOK/family member was given information about the study and asked to consider whether they believe that the patient would be interested in learning more about participating in the study when they are better. If they expressed an interest, permission was sought for me to contact the patient and family member once the patient was discharged from hospital to discuss the study. The RLN communicated the outcome of these conversations to me.

I made initial contact with four of the participants (two patient/family dyads) while the patient was an inpatient on the hospital rehabilitation ward, as they invited me to meet them at this time and place. The remaining six participants (three

patient/family dyads) I contacted via phone once the patient had been discharged home from hospital. Consistent with the relational commitment of narrative inquiry, I engaged with participants with care and respect, ensuring this process was carried out slowly and gently, giving them time to think through the research project and whether they would like to participate (Clandinin, 2013; Clandinin et al., 2018).

During my initial contact with participants, I (a) introduced myself; (b) explained the nature of the study; (c) confirmed that they met the eligibility criteria; (d) explained the requirements for participation; and (e) discussed ethics and gained a shared understanding of informed consent, confidentiality, and expectations. All participants showed a willingness to participate during this first contact, so arrangements were made for the first interview. During this initial contact, I also answered any questions and concerns they had about their participation in the study.

The meeting times and places were chosen in collaboration with the participants. All participants chose to have their interviews in the comfort of their own home. Interviews were in-person, however, there were a few exceptions to this. For one of the participant dyads, two interviews each were conducted over Zoom due to unforeseen circumstances preventing the researcher from travelling.

It was anticipated that participants' first interviews would be lengthy; therefore, most dyads were interviewed on separate, consecutive days. This approach was maintained throughout most of the study, allowing time between interviews for reflection, field note completion, and deep consideration of each participant's narrative before interviewing the other member of the dyad. For one couple, both interviews were conducted on the same day because the researcher was required to travel out of town.

Although all participants were offered the option of having a support person present during their interviews, only one patient participant chose to do so, with his spouse attending a single interview. Anticipating that participants might not feel comfortable discussing their experiences in the presence of their spouse, interviews were conducted in a separate room within the home to ensure privacy and support open, honest conversation. This proved to be an important methodological decision, as both patient and family participants shared deeply personal thoughts and feelings that they acknowledged they had not, and did not wish to, disclose to their spouse. Conducting interviews separately, therefore, created a confidential space in which participants felt able to speak openly about their experiences.

Participants received a koha in recognition of their time and commitment to the research. This was in the form of a NZ$100 grocery voucher.

4.5 'Field Text' (Data) Sources and Collection Methods

4.5.1 Interviews as Conversations

Aligned with the narrative inquiry methodology, the personal narratives of my participants were the main source of field text used to answer my research puzzle (Clandinin & Connelly, 2000). According to Riessman (1993), "narrative analysis takes as its object of investigation the story itself" (p. 1). In other words, the stories, the narratives, are the data. As I came alongside participants, I heard their stories in their words and in their silences (Clandinin, 2007).

The method of interviews as conversations (Clandinin & Connelly, 2000; Hollingsworth & Dybdahl, 2007) was used with participants as the primary data collection method to learn these stories. While interviews are a common approach to gathering data in qualitative research, narrative inquiry prefers to co-compose field texts through the method of conversation acknowledging that active collaboration

between participant and researcher is ongoing throughout the inquiry (Caine et al., 2013). Conversations create a space for the voices and stories of both participant and researcher to be heard and composed. In narrative inquiry, conversations are shaped by both participants and researcher; they are not guided by predetermined questions (Clandinin & Caine, 2013). Clandinin (2013) notes that the methodology of narrative inquiry is fluid and does not comprise a rigid set of procedures or sequential steps that must be followed. Rather, narrative inquiry is relational, and participant led, open to going where the stories of participants' experiences lead (Wang & Geale, 2015).

Hollingsworth and Dybdahl (2007) state that conversation has a critical role in narrative inquiry. They write of narrative inquirers "talking to learn" (p. 146); the researcher coming into a conversation willing to learn from it. Throughout the data collection phase, I employed the method of conversational interviewing (Hollingsworth & Dybdahl, 2007) to specifically learn about patients' and families' experiences and perceptions across the first year following a prolonged critical illness. These conversations were participant-led. I followed their lead to ensure the dialogue remained centred on the aspects of recovery most significant to their unique lived experience. Participants were encouraged to commence their stories where they personally considered that their story began.

Following Hollingsworth and Dybdahl (2007), I prioritised the act of listening as a foundational element of building meaningful engagement with participants. Participants were initially invited to share their stories in an uninterrupted flow, allowing their narratives to emerge in their own words. Subsequently, I transitioned into a more active conversational role to deepen the exploration and co-construct a richer understanding of their storied experiences. This committed approach to

conversational interviewing necessitated a significant temporal investment, with sessions often extending over several hours. Nash (as cited in Florio-Ruane, 2001, p.56) describes how paramount to narrative research this process is: “[Conversation] is at its best when the participants are not impatient to conclude their business, but wish instead to spend their time together in order to deepen and enrich their understanding of an idea.” The technique of storying allowed participants to articulate their experiences freely, in their words and in their time, without externally imposed constraints (Clandinin, 2016; Wang & Geale, 2015). It also allowed me, the researcher, to think about experience as a storied composition; this view of experience underpins the ontological and epistemological position of the methodology whereby experience is seen as narratively constructed (Clandinin & Connelly, 2000).

To facilitate the initial conversations, a brief interview question guide (Appendix K) informed by the narrative inquiry three-dimensional space framework was developed to ensure that the resulting field texts remained anchored in the dimensions of temporality, sociality, and place. This framework ensured theoretical congruency and allowed for the elicitation of rich, three-dimensional narrative accounts (Clandinin, 2013). My inquiries were designed to go beyond mere data collection, seeking instead to interpret the unique, storied perspectives of each participant. Rather than pursuing an objective truth, this approach prioritised the subjective meaning and personal significance within their stories (Clandinin & Connelly, 2000). To ensure that I accurately interpreted the meaning of participants’ stories, I engaged in validation checks with the participants during the conversations. I ensured that I listened and probed respectfully, recognising the importance of the

principles of trust, nonjudgmental listening, equality, and empowerment (Clandinin & Connelly, 2000).

The first conversations with each participant were long as all looked back in time and spoke about their experiences at various significant times, places, and situations in their journey: experiences of becoming unwell (the unfolding critical illness); experiences of the ICU; of the hospital ward; and of transitioning home from the hospital. During these conversations, participants and I negotiated breaks then resumed the conversation afterwards.

Interviews were audio recorded and 36 of the 40 interviews were in-person. This method was chosen given the relational nature of narrative inquiry (Clandinin & Connelly, 2000). For this inquiry, in-person was also most appropriate given the vulnerability of participants and potential for them to have ongoing health issues; during the study design process I felt in-person would enable me as a RN to pick up on signs of distress and discomfort that may not be so obvious using digital interview methods. Interviews ranged in duration from 45 minutes to three and a half hours each. Most participants' first interview averaged 3 hours, and the subsequent interviews were a shorter duration (60-90 minutes). These long durations allowed me to collect rich, thick, and detailed data (Kim, 2016). All interviews were recorded and transcribed verbatim soon after each interview.

4.5.2 Addressing the Proxy Voice

Addressing the proxy voice was a consideration of this study. In instances where the patient was 'absent', family members provided accounts of those timeframes, which was valuable to me as the researcher in constructing a more complete understanding of the patient's experience – that is, what happened to them. This was particularly important when recalling periods that the patient could

not remember, such as ICU experiences marked by fragmentation or *lost time*. I addressed this by treating proxy narratives as complementary rather than equivalent to the patient's own voice, and by clearly distinguishing between direct and proxy perspectives in the analysis. Because my focus during patient data analysis was on the patient's experience from their own perspective, including what was important and meaningful to them, I stayed close to the patient's words and their stories and repeatedly returned to their transcripts.

4.5.3 Field Notes

Clandinin and Connelly (2000) use the term "experiencing the experience" (p. 80), to emphasise that narrative inquiry aims to understand and make meaning of experience. To provide a comprehensive account of my experience with participants, field notes were recorded before, during, and after each conversation. These field notes provided a richness and nuance to the experience by allowing the insertion of personal and social happenings that could not be captured in an audio recording. The process of taking field notes also allowed me to document additional information and details that provided useful contextual detail. I would make notes in a notebook including, descriptions of field observations (attending to place – where the participants and I were physically located and what was around us, observations of the participant); notes on what participants said underlining what I perceived to be key words or statements; notes on participants displays of emotion; notes on my thoughts and feelings; and, notes serving as reminders for what to revisit in future conversations (Clandinin & Connelly, 2000). These field notes allowed me to capture the richness, nuance, and complexity of the landscape in which the participants' stories unfolded – details that memory alone is unlikely to convey.

After each conversation, as soon as possible, I returned to my written field notes and completed a more detailed documentation. This allowed me a time of reflection and contemplation where I expanded on my conversational notes, reflected on what I had heard during the interview, and composed further notes related to thoughts and impressions of the participants' stories, the conversations, and experience.

To *experience the experience*, I also visited the ICUs including the exact bedspaces that each of the patient participants were cared for in. I also visited each hospital's ICU family waiting area (family participants spent a lot of time here) before conducting the first interviews. Placing myself in the field in this way allowed me to "world travel" as Lugones (1987, p. 3) speaks of, to the other world of the ICU and thus better understand what shaped the participants' experience. I wrote field notes during and after these visits.

4.5.4 Analytical Memos

Analytic memos whereby researchers reflect and record on "coding processes and code choices; how the process of inquiry is taking shape; and the emergent patterns, categories and subcategories, themes and concepts in your data" (Saldaña, 2016, p. 44), are an essential part of the research process in many qualitative methodologies. Engaging in the process of thinking and writing about data analysis is a powerful sense making tool that can show the links between data and provide conceptual epiphanies (Miles et al., 2014). I kept analytical memos i.e., brief notes, that contained my thoughts and feelings about the data as well as developing ideas and questions that came to my mind during the interviews, coding, and data analysis.

I used memoing during the interview process to write and record in a journal both descriptive and interpretive data based on my observational experience as the researcher (Miles et al., 2014). During the analysis process I wrote comments and reflections on emerging patterns and summaries of major findings. This process helped me to develop my ideas about what I was seeing in the data and the interconnections between codes, categories, and themes (Bryant, 2013) and ensure I was attending to the dimensions of temporality, sociality, and place. Some of these memos were coded and used alongside transcribed interviews to capture an understanding of the participant's experience of the phenomenon, thus they formed an integral part of the analysis process. In this way the credibility of the study's findings was increased.

4.5.5 Reflective Journal

A reflexive approach to the research process is now embraced in a variety of qualitative research methodologies (Ortlipp, 2008). Researchers are expected to talk about themselves, "their presuppositions, choices, experiences, and actions during the research process" (Mruck & Breuer, 2003, p. 3). Reflective practice such as this aims to make visible to the reader the constructed nature of research outcomes, a construction that "originates in the various choices and decisions researchers undertake during the process of researching" (Mruck & Breuer, 2003, p. 3). Clandinin and Connelly (2000) assert that reflective journals are a powerful way for researchers to give accounts of their experience. They emphasise that keeping a self-reflective journal is a strategy that can facilitate reflexivity, writing that "Field notes combined with journals written of our field experience provide reflective balance" (p. 104).

Engaging with the idea of creating visibility and transparency throughout the research process was an important consideration for this inquiry and so I enacted the strategy of journalling to do this. Keeping and using reflective journals enabled me to make my actions, thoughts, opinions, feelings, and experiences visible and an acknowledged part of the research design, data generation, analysis, and interpretation process (Ortlipp, 2008). I maintained two reflective journals: one was a notebook that was easily portable. I realised early in the research process that I needed something easily accessible and portable as I found that thoughts, questions, and ideas related to my inquiry would appear at random moments and if I did not write them down immediately, they were likely forgotten. For example, while taking a leisurely stroll, working, talking with others, or lying in bed awake at 3 o'clock in the morning! In these situations, I used a pen and paper journal that I could memo and brain dump those thoughts into. I also had a computerised journal where I would write more formal reflections during dedicated study time.

From the beginning of this inquiry, I documented the research processes and my practices as a researcher and reflected critically on those processes and practices (Ortlipp, 2008). Engaging in this process of reflective journaling increased my awareness of personal subjective perspectives and was crucial in ensuring that such perspectives did not affect the research process (Ortlipp, 2008). Before, during and after each participant interview, I would document thoughts and questions along with reflections on how I felt about the experience. I would document the existential outward conditions of what I was doing, situating it in a place and at a certain time. I would then look inwards to give an account of my thoughts, impressions, and feelings during and after each interview (Clandinin & Connelly, 2000). I maintained a written record of what I did, thought and felt during the analysis process. I also audio

recorded doctoral supervision and would listen to the recording afterwards. Additionally, I wrote notes during doctoral supervision and would expand on these afterwards often at the same time as listening to the recording. These journal entries were important field text resources for my ongoing inquiry and for the construction of my research texts. The field notes and the reflective journal both aided triangulation of data, adding context and richness to the data that may not have been captured in an audio recording and interview transcription. In this way the credibility of the study's findings was enhanced.

4.6 Field Text Analysis Methods: Moving from Field Text to Interim and Final Research Texts

The narratives of all the participants were analysed for information that drew meaning around their experiences of ICU survivorship. Data were analysed in two stages:

- **Stage one:** Narrative Inquiry's temporal ordering of events and re-storying using Clandinin and Connelly's three-dimensional space framework (process of mapping the narrative).
- **Stage two:** Reflexive Thematic Analysis using Braun and Clarke's (2006; 2019; 2021) six-step process.

A detailed account of both methods of analysis is presented below. Through the process of re-storying, I developed a holistic (the whole story) understanding of ICU survivorship from the perspective of the patient and their family member. However, while the process of re-storying is a method of analysis, re-storying alone was not enough for this research; the re-storying did help me to see the whole, individual journey, but I needed to fragment the data (break the narratives up into codes) to help me see the systemic failures in the Aotearoa New Zealand health

system. I did this by coding the original transcripts. Appendix L provides an example of this coding process. Through this two-step approach, I gained a deeper understanding of the participants' experiences including how, when, where, and why they struggled, and how they navigated the pathway after critical illness.

4.6.1 First Stage Analysis: Temporal Ordering of Events and Re-Storying (Process of Mapping the Narrative) – The Three-Dimensional Narrative Space Framework

A conscious effort was made to manually analyse the data rather than using data analysis tools, to experience data immersion and develop analytical skills and expertise. Clandinin's (2013) re-storying method of data analysis guided how I approached the first stage of analysis.

After completing the 40 interviews, I had 10 rich narrative accounts, alongside field notes and journal reflections. The huge volume of data, particularly about the ICU and hospital experience, initially overwhelmed me, exceeding my original research puzzle – experiences *after* the ICU. Drawing on Clandinin and Connelly (2000), who describe narrative phenomena as "shifting ground" (p.126), allowing an inquiry focus to evolve, I re-oriented the research puzzle: it was clear that the participants' present realities as ICU survivors were inseparable from their ICU pasts within the three-dimensional inquiry space. This justified expanding analysis to include experiences of the ICU.

In keeping with Clandinin and Connelly (2000) and Clandinin's (2006) method of temporal ordering, the findings follow the timeline from critical illness onset and the ICU admission to one year post hospital discharge. This contextualises change, intertwining time, place, and sociality in the participants' ongoing experiences. The

method of temporal ordering captured progress, setbacks, and evolving realities, making post-illness changes meaningful within the participants' broader life stories.

To do this, I first listened to participants' stories, made notes on what I was hearing, and read the transcripts again. I then looked back on my own field notes and journal entries relevant to the interview. Consistent with Clandinin and Connelly's (2000) iterative analytic process of rereading field texts and "laying them alongside one another" (p. 133) as well as "looking across multiple narrative accounts" (Clandinin, 2013, p.131), I developed a visual messy map of each participant's story (see Appendix M as an example), an approach developed by Adele Clarke and colleagues (Clarke et al., 2016). While Clandinin and Connelly (2000) and Clandinin (2013) do not describe drawing large maps as a required method, they do discuss mapping conceptually as a relational and fluid process of attending to experience across the three-dimensional space of temporality, sociality, and place. The development of messy maps in this study aligned with these principles, and therefore, was considered methodologically congruent with narrative inquiry. This process involved chronologically mapping (temporal ordering) and writing down (re-storying) each participant's story as it unfolded over time on a large, working messy map. I ended up with 10 of these re-storied maps. The map served as a visual reconstruction of the participant's whole story rather than a meticulously detailed account, capturing the key events, transitions, and experiences that shaped their journey.

I then completed more messy maps for each participant, specifically one for each time/place; the time in ICU; the time on the wards; coming home; six-, nine-, and 12-months post discharge. To manage the amount of field text, the mapping process was guided by the research question and the three-dimensional space

framework. The process involved writing down what the participants were saying about their experiences that related to the dimensions of temporality, sociality, and place. I wrote down what mattered to participants, the *lived reality truths*, elements pertinent to them, tensions, and turning points (Clarke et al., 2016; Nordtug, 2022). Using the three-dimensional space framework allowed me to capture context, nuance, and relationships in the data, creating a rich, complex visual that told deeper stories about their experiences across time and in different contexts.

After mapping, I undertook cross-map comparison to identify patterns, similarities, differences, recurring tensions, and turning points within each participant's trajectory (ICU, ward/hospital, home) and between patient–family dyads. Themes were developed by iteratively revisiting the underlying transcript segments represented on the maps, checking whether the interpretation held across time-points and contexts, and refining theme boundaries when exceptions or disconfirming instances were found. My reflexive journal and interview field notes were used as analytic companions to the maps, supporting attention to my own positioning, assumptions, and emotional responses, and helping differentiate participant meaning from my interpretive overlays during theme development. The messy maps were powerful, and this is the methodological approach I had to understanding the themes that emerged (Clarke et al., 2016).

The process of messy mapping took time, and it was a huge amount of work. To summarise, messy maps included:

1. by individual patient across time (ICU, ward, home, six months, nine months, 12-months)
2. combining patients across time (ICU, ward, coming home, time points)

3. by individual family member across time (ICU, ward, home, six months, nine months, 12-months)
4. combining family member across time
5. collating the messy maps across all participants and time.

Examples of these messy maps are included in Appendices M-X.

4.6.2 Second Stage Analysis: Narrative Thematic Analysis

After the initial messy-mapping, I realised that further systematic analysis of the data was needed to gain deeper insight into the patterns and themes that were emerging from the messy maps and, critically, to identify the systemic failures reflected in the data. I therefore undertook a thematic analysis, following Braun and Clarke's (2006; 2019, 2021) six-step thematic analysis process: familiarisation with the data, generation of initial codes and categories, searching for themes, reviewing the themes, defining and naming themes, and producing the report. This approach involved coding the original transcripts, as illustrated in Figure 2.

The structured thematic analysis provided a systematic way to code and organise the transcripts, while the messy mapping enabled me to step back, rearrange the codes, see broader connections, relationships, and patterns that were not obvious during my initial mapping. In this way, coding functioned as a tool to support the development of themes alongside the messy maps, while also providing analytic precision. Although the structured coding broke the participants' stories into analytic pieces (which is philosophically at odds with narrative inquiry as it is concerned with the whole story), messy mapping helped put those pieces back together in a way that revealed larger meanings. The analysis was done twice: first with the patient data analysis and then with the family data analysis.

Figure 2

Overview of Braun and Clarke's Thematic Analysis

4.7 Rigour and Trustworthiness

Ensuring rigor in a study is essential to producing credible, trustworthy, and meaningful findings (Lincoln & Guba, 1985). Ensuring trustworthiness is crucial in establishing the credibility and reliability of qualitative findings, given their subjective nature (Ahmed, 2024). Stahl and King (2020) note that achieving trustworthiness means that "when readers interpret the written work, they will have a sense of confidence in what the researcher has reported" (p.26), thereby assessing the "truth value" (Tuckett, 2005, p.31) and "applicability" (Tuckett, 2005, p.31) of the findings. The concept of trustworthiness comprises several essential elements including credibility, transferability, dependability, and confirmability (Ahmed, 2024; Lincoln & Guba, 1985; Stahl & King, 2020). Throughout this study, I utilised a number of techniques to meet the criteria of rigour and trustworthiness. The techniques are detailed in Table 6. Some of these such as analytical memoing, reflective note taking, and keeping an audit trail have been described earlier in this chapter, others will be described in the following section.

Table 6

Techniques to Demonstrate Rigour and Trustworthiness

Criteria	Techniques Employed
Credibility	Member checking
	Extended involvement in the field
	Triangulation of data sources
	Triangulation of data collection methods
Transferability	Comprehensive and detailed explanations
	Thick description

Criteria	Techniques Employed
Confirmability	Peer debriefing
	Peer review
	Audit trail of data analysis
	Analytical memoing
	Reflexive journalling
Dependability	Audit trail
	Reflective note taking

Member checking was an essential technique to ensure credibility, and this is an important aspect of narrative inquiry where the participant is included in the process of verifying accuracy in field text interpretation and findings (Clandinin, 2013; Clandinin & Connelly, 2000). This is to ensure that the researcher's interpretations of the participants' narrative of their experience are accurate. Throughout the interview process, participants' narratives and my interpretations of their narratives were reiterated back to them to ensure accuracy and resonance with their lived experiences. As I undertook four interviews with each participant over 12 months, I also was able to return to them after reflecting on their experiences and seek clarification if needed to develop a better understanding of a narrative. I continued to utilise regular member checking and validated my understanding with participants as I interpreted and analysed the data. There were instances during these stages of the study where I contacted participants to seek clarification, which the narrative inquiry methodology accepts (Clandinin & Connelly, 2000). This technique of member checking strengthened the credibility of the findings.

Throughout the research process, I engaged in ongoing peer debriefing sessions and peer reviews with my doctoral supervisors to further ensure credibility. In these sessions, the work was reviewed, critically discussed, and input provided. I also engaged in discussions about my research with peers including nurse

academics familiar with the narrative inquiry methodology, university colleagues familiar with qualitative methods and other doctoral students undertaking qualitative research, without disclosing detail that might identify the participants. These measures strengthened the credibility of the findings.

Another method I utilised to ensure credibility was triangulation, which involves the use of multiple data sources, methods and/or researchers to cross-check findings and improve the robustness of my interpretations. Unlike quantitative research, this study did not aim to prove an absolute truth about ICU survivorship. People's experiences, whether positive or negative, cannot be reduced to one reason or a specific group of reasons. The intent of this study was to create new avenues to view experiences after a prolonged critical illness from various perspectives and identify where the systemic failures in the Aotearoa New Zealand health system are that impact on this group of patients.

The study served as a methodological approach to triangulation with the use of multiple sources of data that included transcript data from interviews, field notes, analytical memos, and a researcher's journal to document reflections from the interviews and overall research process. I also visited the environments that the participants were describing, for example both of the ICUs, the bedspaces they were cared for in, the ICU family waiting areas, as well as the hospital wards. Field notes and critical reflection added an additional layer of authenticity by allowing a constant analysis of my own subjectivity and bringing awareness to my role as an *instrument* in the data collection process.

Another recognised strategy to ensure credibility and trustworthiness is prolonged engagement in the research field. Spending time in the research field contributes to the establishment of a trusting relationship with participants and allows

the researcher to get to know the context within which participants live and operate. I collected field text from participants over the course of one year, meeting with them every three months and completing numerous interviews with each participant.

Transferability of the findings in this study is supported by the comprehensive, detailed, and contextualised description of the study setting, participants, care environment, and procedures (Ahmed, 2024). This level of richness has been termed *thick description* (Miles & Huberman, 1994; Tuckett, 2005). It enables readers to assess the extent to which the findings may be relevant to their own ICU or ward context and allows other ICU and ward nurses to recognise elements of the same *landscape* within their practice.

4.8 Reflexivity

Reflexivity in qualitative research emphasises the importance of the researcher's awareness of their own influence on the research process and outcomes. Given the interpretive nature of narrative inquiry, practicing reflexivity was an important component of this research (Josselson, 2007). Additionally, because of the interpretive nature of narrative inquiry, reflexivity is needed for quality assurance and helped to establish the trustworthiness of the research. Olmos-Vega et al. (2023) define reflexivity as "a set of continuous, collaborative, and multifaceted practices through which researchers self-consciously critique, appraise, and evaluate how their subjectivity and context influence the research processes" (p. 241).

Practicing reflexivity involved exploring my position, biases, assumptions, subjectivities, and experiences and in acknowledging these, make explicit my influence on the research process (Palaganas et al., 2017). To maintain a critical, reflexive stance that acknowledges the complexities of my role as researcher I integrated several reflexive practices throughout this inquiry. Throughout the

research process I engaged in a practice of self-reflection and introspection, looking inwards to my thoughts and feelings and documenting these appropriately. I asked myself questions about my assumptions, beliefs, and the impact of my background as an ICU nurse on the research. I kept a personal reflective journal (as described in Section 4.5.5). I used this journal to keep a record of my thoughts, feelings and understandings as I made sense of what was shared with me through the participants' stories, and to keep track of my evolving thinking.

During the study's conceptualisation phase, I engaged in writing an autobiographical narrative. This helped me to identify and make transparent my position in relation to the topic being investigated. During this phase, it was crucial that I recognise my own background, perspective, experience, assumptions, and bias and consider how this might influence the study.

During the data collection phase I was careful not to make assumptions about participants' thoughts, feelings, and experiences, and mindful not to let my voice dominate the narrative, ensuring that I listened attentively, held space for silences and pauses in conversation, refrained from imposing my own judgement, and responded thoughtfully. Being conscious of the epistemological dimension and privilege of co-composing the field text and therefore knowledge with participants in a narrative inquiry, I had to identify and narrate my views and beliefs and how they may influence interpretations of the participants narratives by outlining the research assumptions. I did this by writing analytical memos. This process helped ensure the trustworthiness of the research.

Throughout the research process I regularly shared with my supervisors' messy maps, narratives of participants, samples of my writing, the interim and final research texts, and engaged in critical discussions about my thinking, responses,

wonders, and curiosities about participants' and my stories as they related to understanding the experience of a prolonged critical illness and life after a protracted stay in the ICU. These conversations helped me to place my experiences in context and maintain a reflexive approach.

Given the extended and close engagement with study participants, part of my reflexive practice included attention to the lived, relational experience of being the researcher across the study period. This reflects what is known in a narrative inquiry study as *relational ethics in action*. Throughout the study I reflected on how my feelings changed from interview one to interview four. In a longitudinal study, the researcher often becomes a *witness* to the recovery, and for me, this involved navigating what has been identified in the nursing literature as the act of *bearing witness* or the *burden of witnessing* (Djkowich et al., 2018; Page et al., 2019b) and, finding ways to deal with its emotional impact.

At the first interview, I could see how much the patients and families were *in the trenches*, having only recently returned home and been *thrust into an overwhelming new reality*. They were trying to make sense of their new circumstances and figuring out how to be in this new reality. This created a burden of witnessing: I was not simply hearing about their experiences but observing the struggles and consequences of systemic failures such as inadequate hospital discharge planning and lack of follow-up and aftercare. I was also observing the emotional impact of what they had been and continued to go through; almost all the participants had moments during the conversations where they became tearful. I hoped that with time, things would improve and get easier for them.

However, as the study progressed, it became increasingly apparent that these families were not receiving the support they needed and that their health and

recovery were adversely impacted by this. The burden of witnessing continued; I was hearing about their struggles and observing the ongoing consequences of systemic failures over time, and this left me feeling angry that the system of which I am a part of left these families to cope with problems beyond their capacity to manage alone. I managed this by remaining reflexive, documenting my thoughts and emotional reactions after interviews and throughout analysis (memos), and discussing this with my supervisors.

Page et al. (2019b) in their grounded theory study of ICU nurses' experiences in relation to the survivorship needs of patients, present a novel theoretical understanding of how ICU nurses bear witness to early survivorship. Specifically, nurses bear witness to patient and family members experiencing profound changes in health and facing uncertainty. Interestingly, data from Page and colleagues' research shows that nurses chose to bear witness rather than not bear witness, despite experiencing prolonged emotional burden. Cody (2007) comment that bearing witness to is a method of caring and a way to validate another's experience. Nursing theorists such as Benner (1984), Swanson (1991), and Watson (1985) do not explicitly use the term bearing witness, but many of their concepts such as authentic presence, being with, and caring processes closely align with it. My own experience of witnessing the immense and multifaceted changes the prolonged critical illness brought to the participants lives, their ongoing struggles, suffering, and the lack of structural support they received was a heavy emotional weight to bear.

4.9 Data Management

To ensure the confidentiality of participants, I implemented the necessary protective measures in managing the data collected for this study. Each interview was audio-recorded with a digital audio recording device. Following each interview,

the audio-recording was uploaded and saved as password protected files on the university's cloud storage service OneDrive. The original recordings were erased on the recording device. During the interview process, each participant was randomly assigned a letter (for example, Patient A and Family J). The initial intention was to assign pseudonyms that the participants chose for themselves. This approach was thought to strengthen the person-centred approach adopted in this study and align closely with the ethos of the research. However, early on it became apparent that participants were choosing names that were significant to them, such as their mother or father's name. This presented a potential risk that should their spouse or a family member read the final research texts, they may be able to identify the person. Upholding the researcher's responsibility to protect research participants' anonymity, the use of pseudonyms was abandoned in favour of randomly assigned letters.

During the transcription process, participants' names and all other identifying information (e.g., names of family members; names of health professionals involved in their care; geographic location; and other unique aspects of their experience that could be used to identify them) were removed or anonymised with a letter. Once the audio-recordings were transcribed by either myself or the transcription service, the transcribed interviews were saved as password protected documents on the university cloud storage service OneDrive.

Data was coded and entered into Microsoft Word Documents and saved on the same OneDrive. All paper documents related to the study including enrolment logs, signed consent forms, field notes, memos, researcher journal, and hard copies of transcripts were stored in a locked filing cabinet in the researcher's office to ensure security of the data. After completion of the study, data will be stored in a password protected computer file and retained in accordance with the Massey

University Code of Responsible Research Conduct, then disposed of as confidential waste (Massey University, 2015).

4.10 Chapter Summary

This chapter has outlined the methods applied to the research question using Clandinin and Connelly's (2000) narrative inquiry approach. In total, 10 participants were recruited including five former long-stay ICU patients and five family members of these people. Ethics approval was granted by the NZHDEC to conduct multiple unstructured interviews with each participant over a period of 12 months. The use of field notes and analytical memos assisted the researcher to reflect on the research process and make adjustments before each new interview was undertaken. Data collected were analysed in two stages. Stage one was temporal ordering and restorying using Clandinin and Connelly's (2000) three-dimensional narrative space framework (process of mapping the narrative).

Stage two was narrative thematic analysis using Braun and Clarke's (2006; 2019; 2021) six-step process.

This strategy resulted in six overarching themes (three for each participant group) and multiple subthemes.

Chapter 5: Findings of Patients' Experiences

5.1 Introduction

The previous chapter explained the research design and methods. This chapter presents a discussion of the findings that emerged from analysis of the patients' narratives of their experiences. While this study was initially focused on investigating participants' experiences across the first year after hospital discharge, all patient participants demonstrated the need to talk about their experiences and memories of the ICU and general hospital admission. What became clear, is that their present reality could not be separated from the critical illness and hospital experience; these experiences were intertwined, and they continued to influence their everyday life in profound ways. Therefore, the findings are presented in a way which reflects this, following the timeline of the critical illness and participants' pathways, beginning with participants' experiences of being critically unwell in the ICU to one year post hospital discharge. Thus, the findings tell the story.

Participants' narratives allowed me to see how they would move between the three-dimensional space framework dimensions used in narrative inquiry. I saw how participants looked inward and outward, bringing forth the sociality dimension. I saw how their stories weaved within the continuity dimension, participants looking back and reflecting on their experiences and perspectives from the past and bringing them forward into the present while also articulating their current position. I saw how they projected forward, making statements about their possible futures, including their hopes and wishes for themselves and their family, as well as their concerns. I saw how their experiences happened in places and were influenced by context bringing forth the place dimension. The emotional and cognitive responses to their experiences also emerged.

5.2 Characteristics of Patient Participants

Five patient participants were included in this study, all of whom were male. Three of the participants were in their 40s, one in his 60s, and one in his 70s. Three of the participants identified as Māori, one as Samoan, and one as New Zealand European. ICU length of stay varied from 3 weeks to 11 months. Four of the participants had a tracheostomy. Three participants were working before they became unwell, two were not. To protect participant anonymity, individual demographic and clinical characteristics have not been presented.

5.3 Overview of the Themes

Table 7 presents the narrative themes and subthemes of the patients' experiences of the ICU, of the general wards and across the first year at home after discharge from hospital. The subsequent sections in this chapter will be arranged according to these themes and subthemes.

Table 7

Narrative Themes and Subthemes – Patients

Experiences of the ICU:	Experiences of the General Ward:	Experiences of Being Home:
Being out of Control	***Unmet Needs***	***A Year of Tending to the Self***
Being out of it: Lost time	Unmet care needs	Coming home: Facing a new reality
Bearing the unbearable: Symptom burden	From sanctuary to unknown: Transition-related stress	Everyday struggles
Being misunderstood		Learning to live with a changed body
I want to get out!		I'm focused on getting better
Needing care and connection		Rebuilding the damaged body
		Needing care and support

5.4 Patient Participants' Experiences of the ICU

5.4.1 Overarching Theme: Being Out of Control

The overarching theme of patients' experiences of the ICU was 'Being out of Control'. Participants recalled how life suddenly and unexpectedly changed from ordinary to unimaginable as they encountered their new reality of a failing body and being kept alive in an ICU. Participants spoke of the fear and anxiety associated with having no control over the situation they were in and what was happening to them. They had no control over their critical illness, the impact the illness had on their body and mind – in particular, delirium – nor did they have control over what they were subjected to as part of the context of intensive care. The overarching theme 'Being out of control' portrays their experiences of a prolonged critical illness and extended stay in the ICU. Five subthemes emerged from data analysis: *Being out of it: Lost time; Bearing the unbearable: Symptom burden; Being misunderstood; The journey out of there;* and *Needing care and connection*. The dimensions of temporality, sociality, and place were intertwined and central in identifying the narrative themes.

For the dimension of time, participants reported mostly fragmented or delusional memories of their time in the ICU, creating a sense of 'Lost time'. Retrospectively, the sense of lost time made the magnitude of the critical illness and the ICU experience difficult for participants to grasp. One participant talked about how, because he was "out of it" for so long, he in a way, did not experience it. He understands that he was seriously unwell in the ICU for one month, but he was unable to connect to the ICU experience: "I don't feel I've been through a traumatic experience really, probably partly because of blankness, of being out of it all the time." Patient B.

However, despite fragmented memories and the notion of lost time, all participants reflected on how becoming critically ill was a defining moment in their life where life suddenly changed. They recalled the past before the critical illness and what was a known reality and then faced the time of being critically ill, suddenly finding themselves in a health crisis and being placed in an unfamiliar reality with a failing body and needing to be kept alive by machines in an ICU. The critical illness and its aftermath created uncertainty regarding the participants' futures which endured throughout the entire illness and recovery trajectory.

The social and place dimensions were closely intertwined and highlighted participants' struggles and suffering in this new reality. Participants talked about having to withstand physical, psychological, and emotional symptoms and stressors, of which they had no control over, such as the ICU environment, being confronted with a life-threatening condition, and experiencing a lack of control over bodily functions. Participants described a heavy symptom burden such as pain, difficulty in breathing, thirst, and episodes of delirium in which they could not think clearly. Participants also reported being immobile and voiceless which compounded the feeling of feeling out of control. Participants recalled feeling overwhelmed, stressed, and at times panicked. The sense of vulnerability that participants felt was immense. In the following quote, Patient E who developed Guillain Barre Syndrome, described being in hospital and feeling his body progressively shut down. He remembered the paralysis working its way up and down his body, losing his vision, and struggling to breathe:

> They took me through to there and that's when I could feel myself, feel like I was shutting down. I told [spouse]. I said, 'I can't move my', you know, and I explained like, 'I can't move my knees now.' Like it was working its way up

and down my body. I was like, 'I can't move my toes. I can't move my knees. I can't move my hips.' So, I got to explain all that to her. I said, 'Oh yeah.' I says, 'My vision's getting blurry.' I said, 'I feel like I'm shutting down.' Breathing was getting harder. And then from there, I went to ICU, I think.

Participants' narratives also revealed that a prolonged ICU stay is an emotional experience describing a range of feelings including helplessness, insecurity, worry, frustration, loneliness, panic, and despair. All participants described being confronted with their own vulnerability in this place. Analysis of the narratives identified six intertwining contextual factors that created the overarching theme 'Being out of control': the broader context of being critically ill; the lived experience of delirium; being mechanically ventilated, medication, the physical environment of the ICU; and interactions with others. Patient E often spoke about how little control he had during his 11-month ICU admission and how he had no choice but to trust that the people caring for him would work in his best interest: "It's another thing you can't control, so just put your faith in the people around you and put your seatbelt on."

The experience of being mechanically ventilated for a prolonged length of time was a major contributor to patients' feeling of 'Being out of control'. As the patients' cognitive functioning returned to normal, they realised they could not breathe normally. They became acutely aware of the life-sustaining role of the ventilator. Routine cares such as turns and being repositioned could result in the feeling of being unable to breathe. The complete lack of control they had over their body and their breathing in these situations produced anxiety which compounded the feeling of being out of control:

> When they rolled me to my right side. Hang on. Let me think about that. Oh, it doesn't matter – it was one of the sides – I would instantly panic, because I knew that I wasn't going to be able to breathe for one reason or another, and everyone would say, 'It's okay, you're okay, just calm down, just breathe'. It didn't really matter what anyone said. I was panicking because I couldn't breathe. Patient E

Other factors that contributed to patients feeling out of control were sedation and pain medications. Patients shared memories of feeling drugged and emotional. Not feeling like themselves was unsettling. Patient A did not want to be given opiates because of how they made him feel: "I started to realise every time they gave me an injection or pills, I'd sink back into, you know, you'd get tired and I keep saying to her, 'I don't want those drugs'."

Patient D explained how the drugs he was given in the ICU made him feel emotional and unlike his normal self, highlighting that the long-stay ICU patient is not themselves: "The drugs that are in you just – as in my case – just made me emotional and all sort of – just – yeah – and lots of other stuff that's just not like me."

The narratives revealed that care and connection from family and nurses during this time of vulnerability was an essential lifeline, providing comfort, emotional safety, and functioning to maintain hope for recovery.

5.4.2 Being Out of It: Lost Time

The beginning of each person's illness story was clear and detailed; participants recounted the events that unfolded leading to hospitalisation and then the ICU admission in an ordered and coherent narrative. From this point on however, participants' memories of being in the ICU became fragmented despite spending weeks to months in that place. Participants lacked insight into what happened to

them during that passage of time. The subtheme, ‘Being out of it: Lost time’ encapsulates this ontological gap. The inability to remember much of the ICU experience created a rupture in the patient’s identity that was associated with a feeling of loss: “It feels like big part of you had been missing.” Patient B.

For some, the lost time was upsetting:

> Not being present in my family’s lives has been hard. That's a challenge – missing a chunk of time just makes me unhappy. […] So, when I don't have that time or when it's taken from me, yeah, I get a bit upset about it. Patient E

Participants described an altered perception of time in the ICU. Initially, time stood still. Participants had no memory of early weeks, even months for some. Then as time went on, length of stay was difficult to gauge accurately. Waking up and discovering the length of time they had been ‘out of it’ left patients stunned. Patient C explained his confusion when he learned how long he had been in the ICU for:

> The length of stay, as well, is a fairly deceptive one. Because I didn't believe that I was in there for very long. So how could my body shut down that quickly? And then to find out, no, you were in there for a while, buddy, you were on that bed for a while. And you were sedated for a lot of that time. Yeah, you know, it felt like a few days. So, when I found out that it was, this is the length of time [several weeks], I was quite surprised. I was like, ‘What?’

Patient A also described his disbelief:

> Where I just came from was the being out all that time. I was going, ‘Out?’ And they were going, ‘You were in a coma, induced coma.’ And I was going, ‘Oh, no I don't…’ And they were going, ‘For so many weeks.’ I thought, ‘What, you're kidding me.’

Patient B and C described severe memory gaps from the time in the ICU articulating an awareness that something happened to them which in many ways they did not participate in. This resulted in these individuals being unable to grasp just how significant the critical illness event was. Patient B explained how because of the blankness associated with that time, he now has little idea of it as an experience: "Because I was pretty much out of it for all the time that I was in ICU, I don't have any idea of it as an experience. I sort of didn't experience it in some ways."

The lack of memory of the time in the ICU is also illustrated in the following quote by Patient C:

> I don't remember any of it. Not when my body broke out into a rash, which [wife] showed me a small video which I asked her to show me because you know, it's hard to believe sometimes. I don't remember being in any pain whatsoever – no pain at all – but I must have been in some kind of – so the physical, don't remember being – having a fever or having the – like none of that. Everything revolved around the delirium.

Delirium was reported by all participants. When participants retold stories of their experiences of the ICU, they were often unsure what was real and what was not real; what happened to them and what did not:

> A lot of it [delirium]. That's why probably when you ask me about the early stages of ICU, that's probably the reason that I can't tell you is because I don't and still don't know what's real and what's not. Patient E

Participants' altered cognitive state impacted on their ability to remember staff who had previously cared for them. One participant explained how for weeks when he was awake, he did not recognise nurses and doctors who had previously cared

for him. It is only when his delirium began to resolve that he started to remember these people:

> They used to come in. And you know, I couldn't talk back but, they'd speak to you as if they always knew you. They were going, 'I was your nurse, remember?' And I was going, 'No.' But quite a few of them done it. And even the doctors when they came in, I knew one doctor. That's when I first woke. And they come in and mentioned stuff about me. And he goes, 'Remember me?' I was going, 'No I don't. No, I didn't.' And then it wasn't until I was really coming right with the brain and all that. And then I used to, you know, look at them. 'Oh, you remember me?' 'Yes.' Patient A

Memory gaps from the time in the ICU meant that as the patient was well enough to learn about their illness, they were unable to piece together what happened to them during that passage of time. Participants explained that they relied on family and health professionals to learn about their illness and through these interactions came to the realisation of how unwell they had been and that they nearly died. For some this was emotional. However, these explanations from others intersected with the participants own distorted memories, and it is these memories that family could not explain or help the participant to contextualise. Participants therefore, never fully grasped what happened to them:

> I've heard that I almost lost my life. I heard I was on the brink. There were some struggles in that second surgery that whatever happened, happened. But to hear him say, 'No, I was starting to say goodbye to you', I was like, oh crap. So, there is some truth to me not fully grasping just how close or just how big that event was. Patient C

For some participants, the memory loss during this time had implications beyond the ICU. One participant who developed an ischaemic gut requiring life-saving emergency surgery and was left with a new colostomy, did not remember his introduction to his stoma at all. This was a recurring story that he brought up at each interview across the year. There was an underlying sadness; his eyes teared up; he took a deep breath and sat for a moment in silence contemplating: "I don't remember my introduction to it at all." Patient B.

Several participants wanted to explore more about what happened to them while they were in the ICU asking me for explanations and clarifications. Those whose memories were incomplete or dominated by delirium expressed a need to contextualise these memories. With the insider knowledge that I have being an ICU nurse, I was able to help them fill in some of the gaps, and they reported feeling that the discussions were helpful and therapeutic:

> I was blown away the last time we spoke, and you described the surroundings of where I was in that room, and then there was a reception area just outside and people passing back and forward. That helped fill some gaps, or make a few things seem is a bit more, okay, this is why I thought this was happening. Patient C

5.4.3 Bearing the Unbearable: Symptom Burden

Situated within the intertwining dimensions of sociality and place, participants talked about the symptom load and suffering they experienced across the course of their critical illness and the subtheme, 'Bearing the unbearable: Symptom burden' encapsulates this. Surviving a potentially fatal critical illness came at an immense cost to the participants' body and mind. The initial illness impacted other body systems leaving them dependent on life-sustaining support for a prolonged length of

time. They were shattered and shocked and they could not think clearly. All participants spoke about how when they woke from sedation, they found themselves in a shocking new reality. The critical illness had transformed their body. They were confronted with agonising physical and psychological symptoms and a body that no longer functioned like it used to. Symptom distress was common, and this produced feelings of vulnerability, as stated by Patient A: "It felt like I was just looking at them [the nurses], just lying there, and they couldn't do anything."

Participants described memories of a range of symptoms. The symptoms which appeared to cause the most distress were difficulty communicating due to being voiceless, thirst, pain and discomfort, sleep disturbances, difficulty in breathing, and delirium. These will now be explained.

Being Voiceless: Communication Difficulties. Participants recalled the experience of waking up in the ICU but being unable to communicate effectively. Being intubated and ventilated meant they had no voice, so they were unable to communicate verbally. Initially participants were unaware that that they could not speak. Some remembered waking up in chaos; they did not know where they were and what had happened to them, they had pain and discomforts, they wanted information, and they wanted help. Some recalled their attempts to communicate with nurses, desperately trying to get their attention, speaking, yelling even, but being voiceless. This created confusion, intense frustration, feelings of isolation, and eventually despair. Some felt ignored in these situations. Patient A who had a tracheostomy and was mechanically ventilated explained his experience of regaining consciousness in the ICU. He was trying to wave at a nurse to get her attention but was too weak to lift his hands. He remembered trying to yell in desperation to get someone to notice him, not realising he could not speak:

> Yeah no, that was worse. When I came to, cause one of the nurses, and I was trying to talk. And then she just carried on and I tried to wave at her, but I couldn't even lift my hands, I was going, 'What the hell's going on?' And it was like, you could see what they were doing but nobody's listening to you. And I was trying to yell, and these people – still nothing. Just carried on. I was like, 'What the hell is wrong with them?'

When asked what it was like for him not being able to communicate, he responded, "Ohhhh frustrating. It's like I says, I remember the guy that had a stroke and he threw things around. I didn't want to go that bad, but I felt his pain. Yeah, I felt the same." The feeling of frustration was echoed by Patient E: "It was hard. It was frustrating."

Patient C who also woke up with a tracheostomy and mechanical ventilation explained that for a long time he did not realise he was voiceless. He thought he was talking and that people could not understand him:

> In my mind I was talking the whole time. I don't remember. It wasn't until the whole liquid situation that I fully, I started to understand, actually these people can't hear what I'm saying. Or, I'm not saying anything with my mouth. Because the whole time I thought I was talking and people were just being idiots.

Further to an inability to verbally communicate, participants recounted how most nurses had difficulty lip reading. In addition, they described memories of not being able to write their needs down due to factors such as altered cognition, severe weakness, and lack of fine motor coordination. When participants' attempts at writing failed, nurses tried communication aids such as alphabet and picture boards. However, these were also perceived by participants as largely unsuccessful for the

same reasons. Patient A remembered being so weak that he could not even hold a pen: “They tried to get me to write. But I couldn't even hold a pen.”

Patient B explained that communicating to other people was extremely difficult and aids such as alphabet and letter boards were ineffective:

> One other thing which I should probably talk about, was the whole mechanism of communicating to other people when the tracheotomy was in. You’ve got one thing that's all the letters of the alphabet where you point. That didn't work for me at all.

Wanting to communicate his symptoms and needs, but not being able to, was perceived as the most difficult aspect of his ICU stay: “That was probably the most difficult period. I suppose, partly, because I knew what I wanted, but you've just got this inability to communicate it.”

Participants stressed that their inability to communicate meant that their needs could not be recognised promptly or attended to, contributing to their suffering: “It was hard. It was frustrating at times. Um, but my frustration held – stayed inside. I never let it out. It's not their [nurses’] fault that they can't understand me.” Patient E.

Patients’ stress could not be conveyed in a way that was understood by the nurse. Some patients who remembered experiences of being slowly weaned from the ventilator and having a tracheostomy recall the intense fear and panic they would experience when changes were made to the ventilator and support was reduced. Some recalled encountering problems with breathing, even machines failing. They had limited ability to communicate concerns and when their attempts to communicate went unnoticed or were overlooked, they were left feeling terrified. Patient A remembered an occasion where changes were made to his ventilation and immediately, he had the sensation he was not getting any air. He tried to

communicate this with the nurse looking after him, mouthing "I've got no air", but reports she would not listen to him: "I said, 'I got no air.' Oh, crickey, she wouldn't listen at all. I says, 'But I've got no air'."

He also described another incident where a piece of breathing apparatus was not attached correctly and as a result, he could not breathe. Feeling that something was not right, he identified the problem and attempted to communicate it. However, in this moment his distress was not recognised nor was his concern taken seriously by the nurse. Not only was his breathing momentarily compromised, but he explained that the failure to be seen and heard caused him to lose all confidence and trust in the nurse caring for him. He did not feel safe:

> A nurse that came to me, she didn't know how to use them. She had one of them back to front. And I was going, 'No don't', I says, 'You have to go the other way.' And she goes, 'No, no, no, no. I know I'm the nurse.' And then I thought, 'Oh we're gonna go through this'. And she shoves it in, and then she turns it on. And I was going, 'I can't breathe.' And she was going, 'You breathe, you breathe.' And shit, I had to grab it and thing it out. And then she goes, 'What's the matter?' And I says, 'It's on the wrong way'. Oh, I couldn't speak, so I just turned it around. And then I says, 'Would you get a doctor?' And I says to the doctor, 'It's the wrong way, it was put on the wrong way, I couldn't breathe.' And he came over and he goes, 'Which way did you have this'? She goes, 'Oh this way.' He was going, 'Well, he's not gonna get air.' And I says, 'Don't send me people like that.' Patient A

These findings suggest that when a long-stay patient tries to communicate something with the nurse caring for them, it is often about something the patient considers highly important and that is often related to symptom burden or distress.

This reinforces the importance of nurses being highly attentive to these patients' attempts to communicate and persisting in efforts to figure out exactly what it is that patient is trying to tell them. The finding of frustration of voicelessness also highlights how a 1:1 nursing environment may still involve a loss of agency when the patient is unable to communicate, be recognised, or participate meaningfully in their care.

Thirst. Participants remembered being nil by mouth and had vivid recollections of the sensation of thirst. For some, the feeling was constant and overwhelming. The sensation of thirst was intensified when the patient felt hot for example, from a fever or through the warmer months. To be deprived of anything to drink for weeks, even months was a great physiological and psychological stress. Patient E explained how for over 90 days he was kept strictly nil by mouth, then decided that he could not endure it anymore, so cognisant of the potential risks such as aspiration and lung infection, chose to have ice/water for comfort:

> Thirsty, yeah, a lot. Through the summer months especially. Um, I was nil by mouth for over 80 days. Oh, I think it was 90… 90 days, and it got to a point where in one of the meetings, I just want to have a drink. I'm over it. I don't care about the risk anymore.

Patient B who was also nil by mouth recalled how his thinking became entirely fixated on getting some relief from his constant thirst. He felt that it was not explained well why he was not able to drink: "One thing that was interesting, which wasn't entirely explained well, is that I got this bloody obsession with drinking. It wasn't explained all that well, that most people going through this have to be deprived of water very deliberately."

He remembered dreaming about drinking while he was in the ICU:

> I remember one other thing about that period. I woke up in the morning having thought that I had hopped out of bed, gone down to whatever fridge there was in the ward (laughs) and pinched one of these things [juice]. Then I sort of wake up in the morning and realised slowly that that can't have happened.

Pain and Discomfort. Participants talked about physical discomforts during their long stay, but most did not have memories of being in pain. However, one patient explained how for months he was constantly in severe pain. He felt the pain in his legs, his calves, his hamstrings, and his back. Despite being on a complex pain management regime including infusions of fentanyl, ketamine, and lignocaine, he reported that his pain could only ever be dulled: "They could only dull it. It was always there, for a long time."

Because of the tracheostomy and his underlying illness, often he could not communicate when he was in pain or the intensity of his pain. The psychological implications of this were substantial and resulted in much suffering. Being in pain like this was what he came to refer to in his mind as the "dark place." To survive, he had to figure out a way to bear this unbearable feature of his illness mentally and emotionally on his own. He knew if he could find a way of being comfortable in that place, he would be okay and everything else would be easier to cope with. When I questioned how he maintained this for such an extended time, he responded that he simply did not have any other choice. The suffering and sense of loneliness many long-stay patients feel is immense. The following quote illustrates this:

> I hadn't said it because I couldn't talk, but it was something that I always thought about, and that was being comfortable in dark places. […] Because that was what I used to think about, was if I can be okay at my worst, then everything's going to be all right. So, not being able to speak and being alone

> – and knowing that you have a nurse all the time, but that's different – you are alone, so it was about making myself comfortable in what I referred to as, the dark place. If I could get comfortable there, then I knew that I would be okay because everything else will be easier. […] That's what I used to think about when the pain – the dark place I originally was referring to was when I had the pain – the nerve pain, because that was – whenever that was – hard, so trying to be comfortable there. Then I sort of referred to it also being alone [with it].

Sleep Disturbance. Numerous factors were reported as contributing to poor sleep in the ICU. Patients had very little control over the physical environment and delivery of care in the ICU. An ICU is a highly technological and high stimulus environment with bright lights, constant noise, and busy staff. In addition, the patient's critical condition and complexity of care mandate the need for invasive monitoring and equipment and round the clock care which make achieving quality sleep extremely difficult. Illness and symptoms such as pain and delirium perpetuated the difficulty in achieving quality sleep.

Participants reported that inadequate sleep left them feeling fatigued. Some participants recalled the intense frustration they felt, even voicing feelings of anger towards environmental factors that were perceived as being modifiable to support patient sleep not being attended to, including staff talking loudly, beeping from monitors and alarms, and being disturbed often overnight for nursing cares and interventions. Patient E remembers the loudness of the constant beeping: "Oh, the beeping. Shocking. Too loud. It's like sleeping in the middle of a busy intersection in Auckland full of lights."

Patient D also remembered achieving nighttime sleep was difficult: "Very noisy. Because I'm a light sleeper. That became a problem for everyone, because they were

like, ‘Well, look, you're not getting enough sleep.’ And I'm like, ‘Well it's fuckin’ noisy, there's just alarms going off and beeping’.”

He remembered sleep disturbances from constant monitoring and observation as well as care interactions:

> Just the constant, the constant checking of stuff too. So, they'd come in, you know, so you'd be like, ‘Well, if you're gonna do that every 10-20 minutes, I'm never gonna get any sleep.’ So of course, I'm gonna be sleep deprived.

Patient B remembered being woken up overnight for bloods: “Just the whole ritual of taking blood samples, at sort of 11 o'clock or midnight or whatever, being woken up was a bit of a pain.”

Bearing the unbearable symptoms was something the long-stay patient had no choice but to do: “People always say to me, ‘Oh, I don't know how you did it.’ Well, you sort of have to, don’t you? It's not a choice.” Patient E.

On reflection, each participant verbalised individual characteristics regarding their care needs and this highlights the importance of nurses getting to know the patient through the family so that they can take a person-centred approach to helping the patient cope with symptoms. One patient described how he realised he had to become entirely focused on himself and only had the capacity to deal with whatever he was immediately faced with. Surviving the present was his focus, each hour, each day. Mindset was everything for him; he controlled what he could, then surrendered what he could not:

> It was hard for me, but I always have – oh it just comes back to my mindset. I have a mindset that if I can't control it, I just have to make the best of it. And I

couldn't control anything in there, so I just had to make the best of it and hope that the outcomes were favourable for me. Patient E

Another patient described himself as a problem-solver. To cope and feel a sense of control, he needed information and then went into problem solving mode. When his informational needs were not met, he felt frustrated. Another participant described his ability to enter a meditative sort of state, something he did every day in his work. Another patient found strength through God and his whānau (family).

All these things highlight that people have diverse ways of coping with adversity. This reinforces the importance of ICU nurses working to find ways to get to know the long-stay patient.

Delirium. Delirium was a prevalent symptom that added to participants' suffering. All participants reported delusional memories retelling vivid stories of dreams, nightmares, and delusional thoughts that they had while in the ICU. They described perceptual disturbances and hallucinations. Common themes from these experiences included being in situations that were violent, being close to death, being in danger, feeling unsafe, persecuted by people around them, feelings of powerlessness, and being in bizarre places that did not make sense. Some described seeing frightening animals around them. The delirium left participants feeling confused, frightened, and disconnected from others illustrating that the lived human experience of delirium can be distressing. Patient B remembered the nightmares he experienced while in the ICU. His retelling of this memory was accompanied with tears: "One thing I remember one of the earliest memories, and it might have been to do with the sedation or whatever being turned off or on, whatever, was just incredible nightmares (pause, emotional, tearful)."

He explained that he was in a place where people were shooting at each other and he could not escape. The nightmare persisted for what felt like an eternity until it suddenly stopped, and he realised he was not there anymore, which was a great relief:

> I was just in this place, it was funny, really, it was a set piece, sort of almost a stage, where I was, and I wanted to get the hell out of it, and it just suddenly stopped. […] That was what was most terrifying, I suppose, that lack of ability to do anything about it. […] It seemed to go on for a bloody eternity.

Patient C remembered thinking that all the ICU staff wanted to harm him. He felt his personal safety was in danger, and remembered trying to remove his intravenous lines as he believed the medications that were being administered to him were going to harm him:

> The next day, they were forced to call my brother and [wife]. Because that was the day that I started accusing everyone of wanting to harm me or wanting to do something to me. I was really paranoid. What kind of drugs are you giving me? Trying to rip the needles out of my arm, ah there was one, one of the nurses jumped on my back. Not jumped on my back, but she was holding me to try and stop me from doing what I was about to do.

He remembered feeling afraid for his own safety and attributes his agitated state, resistance of care, and attempts to remove lines as being part of his fight for survival: "It was all about self, self-preservation type. Survival. You know, gotta get away." He also described perceptual disturbances and hallucinations involving scary animals, explaining that what was most terrifying about these situations was the lack

of ability to do anything about it: "There were times where I could see things that obviously weren't there like the whole chimpanzees coming through the ceiling."

He remembered watching, frozen in fear, as meercats ran around his room:

> One of the nurses flipped a switch. And the ceiling went down on an angle, and meerkats came crawling. […] So being frozen, watching these meerkats running around the hospital room, yeah, that was that was pretty scary at the time. Yeah, it was terrifying.

Patient E talked about how he had "all sorts" of delirium and that he "had it going on constantly". There were instances where he thought he was falling through the bed. On other occasions he thought he was in a swimming pool. He remembered the sensation that there was a piece of firewood under his back: "'Get the firewood out from under me. You've got a piece of firewood under my back.' 'Eh?' 'Just move the fire-… Take the firewood out.' 'There's no wood in the bed.' 'Yes, there is.' I could feel it. 'It feels like a stump.'"

He also remembered feeling very hot and believing that he had a jersey on when he did not:

> And, um, 'Take my jersey off.' 'You haven't got a jersey on.' 'Oh, don't lie. Just take my jersey off, please. I am hot.' It comes back to the hot – the temperature. 'Just take my jersey off. It's hot.' 'You haven't got one on.' [Sighs] 'I'm not going to argue about this. Just take the jersey off, eh, take the jersey off.' This is what I'm thinking, because I can't talk.

Patient C was disturbed by memories of his behaviour in the ICU during the time that he was delirious, which he described as completely out of character. He was visibly upset when he talked about how he was not himself during that time. He

remembered being agitated and paranoid, accusing the staff of wanting to harm him. He recalled accusing nurses of running a prostitute ring. He said that he was ashamed of his behaviour and felt a deep sense of embarrassment for talking to people in a way he would never talk to people like in normal circumstances. The guilt and shame ate away at him; he contemplated going back to the ICU to apologise to the nurses. At the three-month follow-up interview, the delirium-related memories occupied his mind daily and still affected him emotionally. He brought up those stories again at the six-, nine-, and 12-month follow-ups illustrating the long-term impact of unresolved delirium memories. At the one-year follow-up, he reflected how his experience of delirium was a "big, scary monster" that had hovered over him for the last year. "I was horrible to people. Oh my god, I still cringe when I think about some of the things I said, it's just horrible."

Patient C became more at ease when I explained to him that many patients in the ICU become confused, delirious, and paranoid and that a person's behaviour can change dramatically too. I explained that most people who are critically unwell become delirious at some stage in the course of their illness and that the ICU nurses are highly trained in caring for people with delirium. He voiced that me sharing this information with him helped him feel a sense of compassion for himself and reassured him that he was not alone in this experience.

Difficulties in Breathing. Participants' memories of the experience of being mechanically ventilated and having a tracheostomy were mixed. Some described vivid memories, others very few. Several participants talked about the anxiety associated with respiratory weaning, specifically when changes were made to respiratory support, as Patient E explained: "When they would take me off or change a setting to see, that was scary, and I would panic. Yeah, I would panic a lot."

Despite people telling him that he was okay, he felt that he could not breathe and so in those moments was not okay: "Everyone would say, 'It's okay, you're okay, just calm down, just breathe.' It didn't really matter what anyone said. I was panicking because I couldn't breathe."

Patient A also found changes to his respiratory support stressful:

> Anything new that came I say, 'But am I gonna breathe?' And they were going, 'Yeah, but it might be difficult at the start'. And geez, I didn't like it. Every time they changed the machine. Because I didn't understand it.

He reflected that he was anxious about his breathing because of an underlying fear of dying: "That's why I'm pretty thing [anxious] when it comes to my air, ah I don't wanna die."

As I considered what the participants were telling me about their ICU experience, I was reminded that the symptom load for the long-term ICU patient is substantial, and enduring this for such an extended period is clearly extremely difficult and a major contributor to a patient's suffering.

5.4.4 Being Misunderstood

In exploring the dimension of sociality, a common thread that emerged from participants' narratives of their experiences of the ICU was the experience of being misunderstood, bringing forth the subtheme, 'Being misunderstood'. The communication barriers caused by the breathing tube, mechanical ventilation, critical illness weakness, impaired cognitive function, and delirium impacted on the participants' ability to express themselves and be understood. Looking backwards in time, participants talked about interactions with ICU nurses where joint understanding was not achieved, and this created interpersonal tensions. This seemed to be in situations where the patients' attempts to express themselves were

either not recognised or understood by the nurses, highlighting that nurses must spend time on communication and understanding the long-stay ICU patients' attempts to express their needs. Participants' narratives suggest discrepancies between a patient's experience and the nurse's perception. This was evident across multiple dimensions of care including symptom assessment and management, communication of information, mechanical ventilation and respiratory weaning, sleep, and rehabilitation. A major underlying factor contributing to participants not being understood was their reduced capacity to communicate secondary to the illness and treatment leaving them voiceless. However, one participant recalled situations where he could speak yet still felt misunderstood.

Patient A retold a story of the time his journey of healing began. After a long time being unconscious and having woken up, he had developed an awareness of how debilitated his body was and that to get off the respiratory support and return home – where he longed to be – he needed to rebuild his incapacitated body. He recognised that the key to this was getting his body moving again. There was not a lot he could do being confined to a bed for most of the day; however, he intentionally moved what he could. He described how at first, he focused on moving his fingers, then his hands. Eventually he could get his legs moving. The gradual return of movement and seeing physical progress no matter how minor, gave him hope that he would get better. The personal significance of this hope cannot be understated; it provided him with motivation for rehabilitation – an aspect of his ICU journey that was demanding but he knew it was necessary for recovery and supported him to cope mentally. Additionally, being acutely aware of how close he came to dying, hope was connected to survival. Patient A explained how, while he was in bed, he would try and strengthen his muscles by doing exercises: leg movements, holding

onto the bed rail, and trying to lift his hips. However, throughout this narrative, he described tension with the nurses, and explained that they did not understand why he was moving and that consequently his behaviour was viewed as problematic:

> I started to heal. I wanted to heal. So started kicking my legs and I wanted to get up and walk. And I was really positive in that way. I wanted my body to move so I used to exercise at night because I got told off during the day. And yeah, and I was doing that and then the nurse caught me and he was going, 'You can't do that.' I was going, 'But I want to move', you know that's what I was tryna tell him.

He felt that he was treated like a difficult patient because of this:

> It wasn't the tube; it was the bed. I was trying to get a grip. 'Leave that alone, don't you break that!' I wasn't trying to break it; I was trying to strengthen my muscles. And I kept getting told off. I know one, she was an old nurse, but she came in and goes, 'I don't want any problems with you, so you know, so you just lie there, I'm gonna watch you.'

Patient D talked at length about his frustration at being spoken to by nurses as if he was "mentally incapacitated". He retold experiences of waking up in the ICU and wanting information about what had happened to him and information concerning his current care, but the nurses did not share this information with him. He explained that he became increasingly frustrated as time went on, wanting information but not getting it. This produced anger, adding to his mental and emotional burden. He stated that he felt disrespected. He emphasised the need for effective communication, and the provision of transparent information sharing between healthcare professionals and the patient. As a nurse, hearing this narrative leaves

me feeling upset and concerned as it is a patient's right to be fully informed throughout their healthcare journey. The following excerpt highlights his experience of being misunderstood:

> A lot of it from a patient's perspective, added to the frustration, and probably, because I was constantly told, oh, my brains not working, my brain's not working. And I was like, 'Well, I'm pretty, I feel personally at the moment I'm pretty fucking cognitive.'

In reviewing these participants' accounts, I became aware of a potentially harmful assumption held by many ICU nurses: that the patient will not remember anything. This view can result in nurses minimising or overlooking the significance of experiences that may be upsetting to patients and cause distress in the short- and long-term. Several participants in this study had vivid memories of being exposed to death and dying in the ICU – seeing and hearing other patients dying around them. When they retold these stories, their discomfort and sadness was visible. They came to the realisation that they were in a place where people die, which highlights that many patients confront death in the ICU. Patient E remembered seeing caskets moved through the ICU: "I saw a casket roll by. Um, yeah, it wasn't easy to see, yeah, but I know that I'm in a place where it happens a lot."

Patient D told stories of witnessing people dying:

> You'd see the teams rush in. Do their best. Go through the normal things. And you're like, oh yeah that person's probably not gonna make it. And then eventually, the noises stop because they've turned everything off. And then obviously the curtains do close until they take that person away.

Patient A was visibly upset recalling his proximity to death and dying. He paused for some time, then his wife continued, recognising that he could not go on:

> After a while he really didn't like that end room he was put in by the door, because then he found out what the door was for. Cause the hearse went out there. Because they'll all come round and shut everybody's curtains and cause you know, you would know what's happened then, cause you could hear people wailing a bit, crying.

In reviewing the narratives, I reflected on another common assumption held by some ICU nurses: that the patient cannot hear. Several patients retold stories of how they overheard conversations that they did not want to hear:

> I heard her [nurse] say that a former patient had been in for six months and that there was no way I was gonna be out in that same time. She didn't say it to me – she was talking to somebody else – but you know, there's nothing wrong with my ears. Yeah, I can still hear everything. Yeah, so yeah, I heard that, and I was like, oh, okay. Yeah, I took it negatively anyway. Patient E

Patient D remembered hearing nurses talking about other patients as well as "slagging each other off", which made him feel uncomfortable. He described these conversations as inappropriate, noting that patients could hear everything in the open ICU environment. On more than one occasion he felt the need to remind staff that such conversations were inappropriate in the presence of patients:

> There were a couple occasions too where I was uncomfortable listening to discussions around other patients. It was like, that's not cool. […] And they

were embarrassing, you know, through situations that are outside their control. […] And so, on more than one occasion, I remember having to have a conversation with some of the nurses saying, 'In this situation, there are no walls. You can hear everything, including all the beeps and noises but you slagging off each other while the patients are here listening to it is not appropriate.'

This data about nurses "slagging each other off" is a significant finding. Framed within the dimension of sociality, it highlights the tension between the institutional professional narrative and the patient's *personal narrative lived truth*.

This tension and emphasis on importance of staff awareness that patients can hear everything in an open environment was reinforced by Patient E, who, having spent many months in the ICU, was asked whether he had any message for nurses to improve future care of this group. He replied, "Tell them that we have ears, and we can hear everything."

5.4.5 I want to Get Out!

All the participants described remembering wanting nothing more than to be out of the ICU, healthy, back home, and with family. From a nurse's perspective, I saw that as an important motivator for participants to move forward, maintaining hope, which sustained and fuelled their recovery and rehabilitation efforts while in hospital. As Patient E stated: "Your biggest journey there is to get out of there."

Emerging in participants' narratives of 'I want to get out!' were stories of (a) wanting to escape in the early stages of the ICU admission when they were delirious and frightened, and (b) regaining lucidity and intentionally working to get stronger and get out of the ICU. Most participants had limited memory of their ICU admission due to the severity of illness and rapidly deteriorating physical health. However,

several participants recalled how during the early stages of their admission, they were desperate to get out. Participants remembered feeling frightened. Their bodily functions were rapidly deteriorating, their ability to think clearly was becoming increasingly impaired. Several hours ago, they knew they were seriously ill and needed to get to hospital, but by now, their health had deteriorated to the point that they no longer perceived that anything was wrong with them and in their unwell state, were unable to rationalise that they need medical care. Furthermore, these participants described that the foreign ICU environment and interactions with staff who were working with urgency to save their life, left them feeling overwhelmed, powerless, helpless, and vulnerable.

During this time the patient is in a precarious state, in the balance between life and death. The participants' narratives reveal it is a time of great mental and emotional stress. Several participants described vivid memories of feeling that their personal safety was in jeopardy, that the ICU staff were trying to harm them. They described memories of feelings of being in danger, fearing for their own personal safety, fearing for their life, and wanting to be rescued by family. For some the fear of being harmed and even death is overwhelming and so they perceive getting out as being necessary to survival as illustrated in the following quote: "It was all about self, self-preservation type. Survival. You know, gotta get away." Patient C.

In the following quote, Patient A's wife, who sat in during his first interview, highlights just how distressed and desperate to get out of the ICU he was at this time, believing that the ICU staff were trying to kill him: "He's telling me, 'Come and get me.' And then I could hear him and getting hysterical and going, 'She's trying to kill me, she wants to kill me'."

Patient C also remembered fearing for his life, yelling at his brother through the phone that the staff were out to get him: “They ended up calling my brother and I was yelling at my brother that they're out to get me, they're out to get me!”

All participants were sedated in the early days/weeks of their ICU admission due to severity of illness. When the sedation was turned off and they regained consciousness, the longing to return home resurfaced. Just like when they were first admitted, upon waking, patients did not realise how unwell they were and did not remember what happened to them or where they are. The desire to get out of the ICU remained strong: “Get me out of here, you know, that's what I wanted, to get out. I didn't realise how bad I was.” Patient A.

As the long-stay ICU patient’s physiological status improves and delirium resolves, brain function gradually improves as well. This return to somewhat normal brain function is followed by an important moment in the patient’s journey where realisation and hope intersect. The long-stay patient comes to the realisation that they are very unwell, and their body is not functioning like it used to. The essence of this realisation is emotional. Patient A retold the moment he realised the severity of his illness and just how incapacitated he was, recognising that while he wanted to get better and get out of the ICU, he was still unwell, physically weak, and dependent: “That's the biggest thing, is I needed to get out of there and to get better, mainly. But by getting better I didn't want to go on my bed outta there. I wanted to walk outta there.”

In considering the idea of wanting to get out of the ICU, by becoming aware of just how debilitated they are, long-stay patients begin to understand that the only way they are going to get out is by getting their body moving again and also, getting stronger. The return of movement is thus a defining moment for the long-stay patient and marks a new stage in their journey. From the patient’s perspective, the return of

movement signifies the beginning of recovery. It is the beginning of them actively working to rebuild their ravaged body. Movement is essential to keeping hope for recovery alive. For Patient E it meant he was a step closer to coming home. This instilled hope and was something that he held onto for the duration of his hospital stay: "Get moving. It's the only way I'm going to get out of here."

It appears that this critical moment in the long-stay patient's journey leads to several shifts occurring within the patient; they move from a state of passively enduring to proactively fighting to survive. Inner strength to keep going is activated; the patient shifts from being helpless to realising that there are some things that they can control. The following quote reflects several participants' moments where realisation, the return of movement, and hope intersect marking the beginning of their journey out of there: "My first goal is I've got to be able to move my hands." Patient D.

This longing to get out of the ICU and determination to move the body remained consistent throughout the course of the participants' hospital journey. They were motivated to move their bodies, to participate in exercises and physiotherapy despite how incredibly difficult it was in the beginning due to factors such as pain, fatigue, and extreme weakness, as the following quote by Patient E demonstrates: "I never got miserable to the point where I didn't want to do it. Stuff that. You know, I wanted to get out of there, and there was only one way."

5.4.6 Needing Person-centred Care and Connection

Participants' narratives highlighted their need for person-centredness in the ICU. Care from health professionals that is grounded in kindness and humanity, care from family, and feeling connected to these people were felt to be essential: "It was just to care, because as a patient, I'm pretty sure, from my perspective, that's what we want. Well,

yeah, it's not what we want, it's actually what we need. […] You can't care enough."

Patient E

Person-centred practice is a holistic approach to care that is focused on respecting and responding to the needs, values, preferences and experiences of the individual. It is a way of thinking about and providing healthcare that is grounded in a therapeutic relationship and philosophy of personhood (Levitt-Jones, 2014). However, participants' narratives highlight both positive and negative experiences of person-centred practice. Furthermore, an important finding that needs to be considered is that only one patient participant spoke about memories of positive, caring encounters with nurses during their ICU admission. This is not to say that the nurses caring for these patients were not well intentioned but rather may suggest that the nurses' approach to care and interpersonal interactions in those instances did not always meet participants' needs.

Patient E described many situations where he felt cared for by the ICU team looking after him and the power this had in helping him get through such a difficult experience. He spoke about how the nurses showed an appreciation for his life outside of the ICU seeking to get to know and understand him and his family, actively involving family in his care, demonstrating empathy, advocating for his needs, and persevering with communication. He commented on how positive his rehabilitation team was in helping him reach his goals, how his bedspace including the ceiling was personalised with photos of family, and how the ICU team organised regular home visits. All of this created a caring, supportive environment that he appreciated. He perceived the care in the ICU as being very good, and attributes having a positive overall ICU experience to this:

It was overall really positive. I don't think I could have been in a better place. The, the staff were, were great. They were – yeah, really, really good – all different in their own ways, but all, all coming from the right place. You know, they weren't there to collect their pay cheque. […] It was really, really good. They really cared.

He shared many examples of person-centredness, including the following:

Another nurse […] she'd seen a lot of Guillain Barre cases before. She asked the right questions for me. […] Like, um, different consultants, different ideas, different views on how my plans should go, and then being on the end of a consultant's decision, and then the next week, the plan changing because of another consultant being on board. So, it was a constant, um, not knowing what the plan actually was for, for progression. And she [nurse] would say, 'Why are we doing this? We've already tried, you know, turning down the ventilator, and he's not hacking it. So, we should be doing this…' […] So I think that's where her, her experience came in really valuable. Um, but not only that, but she actually fought for it for me, and she would talk to [deidentified nurse] the, the Indian nurse, and say, 'Hey, this isn't right,' and they would, they would go into bat for me at these meetings – even come in on their days off, if they knew that there was a, a family meeting, as they liked to call them, to express that.

Several months into his ICU admission, Patient E was still paralysed and ventilator dependent, but his story reveals inconsistency with medical decision making regarding the respiratory weaning plan. He described different ICU consultants having different views and approaches on how to manage the weaning

process, the plan constantly changing and no collaborative approach to decision making. This created a constant not knowing what the plan was for progression. Furthermore, the lack of consistency was contributing to respiratory weaning setbacks, frustrating experiences, and he was not progressing. Patient E explained how because he was unable to communicate, his needs were therefore not included in decisions related to his medical management. Instead, he relied on the nurses who knew him to advocate for him. In this situation several nurses who looked after him often and listened to his spouse's concerns, recognised that the current approach was not having positive outcomes for him, spoke up and challenged the doctors' reasoning for a consistent respiratory weaning strategy and for a collaborative approach to decision making. The outcome of this was that an inclusive and consistent approach to decision making and weaning was implemented. From this point onwards, he felt informed and secure and furthermore, he had fewer respiratory setbacks and began making progress.

The actions of these nurses, specifically foregrounding Patient E's needs based on their knowledge of him, their commitment to his wellbeing, listening with intent to understand his spouses concern, and their stance of advocacy are powerful reminders of the potential impact ICU nurses enacting person-centred practice can make to the experiences and outcomes of long-stay patients.

Patient D described memories of his ICU stay as it progressed. He had limited memory of early on and when he was intubated and ventilated but described memories from later in his stay when this support had been removed. One of his greatest frustrations was not being listened to. He also recalled being labelled and treated as though he was cognitively impaired:

> I'm acutely aware of what's going on around me. I'm not the, you know, the brain-dead patient or stroke victim that you think I am. And that was probably the biggest point of frustration. And yeah, I mean, it led to a lot of the nurses treating me a particular way as well.

He also described care encounters with nurses who from his perspective simply did not care and did not want to be there:

> They didn't really care for their job as much as others. I'm here, and I'm out. I'm not emotionally attached to this job. It's just a job. And you could tell. They were less empathetic and not as effective as nurses, particularly in that ward [ICU]. And for those of us who are probably a bit more cognitively aware, you're like, if I've got that nurse, it's probably gonna be a pretty rough night. They were just genuinely less careful as well. So, a bit more rough. Stop complaining. I've got a job to do. Suck it up, Sally. That was pretty much the feeling of it.

From my position as nurse and researcher, I reflected on this participant's narratives about how he felt about his care at the end of his ICU stay. I considered Minton's (2017) research and how it is known ICU nurses generally do not want to care for long-stay patients at this stage because they are not their usual patient, that is not *real* ICU patients, and nurses cannot control the patient at this stage (the ICU is a very controlled environment and the work of the ICU nurse is very structured and controlled).

Patient B was unable to provide any examples of his interactions with nurses, despite being prompted. It became apparent to me that this was due to his lack of memory of the time in the ICU. He has been left with considerable cognitive

impairment following the critical illness that was still present one year post-hospital discharge. Patient C, who was delirious for the duration of his ICU admission including at ICU discharge also did not have any clear, specific memories of the nursing care in the ICU but retold several stories of when he was delirious, and a nurse was mentioned in these. However, the nurse was not perceived as being caring and reassuring.

The recurring themes across participants' narratives, both positive and negative, concerned how nurses related to patients and their ability to recognise patients' needs, highlighting the importance of relational care, connection, and effective communication with this cohort.

Despite being in a busy place where there are lots of people, and having a nurse to themselves, several participants spoke about how the experience of a long stay in the ICU is lonely. Furthermore, delirium and communication difficulties can place patients in a liminal space where they feel disconnected from reality and isolated from others. Participants spoke of their own vulnerability and having an attentive nurse close by who was always within sight of the patient provided a sense of comfort: "There was quite a few of the nurses here that were always with me. They felt like another part of you." Patient A.

The expression of empathy and sympathy were also perceived as important to participants: "It would always come down to one thing, the individual providing the care. The reasons you remember that is because they were still able to express empathy and sympathy." Patient D.

Also, Patient E spoke fondly of a memory he had of a particular nurse who showed such patience for him and his symptoms, highlighting the value patients place on empathy and patience:

> [Nurse]. He was great. So patient with me, with my hallucinations, with my… The temperature thing for me was hard. It was hot. It was November/December, those first three months, November, December, January, and even though my temperature was okay, I was burning… Yeah, and they were patient.

Emerging in Patient E's narratives is the vital importance of integrating hope into nursing care to help the long-stay patient to endure and cope with the immense difficulties of a prolonged critical illness. He explained the value of nurses who weaved threads of hope into his care. He explained that these nurses would affirm that he would get through his illness, and they would also point out even the smallest signs of physical improvement. To him, the power of these positive comments could not be underestimated; they had the ability to change the trajectory of his day:

> They were positive – 'Looking good.' You know. 'Oh, you can do that today.' Just things like that. That's all you need when you're in a position like that. It really is all you need. I don't, I don't know. I can't speak for anyone else. I like to think I'm a pretty motivated person, but all it takes is a comment and, um, it changes your day. […] Because you don't notice, you know, things in the moment. You don't notice things yourself. You're lying there with the realisation that you're in a bed and you can't move. You need those people around you to point those milestones out sometimes.

Several participants talked about the benefits of humanising care including interventions such as showers, getting out of bed, being taken outside, and efforts made to personalise the bedspace including displaying photographs of family. Patient E explained the therapeutic experience of having a shower:

> They'd put me on the, put me on the mobile ventilator and off we wheeled and, oh it was just, yeah, it was – that was a highlight, was, was the rest of that day feeling clean – um, feeling clean and, and refreshed and energised. I felt – just felt really relaxed afterwards.

An important source of care and connection was family. Family was a lifeline; familiar faces providing reassurance and a sense of security when the patient woke from sedation, anchoring them to reality during delirium, and even guiding them towards life when they were faced with death:

> I felt like giving up. I can't, I can't do it anymore. I can't. I can't get off this train. I can't get out of this building. I've had enough. And then it was at those moments where I felt a hand on my arm, either arm, and I could hear my brother and [wife] saying, 'It's okay. It's okay bro. I'm here with you. Okay, I'm right here. I'm not going anywhere.' 'Hey hun, it's okay. I'm right here with you.' I don't know if that happened or not, but I could hear their voices and I could feel them on either arm saying, 'It's okay. We're here.' Patient C

Patient E remembered how his spouse helped him to be calm and cope: "[Spouse] was there for a lot of those. She calmed me down."

These examples highlight that family members are essential parts of the patient's care team. I reflected on how person-centred practice is enhanced when the nurse and family work together to recognise and meet the patient's needs.

5.5 Patient Participants' Experiences of the General Ward

5.5.1 Overarching Theme: Unmet Needs

The overarching theme from patient participants' experiences of their time on the general wards was 'Unmet needs'. Following their move from the ICU to the

general wards, patients' narratives reveal that the ward was a place where many of their fundamental needs were unmet. The experience of unmet needs began with their transition experience of discharging out of the ICU to ward level care; looking back in time, patients' narratives suggest that they had not been adequately prepared prior to the ICU discharge for the reality of ward-level care and the changes that they would encounter in this new environment. Furthermore, their recollection of the ICU discharge, coupled with feelings of uncertainty and vulnerability, suggest shortcomings in patient education and transitional support.

After a prolonged stay in the ICU where the patient had close monitoring, dedicated one-to-one nursing, and knowledgeable staff looking after them all of which provided a sense of safety, the reality of being on the general ward was perceived as a shock. This is encapsulated in the first subtheme, 'From sanctuary to unknown'. It took time for patients to adjust to the changes on the ward. The participants left the ICU alive, but they were still unwell, unable to walk, and in need of extensive rehabilitation. They had not yet regained their independence and so continued to be reliant on considerable assistance from ward staff and/or family members for fundamental needs such as personal care, hygiene care, nutrition/feeding, toileting, safety, and emotional support. Several were so weak they were unable to reach the nursing call bell unless it was placed beside their hand.

However, participants' narratives reveal that often fundamental needs were not met or attended to. Furthermore, their narratives illuminate that the ward was a place where clinical tasks were privileged over the formation and fostering of person-centred relational care. Nursing care was reported as variable with few examples of care able to be provided that could be considered good. All participants described a sizeable gulf in nursing care between the ICU and the ward, revealing that care

progressively declined as they transitioned through the hospital system as stated by one participant: "It [care] got progressively worse as you left the big ICU area. It definitely dropped off. Big time, biiiig time." Patient D.

This reduction in intensity of nursing care is the essence of the second subtheme, 'Unmet care needs'. It took time for participants to adjust to the less intensive care environment of the ward.

Additionally, patients were psychologically and emotionally fragile, in the early stages of coming to terms with their situation and trying to make sense of their condition. However, this was a struggle and something they could not do alone. Notions of fragility, vulnerability, struggle, and coming to terms with their situation are captured in the following excerpt taken from a reflective field note written immediately after meeting one of the participants while he was still a patient in hospital on the rehabilitation ward, two weeks after he was discharged from the ICU:

> *I am left with many thoughts from this meeting. Firstly, within minutes of us meeting, he became tearful telling me how sick he has been. He also shared that overnight he spiked a fever and this really rattled him. He was afraid of getting sick again, afraid of having to go back to the ICU. While the emotions he expressed were not at all unexpected or surprising to me, how quick he was to share his story and be vulnerable with me was enlightening. It highlighted to me several things including his need to talk with someone who genuinely cares as well as the need for connection, understanding, and support. I was left wondering, what health professional was fulfilling this need. The conversation took time. I was happy to be with him, let him talk about*

what he wanted to, and above all listen, but I was aware that the system does not allow nurses to work in this way.

Secondly, one of the most obvious observations from this meeting is that there are many things that he is currently working through in his head and much of it, he needs people to help him with. But he is not getting this help. He is really only just beginning to process what has happened to him and what it means for him and importantly, his family. He is trying to make sense not only of what has happened to him and his medical condition, but what it all means for his future. He has questions. He has numerous worries. Worries for the future, for finances, for his ability to support his family, for his health. There is so much uncertainty. So many forward-facing stories of which the endings have not been written. What he is working through right now is also emotional work. Reliving the horror of the ICU admission. He is fragile. Visibly tearful. Puzzled. Troubled. He spoke earlier of how talking with someone helped him, so I wonder if there is a need for continued psychological input here. I think this would be very helpful for him right now.

5.5.2 From Sanctuary to Unknown

Participants' experience of discharging from the ICU and facing the reality of ward-level care that was very different to the ICU was perceived as a shock. For many, early days in this new place were particularly stressful. Some participants had no recollection of this transition because they were still delirious. Others could recall this moment in their journey and described mixed feelings about leaving the ICU after such a protracted stay. On the one hand, patients longed to return home and

the journey out of hospital became a sole focus; discharging from the ICU was perceived as a major milestone in their recovery journey. There was relief that they were now well enough to leave the ICU. It meant they were one step closer to being where they yearned to be and provided hope for recovery and returning to normal. However, the impending discharge was also met with apprehension and anxiety. Some participants felt that they were not ready to leave the familiar and secure environment of the ICU and there was a very real fear of the unknown, as the following quote shows: "Really scary. I was leaving my comfort zone. It had become my comfort zone, it had become my home, and I was nervous, and I was apprehensive, and I was shitting myself, because I didn't think I was ready." Patient E.

Several participants highlighted a lack of psychological preparation for the ICU discharge, specifically changes they would encounter on the ward. Patient A had always thought he would walk out of the ICU by the time he was well enough to be discharged but realised this was not going to be, which was an emotional blow. After a five-and-a-half-month admission, he perceived the ICU discharge as being suddenly thrust upon him and did not know anything about the ward he was going to:

> I didn't want to come out how I was. I wanted to walk out. And I thought I was going to, until they said I was going up to the next ward. And even then, I thought, What's the next ward? What's that?

Patient E also spoke of the unknown and worried whether the ward he was discharging to would have the equipment he needed as well as staff that were capable of caring for him: "I didn't know what was down there. I didn't know if they had hoists or not or if they had staff that were trained enough to tend for my needs."

Upon arrival to the ward, some patients reported feeling unsettled in this new environment and longed to be back in the ICU: "I wanted to get out of there [ICU] but after I got out of there, I wanted to go back." Patient A.

The following participant recalled how he was so frightened and anxious arriving on ward that for several days and nights he could not sleep:

> My first two days there, I had a doctor come in, I didn't sleep. I didn't sleep all that day. I didn't sleep that night. I didn't sleep the next day. And I didn't sleep that night. So, they bought a doctor in, and he says, 'Do you feel anxiety?' And I says, 'Yeah'. Patient A

Contributing to the feeling of safety in the ICU was the constant presence of nursing staff. Patients knew that help was immediately available: "In ICU, there's always someone around." Patient C. From my perspective, the ICU environment could therefore, be understood as a *High-Trust, High-Resource Sanctuary*, where physical closeness and attentiveness of nurses fostered reassurance and psychological safety. In contrast, the general wards, where patients might go hours without seeing staff: "You never saw anyone there" (Patient B), could be understood as a *Low-Trust, Fragmented Surveillance Zone*. In the general wards, sparse visibility and infrequent contact with nurses heightened feelings of vulnerability and abandonment. One participant described his early experiences on the ward as "scary and lonely" (Patient E). Nurses were perceived by participants as being busy and stressed with little time to spend with the patients in caring moments. Some participants commented that when nurses regularly checked in on them, they felt more secure, highlighting the psychological significance of ward nurses being regularly attentive to this cohort of patients as they are adjusting to the new ward environment. Also, when nurses let the patient know that someone would be there for them if they needed anything, it

provided a sense of confidence and safety: “She was going, ‘If you need anything I'm just next door.’ And that gave me a bit of hope because she always called in.” Patient A.

5.5.3 Unmet Care Needs

Nursing care was reported by participants as variable but, overall, participants felt there was an abrupt and marked reduction in care and support from the ward nurses compared to the ICU nurses. They reported that nursing presence diminished significantly on the wards. Some participants perceived that nurses on the wards did not understand their needs. Patient B spoke of differences in nursing care and interactions with nursing staff between the ICU at a tertiary hospital and the regional hospital he was transferred to once he was out of the ICU:

> It wasn't sort of anything like as impressive as the care was in ICU. They [ward nurses] sort of didn't seem willing, like you'd have your buzzer which you could press, and sometimes no one would come […] But like, God, they seem to be pretty busy and hassled.

He also made the following statement:

> When I was in [deidentified regional] hospital they were all old nurses, and they’re crotchety old bitches, as well, quite often. They’re not happy people, and they’re not interested in service, really. No, that was a huge, that was quite a dramatic difference in the nursing quality between ICU and out here.

Patient A explained that nursing care encounters centred on the delivery of technical tasks and once a task was completed, he would not see a nurse all day, which reinforces the reality of a systemic culture where biomedical tasks are privileged over relationships: “The staff were, you know, they came in and done the job and left you. And you won't see them all day.”

Most participants perceived that the hospital wards were short-staffed and from their perspective this negatively impacted on the provision of care; interactions between the nurse and patient were brief and they had unmet needs. Missed nursing care was described. For example, Patient D talked about how he was in agonising pain for 2 days while he was on the medical ward. He did not receive timely care and treatment of this pain:

> The last ward I was at, I had two horrific days of pain. And so even trying to get some pain meds just to manage that, that took way too long. Like I was in agony for like hours and hours.

Also evident through participants' stories of their experiences on the wards was that ward nurses did not understand them and their journey. Some patients commented on a lack of empathy conveyed towards them and what they had been and continued to go through. One participant spoke of an interaction with a ward nurse who evidently did not understand him or his need to feel safe on the new ward in the context of a several months stay in the ICU. He had developed anxiety after transferring to the ward and was unable to sleep so the doctor charted some medication to help with this:

> I said, 'What are these?' And she goes, 'They're for your brain'. That's how she put it to me. She goes 'They're for your brain, is there something wrong with you?' And I was going, 'Course there's not'. And she was going, 'Well these are for your brain'. […] I never slept for 2 days. Patient A

This excerpt highlights a lack of nursing knowledge on the phenomena of prolonged critical illness and the challenges this cohort face as they transition out of the ICU after an extended stay. As I review these narratives, it becomes clear that

nurses need to have knowledge on the challenges former long-stay ICU patients commonly experience in this next phase of their journey so that they can proactively plan care and support the patient with navigating these challenges. This will support patients to feel safe, understood, and cared for.

The consequences of the critical illness on the participants' physical body had left them severely debilitated. Upon arriving to the ward, patients described how they were still largely incapacitated and dependent. They needed assistance with mobilising. Most needed to be hoisted out of bed, assistance with toileting, and hygiene cares. Some were unable to feed themselves, even reach the patient call bell as was the case for Patient D: "You would wait because I couldn't even reach the buzzer at that particular time to ask for help."

Patient D had also lost his voice so was unable to yell for help: "I couldn't move or ask for help, and my voice, I'd lost quite a lot of my voice and so my voice volume was really low."

Because of the still resolving delirium, some participants did not have sufficient insight into their physical limitations, which was a patient safety issue. Several described instances where they fell due to a lack of insight into their reduced abilities. They did not have the strength to recover themselves and get back up. Patient A remembered falling in the shower: "I remember I done that [stood up in shower] in hospital, and I fell over, and it took all of these staff to pick me up."

From my reflections on the patients' narratives, it was clear that ward nurses lacked understanding that the long-stay patient is not able to care for themselves fully. The following quote is a salient example:

> I remember my brother saying, 'Can you remember whether the nurses have actually washed you down there properly at all?' And I'm like, 'No, no'. And

so, he's like, ‘I think you've got a double, you've got infection around foreskins and stuff, and you've got that [urinary tract infection]’. And so, when they lifted me up one night, like the second night or third night it was, when they put me up on the commode, he said, ‘Let's have a look’. And he was like, ‘Fuck, yeah, this is bad. Yeah, you've not been cleaned’. And he says, ‘Yeah so you're gonna have to clean yourself’. Patient D

5.6 Patient Participants’ Experiences of Being Home

5.6.1 Overarching Theme: A year of Tending to the Self

The overarching theme from patients’ experiences across the first year at home was ‘A year of tending to self’. All patient participants in this study described how becoming critically unwell was a life-altering experience. The illness upended life as they knew it, and the impact for the patient was profound and far reaching. Patients described experiencing bodily changes that limited their everyday life and changed their daily routines. They described living with new physical, psychosocial, and cognitive problems; living with new or worsened chronic illness and/or disability; and everyday struggles. Situated within the intertwining dimensions of temporality and sociality, the overarching theme, ‘A year of tending to the self’ captured their year-long journey. This theme encapsulates participants’ need to focus on themselves to heal from the trauma of the experience, adjust to living with a changed body, and rebuild their bodies and their lives. The need to focus on themselves and their recovery appeared to be ongoing for most the first year, reflecting the long-term nature of recovery from a prolonged critical illness.

The theme ‘A year of tending to the self’ also encapsulates the notion of patients re-establishing themselves and figuring out how to be in the world again post-illness. When patients first came home from hospital, they were confronted with

a new reality, one where they were still unwell, shattered, and dependent on others. Their previous known reality was no more; the critical illness had destroyed the ability to live the way they had previously lived. They now had to deal with managing new health problems and focus on getting themselves well again. Facing this new reality characterised by an unfamiliarity of the changed self and struggle, was difficult.

Analysis of the narratives identified that the notion of tending to the self can be traced back to the illness experience and time in hospital. All patients expressed knowledge of how seriously unwell they were. They spoke of how they had been confronted with death in hospital, either in dreams, nightmares, or witnessing the death of others, and thus contemplated their own vulnerability and mortality. Participants came to realise how close they had come to dying, and they articulated feeling lucky to be alive and that they wanted to keep on living. Tending to themselves, therefore, was part of the pathway of survival, even long after the ICU admission, highlighting memories of the critical illness experience while in the past, are never forgotten.

Looking backwards in time and comparing the person they were before becoming unwell to the present self, participants' stories revealed how the illness ravaged them physically and mentally. From the moment they regained consciousness in the ICU, they noticed that their body was different. Patients described feeling stunned at how weak they were. Participants described how their body no longer functioned, felt, or looked like it used to. Their narratives reveal that a prolonged critical illness, therefore, substantially changes a person's body. Over the course of the first year, they described having to tend to themselves to learn how to manage their changed body and its new limitations. This was a difficult process,

characterised by adaptation and adjustment. It took time and effort. One participant, who developed an ischaemic gut as a complication of a major surgery and subsequently required a life-saving bowel resection, spoke about how it took him nearly a year to learn how to manage his colostomy: "Getting used to the bag has been a huge thing. It's taken me almost all this time to get to be not having this thing bursting unexpectedly." Patient B.

Rebuilding the damaged body was a feature of the narrative 'A year of tending to the self'. All participants expressed the need to rebuild their bodies. They perceived it as being a prerequisite to regaining independence and rebuilding their lives. Rebuilding the body was a process, but it was not a time bound process; at one-year follow-up, while significant improvements in physical recovery had been made, no participants had returned to their pre-illness level of function or strength, revealing incomplete recovery. Most participants faced the challenge of physical recovery head on, with intentionality, although their approaches were individualised, and support was variable. Some participants had access to healthcare services and practical supports during recovery, others did not, reflecting (a) a continuum of vulnerability that endures long after hospital for the long-stay ICU patient due to a lack of support, (b) a major disconnect between hospital and home, and (c) a context of fragmented care.

All participants were on a personal journey to regain independence and return to "normal." Participants' stories across the year reveal that the journey to recovery after a critical illness is complex, non-linear, and ongoing. It is a difficult journey characterised by prolonged struggle, a continuum of vulnerability, and enduring uncertainty. Furthermore, complete recovery is not guaranteed. All participants were learning to live with a changed self and needed to redefine a new and acceptable

normal for themselves. One-year post-hospital discharge, none had fully recovered, experiencing persistent physical, cognitive, or psychosocial post-ICU problems that impacted on their everyday life highlighting that a prolonged critical illness irreparably changes a person and that person's life.

5.6.2 Coming Home: Facing a New Reality

Participants had been in hospital for a long time and described a sense of gratitude for having survived and finally being able to return home. Home was a place of belonging. It was a place to live and a proper environment to live in after living in the hospital for so long. Home was a place of safety and comfort. It was a place where participants could be reunited with family who they for so long had been separated from: "It's a massive deal; it's a huge deal to be home. It's something that I wanted from day one. Being with my family is a massive thing for me." Patient C.

Home was perceived as a place where participants believed they could heal and rehabilitate. Participants felt that consistently doing the sorts of normal everyday things that they would have to do at home would be more beneficial for their physical rehabilitation than the limited rehabilitation they were getting at hospital:

> I was reasonably sort of insistent that I wanted to get the hell out of there.
> Because I was just convinced that it [home] was the best place for me.
> Because of doing all the things I have to do at home. Patient B

Coming home was also recognised as a milestone in the participants' recovery journey and perceived as the first step in being a part of life again:

> It means everything. It's a, it's a major milestone in my recovery. It means that I can be present in this family. […] It means that I can be present in life again.

> You know. That's, yeah, that's what it means to me. Just to be, be a part of everything, and part of life again. Patient E

However, all spoke of how their everyday life had dramatically changed because of their experience and ongoing health problems and participants were now confronted with a new reality in this place. Initial feelings of joy soon diminished. This was replaced with feelings of anxiety and frustration due to struggling with physical, psychological, and cognitive problems, as well as the relational tensions with spouses that emerged as the couple navigated dependency and the burden of care. Patients described an awareness that they were different from before the critical illness. There was also realisation that despite being well enough to not need to be in hospital, they are still unwell and a long way from where they wanted to be in terms of health, function, independence, ability to work, and general participation in life. Coming to understand themselves and accept this new existence was difficult and there was no one to help them with this:

> I think you go through that initial, it's not a shock, I think you, it's sort of almost like a grieving process where you go, shit, I'm not where I really want to be, and you go through a process of accepting. That journey is a bit hard. Patient D

The stories of participants' experiences at this time were situated in physical places, bringing forth the dimension of place and it was in these places (home) that they had to make adaptations and adjustments to meet their health needs and new physical limitations. Most participants' homes were adjusted for the purposes of safety and comfort; several participants had handrails installed; one had a ramp installed for his wheelchair; one had his chair modified so that he could sit

comfortably; and another had a hospital chair placed in the lounge. All participants adjusted the place where they slept, sleeping independently from their spouses for various reasons.

At hospital discharge, all had new dependency on things such as carers, medication, and medical devices, and were unable to work due to physical and mental problems such as weakness, fatigue, pain, and cognitive impairment. Patient E described his degree of dependency: "I still need help with the shower, yeah, yeah. […] and I can't wipe myself when I'm going to the toilet yet. […] Oh, that's the other thing, I can't put my socks on."

In the home environment, the far-reaching consequences of the illness were now apparent. The effects of the critical illness rippled out in all directions of the person's life and stretched far into their future: physical, cognitive, and psychosocial post-ICU problems which manifested as new health needs, dependence, altered relationships, reduced participation in family life, and strains in finances and work. In the initial few months of returning home, participants had to adjust their lifestyle to fit their new circumstances. This resulted in their world becoming smaller; most were constrained to being at home. Coming home, participants also had to face the reality of a lengthy recovery. Processing and accepting that recovery would take a long time was something all had to confront. Most patients self-identified very early on that recovery would take time and they would not be well enough to manage full-time work for at least a year. For several, not being able to work caused great financial stress. Participants' focus in this new reality was primarily on settling in, managing health needs, adjusting to new routines, and managing fatigue and weakness: "I've had to evolve how I do things." Patient E.

Participants faced many personal challenges. For example, accepting that they were different from before the critical illness, managing difficult symptoms, managing new medication regimes, being dependent on others and medical supports, and adapting in various ways to everyday life. The physical deterioration meant that their ability to perform everyday tasks and activities of daily living at home was greatly limited:

> The post-hospital incredible limitations on what I could do physically, have been pretty marked, like, very marked, like, Christ. For example, we've had some slips during that period that I was in hospital, had a hell of a lot of rain. And there were some slips on our property on the hillside, which I haven't been able to hardly even look at, let alone do anything about. Patient B

Upon returning home, patients' brains were still recovering; memory loss was common with most participants describing instances of forgetfulness, some forgetting words midsentence, some forgetting medications. Some identified they were emotional:

> I'm not emotional normally, but I've noticed that since I've been sick, for whatever reason, I do get a bit more emotional, which is unusual. […] I don't know if it's post-traumatic stress or something, but there'll be a little thing that happens. And then you go, oh yeah, I'm quite sick. Patient D

In most cases, the partner relationship in this new reality changed to patient-carer. For several months after hospital discharge, one participant explained how he was dependent on his wife for all personal cares and activities of daily living: she showered him, dressed him, took him to the toilet, prepared his meals, set out his medications. Another was also dependent on help for a similar length of time to

attend to his activities of daily living. Upon returning home, there was a 2-week gap before a fulltime carer started work so, his spouse had to take on the role of carer including showering him and assisting with toileting. He recalled how from his perspective this created tensions in the relationship. He thought that they would not have lasted much longer as a couple if that arrangement had continued, highlighting the relational paradox: support as a source of burden: "I don't think me and her would have lasted any more than that." Patient E.

One participant recalled the challenges he was aware of his spouse facing as she took on the role of carer. He found her over-attentiveness frustrating and disempowering and reflected on the difficulty he faced in navigating how a couple modulate that role change:

> It was also slightly difficult for me, in that she [spouse] was overprotective, like of me sort of falling over, for example. So, she'd be sort of right behind me holding on. And so, I sort of got a bit brisk about that as well. Telling her to just piss off. Let me just do it myself. Patient B

For some couples, reconciling how to be together again as a couple was a challenge. Working through this took time, as the following quote from Patient E's six-month interview illustrates: "When I came back it was about us adjusting into each other's lives again, and that's not easy, not easy to do. But we'll get there."

In his final interview, one participant described the relational changes between him and his spouse post-illness as being traumatic: "It is a sort of a traumatic change." Patient B.

All participants were hopeful that the challenges they were experiencing in their relationships would be worked out with time.

For some, because of their prolonged hospitalisation, relatives carried out all domestic routines, which created new roles and routines in the family. This, coupled with the participants' reduced level of function and in some cases disability, meant their place in the home and in family life was not what it used to be in the new reality. These participants conveyed a desire to function normally and be a productive family member, but the consequences of the critical illness such as fatigue, weakness, and cognitive impairment prevented them from doing so. One participant explained how the dynamics of the family changed during his absence and fitting back in was not easy. He perceived fitting back in as being his greatest challenge post-hospital:

> It's good to be back with the children. It's good to be back with [spouse]. There is an adjustment period. They've lived, they've continued to live without me for, you know, a year and a half roughly, and now all of a sudden, I'm back. That's not easy. It's not easy to, to just fit back in like it used to be. Things have changed. Patient E

5.6.3 New Everyday Struggles

All participants in this study talked about the struggles they faced in everyday life following the prolonged critical illness. The subtheme 'New everyday struggles' portrays the situation of struggle they found themselves in. Participants described the emergence of physical, psychosocial, and cognitive sequelae of the critical illness – symptoms of PICS – and it is these problems that their struggles were grounded in. In particular, the physical and cognitive impairments made some days particularly difficult and furthermore, restricted their ability to live the life they had lived prior to becoming unwell.

Returning to everyday life post-illness and adapting to the new normal was not without struggle. Many of the problems had an element of chronicity to them,

persisting for many months post-hospital discharge. Some were still unresolved at one-year follow-up highlighting their long-term nature. There were times in the journey when participants articulated feeling as though they were stuck in a long, endless struggle, as one participant reflected on in his final interview: "There have been times where I can't see the end of it. I can't see the other side." Patient C.

All participants verbalised how they were unprepared and unaware of the problems that they would encounter after hospital discharge including PICS. Furthermore, all reported some degree of difficulty in accessing the supports they needed through the health system, especially in the early post-hospital stage, which compounded their struggle, revealing unmet support needs.

The problems that participants struggled with daily varied among individuals. Physical problems included new health problems, disability, generalised muscle weakness, decreased mobility, functional losses, fatigue, feeling breathless, and dizziness: "That happens a lot, my head spins. I don't know how else to call it. Dizzy spells maybe. Yeah lightheaded." Patient C.

Generalised pain and discomfort as well as nerve issues such as pain and numbness and tingling in the extremities were also common. One participant explained the tingling sensation he frequently experiences in his feet: "There's that business I was talking about, about my feet still feeling tingly. Like they do right now. It's really difficult to describe what the feeling is. Yeah. But often it keeps me awake." Patient B.

Another talked about the nerve pain that he often experienced in his feet: "I get these really sharp, shooting pains, almost needle like all around this area. My right foot." Patient C. He also described the ongoing pain and numbness he experienced in his leg:

> The other side of my thigh, from here, right up to the to the hip, doesn't feel like my leg. So, when I touch it, it's tender, it feels really tender. But it doesn't feel like I'm touching it. It feels like there's a, there's a thin pane of plastic, there's almost a numbness to it. Patient C

The struggles participants had prevented them from returning to work. Some participants did return to work eventually; however, their capacity for work was variable, mostly reduced and continued to be influenced by ongoing health issues and fatigue. In his 12-month interview, one participant explained how he had to leave work early and come home to sleep:

> The other day I was at work, and I was like, oh, actually, I think I need to go home and I just, yeah, by the time I got home I was very much just out of the car, up here and then just, brain just shut me down. So, you just go to sleep. Patient D

At times, participants' struggles took a toll on their mental wellbeing. Some days were perceived as especially tough days, even one year after returning home from hospital: "Some days are pretty hard, but I've got good reasons to live still." Patient D.

One participant described becoming depressed within several months of discharge from hospital because he was not well enough or fit enough to do anything. Over time, he noticed his family beginning to move on with their lives; his wife had returned to work, his family would go out, and he was left behind, which left him feeling lonely and sad. At his lowest point, he did not get out of bed for several days and contemplated living: "A few times I went right down there, and I thought, I'm not going to do anything. I didn't even get out of bed. Everything bad came up. What am I doing here? Or even opting out." Patient A. This participant's contemplation of "opting

out" directly reflects the lack of post-hospital support identified in Chapter One and reinforces the rationale for this narrative inquiry. In this way, the *Social Justification* for the study became a lived reality.

At hospital discharge, all described an enormous loss of physical function because of the critical illness, and this created daily struggles. By one-year follow-up, despite making considerable improvements, none of the survivors had returned to the same level of functional capacity as before their critical illness. The following quote is from a participant's six-month interview: "I want to be able to go for a walk without losing my breath or starting to feel dizzy or starting to go blurry, which has been happening, or to get through a round of golf without breaking down." Patient C.

Another explained, "I'm dying to get outside. Everywhere you look, there is a mess. […] Lawns have never been done. So yeah, I like those jobs, I just can't do them." Patient A.

Most described experiencing a deterioration in their cognitive functioning following the critical illness. The most common cognitive deficits experienced were described as difficulties with memory compared to before their critical illness. Most patients reported episodic memory loss, particularly difficulties finding the right words and recalling names: "I just have to apologise a few times saying, 'Hey, actually, I've got a pretty shitty memory in terms of names. I'll remember I've seen you, but I won't remember what your name is.' That's definitely noticeable." Patient D.

Patient B also explained his difficulty in remembering names: "I think my memory for things like names, which has always been pretty crappy, has got a wee bit worse. Like God, the stoma is one word that I could often not bring to mind."

He also described instances of forgetfulness: "I seem to be a wee bit more stupid [laughs] than I was before. Things like, leaving elements on, when I'm cooking, that sort of thing."

Patient C described forgetting actual events that had happened: "It's gone from forgetting a word to forgetting an actual event." This was very upsetting for him.

Over the course of the first year, several participants perceived that their memory was getting worse, which worried them. None of the participants had been informed that cognitive problems were common after critical illness or were provided with information on how to manage them.

Most experienced issues with sleep and these problems were still present at six-month follow-up. The reasons for sleep disruption were variable but included anxiety about a stoma leaking and pain: "Still not great. I still wake up quite a bit. It's mostly just pain. Waking up of pain and then having to move and get comfortable again." Patient D.

Many of the PICS symptoms that participants described initially upon returning home, such as nerve issues, cognitive impairment, and functional losses, were still present at 12-month follow-up. The following quotes from participants' 12-month interviews show this:

> Memory issues are still there. Particularly name associations or people associations. You know the face, but the names won't come. Then just other stuff from time-to-time you're like, I know the answer to this, but it's just the recall is not there. That's definitely still there. Patient D

> I, too, have noticed that, you know, you'll sit there a bit longer thinking, you know the answer to that. But, yeah, it just didn't come out. Patient A.

> Sometimes I'll be talking to one of the kids or [wife], my sister, my brother and I'll forget what the next word is or sometimes forget what I was even talking about. Patient C.

One participant shared in the nine-month interview how managing his stoma was still incredibly difficult. It continued to leak, would "burst all over the place" and his skin was irritated. Another, in all his interviews, shared how he developed disabling anxiety and depression:

> A mixed bag of emotions over the last three months. I've kind of gone through the stage of, man, I'm alive, and then the dropping down, and that emotion tapering off, and going into depression, anxiety, and then those waves.
>
> Patient C

He knew he needed help from a psychologist but was told he would have to wait nine months.

Emerging in participants' narratives of 'New everyday struggles' were stories of silent suffering, and these were situated within the dimension of sociality. Living with the consequences of the critical illness and PICS was difficult. Many of the symptoms that affected survivors were not always apparent to others. The mental burden associated with managing these problems alone appeared to be heavy at times and added to the load of suffering the patients experienced. Participants described tensions that the invisible nature of their suffering created with family; they felt that many of the difficulties they were managing were not seen or well understood by family. The lack of understanding and empathy in some cases reduced participants' willingness to open up and share their personal experiences with spouses. Explaining that which is not visible and the experience of not being understood was frustrating:

> On the bad days it's trying to explain to other people why I don't feel physically well enough to go on that walk that you want me to go on, or go

with you to that place. I'm actually in a bit of pain. Sorry, you can't see it, type thing. So that part of it's a little frustrating. Patient C

Some described putting on a façade to conceal the degree of suffering: "I was explaining it to another guy I work with. He was like, 'At times you look pretty good'. I'm like, yeah, but that's masking you know. Like I've had to work to get to that." Patient D.

Patient A shared in his final interview how he hid his depression from his wife because he did not think she would understand: "I actually told [wife] about it, and she was going, 'I didn't see that', and all that. I said, 'I didn't show you'."

When the ICU survivor is discharged home from hospital, their main point of contact for health issues is their GP. Participants described how even in their engagements with GPs, getting answers as to what was happening with symptoms and how they could manage them was difficult.

Emerging in participants' narratives of 'New everyday struggles' were stories of living with uncertainty. Uncertainty was present across the entire first year with participants articulating uncertainty regarding their future health, recovery outcomes, and PICS (whether symptoms would resolve). As time passed, the uncertainty did lessen, but it remained at 12-month follow-up: "It's also a matter of, like, what has happened – and I think that's probably part of my emotional reaction – is that I've had to adapt to a situation of not knowing." Patient B. Another participant said: "Whatever that new norm is at the end will be unknown at this point in time." Patient D.

Despite the daily struggles and the long, difficult journey after critical illness, participants' narratives demonstrated this groups' resilience in the face of struggle. As they traversed difficult terrain, most mobilised resources that were available to them including intrinsic resources such as adopting a positive attitude and determination, and extrinsic, such as support networks. Through a process of

adaptation and adjustment, participants were able to re-establish themselves in their new reality and with the passage of time, their daily struggles lessened and all perceived that they were getting there slowly, bringing to light that the long-term ICU survivor's story is one of prolonged struggle but also resilience.

5.6.4 Learning to Live with a Changed Body

"It's that whole coming to terms with your body not being your body. Something's happened to it." Patient C. This quote introduces the subtheme, 'Learning to live with a changed body' that is presented in the following section. Situated within the dimension of sociality, it captures the profound bodily transformation associated with prolonged critical illness, as well as the complex personal challenges involved in getting to know and adapt to a changed body. It also highlights the existential nature of this change. In this way, the subtheme contrasts the *medical success of ICU survival* with the *narrative failure of living with chronic illness and disability*.

As previously discussed, PICS symptoms were prevalent among participants, negatively impacting everyday life and for some, resulting in disability. Narratives from the participants reveal that a prolonged critical illness therefore, changes a person's body, their relationship with their body, and generates a need for that person to learn how to manage and live with their changed body. This came forth as being a confronting and difficult process that takes considerable time and requires focused effort.

Participants articulated how their bodies no longer functioned like they used to. Common disruptions in bodily function included changes with movement, physical strength, and fine motor coordination. Several described issues with breathing; one was now dependent on home oxygen, two others mentioned frequent episodes of breathlessness. Participants noted disruptions in bodily appearance including muscle

and weight loss: “I was just amazed at how my biceps had thinned in this dimension.” Patient B. Changes in cognitive functioning were also common as previously described in Section 5.6.3.

Some described permanent medical devices that were attached to their body altering its appearance such as oxygen therapy, splints, and stoma devices. Changes in bodily sensation were variable among participants but included experiences of ongoing pain, numbness and tingling, dizziness, breathlessness, and fatigue: “The physical challenges of being able to stand up without gasping for breath and falling over, that's been a major preoccupation.” Patient B.

On top of this, each participant had one major life-altering bodily change that was the predominant thing they needed to learn how to manage: one participant was dependent on home oxygen; another had a colostomy; another had to learn how to manage critical illness sequelae such as pain, dizziness, memory impairments and flashbacks of delirium; one participant had to learn how to manage severe pain; and another had to learn how to manage a body that was recovering from total paralysis.

For the participant who had a new colostomy, learning to manage it was difficult: “Certainly, coming out of hospital when I had to, oh God, just focus on that, in order to manage it properly, took quite a lot of time and effort.” Patient B.

Patient A’s critical illness left him with permanently damaged lungs and a dependency on home oxygen: “They're damaged. My lungs are damaged.” Upon returning home his body was severely weak and deconditioned. His lung damage left him easily breathless. He was acutely aware of his vulnerability; a recurring story in his interviews across the year is his realisation that he nearly died and “shouldn’t be here.” At hospital discharge and for several months, because of his weakness and breathlessness, he was confined to sitting on the couch all day.

Adaptation and adjustment emerged in the narratives as being an important part of the process of learning to live with a changed body. Participants described the short-term adaptations and longer-term adjustments they had to make to cope with everyday life. For example, all participants had to reduce the amount of physical activity they carried out in a day due to either pain, decreased physical fortitude, or fatigue. Most participants were not well enough to work, however, several did return to work. One had no choice but to work to pay the mortgage. The participants had to limit the hours they worked. Adjustments also had to be made to daily routines as well as family and domestic responsibilities. For some, a significant change was adjusting to new medication including the side effects of medications. Upon returning home from hospital, all participants described how, as part of learning to live with a changed body that had new limitations, they had to integrate rest into their daily life. Most participants described intervening time to rest during the day, commonly in the afternoon. Some described going to bed earlier in the evenings.

Under the subtheme ‘Learning to live with a changed body’, self-management was essential to participants regaining a sense of control as they strived to regain independence and restore their lives after critical illness. For most, the quest to become independent created tensions between them and their family. The patients were endeavouring to recapture autonomy, and part of this process required them to test things out for themselves, test out their limits to determine their evolving capabilities, but they described instances where family struggled to let go out of fear that they would hurt themselves. Patient E explained how he is always keen to give things a try, taking educated risks, but his spouse did not feel comfortable with this:

> I'm always pretty keen to give things a go. I know [spouse's] not always too keen on the way I think about things, but I tell her that it's educated risk. I don't think that makes anything any better for her. Patient E

Patient A explained an argument with his wife, where he was determined he could shower on his own, but she did not think he could:

> I couldn't shower on my own, and [wife], just I think it was last week, we had a bit of an argument. She goes, 'You can't do without me'. I'm like, 'Yes, I can'. She goes, 'No, you can't. You can't shower'. I say, 'But I have already done that'. She goes, 'When was that?' I said, 'I didn't tell anybody because I knew they'll go off their nuts at that sort of thing.'

The process of learning to self-manage was characterised by the need to be attentive to self; surveillance of self; monitoring and managing the body and symptoms; learning about new limitations; acquiring knowledge related to new health issues, treatments and critical illness sequelae; and getting the balance of activity and rest right.

Learning how to manage and adapt to a changed body required a lot of concentration. Participants described how they had to be more attentive to themselves than before their illness:

> Just more obsessed with self, I think. Also, having to be more attentive to myself, like I'm constantly checking this fucking bag, or checking the feeling – what it's feeling like – as a continuous thing throughout a whole day, and then at nighttime, as well. Patient B

One participant recorded his oxygen saturations regularly: "I took my oxygen levels every morning, wrote down what happened during that time whether I felt all right or things like that." Patient A.

Some participants had access to specialised health professionals. Through care and education, these professionals supported them with the process of understanding and adapting to their changed body and new health needs. Others did not have access to such support and were left to try to figure out how to exist in the unfamiliar body on their own. All participants' experiences highlight a need for information related to the health issues they were confronted with as well as practical and professional support.

Each person had specific educational needs that were largely unmet upon returning home from hospital. Patient A returned home from hospital on permanent home oxygen. In hospital, he had no introduction or education on the specific device he would be using at home. He remembered the supplier dropping off the machine and giving his wife and grandson a brief run down on how to operate it. Both him and his wife felt that the initial education provided by the supplier was inadequate. He described several episodes where he became suddenly breathless and "like he had run outta air." These episodes of breathing difficulty were stressful and frightening experiences for both the patient and his wife. They had to problem-solve and think on their feet in a high stress situation. His wife took control of the situation and figured out what to do. They had no point of contact to call in this situation or after. It was incredibly unsettling:

> Partway through the night, I was sorta tryna wake her up. She was going, 'What's the matter?' I say, 'I can't breathe.' She goes, 'Oh no, not now.' And I

was going, ‘I can, but it's just hard to breathe.’ So, she thought, I'll turn the machine up. But that didn't work. Patient A

Emerging in most participants’ narratives of ‘Learning to live with a changed body’ at the six-month interviews were notions of becoming the expert. Most participants considered they were now in a position where they perceived they knew themselves and their body better than anyone else, including family and the health professionals involved in caring for them. Becoming the expert was part of the process of reclaiming autonomy and agency. All but one participant was taking control of their recovery, confidently making decisions about their health. One participant explained this in his six-month interview:

I’m in the position where I know myself the best now. Whereas probably early on in the piece, I needed to rely on those professional judgements to help me because I wasn’t physically and maybe not mentally capable. I don’t know. But now I can take more control of what I’m doing, and I can own what I’m doing a lot more and I can take those educated risks that I think I need to in order to know how far I’ve been and how far I’ve got to go. Patient E

Another explained in his six-month interview how the nurse practitioner suggested he start weaning the oxygen off overnight. However, based on his own knowledge of his low nighttime oxygen saturations, he decided that he was not ready for this yet:

She came again after that and says, ‘We might try the night’. I wasn’t too keen because you are asleep and you’re lying down. When I used to wake up halfway through the night, I took my oxygen levels, and they were quite low.

They were around 79, something like that. I thought no, I'm not ready.

Patient A

Furthermore, participants' narratives highlight that by six months, a shift has occurred where they have learnt to view advice from professionals (and family) through a more critical lens. If the advice feels right for them, they will follow it, if not, they will now do what they think is best: "I think it's that balance and perspective of still being your own individual and just taking everything for the advice that it is and being prepared to challenge the specialists." Patient D.

Another participant explained coming to the realisation that he knew himself better than anyone else and that he needed to do what felt right for him: "Through this journey, I've come to realise that I actually need to start making some decisions for myself, which I did relatively early on when I could." Patient E.

5.6.5 I'm Focused on Getting Better

Across the year, all participants talked about their desire and motivation to get better following the critical illness, and the subtheme, 'I'm focused on getting better' portrays this narrative. The individual driving forces for getting better varied but there were commonalities, and these driving forces seemed to influence their recovery. It became apparent that by six months, participants had processed the initial shock and in some cases grief of adjusting to their new reality and were focused on getting better and improving their health. Their everyday lives continued to be affected by the consequences of the critical illness, but most were slowly starting to get their lives back on track. By six months, all participants were now well enough to gently start reengaging with their world and integrating back into their lives things that were more in alignment with life before the illness such as cooking occasionally, helping with washing, driving, socialising, leisurely activities, and for some, resuming work.

This notion of getting better and moving on with life was characterised by intentionality and the motivation to get up and get moving, to get the damaged body fitter and stronger, so that they could return to normality. The following quote from a six-month interview illustrates this:

> I'm ticking off those small incremental steps on my way to getting better and then dropping things off that were done out there – [hospital] and pulling more things in that are more aligned with how my life used to be – work, for example, and just trying to live as best as I can as the recovery gets better.
>
> Patient E

Over the last six months as patient participants' physical health improved, they had the mental bandwidth to contemplate their illness and its implications, further fuelling their drive to move forward – the previous months of having to move slowly had given them time to pause and reflect. For some, there was an awareness that they had lost time while they were in hospital; life and living had been put on hold. This notion of lost time was a driving factor in them moving forward and reclaiming their life back; they wanted to make up for lost time and regain their losses.

All patients described how a driving force for them getting better, was the realisation that if they stopped physically moving, if they stopped being active, they perceived they would regress in their physical abilities. Keeping the body moving either through activities around the home, hobbies, exercise, or work became a necessity in the pathway towards recovery. One reflected on how throughout his entire critical illness journey from the ICU to home he was always motivated for physiotherapy, but when this service abruptly and unexpectedly came to an end several weeks after hospital discharge despite his body responding well to the

physiotherapy, his motivation went downhill. He explained how when he lost that support and momentum, he stopped moving forward: "I guess if you slow down, you're going to stop like I just did. You're going to not want to do anything." Patient A.

Several participants described that a powerful driving force to get better was the other people in their life who the illness and its aftermath affected, and who would also have good outcomes from the patient getting better. This included close family, dependants such as children, colleagues, and financial responsibilities including mortgages or rent payments. These people talked about how they did not have a choice regarding recovery; they had to get better because others depended on them, and they simply had too much to lose. Patient D explains:

> It's a bit like the old classic pebble into the pond. You see how the ripples around all the people that you have touchpoints with or that are either dependent on you in some way or have a keen interest in your own wellbeing, in terms of how that affects their lives. So, in terms of not just my own family, but the ability to get better and a drive to get better has good outcomes for lots of people.

By six months, three participants had returned to part-time work. Returning to work represented recovery so it was an important part of participants moving on with their life and getting back to normalcy. Although their work capacity was reduced and some changes had to be made to the way they worked, they articulated perceiving returning to work as being health promoting. Positive effects of work included a sense of identity, purpose, mental stimulation, improved mental wellbeing, and social interaction. One participant who started working one day a week around six months post-hospital discharge explained how work has always been an important element of his life and returning to work is integral to how he defines recovery: "Work's always

really important to me. It always has been. I think it's part of a natural progression for me to get better because work was a big part of my life. I really enjoy what I do." Patient E.

In another six-month interview, a participant who had been working part-time for several months explained how working had provided much needed mental stimulation, which he perceived as helping his recovery:

> It's been good. I think, for me, I've got to have that stimulation. I've got to be able to work the brain and I've got to be able to problem solve and do all the other stuff, and I think that's certainly helped with my recovery. Patient D

He also explained other perceived benefits that returning to work provided such as social interaction, mental health support, and a sense of normality: "My work colleagues have been really good in terms of just mental wellbeing as well just to getting some form of normality."

However, despite wanting, even needing to return to employment, not all participants were well enough and at one year post-hospital discharge, two were not working.

Participants spoke of how they perceived that having a positive mindset was essential to them getting better. A positive mindset strengthened the participants' resilience, enabled them to strategise a way forward to deal with the problems and challenges they were facing, and supported them in adapting to their new conditions. These participants appeared to experience better recoveries. Even in situations where medical specialists told patients that their chances of recovery were limited, these individuals were determined to prove them wrong and achieve better outcomes. One participant often talked about the importance of mindset, how a positive attitude was imperative: "A lot of it is in your mind. You either dwell in it and go down further or you pick yourself up and go upwards." Patient A.

Some were incredibly determined:

> That's what I said to the rehab people: 'Whatever it takes, that's where I'm going to be and I'm not going to give up, I'm just going to keep going, I'm not going to feel sorry for myself, I've just got to get on with it.' Patient D

Several participants described themselves as being stubborn. Patient E was totally committed to his rehabilitation regime, demonstrating inner qualities of persistence and determination and he believed this helped with his recovery: "I'm pretty stubborn, too. I don't know if that helps or not, but I think it does."

Importantly, while the overall recovery trajectory was one of improvement, it was apparent that the recovery process is not linear. Participants described successes and setbacks, but as time went on, their resilience and ability to mentally cope with and physically recover from setbacks increased. In these difficult moments, reflecting on how far they had come in their journey reminded them that they were doing okay and instilled hope that they would continue to get better. As Patient E states: "This is where I've been and this is where I'm at now, so I'm actually doing okay."

5.6.6 Rebuilding the Damaged Body

All participants described how following the critical illness their bodies were left debilitated and a focus in their current reality was *working* to rebuild their damaged bodies, bringing forth the subtheme, 'Rebuilding the damaged body'. Participants spoke of how much they had lost because of becoming critically unwell, and to recapture autonomy and re-establish themselves, focused on what they did have control over: rehabilitating their body. Rebuilding the body was seen as a prerequisite to regaining lost independence, returning to a sense of normality, and fundamentally reclaiming one's life. How the participants went about rebuilding their

bodies varied and their approaches were influenced by what rehabilitation supports they had access to at hospital discharge, however, all participants worked to rehabilitate their bodies through various forms of physical activity. All participants acknowledged that an important part of rebuilding the body was also trying to do normal everyday things around the home. Patient E explained:

> I try and do normal things. […] I think, for me, it's about trying to be able to do the things that I used to be able to do normally and normal life – cooking, cleaning – normal – going outside, painting, going outside and trying to build, which is what I still try and do – just normal things – folding washing – just normal run of the day, everyday things.

Rebuilding the damaged body was not a time-bound process; it was slow, with participants describing a gradual progression of physical recovery and at 12-month follow-up, was incomplete for all. Furthermore, no one expected recovery to take as long as it did: "I wasn't aware of how long it was going to take, to get better, and to get back to my previous self." Patient B.

However, common among all participants' narratives of rebuilding the body were the concepts of intentionality and personal effort. One participant stated how for nearly six months he had been focused on getting physically stronger and regaining health, a sentiment shared by the others: "Until recently, just really more mentally focused on just building strength and getting physically better." Patient D.

At six months, all participants reported improvements in physical strength and general fitness highlighting an overall trajectory of physical improvement. Increased strength and stamina meant that the person was now able to do some everyday things that they could not do before such as cooking occasionally and helping with washing. Participants were now independent with many activities of daily living. One

participant explained how he could not walk 50 metres, but at six months, he could walk 50 metres without a problem. At 12-months, it was evident that participants had continued to make progress with their physical recovery. Participants reported comparing where they were at currently with where they had come from, which put into perspective their progress. Patient D explained at his 12-month interview: "I think I'll be about 70 per cent, considering there was nothing – I couldn't move my hands, my legs, I couldn't breathe – yeah, to now. I've still got a little ways to go yet, before I actually come right."

Participants expected that with time and effort, they would continue to improve: "I know that sort of 4-months ago to where I am now, I improved by that much. I don't have any expectation that I'll improve by that much again, but I do have expectation that I will improve." Patient E.

For some participants, rebuilding their body was their way of dealing with life now: "It [rehab gym] means everything. It's my way of dealing with life now." Patient A.

5.6.7 Needing Care and Support

All the participants in this study spoke about the necessity for ongoing care and support after hospital discharge to optimise their recovery and help them navigate the complex health system, with the final subtheme, 'Needing care and support' portraying this need. Importantly, participants' narratives reveal that the type of care and support they require is multifaceted. Also, their needs develop and change over time. The transition home period was identified as being the time of highest need in the first year after hospital. The disruption that the critical illness event caused in participants' lives created a need for continued support yet there was great variability in what support participants received and all reported unmet needs reflecting a disconnect between hospital and home. Stories of their

experiences make explicit what support they themselves viewed as important including access to timely and appropriate healthcare services, informational support, practical support, and social support from family and friends. These will now be explained.

Access to timely and appropriate healthcare services. Looking backwards in time to their experiences transitioning home from hospital, all participants unequivocally emphasised the importance of timely access to appropriate healthcare services and support from caring professionals after discharge. Participants' needs varied depending on the individual health issues and the critical illness sequelae they were managing but reflect a need for holistic and multi-disciplinary care. Some participants did have access to healthcare services, such as nurse specialists, physiotherapy, and occupational therapy, and reported a general satisfaction and appreciation for the care they received. One participant whose aftercare included outpatient physiotherapy, carers to assist with showers, and regular home visits from a stoma nurse specialist, stated he was satisfied with the care that he received after hospital: "In fact, like that sort of wrap-around care, has been pretty impressive really." Patient B.

Another who had severe lung damage from COVID-19 and was dependent on home oxygen therapy was told by medical professionals that he would likely remain on home oxygen therapy for the rest of his life. Initially, he was not under the care of a respiratory nurse specialist, but a district nurse was concerned about the number of asthmatics living in the house, so a referral was made for follow-up by a respiratory nurse specialist. He was then seen by a respiratory Nurse Practitioner. He managed to successfully wean off the oxygen and attributes this entirely to the

care provided by the Nurse Practitioner: “That’s how I actually got off the home oxygen. I trusted her. Well, she's got me to where I am.” Patient A.

Another participant who had a comprehensive package of community care in place including funding for a fulltime carer, twice weekly physiotherapy, occupational therapy, and hand therapy, reflected on the value of continuity of care:

> My follow-up care that I’ve experienced since I got out of hospital, the most comforting part about it is that it all has ties back to when I was in hospital. I’m not seeing anyone new. Everybody I see as an outpatient, I’ve seen as an inpatient. So, even though, from a specific ICU perspective, there’s nobody that follows me on the rest of my journey once I get out, the continuity of the people that I see are still the same. That’s where I’m lucky. Patient E

Not all participants had access to such aftercare with several describing problems accessing the supports they needed. Several were told that someone would contact them to organise follow-up care, however no one did – this was common with physiotherapy. Three months after being discharged from hospital, one participant was still waiting for outpatient physiotherapy to contact him: “I'm still waiting for physio to call.” Patient C.

He did not follow this up because he did not have a phone number to ring. Another also talked about how when he was in hospital, he was informed he would have access to outpatient physiotherapy – something that gave him confidence in being discharged – but this did not materialise. He went to the hospital multiple times to follow-up and was told by one person that his application was still being processed and another that the outpatient rehabilitation service was stressed and chronically understaffed, so they had made the decision to deprioritise him. It is concerning that this decision was made without any assessment or consultation with the patient and

that he was not informed of this change in plan. His health and function had deteriorated since he left hospital:

> The other thing that was really frustrating and it did piss me off was I was promised I would be able to start my rehab within two weeks of leaving. […] So, I rang the hospital and I actually went there physically three times. Twice there was no one at reception, so I got angry. I waited for a long time… […] So, I went there and I says, 'Hey look, I was supposed to, I've had no correspondence, I'm getting really frustrated. I'm actually going backwards.' And she says, 'Yes, we've got your application but it's still being processed.' At this stage, it was, like, it was four or five weeks. I was like, 'Come on. It's gonna be 2023 before you see me and I was promised two weeks.' So, she said, 'I'll make sure someone rings you.' Yeah, well and that's why I went upstairs to their rehab ward that I was in. They said, 'Oh, quite upset,' and then they could see I was struggling a bit. And they says, 'Oh, this is not cool.' But they had no influence, obviously, on people downstairs. And that's when I think it was [deidentified] rang me from the ward downstairs, the Outpatient Rehabilitation, and she was up front. She said, 'Actually we're short staffed, we're two down, have been for over a year. We were the ones that made the decision that you're not priority. And we're really sorry about that. But yeah, everyone told us that you're doing really well.' And I said, 'Well, I'm actually not, I'm going really downhill and the pain is becoming really intense. And I can't even do the rehab exercises anymore.' Patient D

He explained that he questioned how they made the decision to deprioritise him without talking with him and called the practice horrific:

> I said to [deidentified], 'How did you, what was the thought process around de-prioritising me without talking to me?' And you could see she got really nervous. And I said, 'I'm not having a go, I'm just trying to understand how we landed here.' So, I said, you know, 'But you guys chose not to make a single phone call or a checkup before you even made that decision at a meeting.' I says, 'That's horrific.'

He did not end up getting access to physiotherapy despite needing it. He also had to fight to get appointments with other health professionals and services such as pain specialists. This was hugely time consuming and came at a personal and financial cost. He explained how waiting as long as he had to wait to get the medical care he needed to treat his pain was simply "cruel". The consequences of not getting the care and support they needed were catastrophic to these people. They struggled physically, had poorer outcomes and were left feeling frustrated, let down, and abandoned.

One participant reflected on how little help there was once he left hospital and this is what he perceives makes the journey outside of the hospital even more difficult for patients: "No one's going to really help you. The minute you leave that hospital system, whether it be a good experience or a bad experience, it only gets harder." Patient D.

These participants' stories shed light on system failures that meant these patients did not get the care and support they needed after hospital, including delays in referrals being processed, fragmented care, a lack of ICU follow-up and specialised rehabilitation, no point of contact for someone who can help them, lack of person-centredness, and a stressed and chronically under resourced health system. The patient is lost in this system, and this is concerning as the patient is the one who has the most to lose:

> It's a process which is conveniently bureaucratic with people making arbitrary decisions without any contact with the actual patient, to their detriment. And teams not talking effectively together to make sure that outcomes, more than processes are achieved. Patient D

Patient A received physiotherapy upon returning home but felt that it was inadequate. What is more, the physiotherapy was only provided for four weeks. At this stage he was still severely weak, deconditioned and had a lot more physical recovery to make. Being left by the physiotherapist like this with unfinished business and unfulfilled recovery goals also left him feeling abandoned and let down:

> They stopped. They've only got so many weeks. I think it's four weeks. Yeah, something like that. So, the time had run out. And even though it was only 10 minutes, I still enjoyed it, but I wish it had been longer. And more intense. Some of the things were just like, wiggling your toes, do 20 of those. So, you're going jeez what a waste of time.

Given another participant's mental health history of depression, anxiety, and alcoholism, a referral was made for him to see a psychologist in the community, however, he was informed that he would have to wait at least 8-months. By the time of his final interview (12-months post-hospital discharge), he had finally had his first appointment with the psychologist. The greatest challenges he faced following his ICU experience were mental. Additionally, the intersection of unresolved delirium and mental health issues put him at high risk of psychological morbidity. He asserted that access to mental health support earlier on needed to be a priority for his care: "I'm also quite saddened by having to wait months to see a psychologist." Patient C.

The examples shed light on how when the ICU survivor leaves the hospital system altogether, accessing healthcare services as an outpatient becomes difficult. The deterioration of access to services suddenly increases exponentially.

Several participants voiced that they wanted to be able to contact a health professional who could help them navigate the health system and who could advocate for them when they did not get the treatment or support they were promised and/or needed. Some participants reflected on the lack of care coordination and communication after hospital and spoke of the need for someone who is actively caring and helping the former long-stay ICU patient and family through the process of transitioning home:

> There's no one managing the case, or people like us that go through that to make sure we get what was promised or that it's happening. So, no communication in terms of obviously, making sure that I could see that outpatient doctor in the two weeks as promised. Patient D

Informational support. Participants' narratives revealed that they were unprepared for the challenges they would face during recovery and furthermore, uninformed about what to expect following a prolonged critical illness, bringing forth the unmet need for information. None of the participants received any verbal or written information about common post-ICU problems, expected recovery trajectories, where they could go or who they could contact for help, or what they could to do promote their own recovery.

Participants explicitly emphasised the need for the provision of easily understandable information related to their ICU admission including diagnosis and treatment to enable them to understand what happened to them during that time as well as understand and put into context their current health status including post-ICU

symptoms. Given that all participants' memories of the time in the ICU were fragmented and boundaries between the real and unreal were unclear, conversations with me identifying what was real and what was not were reported as helpful. There appears to be a need to make sense of and contextualise delusional memories, in particular. One patient participant whose memories of the ICU were dominated by delirium expressed the need to understand these memories and for reassurance. He also expressed a need for the *full story*, to piece together memories into an *ordered whole* to enable him to make sense of what happened to him.

All the participants reported a need for information to enable them to cope with their symptoms of PICS. Participants were not informed at any stage in their hospital journey about PICS, nor were they provided with any information on how to manage PICS. Participants voiced a preference for frank, honest information regarding PICS and recovery expectations, as then they could work to incorporate it into their lives: "As I said to a lot the departments that I've had to deal with, like, I don't care whether the news is bad or good. I just want some information so I can start making some informed decisions." Patient D.

After hospital discharge, the participants' main point of contact was their GP, however, their narratives of these interactions suggested that the GP had limited understanding of and expertise in managing the critical illness acquired problems. For those participants who had complex post-critical illness health problems, the GP was unable to adequately help them, which left them feeling frustrated. One participant explained how his GP was not familiar with his medical condition: "Even my local doctor, he was like, 'Never even heard of it so I'll have to read up about it.'" Patient D.

Following the critical illness, another participant was left with new symptoms of breathlessness and dizziness, which persisted for months after hospital discharge. He explained it was difficult to get information from his GP on what was happening:

> If I'd sit down on that chair, and sort of recline, if I stood up, I'd just be totally breathless. I could hardly walk. Like you'd have the feeling that you could keel over anytime. But actually, getting any answer as to what was happening when that was happening was a bit difficult, from anyone. Patient B

The lack of support and information resulted in *patient-led* recovery through independent researching of how to manage medical conditions, medications, and possible treatment options, highlighting the need for guidance: "You have to, because no one else is going to do it for you. There's no one there." Patient D.

Practical support and social support from family and friends. Evident in all participants' narratives of 'Needing care and support' was the importance of a supportive social network. Family appeared to be the greatest support, with many participants commenting that family meant everything to them, and they would not be able to manage without them. Family helped by providing emotional support, care, assisting with practical tasks, and inspiring motivation to recover. One woman helped her husband manage his new medical condition and became a lifeline for him. The patient commented that without her, "he would die." Patient B.

5.7 Chapter Summary

This chapter has presented the findings of this narrative inquiry, discussing the themes and associated subthemes arising from the analysis of the patient participants' discussion on their experiences after a prolonged critical illness. The three main themes in this chapter follow the timeline of a prolonged critical illness and its recovery. The identified themes were 'Being out of control', 'Unmet needs'

and ‘A year of tending to the self’. These themes have been explained and examples provided from the narratives to highlight the different aspects of patients’ views of their experiences about life after a prolonged critical illness.

Chapter 6: Findings of Families' Experiences

6.1 Introduction

The previous chapter presented the findings of the patient participants' experiences following a prolonged critical illness, beginning with their experiences of becoming critically unwell to one-year post hospital discharge. This chapter presents a discussion of the findings of the families' experiences. While this study was initially focused on investigating experiences after hospital discharge, all family participants demonstrated the need to talk, in depth, about their experiences and memories of the ICU and general hospital admission. There was a need to debrief their experiences with someone who understood the context and could relate to what they had been through. It became apparent that, after the ICU, no one that was involved in the care of this patient group understood the journey that the patient and their family were on. Furthermore, their narratives revealed that no one was with them on their journey; there was no experienced practitioner with expertise on prolonged critical illness walking alongside the patient and family and helping them navigate the path and the many challenges they encountered.

The narratives brought to light that for family, a prolonged critical illness is a devastating and fundamentally life-altering event. As participants described their experiences, they moved between the temporal dimension of past, present, and future, beginning with looking backwards in time at the unfolding critical illness, their experiences in the ICU and the hospital wards, the time the patient returned home from hospital, to their present and future. Narratives revealed the trauma, stress, and overwhelm of having a close family member suddenly admitted to an ICU. Due to the protracted nature of prolonged critical illness and an even longer recovery period, these difficulties intensified and the strain on the family participants accumulated

over time, culminating in the health of the family participants deteriorating after the patient had been discharged home. The long stay in the ICU caused disruption to the family participants' lives that was immense. This disruption was present throughout the entire hospital journey and continued for many months after returning home.

As a researcher and a nurse, after listening to the challenges of the *post-ICU experience*, I came away with feelings of sadness and disappointment. The individual struggles were substantial and impacted the family participants' lives greatly. Both patients and family were shattered and shocked. They were not getting the help they needed and were having to chisel out a path forward on their own. I reflected on how all the participants appreciated that somebody cared enough and wanted to listen to their story. Realising the limited care and support that these patients and their family received from the healthcare system after the ICU admission that left them feeling abandoned was frustrating, yet it brought to light where change is needed to improve outcomes and, make the lives of future ICU survivors and their families better.

6.2 Characteristics of Family Participants

Five family members of the patient participants were included in this study, who happened to be their spouses and who were all female. Three were in their 40s, one in her 60s, and one in her 70s. Two identified as Māori, and three as New Zealand European. To protect participant anonymity, individual demographic and clinical characteristics have not been presented.

6.3 Overview of the Themes

Table 8 presents the narrative themes and subthemes of the families' experiences of the ICU, of the general wards, and across the first year at home after

discharge from hospital. The subsequent sections in this chapter will be arranged according to these themes and subthemes.

Table 8

Narrative Themes and Subthemes – Family

Experiences of the ICU: ***Being on Life's Edges in a World of Uncertainty***	Experiences of the General Ward: ***Where is the Care?***	Experiences of Being Home: ***Navigating New Realities Alone and in the Dark***
An overwhelming new reality	A shocking new reality	Returning home: Being thrown into the unknown
Being on the brink of life and death	Unmet care needs	Adjusting to changes over time
You never know what's going to happen next: Existing in a realm of uncertainty	We needed to be there	Being in the dark
Feeling the pull to be close	Terrifying hospital discharges	Navigating a different us: Confronting relationship changes
An emotional rollercoaster		A prolonged struggle
Needing care and communication in a time of crisis		Finding a way through

6.4 Family Participants' Experiences of the ICU

6.4.1 Overarching Theme: Being on Life's Edges in a World of Uncertainty

The overarching theme was 'Being on life's edges in a world of uncertainty'. Looking backwards to their experiences of the ICU, all family participants described an awareness of being in a physical place that holds such a different and delicate balance of life, watching on in fear as their relative struggled for survival. Survival was not guaranteed. The overarching theme, 'Being on life's edges in a world of uncertainty' encapsulates the family participants' experience of a prolonged critical

illness and a protracted stay in the ICU. Participants' stories from this time revealed that the onset of critical illness thrust the family into an overwhelming new reality. Family were confronted with being on the brink of life and death as their relative struggled and the threat of death was real, pervasive, and inescapable, placing them in a world of uncertainty. The experience was difficult, characterised by a rollercoaster of emotions and intensity. Care and ongoing communication of information by the ICU nurses and doctors was important to family and made a positive difference to their experience. Support from family and friends was essential for coping with the stress and emotional upheaval of the prolonged critical illness.

6.4.2 Being Thrust into an Overwhelming New Reality

In exploring participants' experiences of the ICU, a subtheme was 'Being thrust into an overwhelming new reality'. Interwoven within this theme are the dimensions of continuity, interaction, and place/situation. All family participants' story of the ICU experience began by looking backwards in time to an ordinary life that was suddenly interrupted by critical illness. Life changed in a moment from ordinary to unimaginable and this moment is never forgotten;

> My phone rang. And I answered it. I was driving – naughty, naughty – but I just put it on the speaker and listened. And it was the doctor who had the next morning, done the surgery, a general surgeon done the surgery to remove his large intestine. And he was just ringing. They must have to ring afterwards to tell you, 'Yep, doing that'. So, he was just telling me this while I was driving along. And I remember that, and I'll sort of remember that forever in a way for some reason. Because I just sort of thought, Holy Fuck. This is something else. Family F

Normal everyday living was abruptly severed as the participants found themselves thrust into a new reality that no one foresaw. Their known stable world was overturned and simultaneously narrowed to overwhelming concern for their unwell family member: right now, nothing else mattered. Feelings of shock and fear characterised the family participants' early experiences of bearing witness to their relative's rapidly deteriorating health and admission to the ICU.

Having a relative become critically unwell and be admitted to an ICU for life-saving care was profoundly stressful. Looking backwards to the early days and weeks in this place, family recalled it as an intense and fast-moving time, often describing that period as a blur. The cognitive load that the participants' experienced was tremendous. They recalled trying to make sense of the situation while also attempting to absorb and comprehend new medical information about their relative's illness and treatment. Several described the mental work involved in managing enquiries from extended family and friends, which added to the mental load and feeling of overwhelm. One participant noted she had difficulty remembering things during this time: "I noticed my own memory was well, I also had so much input […] and I just couldn't remember sequentially things. It was a struggle." Family F.

In exploring the dimension of place, participants described the physical environment of the ICU as being an unknown place adding to their sense of overwhelm. Most had never been inside an ICU before, yet they knew of it as a place where very sick people are treated and die. The monitors, machines, medical jargon, routines, and people who worked in this place were not yet understood, leaving the participants feeling insecure in this place. One participant remembered the embodied fear from the sounds of the monitors and alarms and described how every time an

alarm went off it would "grab hold of her breath." This was triggered by an earlier traumatic experience where she witnessed her relative's heart stop for 30 seconds:

> I don't know at what point his heart stopped, but it did one night. I think everything just stopped for about 30 seconds. The beepers went off. The button was hit, and they asked me to just stand at the back of the room […] Then after that, they're like, 'Are you alright?' I was like, 'I think I need some water.' So, at that point, I felt a bit faint and stuff, but you're still very much in that mode of one foot in front of the other and just having to get through it. Family I

Intertwined within the dimensions of place and sociality, looking inwards to innermost thoughts and feelings, some family initially did not know how to be in this place, experiencing uncertainty regarding their role; some wondering if they should talk to their relative, whether they could touch them, how long they could visit for, and whether they could ask questions of the busy bedside nurse: "I sometimes wondered if I was in the nurse's way and things." Family F.

Family described seeing their relative for the first time in this physical place, attached to life support, as being confronting. Often there were tears as family retold these early moments: "I think it was probably initial shock to see all the tubes and just everything pumping away, and him, because last time I saw him he was in bed, normal." Family H.

Looking backwards, most participants recalled ambivalent feelings in this new reality, ranging from feeling safe to feeling insecure. There was a sense of relief that their relative was being cared for in the ICU and had dedicated one-on-one care, which generated feelings of safety. Participants felt that the ICU was the right place

to be; they were grateful that their relative was constantly monitored and able to receive the care and medical treatment they needed. The highly sophisticated environment and technology was remembered as being scary but also reassuring; participants recognised that without the machines their relative could not recover:

> It was scary at first seeing it, seeing him, he just looked so… it was scary. But then also there was a part of me that was relieved that he was on the ventilator because we'd seen how his behaviour had changed over those first three days. I was grateful for the modern technology, for the medicine and what they can do while they're on a ventilator because I think it just, probably just gave his body time to help him breathe but also heal in the background. Family G

Families' narratives also reveal that they realised they were in a place where people died because they are so unwell, showing that families of long-stay patients confront mortality in this place and the presence of death is real and inescapable: "At one point, he had people tubed all around him, so it was really quiet, except the nurses. There was no life on anybody." Family I.

Family described the profound disruptions that the critical illness and long ICU stay brought to their life situation in this new reality, demonstrating that the critical illness is a catastrophic event for the whole family. There are far-reaching implications. Family life is disrupted, family members often must reduce or stop work, and many face a great economic burden, which in turn adds further stress:

> That involved me putting on hold my whole family life and work and stuff. We always knew he was our first priority, so the children were put on the backburner for a while. I would be at the hospital day and night. Family J

Despite being in turmoil, participants found ways to cope with the overwhelming new reality. All the family participants described the immediate coming together of family. Uniting to support the patient and each other, their narratives revealed how being together helped them to cope with the situation.

6.4.3 Being on the Brink of Life and Death

All family members shared stories of how seriously unwell their relative was, which left them feeling like they were *on the brink*, staring down the barrel of death, bringing forth the subtheme, 'Being on the brink of life and death'; as the following quote shows:

> Something about the eyes, I don't know if it's the colour. They were shut. Maybe they appear more sunken or change colour and then the whole face is just there with that and you just feel like they're not there. […] It's like, oh, gosh, you know, you're on the brink, and I don't know if you're there. It's like you've probably seen someone in a casket who's passed away, kind of close to that kind of a look. Family H

From the moment the patient was admitted to the ICU, the physical unfolding of the illness coupled with the severity of it, placed the patient in a precarious place where survival was uncertain, and the possibility of death was real. Family participants described being in a place where their relative was *on life's edges*, in a liminal space between life and death, making the present a confronting place for them to be. They were in a place where their family member's life was hanging by a thread: "There was a moment there when one of the doctors said, 'We have thrown everything at him, every medication we have and know of at him, this is our last try.' Then I felt as they left, tears ran." Family J.

Facing the possibility of death was deeply upsetting:

> I still remember the day when the doctors must have told them [other family members] […] that his vitals are going down and there's nothing really more they can do. […] He said, 'Prepare for the worst.' And so, he told that to me, and I just, like, broke down. Family H

An important finding of this research is the pervasiveness of the threat of death that the long-stay patient and family are confronted with. The threat of death and uncertainty regarding survival endures over time because of the severity of illness, reduced resilience to medical complications that develops with time, and slow nature of recovery. Family participants commented how several times they were faced with situations where they thought their relative might die: "It looked like he was going to die at first. And then again, it looked like he was going to die, you know, so there was twice I think." Family F.

For another participant, the threat to her spouse's life persisted for nearly six months. She explained that for six months his clinical state would swing between periods of physiological stability and instability, the instability characterised by medical events/complications such as asystole, hypotensive episodes, new infections, sepsis, and severe oxygen desaturations. She recalled how over time his physiological reserves became increasingly depleted and therefore, his body's ability to cope with each new stressor declined. This made each complication potentially life-threatening and left her in a situation where it was unclear what would happen next. The feeling of being *in limbo* depicts her experience of the fluctuating nature of his trajectory in the ICU and the sense of not knowing this brought:

> From early on, the most challenging part was not knowing whether he was going to make it or not. That really went on for six months, yeah, on and off, so it was a long time to be in that limbo of things would just start to settle, and then it would all be ripped out underneath you again. Family I

It was also clear from the data describing how unwell the patient was, that the families of long-stay patients are not simply observers in the ICU, they are *guardians of the narrative* during the patient's period of *being on the brink* or *lost time*. This insight showed that families carry the burden of the story – the emotional and narrative weight of it – until the patient is well enough to receive it.

6.4.4 'You Never Know What's Going to Happen Next': Existing in a Realm of Constant Uncertainty

In exploring the dimension of time, a dominant subtheme in family participants' narrative accounts of their experiences of the ICU was 'You never know what's going to happen next: Existing in a realm of constant uncertainty'. The state of uncertainty was due to several factors: (a) foremost, uncertainty regarding the patient's prognosis and whether they will survive, (b) uncertainty regarding the trajectory of the illness course; and (c) uncertainty regarding the different phases of the illness course. Each phase brought with it new and unexpected challenges that the family participants had to navigate. These will now be described.

Uncertainty regarding the patient's prognosis and whether they will survive. Because of how severely unwell the patient was, there was uncertainty regarding survival from the outset; family did not have certainty that their relative would survive their illness and this was distressing. All family recalled conversations with medical staff early in the ICU admission where they were told that their relative may die or could likely have a poor prognosis. Participants recalled these

conversations as being difficult and upsetting, yet their individual experiences varied. Some found the early discussions with doctors excellent, commenting on how timely, informative, and direct they were. Others felt that either information was not forthcoming or that the doctors painted an unfairly negative picture.

Uncertainty regarding the trajectory of the illness course. Family participants experienced uncertainty regarding the illness trajectory. All family participants described how the patient's path to recovery was non-linear, characterised by new complications such as new sepsis and medical events that resulted in episodes of deterioration, supporting Minton's (2017) articulation of "a long, wavering trajectory" (p. 133). These complications were often life-threatening, leaving the family feeling like they were constantly on a cliff edge and never quite out of the woods. The slow nature of recovery compounded the burden of uncertainty for family. The wavering nature of the illness trajectory was intensely draining:

> Exhausting. Up and down. Yeah. By God, during ICU at the beginning it was like... you know, and then he's getting better, then he's dying. That was like a roller coaster. The *uncertainty was extraordinary*. We all thought that, the three of us, just not knowing which it was going to be. You'd almost think, 'Die, for Christ's sake, because we can't stand this anymore.' So that huge uncertainty. Family F

The uncertainty that the family had to endure generated feelings of dread and worry. Having to leave the patient, such as going home to sleep overnight, was difficult and at these times participants would often worry about the patient's clinical status, hoping that they would not deteriorate, or die, while they were away. Some family members recalled their memories of lying in bed waiting for the *dreaded*

phone call from the hospital: "Sometimes I'm leaving [the hospital] when he's not really that good. It's always that thought of, oh, I don't want to hear that dreadful call from the hospital." Family J.

Uncertainty regarding the different phases of the illness course. Family also described feeling uncertainty regarding navigating different stages in the ICU journey; they were in a place where the patient's condition and plan of care was constantly changing, sometimes for the better, sometimes for the worst and everything was unsettling. This not-knowing what the family participant would be walking into each day resulted in feelings of anxiety in even approaching the ICU:

> The feeling of walking down a hallway to ICU, really anxiety provoking, because I never knew what I was walking into. There'd be times I'd walk in, and he'd be out cold, like in an induced coma because they'd done a trachie [tracheostomy] change. Family I

Navigating the waking up period and navigating delirium was difficult for family. Family participants' expectations of how the patient would be when they woke up drastically collided with reality:

> No one tells you anything about what patients can be like when they wake up. I had no idea. And so, it was kind of like, What?! […] It's just such a change because you've been with this person, really sick, and all the tubes and they're awake and that's great. And then how do you support someone that's got this [delirium]? Family H

6.4.5 Feeling the Pull to Be Close

In exploring the dimension of sociality, a common thread in family participants' narratives of the ICU was 'Feeling the pull to be close'. Participants expressed a strong desire to be in close physical proximity as well as close emotionally to their unwell relative. They felt the pull to be close for several reasons. Firstly, due to the ongoing uncertainty that consumed their relative's prognosis. Family were aware that their relative may not survive; they all wanted time with their relative in the context that their time together may be limited. Being close also enabled participants to see firsthand how their relative was progressing. As time went on, several family participants commented on how they could tell how the patient was doing as soon as they saw the patient and their monitor.

Secondly, family participants felt it was important to be close to the patient so that they could support them. Supporting with communication was regarded as an important family role. For the voiceless patients with tracheostomies, most family participants felt they were the ones who could understand and communicate best with the patient. Family participants of patients who had particularly long lengths of stay (several months) noted how over time they developed the ability to recognise their relative's needs and discomforts, such as common symptom burdens. They felt that they were better at this than the nurses. Ensuring their family member's needs were understood and met was critical to family and contributed to them feeling the pull to be there. One participant explained: "For me, it was so important that he was understood. I wouldn't leave until he was." Family I.

Most family participants spoke of how important their presence was in supporting the patient to cope emotionally and psychologically. This ranged from helping them cope with routine yet stressful interventions such as turns, to willing

them to survive: "I was just talking away to him, telling him, 'Come on there, you can do this.' I said, 'You'd better not bloody die on me.'" Family J.

Several family participants described a desire to help with physical cares and the sense of contribution participating in this gave them. In the context of being in a situation that was beyond one's control and feeling helpless, being able to participate in care was helpful to the relative as it made them feel that they could contribute. Furthermore, this was perceived as strengthening the nurse-family relationship:

> I sort of picked that up and offered, 'Oh, I can help you.' They go, 'Are you sure?' I said, 'Yep, yep, he is my husband, I can help.' So, they let me help and then from that time onwards, that's when the bond really kicked in with the nurses and that because I started to help a lot with him, which was really good for me. Family J

Family participants also reported how when the patient was at a stage when they were awake, the patient felt safe when they were present, adding to feeling the pull to be close. Helping the patient feel safe is work the family participants wanted to engage in. One participant whose spouse spent many months in the ICU remembered an occasion when her spouse's wishes that she be present for nursing cares were ignored by a nurse. He had developed many respiratory complications during the first six months in the ICU, and experienced distress from not being able to breathe properly. He found turns particularly frightening, experiencing panic and a heightened sense of vulnerability. She remembered he had a lot of mucous plugging and would often desaturate.

On one occasion, she walked into his room and his oxygen saturations were 50%. She recalled her spouse explaining to her that every time that happened, it

took him back to being a child with asthma and not being able to breathe. In the ICU, he had no control and he was unable to communicate when he felt like he could not breathe because he was paralysed. She explained how he was dependent on everybody else in the room to notice when something was not right; read the signs and react quickly. He became anxious every time he was turned. She knew him and could read his signs and expressions. One night when he needed a clean-up which required multiple turns, she was asked to leave the room by the bedside nurse:

> There was one night that it took all my power to not lose my shit, because he had been number twos, and they were going to clean him up, and he liked me to be there. He felt secure. He didn't care. I would stand on the opposite side of which way they were going to roll him, so they'd roll him to face towards me, and she said, 'You need to leave the room.' I said, 'Why do I need to leave the room?' She said, 'I'm asking you to leave the room.' I said, 'That's not what [patient] wants.' She said, 'I'm telling you, you need to leave the room.' So, at that point, I – after that, I was really annoyed, because actually, it's not me. You've ignored [patient's] wishes, and actually he has a say, even though he can't say. Family I

As I reflected on this narrative from my position as RN and a part of the research, I considered several problematic factors that can be acknowledged. First, there is a lack of appreciation by the nurse about the history and lived experience of turns for this patient, which suggests she did not know the patient and his journey so far. Second, the patient's wishes were ignored. Third, the family member's needs were ignored. Fourth, this patient had been in the ICU for several months and he had

consented to his spouse being present in all of his cares, yet why the family member could not stay to support him and help with the cares was never explained.

From my position as an ICU nurse, I know that the power relationship between the ICU nurse and family means relatives do not push back too much, so the family member did leave the room. This situation was incredibly upsetting for her. It is difficult to know but it may have had a similar effect on the patient, who evidently was not seen or included in this decision. Furthermore, it is established in the literature that family have specific needs during a prolonged critical illness (Minton, 2017). To be able to meet these needs, effective communication between family and nurses is vital. This situation could have been prevented if the nurse had upheld basic patient rights and practiced person-centred care.

6.4.6 An Emotional Rollercoaster

In exploring the dimension of sociality, specifically looking inwards at family participants' innermost thoughts and feelings, a prominent subtheme in their narratives of the ICU was 'An emotional rollercoaster'. Having a relative admitted to the ICU was an emotional experience. Family participants described a range of emotions such as fear, anxiety, dread, helplessness, loss of control, sadness and hope, making the period tumultuous: "It's a really emotional place to be." Family I.

Family participants' experiences were initially dominated by worry about their relative's health and whether they would live. Each time the patient developed a setback or was unstable the family participant would be swallowed up in worry: "That night, that was a really nervous worrying time. I think me and my mum and my sister are just here and just praying, praying, and crying and praying for like a miracle." Family H.

As the path to recovery became more stable, these feelings lessened. Dominant emotions throughout the duration of the ICU were dread and hope: "There was the two sides – the dread and then the hope." Family H.

Witnessing their relative's suffering was difficult and took an emotional toll:

> He hallucinated a lot, and he got a lot of really strange feelings, so he's trying to tell you something is happening to him that's not happening. So, when you can't talk, trying to understand that, and he'd get really distressed. Those times were so crap. They were shit. Family I

6.4.7 Needing Care and Communication in a Time of Crisis

Another prominent subtheme was, 'Needing care and communication in a time of crisis'. Situated at the intersection of the time, place, and sociality dimensions, family participants spoke of the people who worked in the ICU who had the knowledge and skills to save their relative's life. They felt that their relative was in safe hands. In retelling their experiences of the ICU, all of the family participants spoke emotionally about the people who worked there, how much the ICU nurses cared about them and their unwell family member. All family participants were moved to tears when they described the kindness and humanity that was shown to them in the ICU. Participants described feeling care through conversations, relationship building, caring moments, and the nurse's dedication to one patient. Participants reported that they generally felt supported by the staff in the ICU, however, there were instances where some felt unsupported such as the family member who was sent out of her relative's room for turns. This care helped them to cope with the prolonged ICU stay. One participant described how well supported she felt by the staff in the ICU. The simple act of checking in with her meant a lot. She also

appreciated the nurses getting to know her and her family and recalled instances where the nurses would go above and beyond for her and her spouse:

> The support for me was huge. Yeah, checking in on me, did I need anything, getting to know me, getting to know our kids, making special things happen for [patient] and things like that. I think [patient] worked with [nurse] for our anniversary, when he couldn't speak, to order flowers and get them delivered, like super cute. They were incredible. Family I

Person-centred practice is a way of providing care that focuses on a patient's individual needs and is respectful and responsive to that person's preferences and values (McCance & McCormack, 2025b). The critically ill person is often unable to express their needs and wishes due to the severity of illness and medical treatments such as intubation and ventilation that leave them voiceless. It is therefore, only through family that ICU nurses can begin to know the person who is unwell and learn what matters to them. In this study, a caring environment that enabled family to enact their values and preferences, such as putting photos of family around the patient's bedspace, video calling the patient if they were physically absent, or praying and singing around the bedside of the patient were seen as helpful:

> I asked if we could have karakia [prayer] with him [patient] in there. The doctor said, 'Yeah, that'll be cool.' […] I said, 'Can my grandchildren – because my children can't come in – but can they have karakia with him at night?' They said, 'Yes, or whenever there's a time.' It didn't matter, as long as it was done. So that started up. The grandkids didn't come in. It was done personally with me. The whole family was there [via video call]. Family J

Family expressed how important good communication with the ICU staff was in helping them to understand and cope with the situation and furthermore, trust the people caring for their relative. They explained that ongoing information from both medical and nursing staff throughout the ICU journey helped them to understand their relative's condition in the present moment and grasp the reality of the situation they were facing. Additionally, timely information was reported as being important. All participants expressed the view that they were well informed throughout the ICU stay and most felt that communication of information about their relative was generally of a high standard:

> I was well informed. I was always informed about everything that was going on with [patient] and if they – even when he was in there and they felt a few times like he was going down, they would ring me and I would come in. Family J

One participant described a family meeting where she was delivered upsetting news concerning her husband's chances of survival. From her perspective, the medical staff painted an unfairly pessimistic picture, highlighting the need for a balance between the provision of honest, realistic information and hope in these conversations:

> I just really got the sense of that they're trying to not get your hopes up. […] I mean, you could say, 25% of people don't make it, but then 75% do, so we just have to see. They could have reinforced the good side as well as the negative. Family H

As family navigated challenges through the course of the critical illness, information regarding specific challenges was of great importance. For example,

looking backwards, several family members recall the shock and distress they felt when their relative was delirious. They felt at the time that they were not given sufficient information on delirium and commented on the need to be forewarned and provided with information about the condition so that they could understand it. They felt that this would lessen their concern and provide them with the skills to be able to support their relative through it. One participant found the delirium phase of her husband's illness confusing and upsetting. She was relieved and excited for him to be waking up after being sedated and ventilated for over a week but was not prepared for him waking up and not being himself, a common reality for long-stay ICU patients: "Even in the delirium stage, it was a little bit slightly depressing and sad, because I had no idea about it. I was like, 'He's awake, that's great, but oh what's going on?'" Family H. This reinforces that ICU nurses must prepare families for this.

Being on life's edges in a world of uncertainty encapsulates the family participants' experience of a long stay in the ICU. Families' narratives reveal the experience to be stressful and confronting. The ICU experience was in the past, but the sense of overwhelm, closeness to death, and emotional distress endured throughout the illness course were still remembered long after.

6.5 Family Participants' Experiences of the General Ward

6.5.1 Overarching Theme: Where is the Care?

The overarching theme 'Where is the care?*'* encapsulates the family participants' experiences of transitioning from the ICU to the general hospital ward. Interwoven within the narrative 'Where is the care?' are all three dimensions of temporality, sociality, and place as participants looked backwards comparing their past ICU experience to the shocking new reality they were confronted with on the ward. The ICU experience was remembered as a place of safety that provided

exceptional care and had a workforce of highly skilled, knowledgeable and caring people. Furthermore, the long-stay family had over time developed a trusting relationship with the ICU team. In comparison, the ward experience was characterised by a markedly reduced level of interpersonal relationships, unmet care needs, poor communication, and lack of family involvement in discharge planning, which contributed to family participants' unfavourable perception of care. The theme 'Where is the care?' portrays family participants' perception that the care on the ward was just not there and because of their relative's unmet care needs, family felt that they needed to be there to care for their relative and oversee the situation.

6.5.2 A Shocking New Reality

Looking backwards in time to their experiences on the general hospital wards, a prominent subtheme in family participants' narratives was 'A shocking new reality'. Interwoven within the dimensions of place and sociality, the participants retold stories that revealed it was unnerving to leave the security of the ICU and adjust to a new reality on the ward. Family participants experienced ambivalent feelings leading up to the ICU discharge. Positive feelings corresponded with the patient's recovery; stepping down from the ICU was perceived as a milestone in the patient's path to recovery, reflecting forward progress. Family felt relief their relative was now well enough that they did not require intensive care. However, the transition also created negative feelings; after all they had been through, family experienced fear, apprehension, and uncertainty about leaving the known ICU and entering a new unknown place, generating feelings of insecurity and vulnerability. They were leaving a place with highly responsive care and continuous monitoring that provided a sense of safety. They were also leaving a place where they had a nurse with them 24 hours a day and a skilled multi-disciplinary team looking after them. People who had

become familiar, who they had built trusting relationships with: "We had built such a relationship with the staff that it all felt really foreign going down to rehab. That security was gone, of that knowledge and of someone always being there." Family I.

Upon arriving to the ward, family participants described the transition for both them and their unwell family member as shocking. Looking outward it became clear that it was the stark difference between the two places that caused the sense of shock: "I think we went from being spoilt to like, pushed out on the streets with nothing. That's kind of the comparison I'd probably give it because the care was so amazing in ICU." Family G.

For family, the lack of visible nursing presence in this new reality was a real shock. They went from having a dedicated nurse at the bedside in the ICU to a nurse who they perceived as being mostly invisible on the ward. They reported how they would only see a nurse appear for technical tasks such as medication administration or taking a set of vital signs. Being left alone all day created feelings of abandonment. The following quote highlights the reduced nursing presence that all family participants struggled with:

> When you got to [ward], you don't see anybody. If he was in a room alone, he'd be left alone there only to be checked on if he rang a buzzer or if they came to give medication or take a thing. That was it. You don't see them at all. There was no one, not even a come in to see how you are. Family J

While the long-stay patient no longer required continuous monitoring or invasive interventions on the ward, the family participants recognised them as still being unwell, which compounded the confusion and dismay they felt concerning the perceived reduction in care in this new place. All explained how their relative was so

debilitated from the critical illness weakness and had on-going complications that left them dependent and vulnerable. They were unable to walk, move themselves in the bed, toilet themselves, or wash themselves. Several patients were unable to feed themselves or push their nursing call bell. A few of the patients had ongoing delirium. The following quote shows how the patient is still recovering with ongoing issues that need to be carefully managed: "He was still delirious. He was still agitated and getting used to this thing and trying to communicate, he was frustrated. And he still couldn't walk." Family G.

One participant highlighted that there was no formal follow up from the ICU staff after discharge. She felt follow-up was necessary after an extended ICU stay to ensure that her husband's ongoing medical issues were being properly managed:

> I think follow up should have been from them [the ICU staff] because they were the ones in the beginning. Chucked up to [ward]. Nobody. They didn't – they did come visit but it was friendly visit. It wasn't to do with his health issues or anything. It was just a visit. 'Hi, [patient]', because they [ICU nurse] were in the ward. Family J

Another participant highlighted the reality of fragmented care. She verbalised the need for someone to act as a link between the ICU and the ward during the transition process: "There definitely needs to be some kind of link between the two." Family G.

As a nurse, and on reflecting on the interviews, the need for a step-down unit between the ICU and the ward was becoming patiently clear for me. One participant commented that her spouse did receive follow-up from a Patient At Risk (PAR) nurse, and this provided a sense of security; however, she felt that the follow-up

needed to be ongoing across the first week of transition and that it needed to be multiple times a day rather than a one-off visit for former long-stay ICU patients and families. This would help both the patient and family to psychologically adjust to the new environment:

> They've got the PAR nurses, which is good, because you've got that security. It would be good if in that first week, they could pop in two or three times a day, not just the once. That familiarity, that just checking. As a carer and also as a patient, that would be really reassuring that there's a crossover of that care. Family I

As a nurse, I know that there is a process where PAR nurses review ICU discharges. The focus of this review is very medical; assessing the patient's clinical status and vital signs. After reflecting on the narratives of participants, for the long-stay patient and family, settling into the new ward environment is a process of psychological adjustment and the needs of the patient and family are constantly changing. From my experience as a nurse alongside the narratives, it is clear that existing ICU follow-up processes during the transition to the ward could be strengthened by ongoing follow-up across the first week and by adopting a holistic family-centred approach. Family participants spoke of how ICU follow-up with them, as well as the patient, would have been reassuring and provided a feeling of safety. This highlights that being included in ICU follow-up is important for the family too.

Looking backwards and reflecting on what would have made the experience of transition to the general ward more positive and helped families to adjust psychologically, family participants verbalised the need for adequate discharge preparation and planning from the ICU staff, specifically communication and

information. They expressed the need to be warned prior to leaving the ICU about the differences in the ward environment and reduction in care. They expressed the need for information so they could manage their expectations, and a few spoke of the value in an orientation visit to the ward. Family felt that these things could have lessened their apprehension. Only one family participant was forewarned about the drastic change in level of care they would encounter on the ward, highlighting the missed opportunities for communication from ICU nurses that left the other family participants feeling unprepared with no idea about what to expect in this new place. Looking back, she was so appreciative of this:

> One of the things that just was I felt it was really good in ICU, that it was actually the physios who said to [husband] and me, 'It won't be like this when you get on the ward.' Like they gave us just that warning. I think that was really good that they said that, like I hadn't thought about it much. Cause I don't try and think too far ahead. But I think it was, it's really good to give people a warning. That there will be half a nurse there not 10. I think that was good. Because it made me suddenly start thinking about that next step.
>
> Family F

This quote about the physiotherapists giving a warning is significant. It contrasts with the other family participants who felt terrified at key transitions in the trajectory reflecting the total lack of a roadmap for most families after an ICU admission.

The shock accompanying transition was a complex and emotional process for the family participants and the reduction in nursing care and attention was a major psychological adjustment that compounded family participants' stress and added to

the carer burden. Family participants were unprepared for the new reality and lacked information on what to expect both prior to leaving the ICU and upon arrival to the ward and they did not feel they were supported adequately. Families' narratives reveal that there is no one actively caring or managing the process of transition out of the ICU after a long stay.

6.5.3 Unmet Care Needs

Family participants' narratives of care experiences on the ward were overwhelmingly negative. The common thread among their stories was 'Unmet care needs' reflecting both unmet needs and missed nursing care. Most of their narratives of care on the ward reflected unfavourable perceptions of care, and through analysis it became clear that what was missing was nursing care that was attentive and responsive to the patient's needs. Throughout the narrative, there was tension within the delivery of nursing care, and this was situated within the place and sociality domains as family discussed the ward environment their relative was in and how the care delivered was influenced by the social interactions of doctors and nurses. Under the 'Unmet care needs' narrative, family members commonly reflected three sub-narratives relating to lack of trust, poor communication, and lack of person-centredness. These will now be explained.

Lack of trust. It is widely accepted that a trusting, therapeutic relationship between care providers, care recipients, and family is a prerequisite for the provision of safe, quality care (Kitson, 2018; Kitson et al., 2014). The participants needed to trust the people caring for their relative, and it was clear that the early care encounters were critical to the nurse establishing trust with the patient and family. As a researcher and nurse, it was confronting to hear family experiences describing unsatisfactory interactions or care encounters with nurses, which in many cases,

occurred as soon as the patient arrived on the ward. For almost all family participants, this lack of trust emerged as an environment of poor communication and a lack of fundamental care that intersected dimensions of place and sociality. Additionally, the temporal flow of experience was evident bringing forward the dimension of continuity, with family participants' expectations of care that their relative should receive related to looking backwards at their experiences of care in the ICU, for example, "The care has gone from consistent to, where are you?" Family G.

Family participants disclosed concern about the level of skill of nurses to care for their relative. As one participant stated, "Quite a lot of them [nurses] were a [night]mare. It was sometimes really hard to tell the nurses apart from the care assistants. It was just because of the quality of their care." Family F.

One participant told a story of how within 48 hours of her relative arriving on the ward, he developed a pressure injury, which she perceived represented a lack of fundamental nursing care, poor clinical assessment skills, and a lack of insight into the patient's vulnerability. This was a disappointing introduction to the standard of care they now found themselves under, increasing the family participant's feelings of worry: "Not picking up on those small things and doing those little things and really taking the time to check over from head to toe that everything was okay each day." Family I.

Another participant explained how she perceived that the staff attempting to regularly draw bloods from her husband did not demonstrate the necessary skills, resulting in unnecessary suffering and undermining the patient and family's trust in the clinical competence of those ward staff. Drawing from my knowledge as a nurse, it is not uncommon for long-stay ICU patients to have difficult intravenous access. However, this narrative does reflect a broader issue of ward staff not understanding the unique features of former long-stay ICU patients and planning care accordingly.

This patient needed someone skilled in phlebotomy to draw the blood, the implementation of comfort measures, as well as an individualised plan for sustainable future needle access and procedures:

> Getting blood out of [husband] was a constant issue. He had people not very good on the wards trying to get blood and I think he was like, 'No, you have one more chance and if you can't get it then I'm not letting you do it again.'
>
> Family H

As another example of poor care, Family I described how upon arrival to the ward her spouse, who was still immobile due to paralysis, was fully dependant on others for help. She explained how because of the paralysis he was unable to move to reach the nursing call bell and so it always needed to be placed within his reach. However, after interventions such as turns or position changes, the nurses would sometimes fail to put the call bell within his reach, suggesting they did not understand the patient's condition and therefore, did not meet all of his needs, particularly his fundamental need and patient right to be and feel physically safe:

> The other thing was the call bell. Them not always making sure, they'd come in for a roll or a change and not put it back where it needed to be, those kinds of things. So, a huge, huge security blanket gone.

Several participants recalled how on the wards, they took on the role of carer including toileting and showering the patient because they realised that if they did not, these fundamental cares would not be attended to. One participant came to this realisation within the first day of being on the ward and described how she did almost everything for him: "I would get the pan and put it under him. Clean him up and take it away and clean that up. […] I practically did everything for him." Family J.

Family J also noted that the culture of the ward, which in turn influenced how nurses organised their work, was focused on completing clinical tasks. For example, her husband was told by nurses that he had to be washed at 7.00am, despite his preference to be washed in the evening so he could feel clean and comfortable before sleep: "He doesn't like having a shower in the morning. He wants to have one before he goes to bed. They only did it in the morning."

Poor communication. All family participants described a lack of communication with the nurses on the ward, which left them feeling excluded. Situated within the intertwined dimensions of interaction and place, participants' stories of their interactions with nurses commonly reflected a lack of communication between the nurses and them. The family participants described struggles obtaining information about their relative's condition, treatment, and a lack of involvement in decision making and hospital discharge planning making their experience more burdensome. Participants explained this left them feeling uncertain about what was happening, angry, frustrated, and excluded, and they believed this lack of information was not good enough.

The absence of communication was particularly upsetting for family of patients who were delirious or cognitively impaired on the ward. These family members were astounded that the ward staff had spoken to the cognitively impaired patients and not them. This highlights a common intertwining thread in the narratives – lack of person-centredness – where the care team was treating the patient but were unaware of the full person. For me, this signalled a lack of understanding by ward-based nurses, of the phenomena of prolonged critical illness and the journey that the patient and family are on.

One participant retold her experience of poor communication while her husband was on the ward and explained how for the entire course of his stay a nurse never spoke with her. This is also situated within the context of her husband contracting COVID-19 while he was on the ward, and because of this she was unable to visit him: "Their communication was shocking. I didn't speak to a single nurse. He was only there for maybe two weeks or something, because he got COVID. But no nurse ever spoke to me, and I think that's poor." Family F.

Many family participants realised that when they wanted information about their relative's condition, treatment, or plan, they needed to be proactive and seek it out themselves, initiating conversations with nurses. They said this was tiring. Furthermore, they found it exasperating when the nurses were unable to answer their questions. One participant's story described the frustration she felt that no one included her in conversations regarding the opportunity of her relative to have day leave from the hospital. Her story also described the consistent pattern of poor communication between the nurses and her during their time on the ward:

> They go, 'Oh the doctor has actually said he can go on day leave today.' Then why didn't anybody tell me? Oh, they told [patient]. He's delirious! What the heck! And so, for someone coming out of ICU who is a little bit confused, and the doctors are telling them stuff, I think they should probably know better. And all of that stuff was never relayed on to me. I didn't find out about any of that. Unless I went in and I said to the nurse, 'What was discussed? What did the doctor say?' 'Oh, I'm not sure, that was in the morning and I've just come on, it's late in the afternoon.' […] So yeah, there was no communication.
>
> Family G

Being involved in hospital discharge planning was considered important to family however, most voiced that they were not included. Several participants reported feeling dissatisfied with discharge arrangements. Several participants felt that the hospital discharge was thrust upon them without consultation or warning, which left them feeling concern that there was little time to prepare.

All family participants were apprehensive about their relative returning home for various reasons. Some felt the patient was still too unwell, some were concerned with how they would manage ongoing health issues. Others described feeling overwhelmed and unprepared for the perceived caring responsibility at home:

> Quite sort of, not terrified, but of having to look after this person. Because you've seen them, the amount of care that's being required, and see how hopeless they are. The physical state they're in. Holy Jesus, I have to look after that? I'm not a nurse, and he doesn't listen to me. Family F

The notion of dread about the patient returning home is echoed by another:

> The closer it got to him coming home and the realisation of what that meant for me, of having another person that depended on me 24/7, the more it wasn't a celebration for me. I was like, here goes. The work begins again. So, it's not all it's cracked up to be for the carer person. Family I

Another participant said, "He was determined to come home. I was terrified, because I didn't know how to care for him, what to look out for, you know what to do if anything happened, what that looks like." Family G.

During analysis, it became apparent that family knew the patient better than any health professional they encountered, and family accurately predicted the challenges that unfolded when the patient returned home.

Lack of person-centredness. The narrative of 'unmet care needs' also emerged in family participants' stories of their observations of nursing encounters which reflected a lack of person-centredness. Family recalled moments where they perceived the nurses' actions or communication demonstrated a loss of dignity, a loss of respect, or a lack of compassion for their relative: "There was a couple in there that just made you feel like – yeah, I felt for him, like with clean-ups and things like that… Just made you feel like it was a fucking chore [for the nurses] and they shouldn't be doing it." Family I.

Another participant highlighted a lack of nursing knowledge about the long-stay ICU patient and where they have come from – their journey: "I said to her, 'You know he's just woken from a really long coma?' She [nurse] goes, 'Oh I haven't had a chance to read the notes yet.'" Family G.

This also reveals how fragmented care is as the patient moves through the system and missed care – how little time the nurse has had (or taken) to read the patient's history before commencing the shift.

Despite family participants' experiences of poor nursing care on the ward, some indicated that interactions with staff were satisfactory. These moments included observing clinical confidence and competence, nurses taking the time to talk with them, getting to know them, and demonstrating kindness:

> There was one guy up there, and he was a care assistant. He was actually fantastic. He was training to be a nurse here. Just his level of sort of

confidence, his willingness to talk. Kindness to [husband], you know, this utterly munted man at that stage. Family F

I found the accounts of poor care confronting, and I felt powerless to explain or defend the nursing profession whose core work is to care. Yet I knew that this could not all be about *uncaring*, knowing from my reading of workload allocations that the allocation of time nurses have for each patient is driven by budget and not individualised care (Harvey et al., 2016; Willis et al., 2017).

6.5.4 We Needed to Be There

Family felt they needed to be physically present on the ward for several reasons: (a) because of the reduction in nursing care, (b) to get information, and (c) to care for the patient.

To begin, the reduction in nursing care and attention in the context of a person who was still unwell, debilitated, and dependent left participants worried that their relatives' needs would be unmet and hence they felt they needed to be there to help:

> They come in for doing your medicine. Or if you ring the bell, they'll come in. But apart from that, I think that's a time where it was quite important that we were there as a family. So, we were trying to be there pretty much around the clock, because he couldn't move. Like he literally couldn't move. He couldn't hardly push the button if he needed it. Family H

One participant recalled how the ward nurses "did nothing". She often observed them to be sitting around talking to one another, when from her perspective the patients needed them to spend more time with them: "I always used to think to myself, how can you be short-staffed when you're just standing around?" Family J. She spoke about how because of this she needed to take on the responsibility of

carer, which included attending to her husband's fundamental needs such as washing and toileting.

Some family participants felt the weight of the added responsibility of care in the new ward context, highlighting that for family of long-stay ICU patients, the caregiver burden increases on the ward: "I felt like a whole more landed on my shoulders." Family I.

For some, the narrative 'We needed to be there' emerged in family participants' stories of needing to be there to keep the patient safe. Part of this role was being an advocate for the patient. One participant described a situation where her spouse phoned her because he was in so much pain. Upon arrival to the ward, she immediately noticed that something was seriously medically wrong with him. She sought an urgent medical review, reflecting in this situation both how well she knew the patient and her ability to recognise and act on deterioration before the nurses:

> When he got pancreatitis in [ward], he rung me and he said, 'I'm in so much pain'. I was like, that's really weird for him. He's in a lot of pain if he's complaining about pain. […] I went, and by the time I got there, I walked in, and he was sweating, and he was grey, and I went and got the doctor straightaway. I was like, 'That's not right. He's not right.' Family I

6.5.5 Terrifying Hospital Discharges

The final subtheme in family participants' experience of the hospital wards is 'Terrifying hospital discharges'. This experience stemmed from their stories of a lack of involvement in discharge planning; feeling unprepared for the role of carer that they would have to assume and the challenges that lay ahead; a lack of information provision; and lack of adequate support with the transition home. Participants also

reported feeling anxious about their relative being discharged home from hospital because they were still recovering from the critical illness and in need of assistance. When the patients left hospital, some family recounted that they could barely walk. Most could not shower on their own. Several could not toilet independently. Many had ongoing medical issues that needed careful managing. Most family participants had to take on a carer role and help the patients deal with the effects of the critical illness. Without sufficient guidance or support, this responsibility was daunting:

> Still had to do almost everything for him. Yeah, help him to the toilet. Help him, you know, wash. And we had a nurse that would come around and change the dressing. And then after a couple of days, they stopped coming and I just changed it myself. So, I had to do everything. […] It was just a bit daunting because that's not my background. Family G

Family participants were acutely aware of how vulnerable their relative's health was at the time of hospital discharge:

> I sort of think to myself, if he had to go, how am I going to breathe into him? I'm too frightened I might break him. Or even CPR [cardio-pulmonary resuscitation], I could press on his lungs and break his lungs by mistake even though I've done the courses that many times. Family J

For some patients, hospital discharge was sudden, and the family did not agree with the medical view that the patient was well enough to leave hospital, which added to the experience of terrifying hospital discharges. Better physical recovery and functioning was commonly expressed as being optimal: "I don't think he was physically ready to come home." Family G.

As a nurse, hearing these stories was distressing. Given that this cohort are long-stay hospital patients, this lack of advance notice and planning with family, in my view, was unacceptable.

Family participants recalled how they felt unprepared for the patient to return home, concerned that they did not have the medical knowledge or caregiving skills to care for their family member and worried how they would cope. Several also expressed fears about their ability to manage potential complications, even medical emergencies at home without help should these occur. These factors created feelings of overwhelm and fear related to returning home: "He was determined to come home. I was terrified, because I didn't know how to care for him, what to look out for, you know what to do if anything happened, what that looks like." Family G.

One patient participant was told by medical staff that following his critical illness he would likely remain on oxygen for the rest of his life. He was discharged from hospital on continuous home oxygen. As also noted in section 5.5.3, the patient and his wife received almost no education from hospital staff on how to use the home oxygen device, which turned out to be different to the hospital equipment they were used to. Nor did they receive education on potential device issues or medical complications and what to do should such problems arise:

> I was prepared for all the stuff I have to do for him but not prepared if it failed. Like with the breathing thing [patient was discharged from hospital on continuous home oxygen]. I wasn't prepared for anything like that. If anything happened during the breathing, what the hell am I going to do? I said, 'I only know CPR. […] I don't have a defibrillator or anything'. But I worry about that, and that we might have to do that on him. Family J

The absence of expert guidance during the transition home, absence of ICU follow-up, and lack of information provision particularly around what to expect and who to contact should they need help, contributed to the problem of family feeling unprepared and alone in their journey.

While the prospect of returning home from hospital was terrifying and the transition itself was a very difficult time, with the passage of time, their situation did get better and their anxiety lessened, "I've calmed down. I feel much better in myself and less anxious." Family F.

6.6 Family Participants' Experiences of Being Home

6.6.1 Overarching Theme: Navigating New Realities Alone and in the Dark

The overarching theme of family participants' experiences of being home, and across the first year after hospital discharge was, 'Navigating new realities alone and in the dark'. All family participants spoke of many new realities emerging in the aftermath of the critical illness that they had to navigate with no guidance and limited support. The overarching theme, 'Navigating new realities alone and in the dark' captures this.

All family participants considered that their lives had fundamentally and permanently changed because of their relative's illness and its consequences, and all struggled, particularly in the first few months following return home, with the change in how life was lived in the new reality. What the family of long-stay patients had to navigate in the aftermath of the critical illness was enormous and this was situated within all three dimensions of place, time, and sociality; all of the participants talked about facing unsettling new realities in returning home including living with a changed person, altered everyday routines, changes in relationship roles and

dynamics, financial stress, and living with uncertainty. Over time they engaged in a personal process of adjustment to the changes.

Participants described the transition home from hospital as terrifying, overwhelming, demanding, and stressful, and verbalised being thrown into unknown territory. All described being completely unaware of the challenges they had to navigate in coming home. The transition home was difficult; both the patient and family faced challenges, and there was no one who could provide expert guidance and support during this time.

Family participants described feeling alone and in the dark about how to manage their new reality at home including how best to support their family member's recovery. Several expressed confusion and concern about the slow nature of recovery. They worried about ongoing critical illness sequelae such as nerve pain, fatigue, breathlessness, and cognitive impairment, common post critical illness problems that had not been explained to them. Several were concerned that promised aftercare and rehabilitation for their relative who was still unwell and in need of extensive rehabilitation did not eventuate. All family participants perceived that ongoing rehabilitation was essential for their relative's recovery. These narratives are accompanied with disclosure of not knowing who they can contact or where they can go for help. Family participants described the negative impact the prolonged stress and the strain of their situation had on their own health and wellbeing, reflecting the cumulative burden of caring and their unmet support needs.

One year after hospital discharge, all family participants reported that their relative was either still recovering from the critical illness and/or living with long-term health issues revealing the reality that one year after a prolonged critical illness, life did not return to normal (that is what normal was before the hospital admission) and

some things were never the same again. The family participants expressed a desire to return to normal in the sense of what normal life was before the illness, but with time they realised that the critical illness had changed their relative and they would not recover to their pre-illness level of health and function, thus the family participants had to reconcile themselves with a new normal.

Hearing these accounts of hardship was not easy for me, and it reinforces the need for professional psychological help; someone who can help family with the complexity of their relative's recovery and in adjusting to major life change. The family participants' journey is characterised by uncertainty, prolonged struggle, exhaustion, and emotional complexity. It is a journey that is in temporal flow and continually evolving. Despite the challenges the family participants experienced, all found ways to keep going and carry on.

6.6.2 Returning Home: Being Thrown into the Unknown

The subtheme 'Returning home: Being thrown into the unknown' describes the family participants' perception that following hospital discharge, they found themselves thrown into unchartered territory, navigating a path rife with challenges they were completely unprepared for. The struggles were immense and multidimensional with family contending with daily stress and anxiety. Furthermore, these struggles took many months to resolve within a context of limited professional support.

Participants recalled the past, their lives before the critical illness and what was a known reality and then faced the time of coming home, a transition to a new reality and uncertain future. To leave the hospital after such a long stay, with a person who was still unwell, was daunting.

Family participants described feeling overwhelmed, attributing this to both the marked reduction in formal healthcare support and the sudden assumption of caregiving responsibilities. This shift evoked significant emotional distress, emerging conceptually as being thrust into an uncertain, worrisome, and indefinite journey. Reflecting on the early months at home, participants recalled feeling trapped, swamped, helpless, hopeless, and unable to see a way forward. However, as the patient's recovery progressed, these emotions gradually eased. Within the subtheme 'Returning home: Being thrown into the unknown,' two recurring narratives emerged: experiences of careless hospital discharges, and the sense of being swamped in caring. The burden on family participants during this period was considerable, yet no formal support was provided.

Paradoxically, despite being fearful about going home, participants recognised discharge as positive; a sign the patient was progressing with their recovery. They described feeling relief that their relative was now well enough to leave the hospital. They had wanted them home for so long, and this desire was intensified with dissatisfaction with the care and rehabilitation provided on the wards/inpatient rehabilitation. One participant explained: "I was really quite glad for him to come out of rehab. Because I really didn't see much in the way of his rehabilitation in there." Family J.

After spending over a year in hospital, one patient was coming home largely dependent; he needed assistance with most activities of daily living. His spouse's realisation of how reliant on her he would be and the additional caregiving work around him on top of managing an already busy household with children was daunting and created a sense of overwhelm. The homecoming was therefore, not perceived positively: "It wasn't a celebration for me." Family I. Similarly, another participant dreaded her family member returning home because of the anticipated

challenges that lay ahead: "I was really dreading him coming home out of the hospital. Oh god, I was dreading it. It was difficult." Family F.

Despite their fear of *the unknown*, my reflections on these interviews revealed that the family participants knew the patient better than any health professional they encountered, and they accurately predicted the challenges and struggles that unfolded when the patient returned home. This confirms their insights were valid.

Participants spoke of the new limitations and needs the patient faced after their illness. Bedrooms were relocated, new beds installed, bathrooms modified, and various aids, such as walkers and hospital chairs, had to be collected and set up. One participant recalled receiving a call on the day of her spouse's discharge, asking her to come and collect him. However, not once during his ward stay had any of the ward nurses communicated with her, so his sudden discharge came as a surprise. She was unprepared for him coming home both psychologically and practically, as the house was not set up for him. Another participant described her husband's hospital discharge as feeling rushed, making comments about a doctor who she perceived was trying to "push him out the door." She also described how she had no time to prepare the house practically, creating feelings of stress. The day of his discharge she recalled running around collecting equipment that they would need at home. Additionally, she described how medical equipment failed to be delivered and as a result, she was lucky to have her husband's discharge delayed:

> They said they had put some support in place for him and that was concerning rehabilitation at home. I thought, oh great, this'll be really good but there was sort of a thing anyway… muck up about coming home because

> nothing was really ready for him. Like I spent the day running around picking up all this equipment. Family J

Family participants' descriptions of the amount and type of practical support that was put in place for patients after discharge suggest it was limited. Some patients received support in the form of various aids such as walkers, toilet seats, commodes, hospital chairs. Others needed supports but did not get them initially, until they realised, after they returned home that they were required. Even those participants who did receive appropriate support at home spoke of how they had to drive it, advocating for their relative and fighting the system for what they perceived they needed: "We fought for everything he needed. Well, I did, I fought for it and got it. I refused to give up." Family I.

One participant talked about the difficulty she experienced in getting access to a simple practical support such as a wheelchair, which her husband, dependent on oxygen and unable to walk, needed to access his many medical appointments:

> You come home and then they want you to take him to places, and you don't know. You're trying to figure out how are we going to get him to walk there? He can't walk. […] How am I going to get him here, because they said he can't have a wheelchair. Family J

Another reinforced the experiences of feeling abandoned and having to be the main driver coordinating aftercare and problem-solve challenges:

> Where's your support? There's none of that. There is absolutely none of it, because when you're saying, what supports are in place when you come home, as a patient, all your medical therapy and things like that that you

need – not a lot. A lot of it has to become self-driven. As a carer, what supports are in place? Nothing. Nothing. Here is some individualised funding that's also going to put more pressure on you, because you have to do contracts and submit things. Here's some money, but you find somebody. That was daunting too. Family I

Not all participants failed to receive the practical support they needed. One participant described how they had access to what they needed, although she emphasised that communication with the physiotherapist and occupational therapist prior to discharge assisted this outcome: "They provided everything he needed for his day to day here, and we had conversations around that. We were like, we want a hospital bed. […] So, advocating for all that kind of equipment, asking." Family I.

Upon returning home, some participants shared stories of promised post hospital services failing to manifest. This was a common occurrence with physiotherapy. Participants either voiced their spouse got none when they were told they would, or less than what they had been told: "We asked how much physio we were going to get and occupational therapy, and what we were actually told was not what happened." Family I.

Participants saw this as broken promises and feeling let down and unsupported from the health system. While in hospital all patients were getting daily physiotherapy and rehabilitation, so family were bewildered that upon hospital discharge, the reduction in services was so stark. Their descriptions of how physically weak their relative was and the functional losses they experienced combined with my observation of the patient through the lens of a RN highlight that survivors of prolonged critical illness are still physically debilitated upon return home

and need ongoing rehabilitation. None of the patients had access to dedicated post-ICU rehabilitation however, three patients had limited access to outpatient physiotherapy, one to occupational therapy. The remaining two were promised physiotherapy but nothing came of it. At her six month follow-up interview, one participant explained her lingering feelings of disappointment at the lack of rehabilitation:

> Feeling let down that he still hasn't had any physio. It was feeling really let down by [hospital], the health system. Fine when we were in there, but when we left it was like, you're on your own now and kind of sink or swim. […] That's a big change from everyday rehab and all of that. Family H

Family J perceived the 10 minutes of daily physiotherapy that her husband received as being "a waste of time" and not tailored to meet his individual goals. After four weeks, despite her husband still being largely immobile, the physiotherapy treatment ended:

> That's the only exercise he ever did was with them, and I really felt that was just a waste of time coming here and doing that for four weeks. Run in and run out. Doesn't even take them not even the half an hour. I would go, God, that's not even half an hour. You're meant to be here half an hour doing him. Nothing to do with his arms. No exercises for his arms. Family J

The family were told that someone would get in touch with them from the hospital to arrange further rehabilitation. One month later, they still had not heard from the hospital and were left wondering how to progress his recovery: "He feels like

they've let him down a bit because they say we can do this for you, we can do that, but it's not really happened." Family J.

Ongoing rehabilitation was perceived by family as essential to the patient regaining lost strength and function and ultimately, getting back to normal: "There definitely needs to be more of a push for when you go home to still have those services available of physio, of occupational therapists. Really pushing it to get him back to normal. That's what we want." Family H.

Being Swamped in Caring. Even though the family participants had to varying degrees been caring for their relative while they were in hospital, the carer role in the home environment was considerably different; it was more demanding and intense. Upon the patient returning home, almost all found themselves swamped in caring. Also, some patients had medical devices that required management at home. Education about what to do and how to act was important when taking on the responsibility for creating a safe home space, however, most family participants did not receive the education they needed. They described the need for information and skills to help them manage the patient's care needs. Navigating the new reality as a carer without information and support was extremely difficult: "It's hard, because the reality kicks you, really kicks you, and actually that's probably when more of the support is needed." Family I.

Looking backwards in time, one family participant told her story of the transition home, realising in hindsight that she needed to acquire knowledge and create for herself a new understanding on how to manage her husband's health condition and new medical equipment to keep him safe in the home, reflecting unmet educational needs: "No one taught me the settings so here am I putting it on wrong.

Giving him too much oxygen because everything's so different. I could have killed him." Family J.

Participants described parts of the role that they just did not want to do such as helping the patient with toileting. For two weeks before help arrived, one participant had to clean up her spouse after he had had a bowel motion; this had a huge impact on her wellbeing as well as her feelings of closeness and attraction to her spouse. Another participant's husband had a new colostomy, and she decided right from the beginning that she was not going to have any involvement in managing the stoma: "I could see my life just being sort of swamped, you know, like doing this. And I didn't really want to be a caregiver." Family F.

6.6.3 Being in the Dark

Navigating the challenges and complexities that unfolded across the year emerged as being thrust on an unknown journey, alone, and in the dark. Looking inwards, family participants talked about how the unknown generated feelings of fear and worry. The subtheme 'Being in the dark' captures family participants' experiences following hospital discharge of being uninformed and unsure of (a) what to expect in the context of recovery from a critical illness, (b) not knowing what supports them and the patient will need once at home, and (c) what to do about new problems the patient was experiencing post critical illness.

Reflected in the participants' narratives of 'Being in the dark' was the need for: recovery information for critical illness survivors; access to appropriate and timely healthcare services for the patient and support services for the family carer; and navigation during recovery from someone who understood and could relate to their experience and most crucially, help them. At hospital discharge, communication gaps were highlighted with participants articulating frustration with ineffective

communication to prepare them for hospital discharge. After discharge, family participants revealed how unsupported by the healthcare system they felt, commonly voicing anger and disappointment at the fragmented care and lack of support they had access to in the community setting. One participant reflected on how clueless she and her husband were about the reality of what life would be like when he was discharged from hospital. They did not realise that despite having ongoing complex medical issues that needed addressing and requiring extensive rehabilitation, he would get next to no care, highlighting a continuum of vulnerability that continues for the long-stay patient and family long after hospital discharge:

> You just don't know all the things that you don't know, like what it's going to be like when [patient] comes home and he's going to get basically no care from anywhere and things like that. Thinking that you were going to keep having ongoing things. In the end you just have to deal with it all yourself, what's going on. No one's going to deal with it for you. Family H

None of the family participants received any information, written or verbal on recovery trajectories following a critical illness and what to expect during the recovery journey. Participants commented on the need for information on critical illness recovery including expectations and timeframes; physical rehabilitation and exercise; common post-ICU symptoms for example breathlessness, nerve pain, cognitive impairment, fatigue management, rest and sleep; return to activity; and return to employment. Concerning themselves, they commented on the need for information on being a caregiver, relationships, and stress management. Moreover, family participants expressed that they did not know who they could contact once discharged from hospital if they needed help or guidance. The following quote

highlights this: “Even knowing who to call. The first time [patient] fell over, I rung his physio from ICU. I was like, ‘Shit. He's fallen. How do I know how bad this is? What do I do?’” Family I.

In each of her four interviews, Family F emphasised the value in preparing families for what to expect in the journey after critical illness as an intervention to lessen the burden associated with the unknown. Since hospital discharge, she had not interfaced with anyone who understood the critical illness recovery journey and underlined how useful a pre-discharge conversation, coupled with the provision of a post-ICU information leaflet would have been in helping her navigate the different stages of the recovery process and the complexities she was facing every day:

> How sort of you guys in ICU can prepare people for all this. You must have headings like social support and all those kinds of things. Acceptance, adjusting, and kind of I don’t know, to plan. I think that if you did that I think that would be a really good idea, and having a conversation would be great, but I also think that a bit of paper with just that, because you'll only absorb so much information and just knowing, having it to reference back to six months after. Oh god, other people were feeling like this. It would be kind of really useful. Family F

She explained the particular importance of conveying to families common unsettling feelings to reassure people that what they are experiencing are common and therefore, lessen their feelings of worry about themselves:

> You may be able to give them a sheet that says, it’s likely that you will have feelings of blah, blah, blah, blah, blah, blah, blah and these may persist for at least. I think that would be really […] useful for people to know, I think.

> Because there's that whole, you feel worried about yourself if you think it's not normal, what you're going through. But if you know it's normal – normalising is one of the biggest things psychologists do –, that's fine, that's what everyone feels like. Family F

Often during interviews, I would share with participants that the difficulties they were facing were experienced among spouses of prolonged critical illness survivors and this provided some comfort and reassurance: "For you to say, 'I can tell you you're not the only one', that's huge." Family I.

Participants perceived the overall lack of support as simply not good enough: "If the Prime Minister's wife had been through that and then left and came home and there was nothing, would he see that as good enough? No." Family H.

One participant expressed anger and despair at the impossibility her husband encountered in accessing essential services regarding his rehabilitation and worsening pain. She explained a seemingly routine test performed several days before her husband was discharged home from hospital left him with a new onset, severe nerve pain throughout most of his body – a pain he had never experienced during several months in hospital. There was no medical follow-up for this, so the patient and his wife were in the dark about how to treat his pain: "You almost feel like you're back in the normal system where you have to go to your doctor and get real sick again to get, like, it feels like that because there's just been no follow up." Family H.

The patient's nerve pain dramatically worsened after leaving hospital and his GP stated he felt out of his depth treating it. The family participant explained that in the doctor's opinion the patient needed to see a neurologist but he had to wait months. The family participant reported that it set back his health and physical

rehabilitation greatly. She emphasised the profound disruption it has caused to their lives as a family: "What this has done has been huge to us. It's the pain. It's the financial. The financial and the quality of life is just like completely huge."

Several other family participants described situations where the patient did not receive timely and appropriate access to health services, leaving the couple in the dark on how to navigate complex health issues. Family G's husband was informed that he would have access to outpatient physiotherapy once discharged from hospital, but the patient was never given any information on the service or contacted for follow-up: "A physio, that would be great. We're still waiting to hear. They said that someone was going to contact us from [deidentified] hospital. We haven't heard a thing."

Furthermore, her husband needed psychological support but, he had to wait nearly a year for his first appointment with a psychologist: "It's a nine to 18 month wait. I was like, by the time people get seen, they're either going to be better, or they're going to be dead. Like it's just ridiculous."

The only person who her husband could talk to about his ICU experience was his family but by then, they had moved on: "It was over for me. I don't really want to revisit that time."

All family participants considered that they would have benefited from support and reassurance from someone who could relate to their experience. They specifically articulated the need for someone who could navigate the health system to ensure the patient had access to the aftercare they required and provide guidance with recovery, reflecting the unmet need for navigated care post hospital discharge:

> That would be nice to have an advocate for the family who knows about things. […] If there was someone there that had the family's best interests

and patient's best interests at heart that could manage it a little bit more, especially the coming home. Family H

Participants also considered that it would have been beneficial to have someone with knowledge of life after a critical illness to talk to about their struggles. Reflecting on these narratives left me sad and angry, and I came away feeling that in fact, the health system had abandoned these extremely vulnerable people.

6.6.4 Adjusting to Changes over Time

The illness and its aftermath brought significant life changes and the subtheme ‘Adjusting to changes over time’ encapsulates the profound changes that family participants had to manage, bringing to light how family of prolonged critical illness survivors must adapt to their new reality and engage in a process of adjustment over time as they navigate the path to the new normal. The notion of adjustment was present in interviews across the year of follow-up, revealing the everchanging nature of adjustment family had to make. In unpacking the ‘Adjusting to changes over time’ subtheme, participants’ stories commonly reflected four narratives: (a) adjusting to a changed life, (b) adjusting to living with a changed person, (c) adjusting to becoming a carer, and (d) adjusting to living with uncertainty. These will now be explained.

Adjusting to a Changed Life. Family participants’ stories reveal that the critical illness event was extremely disruptive, overturning their worlds and creating a rupture in the story of their lives. Life as it had been, was completely changed; the critical illness derailed their present and future plans. For the duration of the hospital stay, the family participants’ everyday lives were disrupted impacting on their daily rhythm and routines. Moving forward in time and describing their experiences in the present, it became clear that the disruption endured long after the time in hospital

with all participants walking a different life path, highlighting the temporal flow of experience as the illness, while in the past, continued to influence their present and foreseeable future. Family participants described disruption across their circumstances, everyday routines, work, and identity; shifts experienced as profound loss: "We've lost our jobs. We've lost life as we knew it. [Patient] missed 13 months of his son growing through rapid change. It's affected our children, who we are as people. There's trauma." Family I.

Returning home from hospital, life was not the same as was before for the family participants. They struggled to see a future in which life would return to what it was because of the long-term nature of recovery coupled with uncertainty about how much the patient would recover: "It's a massive adjustment because things aren't the same as they were before. I can't imagine they ever would be." Family F.

The degree with which their everyday lives had changed varied. Exploring the dimension of place, participants' stories of home described the marked limitations in activities of daily life for both them and their relative. Every day routines were different post illness. The home was different. Most family participants described how when their relative came home from hospital for several weeks they (the relative) spent a lot of time sitting or lying down which many found difficult: "It was just really difficult because he couldn't do much. And he'd just sort of sit there or lie there." Family F.

Some were not bothered by the changes, whereas it challenged others:

> All the equipment that's around, I got - I had things a certain way, and I used to keep it, and everything had a place and made spaces, made the bedroom somewhere where I could just chill. It was my little sanctuary to escape things, and then suddenly, there's someone in that space all the time, and I

> no longer have a space in the home. There's a hospital bed, and there's a commode chair, and there's a wheelchair, and there's a walker, and there's a fucking toilet seat. Family I

What became apparent through this study is that the longer the length of stay in the ICU, the greater the degree of change. Family I spoke of the profound sense of loss she experienced because of the critical illness: "When you think about it really, it's stripped away our entire life. That identity and everything you work for, you're reduced back to nothing and starting again in a lot of ways."

She explained personal and invisible losses. For so long, hospital and home formed the boundaries of her existence; she found herself suddenly removed from normal life and routines:

> I'd recently become a mum again. I'd just developed - was starting to develop a career of working for myself, so I lost all of that. I lost my social life, my sport, all of it. My whole life then became dedicated to this household and to [patient]. Family I

In the early post-hospital phase, the family participants described a new reality in which they were having to juggle many complexities including managing family life and routines, being a carer, work, and finances. This was both demanding and stressful, and overtime, they became exhausted:

> It was taxing. It really was. I just felt like I had nothing left in there for me. Yeah, it actually took a lot out of me. And I was really, really tired. But I was still trying to balance work, caring for [husband]. And I still don't think I've gotten the rest that I've needed. Family G

Navigating the complexities of their changed everyday life took an emotional toll on the participants. Within the first six months of returning home from hospital, all described reaching 'rock bottom', attributing this to feeling stuck in their situation and unable to see a way out. One participant recounted how she felt depressed: "It's just such a massive adjustment that you're just busy managing that. Then the next bit you're starting to think, oh my God this isn't settling. So, it's been an adjustment, definitely." Family F.

All but one family participant described symptoms of depression and anxiety highlighting the mental and emotional burden family can experience during this period in the journey: "Those first few months there was the low part, the depression and that." Family H.

However, over time, as the patient's recovery progressed and the family participants adjusted to their situation, the mental health effects lessened: "Just time. Just adjusting. I feel much more adjusted and accepting of the way things are, which is different." Family F.

Family participants reported a negative impact on family income due to the patient being unable to work for an extended period of time, and the family member needing to take time off their work to care for them and manage the family. These financial implications created additional challenges and burden. Instead of reducing work, one participant was working three jobs to make ends meet. Another experienced major stress associated with dealings related to payouts from an insurance company. Another described the socioeconomic impact of the critical illness as being significant and long-lasting. She explained they went from being a household with two people earning good money to being beneficiaries: "We've gone down to being on a benefit from two people getting pretty good money." Family I.

Adjusting to Living with a Changed Person. Under the 'Adjusting to changes over time' narrative, participants told stories of their experiences in adjusting to living with a changed person. This story featured prominently in their interviews across the whole year. Notions of frustration, resentment, and loss emerged. The critical illness and the critical illness sequelae had caused profound changes to the patient. For some, these were physical changes, others cognitive. The changes varied among the individual patients but included weakness, physical disability, inability to walk independently, colostomy, changes in bodily appearance, breathlessness, dizziness, pain, and memory impairments: "His smile's not the same, his eyes don't light up the same, he doesn't speak the same." Family I.

Adjusting to the changes was difficult: "I was finding that it was a huge adjustment to having [spouse], sort of different, more dependent, it felt." Family F.

Most participants came to the realisation early in their relative's recovery journey that despite making progress with physical recovery, the patient would not return to their pre-illness level of function: "Watching him every day, although he's progressing, I think the reality's starting to kick in for me that he's never going to be what he was before he went in." Family I.

For some, this generated feelings of loss, for themselves, their relationship, their past life, and their future. One participant described the stark change in her husband's health after the critical illness. Seeing him so vulnerable created considerable worry and watching him struggle was at times unbearable:

> A lot of worrying, a lot of tears, a lot of everything, just watching the man that he was struggling all the time, and then can't hardly breathe or do

anything. You think, oh my gosh, sometimes you just can't bear to be with that. Family J

For some, the narrative of adjusting to living with a changed person emerged in their stories of the patient's deteriorating cognitive function. Neither the patient nor family received any information on cognitive impairment following critical illness. The extent of impairment and trajectory of cognitive recovery varied among the patients however, there appeared to be three who were left with significant cognitive impairment at 12-month follow-up. The family participants of these patients reported in their final interview that from their perspective, their relative's cognitive function had not improved, in fact they perceived that the cognitive deficits had worsened over the course of the year. One participant described the changes she has observed in her husband's cognition in the nine months since he left hospital:

Great cook. It's like he can't remember how now. I think it's the connection's a little bit broken. If he does, he'll cook like a chicken. I'm like, 'What are we having with it?' […] Sometimes he takes ages to string a sentence together. […] I feel like it's getting worse. Or he would've already told me – he'll tell me something. I'm like, 'Oh yeah, you just told me before.' He's like, 'Did I?' Or the other way: 'I told you that.' I was like, 'No, you didn't.' 'Yes, I did. I did so.' He gets frustrated. But I'm noticing that the stringing of his sentences together is getting worse. I don't know what that is. […] But that part's getting worse with the speech. It just takes a little bit longer to kind of think about what he – he doesn't give up though. I'm just like, oh my God, fucking spit it out. Family G

For one participant, the biggest difficulties she had to confront and navigate in life after critical illness were the everyday tensions and struggles relating to her spouse's cognitive deterioration. In early narratives, her stories reflected notions of *grappling with* and *figuring things out* – how to act, how to talk to him, how much to intervene, how to maintain his autonomy and dignity – but over time, she learnt to manage the complexities and felt more adjusted and accepting of the new situation. The following quote from her nine month interview gives insight into his degree of cognitive impairment and the impact it had on her:

> For me, the biggest difficulties are still, well there's the relationship, but is the cognitive difficulties. Because he's really quite a different kettle of fish in that regard. You know, like he was an intelligent, capable man. […] Perhaps the most difficult bit is his memory because I'll tell him something and then he won't remember. That's problematic. But so is the not being able really conceptualise things. Like if I say something that's quite big or say a bit of a scenario, he just can't hang onto it all at once and so he can't understand it. He says, 'What do you mean, [de-identified]?' So, like I can't have the same conversations if you know what I mean? Like there's a lot of things now I just don't bother bringing up. For example, my work. […] So that's sort of gone.
>
> Family F

Adjusting to Becoming a Carer. When describing the caregiving role, participants' situations and roles were unique and largely depended on the patient's level of physical function, but all described the new reality in coming home in which their role had changed to carer. Participants told how being a family carer was difficult, especially in the beginning. Figuring out each person's place and their role,

what to do, how to do it, took time and often there were tensions with the patient navigating this changed dynamic: "I'm figuring out what my role is and to support him." Family H.

In the early post-hospital phase, because of the patient's limited function and frailty, family were cautious and highly protective of their relative, doing almost everything for them. Over time this amount of giving became unsustainable with family developing feelings of fatigue and frustration: "It can get overwhelming, too. Like sometimes here he wanted a thing, and I would sometimes get a bit frustrated with it because I'm thinking, oh will you just get up and get it? Knowing very well he can't." Family J.

Some participants described the hands-on role they had in supporting the patient with managing their medical condition. One participant was critical in her husband's health, managing his medical condition and believed that without her, he would be dead: "I sit him up and do all sorts of different breathing techniques. 'Come on, in and out, in and out. Take your time. Calm down.' Take his anxiousness thing away." Family J.

Participants described the cumulative strain of caregiving: "I think the tank's just empty." Family I.

Adjusting to Living with Uncertainty. Family participants predominantly expressed uncertainty regarding the patients' health, critical illness recovery, and their own future. Because of this uncertainty they found themselves in an uncomfortable liminal space between 'what was' and 'what will be' – the known past and the unknown future. The following quote illustrates this:

> The journey has been an ever-changing one, and really uncertain in lots of different ways, so that major fear of how much is he going to recover, what's life going to look like? Now we're home he's recovering quite quickly, but now I wonder, will he ever get his full smile back […]. Will he ever walk normally? Family I

Across the year, family participants outlined uncertainty about their relative's health, conveying undercurrents of worry of further health deterioration. For some, complications and health setbacks added to their worry revealing a continuum of vulnerability the patient and family experience. For others, it was the knowledge that their relative would require future medical interventions. The fear of whether their relative would get seriously unwell again was always there. Even in the 12-month interviews this was raised by most participants, highlighting that the fear of becoming unwell lives in them:

> I can see things like this breathlessness and this unusual colouring. Sometimes, well, pretty well always, his hands are freezing cold. He never used to really be like that before. So, I can see that there's things that will get him. Because his whole system's been hammered and compromised. So, I can see that, well, I think that, that he could die. Family F

All family participants expressed uncertainty about their relative's post critical illness recovery trajectory. Early in the recovery journey, family came to the realisation that their relative would not return to their pre-illness level of function but nonetheless hoped for continued recovery. They voiced uncertainty concerning common post-ICU sequelae they observed in their relative often raising in the interviews concerning symptoms such as ongoing pain, breathlessness, dizziness,

and memory impairments. The family participants also expressed uncertainty in their questions regarding recovery timeframes, highlighting the need for information on this as previously discussed. One participant described the implications of her husband's chronic pain and uncertainty concerning how long it will continue for. She hoped there would be an end to it:

> I just want him to get better. Yeah. So, the pain and just everything coming from that, the tiredness, the lack of strength, the quality of life, because his life is painful and it's sore to do anything. And I see him moving, I see his eyes and his whole face kind of like, I'm like, 'Honey, you've got your painful look, like you've got a painful look and I can see it.' And it's even hard for him to get out of bed because he said he has to writher round, so all the things, all the little things are probably really hard for him. So, yeah, it's definitely still continuing. And we don't know how long. I hope there will be an end to it.
>
> Family H

Several participants also expressed uncertainty about their own future: "It's all of those things of what the future and retirement and all that looks like, now feel unattainable and that uncertainty." Family I.

6.6.5 A Prolonged Struggle

Situated within the intertwining dimensions of sociality and temporality, the subtheme, 'A prolonged struggle' portrays the family participants' experience of the ongoing struggle that characterised their lives across the year. Participants articulated the year as being a mental and emotional struggle, with certain transitions and challenges being particularly difficult to navigate. All participants described the toll that the ICU and hospital experience took on them, revealing they felt exhausted

by the end of it. During the transition home period family participants' narratives reveal they felt as though they were *in the trenches*, just getting through, figuring out their new situation, and attempting to balance caring for their relative with work and other life responsibilities. The participants indicated that balancing their own health needs at this time was extremely challenging; they simply did not have time to focus on their own needs initially but came to realise this was important as their health and wellbeing deteriorated. Furthermore, they did not have time to process what happened, get themselves well, and recharge because the work and stress intensified when the patient came home.

The initial struggle continued for several months before participants felt they were on stable ground, reflecting it took time to learn to manage their new situation and for the patient to make progress with recovery. As patients improved, family participants described the weight of caregiving and worry beginning to lift. However, by six months, the sustained burden of caregiving and the long period of stress from the ICU, hospital, and transitioning home caught up with them, manifesting as worsening general health, physical illness, or depression: "My health was terrible a couple of weeks ago. I had a kidney infection. […] It was all the stress, and kind of everything, I think." Family G.

Family participants talked about the accumulated toll that the hospital experience, caregiver burden, stress associated with managing life at home, juggling work, despair about their situation, and lack of time for themselves took on their own health. They reported deteriorating physical and mental health including chest pain, recurring infections, depression, anxiety, difficulty sleeping, and a deterioration in the overall quality of their lives. One participant retold how within the first few months of her spouse returning home, her anxiety was so bad that she developed chest pain: "I

was having sort of not pains, but a feeling down here (points to chest). And I know that it's an anxiety thing because I've had it at other times in my life." Family F.

Notably, all but one family participant talked about developing symptoms of depression, a narrative commonly accompanied with tears. The health problems were most prominent in the first six months of being back at home bringing to light the profound cumulative effects of a prolonged critical illness on the family. One participant shared her experience of depression: "I was getting quite depressed. […] I was getting to the point that I was like, I don't know how to pull myself out from this." Family I.

As the patients improved, the family participants concern began to shift away from their spouse, and they began to confront their own issues. Enduring struggle for so long, they perceived the need for a break. Several went away with friends or family. Others sought solace in their work or in the quiet solitude of their bedroom: "That's my only solace really is time for me to focus on me, even if I was just lying in bed to go to sleep, because no one's stripping anything from me." Family G.

All family participants commented that it took much longer than they expected for their situation to improve, generating feelings of both frustration and despair during the early post-hospital struggles. Participants strived for normality, clinging to hope that life would return to how it was before the illness but they were not prepared for how long the process of returning to "normal" took. With time, they came to the realisation that life would most likely not return to normal and they needed to define and reconcile themselves with a new normality.

Looking backwards at the time that had been from the ICU experience to the 12 months after, family participants spoke of how tough the year post critical illness had been for them. They reflected that while their relative was in hospital, they

functioned in survival mode, "putting one foot in front of the other" and "just getting on with it" because that is what they had to do: "You get through the time that you have to, because you just have to, and you keep going. […] You've had all this big trauma, but you've still got to get up, get the kids, get food, get playing." Family H.

A prominent thread in participants' narrative of 'A prolonged struggle' was *emotional struggle,* reflecting an unmet need for emotional support. For most participants, the emotional side of the experience was reported as being the most difficult: "It's definitely been more the emotional side of things as being the hardest journey." Family I.

Adding to the emotional struggle, family participants emphasised that the journey after a prolonged critical illness was lonely. Participants felt it was difficult to explain to others what they were going through; they perceived that others found it difficult to understand their situation. One participant commented how the support for her and her spouse in the beginning was immense, but then with time, the support dropped off and she felt like she was the only one left dealing with the aftermath: "It is a lonely journey to go through something like that. Even when he was in hospital, it was, it was really isolating, like a tangi, everyone's there at the beginning and then things drift off." Family I.

At 12-month follow-up, some participants felt optimistic about their future, while others found looking to the future daunting, knowing that their difficulties were not going to resolve or that they were only going to get worse. Their journey was not over. A difficult road still lay ahead of them, marked with uncertainty. Family G did not know how she could get through another year: "I don't know where to from here. I know I'd do another year, but I just don't know how I'm going to do that."

6.6.6 Navigating a Different Us: Confronting Relationship Changes

The subtheme ‘Navigating a different us: Confronting relationship changes’ encapsulates the relational changes that family participants had to navigate post-critical illness. All family participants described the changes they experienced in relationship dynamics with their spouse. Participants described changes in how they related to their spouse and, how they viewed themselves within the relationship. These changes were most pronounced in the early months following hospital discharge when the patient was still very dependent but were still present one year later. None of the family participants were warned about the potential for relationship challenges, and no support was offered to help them work through these: “Warn people that relationships will change. The dynamics will be different and there'll be some aggravations.” Family F.

Coping with new chronic illness, disability, and figuring out how to care for and support their family member was particularly challenging for the participants. This was especially relevant for the spouses of patients with cognitive difficulties, mental health problems such as depression and anxiety, and physical disability. In addition, despite living together as a couple, several participants talked about experiencing feelings of loneliness within the relationship. Over time, some family participants were able to navigate these difficulties, remaining close to their spouse with a continued sense of togetherness. Others struggled and described what they perceived as immense relationship changes, and a loss of closeness creating an uncertain future.

Upon return home from hospital, all family participants described how assuming the role of carer altered the dynamics of the couple’s relationship. It changed from being a partner to more of a carer relationship. The carer role also

came with increased responsibility and demands, and contributed to feelings of burden.

For several family participants, negotiating caring also proved to be challenging with some describing tensions with their partner concerning how much to care. Initially, participants recalled feelings of overprotection of the relative, but this lessened with time as the patient made progress with recovery. All family participants perceived that the illness and its long-term consequences resulted in their spouse acquiring a degree of dependency. For some this was on medications, for some medical therapy like home oxygen, for others dependency on someone always being around. Eventually the family participants came to the realisation that they were better off stepping back, intervening less, and interacting with their spouse in a way that enhanced their independence, to help them feel a sense of empowerment and ultimately find their feet in the new situation, as opposed to them feeling undermined. Initially family participants perceived this pulling back was met with apprehension by the patient and the family participant had to be assertive, as reflected by Family J: "I started to push with him. I started to get more pushy and where I would say yes to a little thing, it was a no. You get it for yourself."

The transition from being closely involved to pulling back with less surveillance was reported by family to have had positive effects on relationship dynamics and the patient's recovery with this process notably occurring over time:

> It's certainly different, and in a positive way. I don't feel even the need to keep checking that he has taken his medication, which was a constant thing. Even though I still watch, I don't comment, unless I have not observed him take it. But he seems to be taking it more. He would often forget before, and

there was difficulty. You see that entailed me asking him or telling him. So, there was just that whole thing of the tension between feeling independent and actually not being independent. Family F.

Several family participants described the burden of bearing everything alone and of being responsible for the functioning of the daily life of the family. This was exhausting. Some expressed that these changes resulted in them feeling a loss of partner. This was especially noticeable for the families with young children as these participants spoke of the increased parenting and household load that they had to carry: "I don't have that person who I can rely on or who contributes." Family G.

A few of the family participants talked about changes in intimacy and sexual life following the critical illness. The women highlighted a loss of intimacy, openly expressing their lack of desire for intimacy with their partner: "After everything that's happened, we don't have that relationship anymore, and then of course he is so different, as shitty as that sounds, I'm not attracted to him anymore either." Family I.

On reflection, I realised just how sensitive these relational changes for the family participants were. Navigating these changes was difficult and there is a need to better support the caregiving spouses and the couple. As time passed, the relational difficulties did appear to lessen. At 12-month follow-up, some participants reported no relational difficulties whereas others still faced these, articulating that the greatest difficulties they were facing now in their everyday life were relational problems. Despite the relational challenges that all family participants had to navigate at various stages in their journey, all had found a sustainable way of being together as a couple.

6.6.7 Finding a Way Through

The final subtheme, 'Finding a way through' portrays a powerful theme of resiliency that emerged in family participants' stories of enduring, adjusting, and finding ways to cope with the critical illness and its aftermath. The post-ICU journey for family of long-stay patients is a long-term one, entangled in complexity and struggle yet, each found ways to keep going and carry on. The experience was constantly changing with new difficulties arising, but family participants slowly worked through them, engaging in a process of adaptation and adjustment to their new circumstances:

> You're in a tricky position as the well person. Especially if you feel a bit pissed off and resentful, so you've got to get over that, and you've got to adapt to the changes to your own life. Then try and move on with it as well. Family F

Ways of managing the stresses and struggles varied among participants but all drew on various external and internal resources including accessing social support resources such as family and friends, working, keeping busy, and striving for balance. With time, as their relative's recovery progressed and both found their feet in the new situation, the family participants worked to "chisel out a path" (Family F) of their own and rebuild their lives.

Most family participants talked about the time in their post critical illness journey where they developed symptoms of depression. The participants realised themselves that they were in a vulnerable place, and each talked about how they tried to find a way through this tough time: "There was that low at about three months when I was depressed and then had to do some things to change that and help my mood and help just me." Family H.

Social support across the entire illness trajectory from the ICU to beyond, appeared to be essential for all family participants. Family and friends provided psychological, emotional, and practical support which helped the participants to get through. Several shared how their family also provided financial support. Several talked about how helpful the gift of food was: "Some people brought food. People have come and not stayed. Some people have just left it on the veranda. It's just food and that's been helpful." Family F.

Family participants expressed how having a good friend to talk to was perceived as being therapeutic. "She says, are you in need of another coffee or something. […] She's been wonderful." Family F.

Work was considered an outlet for some participants. It allowed them to escape the reality of home life, step out of the caregiving role, and have space for themselves. When asked how she was coping with the challenges surrounding her husband, one participant replied: "I just bury myself in work." Family G.

Family I had an extended period off work supporting her spouse. When she returned to part-time work, months after her spouse returned home from hospital, she spoke of what it gave her. Work provided more than a pay cheque; it provided a much-needed break from the demands of being a carer, cognitive stimulation, and a sense of achievement: "It's nice to get the brain engaged again. So, it's a time out, it's a sense of doing something and a bit of achievement and then also it's not actually stressful." Family I.

For family, the first year after prolonged critical illness is tough, characterised by many ups and downs and ongoing uncertainty, but participants did find ways through the adversity. One year after hospital discharge, most family participants felt that they were now on stable ground. Despite none of the patients returning to their

pre-illness level of function, they had made improvements in physical recovery. All but one family participant commented that by now their relative had developed a lot more independence and seemed to be managing their condition and own life well, highlighting it takes time for the long-stay ICU survivor to find ways to adjust to their new situation. Family walks alongside the patient in this journey of adjustment, but their journey and their needs are different. At one year, life was still not normal in the sense of what normal was before the critical illness because of the patients' ongoing recovery and health that needed to be managed, but family participants felt they had settled into the rhythms and routines of a new normal and were feeling closer to their old self, as the following quote from a 12-month interview illustrates: "After all the rollercoasters of ups and downs, probably feeling more normal, like my old self more than - a more stable, normal, old self." Family H.

6.7 Chapter Summary

This chapter has presented the findings of this narrative inquiry, discussing the themes and associated subthemes arising from the analysis of the family participants' discussion on their experiences after a prolonged critical illness. The three main themes in this chapter follow the timeline of a prolonged critical illness and its recovery. The identified themes were, 'Being on life's edges in a world of uncertainty', 'Where is the care?' and 'Navigating new realities alone and in the dark'. These themes have been explained and examples provided from the narratives to highlight the different aspects of family participants' views of their experiences about life after a prolonged critical illness.

Within this study, the experiences of the family participants were not ranked in order of significance; however, it was identified that all the subthemes were intertwined, creating a thematic tapestry revealing the story of families' experiences

after a prolonged critical illness. The findings presented in this chapter suggest that for family, the ICU experience does not end at ICU discharge but rather, discharge marks the beginning of a long and difficult journey to a new normal. This journey is characterised by catastrophic gaps in the care continuum, a lack of professional support, and a journey that all were completely unprepared for. Family participants' narratives identified a continuum of vulnerability concerning communication gaps in the multiple transitions of care across the care continuum. Furthermore, their narratives revealed unmet care needs on the general wards, terrifying discharges, and a reality of having to navigate new realities alone and in the dark as they move through the hospital system to home, reflecting a current fragmentation of care.

Chapter 7: Discussion of the Research Findings

7.1 Introduction

In this chapter, the findings are explored in terms of what they may mean and how they may be valuable for prolonged ICU patients, families, and health professionals. They are also discussed considering the research questions and in the context of existing literature, theory, and the theoretical framework. In doing so, this chapter critically analyses the findings of the research.

7.2 Summary of Findings

Participant narratives revealed that recovery from prolonged critical illness is complex, non-linear, and takes time. Recovery is also not guaranteed; at the final 12-month follow-up, all patients in the study had not returned to their pre-illness state of health and continued to experience complications known as PICS, negatively impacting their life situation and that of the family. For the family participants, stress and exhaustion accumulated overtime; all experienced a deterioration in their physical and mental health within six months of hospital discharge, consistent with PICS-F. The journey for both is personal, complicated, and marked with struggle.

This study's findings identify that after intensive care, there is a lack of understanding and effective supportive services to meet the needs of both survivors and their family in Aotearoa New Zealand, despite international recommendations for aftercare (Mikkelsen et al., 2020; NICE, 2009). Existing support is not focused on patients' and families' psychological, emotional, social, and rehabilitative needs, nor is it equipped to deal with the complexity of issues that ICU survivors and their families, are often faced with. The psychological and emotional impact of a critical illness experience on both the patient and family is widely reported in the literature (Harlan et al., 2020; Hatch et al., 2018; Johnson et al., 2019; Nelderup et al., 2018;

Rai et al., 2025). King et al.'s. (2019) review of patients' support needs following critical illness found that patients felt they did not get sufficient attention paid to their psychological and emotional health. Similarly, Heydon et al. (2020) identified mental health as an area that survivors of critical illness with PICS need more support in. Kang (2023) identified deteriorating physical health and accumulating mental distress in family carers that could be attributed to trauma from the ICU admission and stress from caring for relatives who entered a long-term recovery trajectory. Most recently, Howard et al. (2025b) highlighted that many family carers shoulder intense physical, emotional, and mental demands which leads to a gradual erosion in their own wellbeing.

This study identified that the core problem in Aotearoa New Zealand is that after ICU and even more so, after hospital discharge, long-stay ICU patients and their family do not get the support they need. Multiple systemic issues were found that shaped this experience. These include:

- Prolonged critical illness survivors and their families need ongoing support, rehabilitation, and ICU follow-up, but currently these services are lacking in Aotearoa New Zealand.
- Patients and their families are having to navigate fragmented care systems across the continuum of care (from hospital to the community).
- There is no one involved in the care of this cohort who understands the entire illness-recovery continuum, that is, the entire journey that the patient and family are on.

7.3 Patient Complexity

The research highlighted that prolonged critical illness survivors have complexities beyond conventional definitions of *complex patients*, and this must be

acknowledged first to understand why the health system fails to provide the sustained, integrated, and comprehensive support this population requires. While the legacies of survival are chronic in nature (new long-term health problems and disability), the complexity of the long-term ICU survivor is fundamentally different from, and more profound than that of the typical chronic care patient. The chronic care patient's complexity is often *additive,* i.e. an accumulation of distinct diseases and their treatments over time, whereas the long-stay ICU survivor's complexity is *synergistic and emergent*. It stems from a single, catastrophic physiological event (sudden ‘big hit’) that simultaneously damages multiple organ systems, catastrophically derails the patient's life trajectory, creates a deeply interconnected syndrome of impairments, and leaves the patient to navigate a fragmented care system that is ill-equipped to manage their unique needs. The conventional metrics used to assess complexity in chronic care, such as the number of comorbidities or prescribed medications, are insufficient to capture the reality of the long-stay ICU survivor. A simple count of diseases fails to account for the *profound interconnectedness* and *simultaneous onset* of the impairments seen in PICS. Also, the pathophysiology of critical illness does not respect anatomical boundaries; a single inflammatory cascade can precipitate muscle wasting, nerve damage, and diffuse brain injury concurrently. This creates a clinical picture where the problems are not just co-occurring but are mechanistically linked manifestations of a common insult.

Table 9 presents these differences between the ICU survivor and the chronic care patient.

Table 9

Complexity of the ICU Survivor versus Chronic Care Patient

Domain of Complexity	ICU Survivor	Chronic Care Patient
Onset & trajectory	Sudden, catastrophic "big hit"; unpredictable, non-linear recovery; fundamental baseline reset	Gradual or stepwise decline; relatively predictable trajectories
Pathophysiological basis	Single, systemic inflammatory cascade causing simultaneous, multi-organ injury	Accumulation of distinct, often organ-specific, pathologies over time
Primary morbidity	An integrated, multi-domain syndrome (PICS) with synergistic impairments	An aggregation of discrete conditions (multimorbidity) and their treatments (polypharmacy)
Care demands	Discharged into a fragmented, reactive system lacking a dedicated care model	Managed within established, proactive models
Psychosocial	Acute, shared trauma impacting the patient-family unit (PICS and PICS-Family)	Chronic stressor associated with long-term caregiving and disease management

7.4 Where is the Care?

Both patient and family participants' transitions from the ICU to the general ward and then to home were the most challenging times in their journey. The ward was a place where both groups (patients and families) struggled because from here, care for the patient, support for the family, and communication from the healthcare team progressively declined. Patients were still unwell with heightened emotional and psychological needs because this was when they had the cognitive ability to start the process of making sense of the ICU experience and of what happened to them; however, patients did not get the help they need with this aspect of psychological recovery. Families' need for inclusion in care planning, particularly hospital discharge planning, and their need for information was heightened on the

ward; however, their experience was that of exclusion and inadequate information provision which left them feeling frustrated, vulnerable, and feeling abandoned.

7.4.1 The Established Problem of Gaps in Care

These experiences are well documented in the literature with Twamley et al. (2023) and op ‘t Hoog et al. (2020) identifying a lack of communication as a major factor in reconciling the ICU experience of survivors. Research highlights the challenges patients and families encounter during the transition from the ICU and eventually to home, depicting it as difficult and poorly supported phases of their journey (Major et al., 2019). Studies exploring the ICU patients’ experience of transfer to the ward describe it as being a shock (Cuzco et al., 2022) and something they are not mentally prepared for (Gullberg et al., 2023). Patients particularly feel inadequately prepared for the change in level of nursing care. Stress and anxiety are commonly reported as are feelings of insecurity and vulnerability (Gullberg et al., 2023) due to leaving the security of 24/7 monitoring in the ICU and no longer having dedicated nursing care (Herling et al., 2020). Studies on the families’ experience report a lack of guidance, sense of not being involved, limited information provision, and lack of acknowledgement as carer (Meiring-Noordstra et al., 2024; op ‘t Hoog et al., 2020).

Plotnikoff et al. (2021) reviewed patient discharge from the ICU and found that discharge education for both the patient and family was the most reported facilitator for a successful discharge. Important facilitators were patient and family involvement in discharge decision-making and effective communication between patients and health professionals and between health professionals themselves. Gullberg et al. (2023) reported that patients meeting nurses from the ward before transferring out of the ICU created a sense of trust and safety. When patients have been in the ICU for

a considerable amount of time one should anticipate that discharge planning for this group of patients should be different from that of short stay patients. I know from my position as a nurse that there is likely to be an estimated discharge date and therefore planning and preparation should be able to take place to support a seamless transition.

Transition is a central concept of nursing. Meleis' (2010) transitions theory aligns well with the needs of long-stay ICU patients for navigated care by emphasising the complexities and vulnerabilities inherent in transitions, such as transitioning from the ICU or to home. The theory highlights that these transitions are complex requiring individualised, holistic support. The theory encourages nurses to recognise critical points in a patient's journey, helping them anticipate challenges that the patients face. Meleis' (2010) theory also supports the implementation of nursing therapeutics such as comprehensive assessment, emotional support, education, and coordinated care to guide patients through difficult transitions. For Meleis, preparation and knowledge about what to expect facilitate transitions. Thus, the importance of preparation, education, and setting realistic expectations for the ICU patient transitioning to the ward and to home is huge.

Then, for patient and family participants, coming home from hospital and facing their new post-critical illness reality was another profound shock that both groups perceived they were unprepared for. Two patients in the study were discharged home from general hospital wards, three from a hospital rehabilitation ward. The family participants whose spouses were discharged from general wards perceived discharge to be rushed and abrupt; hospital discharge planning was something that was done *to* the patient and their family, not *with* them. Notions of family being excluded in discharge planning and patients being *pushed out the door*

have been described in other studies as well (Howard et al., 2025a; Jones et al., 2023; Meiring-Noordstra et al., 2024). Family participants, who knew the patient best, could clearly see the patient was still unwell and not yet themselves. This, combined with their knowledge of home life made the prospect of the patient returning home terrifying.

Most family participants were also fearful at the prospect of becoming a carer and the responsibility of caring for their spouse who was still unwell. Several patients went home with new medical devices. The family of these individuals knew the patient would be unable to manage independently and this worried them. Family did not recall receiving sufficient discharge education voicing concern that they were unaware of things to look out for, red flags, and who to go to should they need help, findings that have also been found in other studies of family carers of ICU survivors (Bristol et al., 2023; Flinterud et al., 2023). Family of post-ICU patients perceiving themselves as being unprepared to assume the complex role of carer upon hospital discharge has also been highlighted by Danielis et al. (2022) and Meiring-Noordstra et al. (2024). Alrø et al. (2025) reported that the weight of responsibility was overwhelming. Without sufficient knowledge and resources, family felt highly vulnerable (Arlø et al., 2025).

Once home, both patient and family participants described feeling abandoned by the health system, unsupported, and in the dark while having to find their way through a difficult and uncertain recovery process. Furthermore, they described having to navigate a complex, fragmented healthcare system on their own and several patients got lost in the system experiencing missed or misunderstood care, expressing feelings of abandonment, and not knowing how to navigate the multiple appointments, services, or medical directives, these findings being supported by

others (Alrø et al., 2023; Calkins et al., 2021; Nazeer et al., 2026). The sense of abandonment has also been highlighted in the international literature (Allum et al., 2018; Sutton et al., 2025b), and fragmented care is internationally recognised as a significant barrier to recovery after the ICU (Nazeer et al., 2026). Individualised navigated care is something that is greatly needed (Nazeer et al., 2026) as is information provision, especially concerning PICS and PICS-F, recovery expectations and timeframes, delirium education, and who to contact should patients or families need help (Allum et al., 2018; Alrø et al., 2025; Flinterud et al., 2023; Meiring-Noordstra et al., 2024; Rea et al., 2023; Sutton et al., 2025b).

Both Bourjois et al. (2017) and Mold (2017) highlight a profound disconnect between clinical problem-solving and the social and personal realities that dictate patient outcomes. Mold argues that problem-oriented care leads to team dysfunction where different disciplines define their own territory, causing the patient's actual goals to be lost. This context-free approach makes care feel mechanical and dehumanising, as the clinician is the distant expert and the patient's personal goals are lost. Bourgois et al. point out that even highly successful programmes designed to coordinate care for high-user patients (who share similar complexity to ICU survivors) are often cut during budget crises. These administrative annual budget processes then overlook long-term benefits in favour of immediate savings. Clinicians facing these time constraints often feel helpless or frustrated. Time-limited settings mean that complexity is seen as expensive and it is these structural vulnerabilities that sabotage the patient's recovery upon discharge. Patients, particularly those with complex needs like ICU survivors, feel abandoned because the system focuses on correcting abnormalities rather than their actual survival context. This neoliberal approach to lean thinking and annualised budget allocations

based on an algorithmic model, has been supported by neoliberal ideology for several decades in OECD countries, and what it has done, is “govern nursing performance as a neutral stance of care that neglect emotional engagement”, thus “dealing with a patient as an object that violates all dimensions of patient recognition” (Al-Chami, 2025, p. 1). Aotearoa New Zealand and Australia have both followed a modified neoliberal model, resulting in long standing inequities in care (Adams et al., 2024; Barnett & Bagshaw, 2020; Charmaz, 2020).

7.4.2 Neoliberal Ideology and a Lack of Support for Prolonged Critical Illness Survivors and Families in Aotearoa New Zealand

A critical issue that this research has identified is that prolonged critical illness survivors and their families need ongoing support, rehabilitation, and ICU follow-up, but these services are currently lacking in Aotearoa New Zealand (Minton et al., 2020; Sutton et al., 2025b), evidenced: by no national guidance or service specification; sparse and inconsistent follow-up; limited measurement and data systems; and equity gaps.

These findings are systemic in nature as well as being a contextual issue. Acknowledging the importance of context, Clandinin and Connelly (2000) discuss the fact that such issues are temporal and that one must explore the context within which a participant is describing their experiences. This recognition that the ICU survivors of this study were largely left to self-care despite significant life changes, must therefore be examined drawing on the three-dimensional space framework, specifically attending to the dimension of situation, and the context that experiences take place within.

Aotearoa New Zealand’s healthcare context is shaped by neoliberalism, influencing everyone’s experience of health services through factors such as

underfunding/underinvestment of public health services, a focus on cost efficiency, and decentralisation (Adams, et al., 2024; Barnett & Bagshaw, 2020). It is relevant to acknowledge the neoliberal context in this narrative inquiry as the neoliberal framework is not just a backdrop but a dynamic force that shapes social inequalities, healthcare experiences, and the lives of chronically ill people (Vassilev et al., 2017) and therefore, needs to be considered alongside the personal narratives (Charmaz, 2020). Information seen through the research findings provides evidence of the theory of neoliberalism (Harvey, 2005; Wilson, 2017) and highlights the issue of how the neoliberal ideology underpinning the Aotearoa New Zealand healthcare system hinders the support of these very complex ICU survivors. This is evident in the findings on the transition from the ICU to the general ward and then to home, and across the first year after hospital discharge.

Viewed through the lens of neoliberal theory, the issue that ICU survivors are suffering and not receiving the holistic, longitudinal support they need is unsurprising, as this ideology has systematically contributed to the underdevelopment of ICU aftercare in Aotearoa New Zealand. Neoliberalism is defined by three principles: individualism, free market via privatisation and deregulation, and decentralisation (Harvey, 2005). When applied to health policy, these principles lead to the restructuring of healthcare delivery into a commodity to be purchased rather than a social right (Bourgois et al., 2017; Sakellariou & Rotarou, 2017). The state's role is minimised or targeted to acute (often lifesaving), time-limited episodes. Governments limit spending on public services, including healthcare, resulting in chronic underfunding of public health systems. Services with clear return on investment or political visibility get funded; low-visibility, high-complexity ICU survivorship care struggles to attract sustained investment.

Persistent pressure to reduce public spending squeezes non-acute, multidisciplinary supports that do not immediately show savings.

Therefore, systems invest heavily in ICU technology and acute rescues (visible, measurable) but underinvest in the slow, complex, multidisciplinary recovery work post-hospital discharge (less visible, diffuse benefits). The persistent underfunding hinders the development of comprehensive publicly funded ICU aftercare services because the focus is on cost efficiency and annualised budgets (rehabilitation and long-term care services show return on investment over time). The *cliff edge* of hospital discharge that this study identified, is therefore an intended byproduct of the neoliberal efficiency model, which views *acute stability* as the end of the hospital's responsibility. Furthermore, neoliberalism's focus on decentralisation shifts responsibilities between silos of hospital departments and on to local health services with limited budgets, further undermining national, standardised ICU aftercare development (Bourgois et al., 2017) and perpetuating inequities.

Neoliberalism works through long-standing ideologies of personal responsibility and personal autonomy (Wilson, 2017); individuals are personally responsible for their lives and outcomes, not the powerful structures that govern them (Charmaz, 2020). Thus, neoliberal ideology frames health as an individual responsibility and in doing so demands that individuals take control of their health, but also managing their ill-health (Vassilev et al., 2017). The emphasis is on personal choice/self-reliance over collective provision and so the state's role is minimised. Efficiency, cost control, and standardisation take precedence over individualised, holistic care (Bourgois et al., 2017).

ICU survivors and PICS do not fit this model. PICS requires complex, customised treatment, and as indicated earlier, long-stay ICU patients are more

complex than the ‘normal’ chronic care patient, so the underfunded public health system struggles to fund comprehensive infrastructure like dedicated PICS follow-up clinics. The chronic nature of PICS fundamentally clashes with a healthcare infrastructure optimised for short-duration, high-cost, acute episodes. Because PICS requires continuous, individualised, holistic, and high-touch chronic care management, the imposition of an acute, transaction-focused, budget-driven system guarantees fragmentation will occur (Barnett & Bagshaw, 2020; Church et al., 2018).

The fragmentation experienced by the patients and families in this study is not an operational anomaly but rather the predictable structural consequence of health systems engineered by a foundational neoliberal paradigm. Systems influenced by this ideology prioritise maximum efficiency in the acute setting with high throughput and fast patient turnover, while the necessary long-term service required for comprehensive ICU recovery is systematically discounted. The system focuses on short-term fiscal goals, defining success narrowly by the immediate product (*the saved life*), and structurally ignoring the required, integrated service (*the rehabilitated life)* (Bourgois et al., 2017). The critical task, therefore, is to move beyond clinical recommendations and provide a political-economic critique that establishes how macro-ideological choices predetermine micro-clinical fragmentation.

The principle of individualism demands that health is primarily the individual’s responsibility, requiring personal investment (Wilson, 2017). This ideological framework actively reframes systemic failures, such as inadequate post-ICU support, as personal management problems of the patient. The shift prioritises consumer choice and market mechanisms over collective access and equity. Commoditisation reduces the healthcare services to a series of tasks and transactions, fundamentally

eroding the longitudinal, trusting, personalised relationships, often required for chronic, complex PICS recovery, by pressure to optimise efficiency.

Also, the devastating effects of PICS are fundamentally inseparable from the burden placed on family members, termed PICS-F (Alrø et al., 2025; Tejero-Aranguren et al., 2024). The physical, psychological, and socioeconomic burdens experienced by family participants in this study resulted in health deterioration, lost income, and increased caregiving demands of those caring for the patients, as well as the loss of value and worth of the patient themselves. The sudden and unprepared assumption of this intensive caregiving role led to stress, social withdrawal, relationship strain, and psychological sequelae such as anxiety and depression, findings that are consistent with other research (Flinterud et al., 2023; Shirasaki et al., 2024; Wen et al., 2025). Applying the theory of neoliberalism, PICS-F serves as a key socio-economic mechanism through which the health system achieves apparent “efficiency”. By failing to fund comprehensive, institutional post-ICU resources (ICU-follow-up clinics, dedicated rehabilitation, dedicated nursing), the complex and time-intensive labour of recovery is structurally externalised onto the family unit. This shift effectively transfers massive economic and social costs onto the most vulnerable private actors (Alrø et al., 2025) masking the true costs of critical care survival and perpetuating financial and social disruption within the household (Griffiths et al., 2013).

As was the case for the patients and families in this study, the neoliberal ideology of self-care and of treating health as a private rather than public good, means that once discharged home, ICU survivors must now take over responsibility for managing their health and recovery, not the state. While the goal is always good

health, ICU survivors are vulnerable for an extended period of time, and cannot take control of care that remains complex, even after discharge.

Vassilev et al. (2017) argue that the neoliberal health framework is a dynamic force that shapes patient experiences through the promotion of individual responsibility that transfers the burden and responsibility away from the state and onto individuals and families, regardless of how complex care is. This was the case for all participants in this study; all were left to navigate the path forward on their own with no road map and received no post-critical illness resources (information about PICS and PICS-F, ICU follow-up, dedicated post-ICU rehabilitation, dedicated nursing) or expert guidance leading to what most perceived as a sense of abandonment. The findings ‘Unmet Needs’, ‘Terrifying Hospital Discharges’, and ‘Navigating New Realities Alone and in the Dark’ show this approach is a moral and systemic failure.

However, findings of this research point out that for the long-stay ICU survivor this task of self-care/self-management is problematic because these people do not fit this model. Under this model, survivors are expected to navigate complex, fragmented systems, self-manage the recovery process and symptoms of PICS, and “choose” post-ICU care (for example, Patient E who was given access to a sum of money and told he can choose what health services he spends it on, and Patient D who had to choose and pay for care for treating his chronic pain), despite cognitive/psychological impairment, fatigue, disability, and limited health literacy. Also, the notion of self-care is reliant on a person having to make decisions about things that they do not even understand or know. These points highlight a classic mismatch of responsibility versus capability for the long-stay ICU survivor.

The neoliberal ideology of individualism means costs then shift to patients and family (for example, costs of health services, time off work, transport, caregiving, mental health burden) and to primary care, which lacks dedicated funding for intensive post-ICU follow-up. Under this model, those who have economic, physical, and cognitive/psychological resources may be able to access the care they need (if such services exist); structural inequity becomes amplified – Māori, Pacific, low-income, and rural survivors face higher barriers to self-navigation and access to services. Therefore, neoliberalism's emphasis on individual responsibility widens disparities. Further, culturally-anchored, community-based supports and family/whānau services are under-resourced because their value is relational, long-term, and hard to capture in narrow economic efficiency metrics.

Neoliberalism's focus on individual autonomy and self-care is also a colonial construct that marginalises Māori ways of knowing that prioritise the whānau (family) collective. The current study's finding of 'Unmet Needs' on the ward was particularly acute for Māori participants because the system structurally ignores the sociality commonplace required for Māori healing and prioritises biomedical care over relational care.

Neoliberalism's principle of New Public Management, which emphasises general managerialism and the application of business models (Barnett & Bagshaw, 2020), is the mechanism through which the ward care was degraded (Adams et al., 2024). For example, when one family participant observed nurses "sitting around" (Family J) while her husband's fundamental needs were unmet, this was not an individual failure but a symptom of a system that manages by managerial accountabilities as opposed to patient-centred outcomes.

The overarching issue that after prolonged critical illness survivors and their family lack access to effective support services is a systemic issue. It is an issue that is set in a health system that does not see the patients' and families' needs once they leave the ICU and the hospital. Even if some clinicians do see the patients' needs after hospital, there is no way to provide the care needed because currently in Aotearoa New Zealand there is no means or funding offered to it. Long-stay ICU patients are very expensive to care for and either the system cannot or does not want to deal with it. This issue is not a new phenomenon: patients' need for and lack of ongoing supportive care, follow up, and rehabilitation after a critical illness is an issue that has been highlighted in the literature since the 1980s (Griffiths & Jones, 2002). Family and family carers' need for professional support related to the burden of PICS-F, understanding the complexity of the patient's recovery, and navigating ongoing care has also been highlighted in the literature for several decades (Davidson et al., 2012).

Bringing to light where the system is failing long-stay ICU survivors, and their family is a necessary first step in addressing this problem, which this discussion will do. This will allow space to be created for alternative ways of doing things, that is, the system changes that are needed to improve service provision and outcomes of this group. These changes are necessary to improve the lives of future long-stay patients and their family. This challenge reflects the broader *wicked problem* introduced in Chapter One, where complex and intersecting systemic factors such as fragmented funding models, insufficient resourcing, and inadequate post-discharge support, demand integrated solutions.

7.5 No One Knows the Long-Stay Patient and Family's Journey

A critical issue this research identified is that there is no one involved in the care of this cohort who understands the entire illness-recovery continuum; that is, the whole journey that the long-stay ICU patient and family are on. This study revealed that for the patient and family, the critical illness experience encompasses the entire journey, which begins at illness onset and continues through the ICU stay and through the recovery process, which was still ongoing at one year follow-up. Currently, the way that the system cares for this group is based on a medicalised view that critical illness is something that just happens in the ICU. This is problematic because it fundamentally reduces a person's critical illness experience to the time in the ICU and thus suggests a fixed, linear progression from illness to recovery, overlooking the continuing and multifaceted impacts of the critical illness. This view oversimplifies what is often a complex, ongoing journey that can deeply affect a person emotionally, psychologically, and existentially, evidenced in this study by a lack of awareness about, and support for, these impacts.

At the outset of this research, the intention was to investigate participants' experiences after the critical illness. However, during the first interviews it became clear that a person's post-ICU experiences cannot be separated from their ICU experience – the two are inextricably linked. Drawing on Clandinin and Connelly's (2000) dimension of temporality and Dewey's (1938/1963) theory that the past, present, and future are connected in a continuous fluid flow, it was apparent that the aftermath of a person's ICU stay is deeply shaped by their ICU experience. Because of this, a person's post-ICU experiences cannot be fully understood in isolation from their time in the ICU. Moreover, it is this realisation that gave rise to the conceptualisation of the journey framework.

Each participant's story began with an account of the onset of illness and the ICU experience, which evidently marked the onset of a long journey. This account was important contextually as it explained many of the current struggles they had. Following Clandinin and Connelly's (2000) approach by looking at context, time, and place, participants' narratives revealed the journey is prolonged, evolving across time as a series of distinct phases and transitions, each characterised by its own unique challenges and struggles that patients and families must navigate, findings that align with previous research (Dammann et al., 2022; Minton 2017; Nelderup et al., 2018; Schwitzer et al., 2023; Sutton et al., 2025a). Family live the journey with the patient, but their journey is different and they face different challenges, a finding that concurs with Page and colleagues (2019a) theory of *dualistic worlds*. Viewing prolonged critical illness through the framework of an unfolding journey with distinct phases, transitions, and challenges unique to each phase will help nurses and other healthcare professionals anticipate and address the evolving needs of the patient and family (Minton 2017; Sutton et al., 2025a).

Supporting the notion that the critical illness experience does not end when the patient leaves the ICU is that, for patients and family in the present study, no matter how far away they moved from the ICU, memories of that time were not forgotten. Family described how they would never forget the horror of what they went through in the ICU, a finding that aligns with Hirshberg et al. (2020) and Zhang et al. (2024) who identified that such memories of the ICU experience can remain vivid and endure long after the event. The psychological distress (Blok et al., 2023) and emotional turmoil that many family members of ICU patients experience from witnessing their relative's critical condition is well reported in the literature (Asadi &

Salmani, 2024; Dammann et al., 2022; Halain et al., 2022; Minton et al., 2019; Page et al., 2019a).

Patients comparatively did not remember it all however, all remembered elements of their experience. In the literature, ICU survivors recall surreal dreams, nightmares, hallucinations, and delusions from the time in the ICU, which are predominantly unpleasant, upsetting, and scary (Maartmann-Moe et al., 2021) and place them in a different world or liminal space (Page et al., 2019a), also described by patient participants in this study. Themes of vulnerability, dependency, feeling unsafe, closeness to death (Danielis et al., 2024; Maartmann-Moe et al., 2021; Vogel et al., 2023), and being captive (Vogel et al., 2023) are common, evoking the sense of being out of control as well as feeling exposed and alone, generating feelings of fear, again experiences described by participants in this study. Vogel et al. (2023) found that for many, the feeling and experience of memories persisted for months after discharge, causing anxiety and distress. Making sense of the memories and emotionally processing them is a difficult and important part of recovery that takes time (Vogel et al., 2023); without adequate support patients are unable to do this and there are potentially negative outcomes such as anxiety, depression, and post-traumatic stress.

Drawing on Clandinin and Connelly's (2000) dimension of sociality, this study revealed that the experiences of patients and families throughout this journey are also shaped by the context and care environments they move through and the interactions with healthcare professionals they have along the way. Truly effective care is only possible when healthcare providers understand and therefore address the entire journey, attending to the complex and changing needs of both patients and families throughout every phase, a perspective also endorsed by others (King et al.,

2019; Palesjö et al., 2015). However, findings of this study indicate that the full extent of the journey that long-stay patients and their family undergo is not fully grasped by those providing care to them; their story, what they have experienced and overcome to get to where they are today, why they have the problems they do, and how all of this is located within the big picture of the person's life. This narrative knowing is important for clinicians. It is a pathway to knowing the person (Ragan & Kanter, 2017) and is essential for the delivery of truly person-centred care (Schwind et al., 2016). So, this thesis prompts the question: *If nurses do not understand each long-stay patient and family's journey, then how can they enact person-centredness and properly care for them?*

Understanding participants' narratives through the dimension of temporality – the connection between their past experiences and current reality – enabled appreciation of the long-stay ICU patient and family's whole journey. Reflecting on this as a nurse, it became clear that appreciating the whole journey is important for all nurses. Regardless of what setting the patient is being cared for in, the ICU experience cannot be separated; it always informs their present situation. In practice, this means that while the ICU experience may be in the past, the human experience of a prolonged critical illness is ongoing regardless of what phase of the illness-recovery continuum the patient is at and consequently, their support needs are always informed by this experience. For example, nurses caring for the patient after intensive care need to understand the triggers that may come up along the way that can cause unpleasant memories to resurface and take the patient or their family back to the time of the ICU.

This insight revealed that the way the system currently cares for these patients is problematic, because once the patient leaves the ICU, the system does

not systematically acknowledge the person's ICU experience and care for them in a way that addresses the trauma and potential long-term complications of the ICU experience. Nurses who are caring for the patient after ICU in different healthcare settings have expertise based upon their own specialities (Twamley et al., 2023), which raises the question: *What do general ward and rehabilitation nurses know about the ICU experience and ICU survivorship?* Drawing on the "Expert versus Learner" tension, the ward nurses are *experts* in clinical tasks but often *learners* regarding the patient's long-stay history and personal experience; this needs to be recognised and addressed by finding out about the patient's journey. Yet because of the *lost time* and *fragmented realities* that patients in this study described, families are not just observers, they are the *guardians of the narrative*. This insight shows how it is through the family that the nurse can gain an understanding of their journey. Yet the families in this study reported that no one inquired into their story. These points highlight that the system is fragmented, comprised of medicalised silos with no continuity of care.

Applying the theory of neoliberalism to this problem that no one understands the journey brings to light the current reality of neoliberal nursing care, which can be seen in the themes *Bearing the unbearable: Symptom burden; Being misunderstood*; *Unmet needs*; *Where is the care;* and *Navigating new realities alone and in the dark*. Neoliberalism structures nursing care by prioritising economic efficiency, accelerated care processes, standardisation, and scientific biomedical caring approaches (Al-Chami, 2025). Therefore, under neoliberal policies, nursing care becomes increasingly technical and task-oriented, often at the expense of relationship-based, person-centred care (Al-Chami, 2025). For over 50 years, nursing theories have emphasised the centrality of the nurse-patient relationship (Peplau, 1952; Watson,

1985; Swanson, 1999) and the importance of the nurse working with the patient and their family carers/members in ways to optimise healing, wellbeing, independence (McCormack & McCance, 2006), and ensure patients are and *feel safe* (Kitson, 2018). Also, relationship forms the foundation for establishing trust (the nurse being trusting is emphasised in many nursing theories such as Peplau, 1952; Swanson, 1999; Watson, 1985), knowing the patient, and effective communication (Kitson et al., 2013; Kitson, 2018); essential for patients to *feel seen and heard*. In the modern healthcare system that is driven by neoliberal rationality it has become increasingly difficult for nurses to incorporate caring values and enact therapeutic relationship building in their practice (Al-Chami, 2025). This was evident in the findings from participants' time on the general wards.

Al-Chami (2025) points to the way that under neoliberalism nursing care becomes a rationality that "diminishes any possibility for nurses to engage with patients and understand their unique phenomenological world necessary for coping and recognition" (p. 1). Nurses become what Thompson (2023) refers to as "obedient bodies" (p. 6), trapped in a system that rewards *task and time* nursing instead of personalised care (Aiken et al., 2014). Similarly, Feo and Kitson (2016) point out that nursing is constrained by a *checklist* mentality where *getting through the task* is more valued than meaningful patient engagement. Applying Honneth's (2008) theory of reification, Al-Chami (2025) argues that in a neoliberal context, nursing care becomes a form of reification, defined as "a type of human behaviour that violates moral or ethical principles by not treating other subjects in accordance with their characteristics as human beings, but instead as numbness and lifeless objects, "as things" or commodities" (Honneth, 2008, p. 19). The experience of the patient participant in this study who was not washed properly and developed a

double infection, together with the quote, "I had to become an object" by another patient participant who was speaking of his time in the ICU illustrates this.

Understanding prolonged critical illness as a journey brings to light systemic issues that hinder the delivery of support for survivors and families. Addressing these is necessary to improve outcomes. Such issues will be discussed in the following sections, framed as:

- the need for person-centred practice
- the need for nurse education
- the need for nursing leadership and navigated care.

7.5.1 The Need for Person-centred Practice

The issue that there is no one involved in the care of this cohort who understands the whole journey that the long-stay ICU patient and family are on highlights that person-centred care is not being delivered to these patients. Despite the global movement for person-centredness in healthcare and crucially, person-centredness being a philosophy of nursing practice (McCance & McCormack, 2025), the system does not yet support nurses to deliver *real* person-centred care (Al-Chami, 2025). The narrative accounts of participants in this study suggest that few health professionals involved in the care of these patients had any idea about who the person is – their *personhood*; their values, beliefs, hopes, dreams, and desires (McCance & McCormack, 2025), their unique illness experience, and the context of what they had been through in the ICU.

Many nursing theories emphasise the centrality of nurses knowing the person and understanding their lived experience of illness (Peplau, 1952; Swanson, 1991; Watson, 1985), with point-of-care theoretical frameworks for person-centred care emphasising nurses engaging authentically with patients and families in ways that

create meaningful connections in any caring moment (Kitson, 2018; McCance & McCormack, 2025). Carper's (1978) theory of the patterns of knowing in nursing terms this *aesthetic knowing* or the *art of nursing* and describes how the nurse must focus on understanding a patient's unique situation. Aesthetic knowing involves empathy and appreciating the subjective, personal experience of the patient (Carper, 1978). To know a patient therefore goes beyond knowledge of empirical data to understanding them as a unique individual including their personal journey. Through acquisition and use of this knowledge, a nurse can provide holistic care (Kitson, 2018; McCance & McCormack, 2025).

Although knowing the person and their illness experience is central to nursing philosophy and theory, the dominant biomedical model, a product of neoliberal ideology (Al-Chami, 2025), emphasises medical tasks and relational work is not valued within this model (Minton, 2017). Nurses are left with little time to truly know the person, leading to a loss of person-centredness (Minton, 2017). Kwame and Petrucka's (2021) review showed the more task orientated the care in a setting is, the more person-centredness is lost. This short-term, data-driven care, leaves little time for relationship-based strategies that, in fact, form the foundations of nursing work (Harvey et al., 2017; Mold, 2017). This is particularly significant in the ICU where care is driven by biomedical priorities and medical tasks (Jakimowicz et al., 2017). Yoo et al. (2020) showed that ICU nurses were more focused on urgent tasks directly linked to maintaining patients' health, such as stabilising vital signs, than on communication. The emphasis on tasks is also a common occurrence on the hospital wards. The failure of the nurse to provide Patient A with the psychological support he needed during his transition to the ward and the persistent neglect of Patient D's pain management represents a hegemony of biomedical monitoring over

relational care, extending Honneth's (2008) theory into the Aotearoa New Zealand ward context.

Considering the erosion of person-centredness, continuity of nursing care for the long-stay patient becomes essential as it provides the opportunity for relationship-building and knowing the patient and family and thus understanding their journey through repeated encounters. This knowledge enhances nurses' ability to identify and anticipate needs and provide holistic care (Minton, 2017). What is also needed for the long-stay patient is a team of primary nurses to provide continuation of carer over several shifts because a nurse will never know the whole person in one shift, a view supported by Minton.

The lack of person-centredness in the care of long-stay ICU patients is not a new issue. Several years ago, Minton (2017) identified this issue and advocated for a person-centred approach to care specifically recommending the Kitson et al. (2013) Fundamentals of Care Framework as a point-of-care theoretical framework. However, this research suggests that despite Minton's earlier recommendations, little meaningful progress has been made to change practice.

This research also identified prolonged critical illness is traumatic for both the patient and family and yet, after the ICU, the trauma was not recognised. It is acknowledged in the literature that critical illness and the ICU can be a traumatic experience (Alonso-Ovies & Heras La Calle, 2016; Burki, 2019; Halain et al., 2022; Kang, 2023; O'Neill et al., 2024). ICU survivors can re-experience the trauma through intrusive memories, flash backs, and nightmares. Mental health conditions can arise after trauma such as near-death experiences and severe illness, including anxiety, depression, and post-traumatic stress disorder (König et al., 2019). In line with person-centred practice, if nurses truly understood the patient and family's

journey, they would also understand the trauma. Understanding the trauma would support nurses to help patients and family to cope, recognise trauma-related needs, and arrange appropriate psychological support to mitigate the long-term effects on the patient and their family.

This is particularly significant for general ward and rehabilitation nurses as after ICU, patients begin the process of understanding what happened to them. It is something they can only do with support. Minton (2017) showed that it is emotional work and takes time, but the system is not set up to allow nurses to do this work. Also, after the ICU there may be triggers that take the patient or family back to the ICU and so nurses need to understand these.

One potential source of psychological triggers is the *burden of witnessing*, a concept that emerged from family participants' narratives and aligns with existing research on families' experiences in the ICU. Abdollahimohammad et al. (2024) describe the indirect *care-related suffering* that family experience as they witness the patient's pain, distress, and uncertainty. Similarly, the concept of burden of witnessing fits with the broader literature on PICS-F which identifies anxiety, depression, post-traumatic stress symptoms, and complicated grief as common psychological sequelae among family members following critical illness (Shirasaki et al., 2024; Hartley et al., 2025).

Lastly, person-centred practice is essential to nurses being able to support long-stay ICU survivors with *biographical repair* work (Bury, 1982). Bury's theory of illness as biographical disruption describes how chronic illness shatters a person's normal life, disrupting their sense of self, everyday activities, and future plans. Bury's theory posits that illness creates a rupture in a person's life narrative, forcing them to renegotiate their identity, manage new physical limitations, and find new resources

as they attempt to rebuild their lives and create a new normal, what Bury refers to as “biographical repair”. More recently Palmer (2025), in her work with long term renal patients confirmed this by suggesting that patients go through a “cyclic reset process and translational change” (p. 254) as they constantly accommodate their changing lives with a chronic and inevitably, terminal condition.

The notion of biographical disruption and need for biographical repair was evident in the findings. All patient participants needed to understand their medical condition and what happened to them; re-examine their lives in view of new health issues and adapt; rebuild their bodies and their lives; renegotiate identity; and reconcile themselves with a new normal. In essence, address the biographical disruption the illness caused and re-establish themselves. There is a scarcity of literature on the concept of biographical disruption and repair following critical illness, so it is something that needs more understanding. Bury’s theory closely aligns with nurses enacting person-centred practice, as person-centred nursing prioritises understanding the patient’s life story, illness narrative, values, and unique experiences. By engaging in biographical work, nurses can deliver care that helps to re-establish the patient’s sense of self during the recovery process. This also highlights the need for ongoing psychological support to help patients with this work.

7.5.2 The Need for Nurse Education

Another issue this study found that contributes to these patients not getting the care they need after the ICU is the lack of education for all healthcare professionals involved in their care throughout the whole journey. If those caring for them had sufficient knowledge on the phenomenon and subjective experience of prolonged critical illness, patients and families would have better outcomes and care experiences. Ward nurses need to be educated on the phenomenon of prolonged

critical illness, what is to be expected after an extended ICU stay, and the challenges they may face at this stage of their journey. Also, given PICS and PICS-F is an integral part of the critical illness continuum – a whole journey problem – it is critical that ward and rehabilitation nurses as well as community nurses such as GP nurses, receive education on these phenomena. Only then can they provide the patient/family education and supportive care that is needed. Further research is warranted to determine whether PICS and PICS-F is taught to nurses who work outside of the ICU context in Aotearoa New Zealand, but it is understood that it most likely is not.

Knowing about the phenomena of prolonged critical illness would support ward nurses to provide timely education and guidance to both the patient and family, which in this study was missing. If nurses have knowledge on what is common post a long stay in the ICU, for example, transition stress and anxiety, difficulty sleeping, then the patient and family can be better supported.

As another example, if ward nurses knew about critical illness-acquired weakness, they would place the nursing call bell close to the patient so they could reach it. Several participants in this study described how despite being unable to move their arms when they arrived on the ward, nurses would leave the call bell out of reach. These participants recounted waiting for hours before someone returned, and they could express a need. This is also about essential patient safety. The patient being able to reach their call bell allows them to summon help for urgent or fundamental needs (Kitson, 2018). Nurses placing the call bell where patients cannot reach it is a major safety problem that shows a lack of critical thinking.

This study also highlighted a lack of emotional and psychological care with limited patient and family education occurring. If nurses on the wards had enough

knowledge on the ICU experience, they would be able to reassure the patient that what they are experiencing is normal. For instance, they would be able to explain to the patient that it is normal to feel anxious and vulnerable, it is normal to have trouble sleeping, it is normal to have flashbacks, it is normal to be weak and feel fatigued. However, nurses also need to have the time provide this care and share such knowledge. Yet in the neoliberal context that places limits on time to care, imposed through units of labour in time, this is difficult to achieve (Al-Chami, 2025; Harvey et al., 2016).

7.5.3 The Need for Nursing Leadership and Navigated Care

This research found that upon arrival to the ward, care and support for the patient and family progressively declined despite the patient still being unwell. Also, after the ICU admission there was no practitioner involved in this group's care with expertise on the phenomenon of a prolonged critical illness. This study has therefore raised the question of: *Where is the nursing leadership for this group as they move through the hospital system and transition to home?* Twamley et al. (2023) and Nazeer et al. (2026) also found that after the ICU stay, there is no healthcare professional who is coordinating care for post-ICU patients. This notion of no one systematically being responsible for caring for the patient and family throughout the journey is also identified in the Basso et al. (2024) systematic review and emphasised in the following quote*:* "There isn't someone managing the whole thing, managing all the components of his life… like how to fully recover, there should be someone managing the whole case…" (p. 1512).

The lack of nursing leadership for this cohort is problematic because long-stay ICU patients are a unique patient group, with complex care needs that are very different to the typical ward patient, and this complexity makes them vulnerable.

Additionally, the patient and family's needs are constantly changing as they progress through the phases of a prolonged critical illness (Dammann et al., 2022; Minton et al., 2019; Minton et al., 2020). This makes them complex patients, and this complexity makes them vulnerable to care needs not being addressed, which was at times the case for participants in this study.

Nursing leadership is also needed post-ICU because the current health system that these patients are being cared for in with its biomedical dominance, fragmented care, and focus on patient flow and efficiencies has created the situation where the staff nurses caring for these patients are not afforded the time to meet the holistic needs of patients (Al-Chami, 2025).

One way to address these issues may be for an experienced practitioner, such as a specialist nurse with expertise on prolonged critical illness and recovery to be in a nurse navigator role leading care and supporting the patient and family as they navigate the major transitions (to the ward and to home), recovery process, and move through the fragmented health system. This recommendation was specifically made by several patient and family participants in this study. Several other studies also recommend a similar approach (Basso et al., 2024; Nazeer et al., 2026).

Research shows that people with long-term conditions achieve better outcomes when they actively manage their health day-to-day (Huang et al., 2024), supported by structured education, goal setting, and problem-solving, a form of self-care (Ong et al., 2014). But the long-term ICU survivor cannot cope with this because of critical illness sequelae such as cognitive difficulties, psychological distress, physical limitations, and overwhelming fatigue, justifying the need for navigated care. Bandura's (1977) Social Cognitive Theory suggests self-efficacy is a major determinant of self-care. The theory states a person's belief in their capability

to perform a coping behaviour (self-efficacy) strongly predicts whether they will initiate, persist, and succeed. Persistence, through experiences of self-mastery and accomplishment further enhance self-efficacy. Higher self-efficacy leads to greater effort, resilience, and better outcomes (Bandura, 1977).

Tan et al. (2021) found an association between self-efficacy and self-care in chronic illness management. As was the case for patient participants in this study who were shattered, shocked, and clearly debilitated after the ICU stay, the motivation to self-care might be there but the reduced capacity to self-care and persist in those first months at home, means that the task of effective self-care is unattainable. This really highlights the individual navigation that these people need.

Conceptual and theoretical descriptions of self-management have evolved since 1985 when Corbin and Strauss (1985) developed the chronic illness trajectory framework, which identified three lines of “work” that a person living with chronic illness needs to undertake at home: illness work, everyday life work, and biographical work. Later, further self-management processes were identified including problem solving, decision-making, resource utilisation, partnerships with healthcare providers, and taking action (Lorig & Holman, 2003). Other models such as Lorig’s (1996) model of chronic disease self-management suggests that illness management comprises a number of components:

- symptom management: Recognising, tracking, and responding to symptoms (e.g., dyspnoea, fatigue, pain, sleep disturbance)
- medication and treatment management: Understanding regimens, side effects, and interactions; coordinating multiple providers
- role and behaviour management: Adjusting activities, pacing, energy conservation, returning to work/whānau (family) roles

- decision-making and problem-solving: Identifying barriers, generating options, trying solutions, evaluating, and iterating
- resource utilisation: Knowing when/how to access services, peer support, and community resources
- partnership with health professionals: Shared goals and action plans; co-production of care.

The long-term ICU survivor cannot cope with all of this work, reinforcing the argument for individualised, navigated care.

The issue that there is no one involved in the care of this cohort who understands the whole journey highlights that the concept of fragmented care is alive and well in the Aotearoa New Zealand healthcare system. Despite all the information and research around the needs of people with chronic or complex illness, the system does not yet support real coordinated care. Integrated care still relies on siloes of medicalised systems. In the current neoliberal healthcare context, which demands a culture of individual responsibility, ICU survivors and their families are expected to navigate a complex and fragmented care system on their own (Nazeer et al., 2026), regardless of circumstances and capabilities. This is a harsh and unrealistic expectation for ICU survivors.

The Queensland Health Nurse Navigator Service (Byrne et al., 2021), a nurse-led model of care for people with chronic and complex conditions, is one model that potentially would work well for survivors of prolonged critical illness and is worthy of further study to evaluate how it could improve outcomes for this population. Navigators collaborate with multidisciplinary teams, serving as a central point of communication and coordination. They navigate across all aspects of hospital and social services, liaising, negotiating, and connecting care as needed, enhancing

patient outcomes. People stay with Nurse Navigators for as long as required, though the intent is to transition them from high-care needs to self-management (Byrne et al., 2024). An evaluation of the programme showed that the navigation model supports hospital avoidance and self-management. Additionally, each Navigator saved the health system one million dollars annually (Harvey et al., 2021).

7.6 The Need for Rehabilitation and ICU Follow-up

This study and others have highlighted that common post-ICU problems like physical weakness, impaired mobility, fatigue, breathlessness, pain, hair loss, impaired cognitive functioning, poor memory, anxiety, flashbacks, sleep problems, nightmares, and mood changes do not just go away when the patient leaves hospital (Schembari et al., 2024). Symptoms of PICS and PICS-F often are present and ongoing for months or years after leaving the ICU and can have a longstanding impact on a person's wellbeing (Chu et al., 2025). This stresses the urgent need for ongoing support and management, and the necessity for health professionals providing PICS follow-up care to address the person's needs holistically. Patients in this study had a need for rehabilitation (both inpatient and home/community based) and patients and families need ICU follow-up to address symptoms of PICS and PICS-F to improve their outcomes and the survivorship experience.

As survival after critical illness has risen in recent decades, more attention has been given to understanding the impacts on survivors (Inoue et al., 2024; Kean et al., 2021; Needham et al., 2012; Page et al., 2019a; Prescott et al., 2019). International research has revealed the burden of PICS on patients and families and highlighted that PICS may persist for more than 10 years (Geense et al., 2021; Marra et al., 2018). Building on this, post-ICU recovery and understanding how to best support survivors has become a growing concern. To improve recovery

outcomes and address the burden associated with PICS and PICS-F there have been guidelines written and recommendations made by professional organisations such as The Society of Critical Care Medicine (Mikkelsen et al., 2020) recommendations for screening and assessment of PICS; The UK National Institute for Health and Care Excellence (NICE, 2009) Rehabilitation After Critical Illness in Adults clinical guideline; and The Faculty of Intensive Care Medicine (2019) and Dutch guidelines for ICU follow-up services (Van Der Schaaf et al., 2015). The UK, USA, and some European countries have embraced these implementing recommended ICU follow-up services (Jensen et al., 2015; Kovaleva et al., 2023; Rosa et al., 2019) and physical rehabilitation programmes (Connolly et al., 2021; Sevin et al., 2018; Taito et al., 2019; Thoresen & Fosser Olsen, 2025; Van Der Schaaf et al., 2015).

In contrast to this, in Aotearoa New Zealand such services are sparse and inconsistent. In 2023, the Critical Care Infrastructure National Service Plan for Aotearoa New Zealand 2021-2035 was published (Te Whatu Ora – Health New Zealand, 2022). The plan outlines a future-oriented national delivery framework and provides a demand forecast for infrastructure over the next 15 years to meet future service needs and thus inform development of services. This plan “takes a whole system view to enhance opportunities across the entire patient journey as each person interacts with each part of the system, from before admission to a critical care unit, through to after discharge from the unit” (Te Whatu Ora Health New Zealand, 2022, p. 9). Yet despite this view of the “entire patient journey”, PICS is not mentioned once in the plan, and there is an absence of attention to the need to fund the establishment of post-ICU infrastructure including follow-up and rehabilitation services. The significance of the problem, that is, the burden of ICU

survivorship to individuals, families, society, and health services, remains unrecognised in the healthcare systems priorities. This is concerning and shows the lack of big picture thinking by those writing the document.

Over 30 years since arguments for ICU follow-up began and 16 years since Iwashyna's (2010) urgent call to action, nothing has been done to systematically acknowledge and meaningfully address the problem of ICU survivorship in Aotearoa New Zealand; the system continues to overlook it. Consequently, patients and families experience a continuum of vulnerability that this study showed begins on the first day in the ICU and endures across the first year after, where they are vulnerable to potentially treatable PICS and PICS-F symptoms going unnoticed, poor outcomes, unmet needs, reduced quality of life, relationship strain, carer burden, and lost income. However, the consequences go beyond that; because of the trauma that the patient needs to work through but is not supported with working through due to a lack of psychological support, they may be affected forever and have the potential for poor long-term outcomes. This failure to effectively support and rehabilitate the survivor may ultimately make them a burden on society through lost productivity and costs to the state (such as health-related and welfare).

Intensive care is expensive care. Long-term intensive care is very expensive care (Iwashyna et al., 2016). Given the Aotearoa New Zealand health system is investing substantial amounts of money into caring for long-stay patients in the ICU, there must be continued investment beyond the walls of the ICU into supporting survivors to health and to maximise their recovery and rehabilitation potential, so they do not further burden the health system through increased healthcare utilisation and hospital readmission. The system also must invest in the recovery and rehabilitation of these people so that they do not become a burden on society – so

that they can be functioning and productive members of society and return to work. While there are upfront costs associated with establishing and maintaining ICU aftercare programmes, potentially, the long-term benefits to the health system such as reduced readmissions, treating PICS/PICS-F, and improved long-term outcomes can outweigh the initial investment.

The current reality of *front-end* investment (recent funding allocation of NZ$644 million to increase ICU capacity) without *back-end* infrastructure is a fiscal and moral failure. While the primary role of the ICU is to save lives, when it comes to the long-stay patient who is discharged alive but left with profound and disabling new health problems as well as mental trauma, the work is not complete. Completing the work looks like supporting these people and their families, who have had so much resource invested into them, to live well after critical illness, that is, to rehabilitate; get back quality of life and reclaim their place in society, even, to flourish.

7.6.1 Rehabilitation

Patient participants in the study voiced the need for both inpatient rehabilitation at a dedicated rehabilitation setting and for rehabilitation to continue in the community, a view echoed by family participants. However, only three out of the five patient participants spent time at a rehabilitation setting before being discharged home, and only two received ongoing rehabilitation after discharge. This is consistent with findings of a recent comparable qualitative study that was conducted at multiple ICUs within the Aotearoa New Zealand public health system (Sutton et al., 2025a), which identified that despite the need, not all patients received rehabilitation. Findings from these studies shed light on the inequities in ICU rehabilitation services in Aotearoa New Zealand. Those participants who did receive rehabilitation perceived it was essential for recovery, specifically for regaining

physical strength, recovering function, and progressing towards independence. This adds to the evidence that rehabilitation is important for physical rebuilding after critical illness and improves outcomes (Corner et al., 2019; Sutton et al., 2025b).

Participants who had access to rehabilitation made impressive recoveries. One was told by doctors that he would require permanent home oxygen. His goal was to "get off the oxygen". He successfully weaned off it and was independent at 12-month follow-up. He attributed this to continuity of care from a respiratory nurse practitioner and his ongoing outpatient rehabilitation programme. Another who spent 11-months in the ICU had a comprehensive rehabilitation programme upon hospital discharge including gym sessions, hydrotherapy, and hand therapy. Astonishingly he had returned to work, albeit a different job, almost full time at 12-month follow-up. These examples illustrate what is possible if long-stay ICU survivors receive ongoing and personalised rehabilitation. Comparatively, those who did not get the rehabilitation they were promised, continued to experience physical and cognitive problems one year later. A recent study analysing cost efficiency of inpatient rehabilitation following acquired brain injury showed that for every dollar spent on inpatient rehabilitation in this cohort, an estimated AUD$91 was saved long-term (Lannin et al., 2024). Lorenz and Doonan (2021) demonstrated that access to rehabilitation following brain injury resulted in average lifetime savings of $1.50 million per person, with costs recouped within 18 months. These studies show the long-term value of investing in good rehabilitation.

Patient participants' narratives also revealed that physical rehabilitation was vital for their mental health and important in helping them manage the psychology of recovery. Exercise and physical activity coupled with goal setting motivated the patients, helped them to feel confident and stronger, and enabled return to activities

they previously enjoyed all of which supported mental health. The mental health benefits of physical activity are well established in the international literature (Firth et al., 2020; Noetel et al., 2024). O'Neill et al. (2024) found that physical rehabilitation supported post-ICU patients' recovery of mental health. Berntzen et al. (2024) found that for patients, any evidence of physical progress created hope of regaining health or living longer. The emotional and mental processing of an illness is a crucial part of rehabilitation and something that can take time (Clarke et al., 2024). In this study, patients who had rehabilitation reflected they had time to understand and process what had happened to them. A recent qualitative study of 20 ICU survivors who had accessed psychological therapy following discharge from an ICU in the UK found that psychological therapy is viewed by patients as an important part of recovery (Clarke et al., 2024). Psychological therapy supported sense-making, acceptance, and moving forwards, showing that therapy alongside other rehabilitation interventions, can facilitate recovery after critical illness (Clarke et al., 2024).

Also, by attending to the proxy voice during analysis, that is, family members narratives of instances where the patient was absent due to memory fragmentation or lost time, it became clear that the families are *guardians of the narrative* and they carry the burden of the ICU story until the patient is well enough to receive it. All patients in this study spoke about the need, as part of their healing journey, to understand what happened to them in the ICU. This thesis therefore raises an important question: *What happens when there is no family?* A patient without family may never come to know their story. This finding reinforces the need for psychological support as part of the rehabilitation journey, as well as the person-centred navigated care model proposed in this thesis. Both have the potential to

support the patient in the rehabilitation work of storying and biographical repair required by long-stay ICU survivors.

Moreover, aware of new health vulnerabilities, several participants viewed rehabilitation as essential to their continued survival. One explained that his gym sessions meant "everything – it means life." This is an important finding because many ICU survivors experience uncertainty regarding long-term recovery outcomes. Therefore, amid such uncertainty, hope becomes vital, something Berntzen et al. (2024) describe as an "inner resource, mental state and a fundamental confidence that there is a way out of difficulties" (p. 120). Consistent with Wade's (2024) theory, rehabilitation not only restores function but also catalyses and assists adaptation to life after illness.

An unexpected finding of this study was the widespread occurrence of cognitive impairment, evident across the year of follow-up, and the clear need for cognitive rehabilitation, yet this was not provided. Critical illness survivors frequently have a prolonged form of cognitive impairment; a landmark study found that at 12-month follow-up, one in four survivors had cognitive impairment similar in severity to that of patients with mild Alzheimer's disease, and one in three had an impairment typically associated with moderate traumatic brain injury (Pandharipande et al., 2013). Recognised causes of cognitive impairment in the critically ill include hypoxia and delirium (Brummel et al., 2014; Wang et al., 2022). It is likely that during the ICU admission long-stay patients experience episodes of hypoxia due to hypotension and low oxygen saturations and consequently may suffer some form of brain injury from this. Exploring the incidence of this for each participant went beyond the scope of this study, but some family participants recalled accidental extubations resulting in very low oxygen saturations and other instances of episodes of sustained low

oxygen saturations due to respiratory complications, hypotension, and even asystole events that required emergency attention. Hypoxic brain injury is a criterion for rehabilitation referral in Aotearoa New Zealand, so this is a phenomenon that warrants further research. Formal identification of hypoxic episodes occurring during the ICU admission, episodes that are often undocumented, may represent an underutilised opportunity to facilitate access to rehabilitation for more long-stay patients following their ICU stay.

Delirium, also known as ‘critical illness brain injury’, is also associated with long-term cognitive impairment (Girard, 2018; Pandharipande et al., 2013). Delirium is prevalent among ICU patients, affecting more than 33-50% of patients during an ICU stay and up to 80% of patients who receive mechanical ventilation (Girard et al., 2010; Pandharipande et al., 2013; Wu et al., 2023). Longer delirium duration is independently associated with disability in activities of daily living and worse motor-sensory function in the following year (Brummel et al., 2014). Delirium may therefore represent another underutilised opportunity to facilitate access to rehabilitation for more long-stay patients following their ICU stay.

This study highlights that long-stay ICU patients need a continuum of rehabilitation; rehabilitation must begin early during the ICU admission and continue through to home and the community. The Australasian Rehabilitation Nurses Association (ARNA) (2023) emphasise rehabilitation is a process, the outcome of which is maximised when rehabilitative nursing care is provided throughout the entire episode of health care of the illness trajectory regardless of the diagnosis, prognosis, age, or setting. In 2009, the UK National Institute for Health and Care Excellence (NICE, 2009) provided the first clinical guideline for rehabilitation services after critical illness stating that for patients at risk of morbidity (one risk factor being

anticipated long duration of ICU stay) rehabilitation should begin as early as possible in the ICU and continue through the continuum of care to home. It also recommended functional reassessment of patients two to three months after discharge from the ICU by an appropriately skilled healthcare professional who is familiar with the patient's critical care problems and rehabilitation care pathway. The World Health Organisation (WHO, 2024) states that “rehabilitation is an essential health service for anyone with an acute or chronic health condition, impairment or injury that limits functioning, and as such should be available for anyone who needs it” (para 10).

This thesis challenges notions of recovery and rehabilitation after prolonged critical illness. As was the case for participants in this study, each person’s journey of recovery was unique therefore, what it means to be recovered from the critical illness experience will be different for every person too. The goal should not be for critical illness survivors to merely “survive” or “recover” functional ability as is the dominant narrative in medical discourse (Jones, 2014; Thurston et al., 2020), because this study and others suggest that after a prolonged critical illness, a person does not “recover fully” and return to their previous level of function (Farley et al., 2016; Oliveira et al., 2019; Schwitzer et al., 2023); survivors experience important continuing problems. Therefore, a reframing is needed. This study draws inspiration from Greek philosopher Aristotle’s concept of human *flourishing*. For Aristotle, human flourishing was a “rich, holistic concept about a life lived well until its ending” (Donaldson, 2024, p. 120), a concept that fits well with people who have experienced critical illness as it incorporates both living and a good death (Donaldson, 2024). Potentially the guiding goal in post-ICU care should be not merely for patients and

families to *survive* or *recover* but move beyond this to promoting everyone to *flourish* (Buetow et al., 2019) in the aftermath of critical illness.

Building an innovative post-ICU rehabilitation model comprised of a network of rehabilitation services for the Aotearoa New Zealand context that goes beyond physical recovery is essential, because physical restoration is not the only thing that needs to be considered if survivors and their families are to flourish as human beings and make the most of life in their new post-illness reality. Rehabilitation practice needs to expand to become truly comprehensive attending to the deeper psychological, emotional, social, and existential impacts of prolonged critical illness on both the patient and their family. It needs to become about empowering them to overcome adversity, learn how to manage new health issues, and adapt to life post-ICU. At its core, the goal of rehabilitation should be to enable survivors to flourish in their post critical illness lives. Underpinning this view is the notion that human beings have an innate need to flourish and, in general, want to make the most out of life (McCormack, 2024).

7.6.2 Post-ICU Follow-up

Neither patients nor their families in this study received any ICU-follow-up regarding the critical illness, PICS/PICS-F, or recovery. These findings are unsurprising as currently in Aotearoa New Zealand the speciality of intensive care mostly separates itself from the patient after the ICU stay.

ICU follow-up is one strategy that would address many of the unmet needs of survivors and their families in Aotearoa New Zealand such as continuity of care; expert oversight; physical, emotional and psychological support; symptom advice; timely referral to other specialists; information provision; education; understanding; reassurance; and an opportunity to debrief. Various terminologies are used in the

literature to describe ICU follow-up, including “PICS clinics”, “ICU follow-up clinics” and “ICU recovery centres” (Nakanishi et al., 2024). With growing attention on supporting patients and families with ICU survivorship, follow-up services have been developed as an attempt to help survivors deal with the problems that can arise after the ICU (Nakanishi et al., 2024; Svenningsen et al., 2017) by providing ongoing care and support. Key principles of follow-up include early identification and treatment of PICS and PICS-F to allow for timely interventions and referrals to specialists if needed; provision of information and education, guidance and support; multi-disciplinary in approach; and monitoring and service evaluation (NICE, 2009).

Early research into follow-up focused on measuring the impact of critical illness on quality of life and the efficacy of these services in improving outcomes. Studies did not demonstrate improvements in long-term outcomes such as quality of life (Cuthbertson et al., 2009). However, a 2015 systematic review showed that routine follow-up may reduce post-traumatic stress disorder symptoms within three to six months after ICU discharge (Jensen et al., 2015). Another systematic review in 2019 showed that follow-up was associated with improvements in psychological symptoms (depression, post-traumatic stress disorder) and mental health quality of life (Rosa et al., 2019). Qualitative studies have long highlighted that survivors value having ICU follow-up services (Farley et al., 2016; Prinjha et al., 2009). Follow-up can help survivors gain an understanding of their PICS symptoms, make sense of what happened to them, and offer an opportunity to debrief their ICU experience with a clinician who knows what they have been through (Hanifa et al., 2018). Collectively these studies indicate that ICU follow-up has potential benefits.

Over the last three decades, the UK, the USA, and several Scandinavian countries have established ICU follow-up services (Connolly et al., 2021; Egerod et

al., 2013; Sevin et al., 2018; Thoresen & Fosser Olsen, 2025). A recent survey of UK hospitals reported that inpatient recovery and follow-up services were present at 127/176 hospitals (72.2% of respondents) (Connolly et al., 2021). This service was considered such a necessity that it became embedded in the NICE rehabilitation guidelines in 2009 (NICE, 2009). In contrast, in Australasia, follow-up is not common (Dafoe et al., 2026). A 2021 survey of Australian ICUs revealed that only two centres (2% of respondents) run a dedicated follow-up service (Cook et al., 2020). More recently, a 2026 survey of Australian and New Zealand ICUs showed that only 29% provided any form of ICU follow-up for patients and 25% for families, and this follow-up is largely ad hoc and unstructured (Dafoe et al., 2026). The prevalence of ICU follow-up specifically in Aotearoa New Zealand was not reported, but it is understood that follow-up is even more limited here (Sutton et al., 2025b).

Practices differ across countries but most described are ICU follow-up services in the form of formal clinics and nurse-led telephone or internet-based follow-up (Connolly et al., 2021; Haines et al., 2019; Hanifa et al., 2018; Jensen et al., 2015; Leggett et al., 2024). Other services include visits to the patient's home or facility or questionnaires posted or emailed to the patient's home (Hatakeyama et al., 2024). The optimal model of follow-up remains uncertain (Hatakeyama et al., 2024) and there is no gold standard to benchmark services across (Connolly, 2015) however, a recent systematic review describing existing models of outpatient ICU follow-up care found that follow-up without in-person attendance at the index hospital potentially has higher rates of recruitment, intervention delivery success, and increased participant retention when compared to hospital-based interventions (Dimopoulos et al., 2024).

Recently, the feasibility and efficacy of virtual follow-up have been explored, which offers promising results (Kovaleva et al., 2023; Leggett et al., 2024). Considering factors such as the heterogenous nature of the ICU population (Dimopoulos et al., 2024; Rea et al., 2023), international differences regarding ICU resourcing, and variations in geographical location that can play a significant role in determining availability and ease of access to ICU follow-up services, it is likely that one approach may not work for all patients and all contexts. In Aotearoa New Zealand for instance, individuals residing in rural areas and those who face challenges related to social determinants of health such as finances, transportation, and social support may have difficulty accessing follow-up clinics (Sutton et al., 2025b). Notably, because Aotearoa New Zealand is a small country, different regions may not have the speciality knowledge around post-ICU recovery processes and PICS/PICS-F. Also, because different hospitals receive different funding there are equity issues. These points highlight the need for a centralised service.

It has become increasingly suggested in the literature that ICU services should have responsibility of follow-up care for patients and to identify and treat the consequences of critical illness for patients and family (Mikkelsen et al., 2020); ICU doctors and nurses have the knowledge and skills to deal with multisystem disorders common in critically ill patients and this positions them well to understand the multisystem, whole person recovery that is required. Also, they understand the journey that the patient and family have been through in the ICU (Hanifa et al., 2018). Moreover, ICU treatments, often harsh and painful, are responsible for the life-altering complications that many survivors are left with. It has been suggested that if intensive care is truly to advance as a speciality, it must understand the

outcome of its patients to improve care practices within the ICU (Iwashyna, 2010); it must hear from people who live with the consequences of the care it has provided.

Comparatively, research suggests that GPs have limited knowledge on critical illness, the problems survivors are likely to encounter and the services that are available to help them (Castro-Avila et al., 2021; Leggett et al., 2023; Sutton et al., 2025a). A recent qualitative study of UK intensivists and GPs found that both groups felt hospital services were better placed to follow-up patients discharged from the ICU because they have a better understanding of the patient's needs (Castro-Avila et al., 2021).

The ideal timing, frequency, and approach for ICU follow-up is not clearly defined in the literature. The Society of Critical Care Medicine and Dutch Guidelines recommend screening of PICS begins early within 2-4 weeks of hospital discharge for high-risk patients and that these patients are followed up 6-12 weeks after hospital discharge (Mikkelsen et al., 2020). The Society of Critical Care Medicine recommend sustained, serial assessments continue along the path of recovery. A recent review identified the incidence of PICS was 64% at three months after ICU discharge and 56% after 12 months, emphasising the need for long-term follow-ups (Hatakeyama et al., 2024).

There is also a lack of clarity on who should be targeted for ICU follow-up because it is unknown which groups of patients benefit most and from which interventions (Connolly et al., 2021). Evidence suggests that those at greatest risk for PICS should be prioritised for follow-up, such as patients with a relatively high severity of illness, ICU admission beyond 48 hours, ventilated, sepsis, and delirium (Hatakeyama et al., 2024) as well as women, older adults, and those with pre-existing frailty or mental health issues (Nakanishi et al., 2024). Within the context of

Aotearoa New Zealand, ensuring equity for Māori and Pacific peoples in the planning of follow-up services is also crucial (Sutton et al., 2025b). Yet this constant concern over who to prioritise fits right in with the neoliberal ideology that expensive care is not efficient care (Wilson, 2017). Whilst it must be acknowledged that there are finite economic resources, Harvey et al. (2021) showed that with effective coordination of patients with the most complex chronic conditions, efficiencies are realised and the budget can still be contained.

The best timing of screening and follow-up for PICS-F is also unclear (Shirasaki et al., 2024). However, Shirasaki et al. (2024) emphasise it is essential to consider screening alongside the patient's trajectory. They note that evaluating PICS-F too early during this period may not capture the full extent of the family's challenges, however, evaluation left too late may miss the opportunity to manage those with PICS-F.

7.7 Chapter Summary

This chapter has discussed the findings of the research in terms of what they may mean and how they may be valuable for future prolonged ICU patients, families, and health professionals in Aotearoa New Zealand. They have also been discussed considering the research question and in the context of existing literature, theory, and the theoretical framework. The impacts of a prolonged critical illness on the study participants as well as the individual struggles of these people have been highlighted. Furthermore, how participants' struggles are linked to the big picture where no one is with them on their journey has been discussed. This chapter has also highlighted how very little has changed in respect to the provision of services to help survivors and their families cope with the legacies of the ICU experience in Aotearoa New Zealand despite 30 years of evidence.

Chapter 8: Conclusions and Recommendations

This study came about because I questioned how long-stay ICU survivors and their families were cared for in hospital and in the community. I saw gaps in the various contexts of care that these patients and families move through in their journey that had significant consequences for them. I saw gaps in healthcare professionals' knowledge of how patients and families experience a prolonged critical illness. I recognised that many long-stay ICU patients literally do not have a voice, thus many do not feel heard. I was aware that ICU nurses rarely get to hear the stories of survivors.

The preceding three chapters presented the key findings and discussion of this research, which have provided new understandings and greater insight into the experience of a prolonged critical illness and the first year after a protracted ICU stay from the perspective of survivors and their family. These findings are significant since before this study, as identified in the literature review, very little research had explored the topic of patients' and families' experiences during a prolonged critical illness and across the first year after discharge.

Subsequently, the depth of existing knowledge on this topic and current understanding of how patients and their family experience a prolonged critical illness across the various contexts of care has been expanded and new insights have evolved. The knowledge generated from this study is innovative and the approach used gave voice to survivors and family. This voice presents a new way of understanding and conceptualising what it means to be persistently critically ill and what it means to survive an extended ICU stay. It is anticipated that this new knowledge will help inform practice and interventions that may transform long-stay ICU patients' and families' experiences of healthcare during and after the ICU and

subsequently improve their health outcomes in the future. This work does not provide definitive solutions to the problems that have surfaced. It does however, present a compelling challenge to the assumptions that underpin current management and aftercare of this cohort as they transition through the hospital system and return home.

The final chapter of this thesis draws together conclusions from this narrative inquiry and presents recommendations for clinical practice, education, and research. It also discusses the strengths and limitations of this study. Lastly, a concluding statement is provided.

8.1 Summarising the Study

The findings of this study revealed that long-stay ICU patients and their families experience a continuum of vulnerability after a prolonged critical illness, and this is due to multiple, overlapping systemic factors. First, this population needs ongoing support, rehabilitation, and ICU follow-up, but these services are currently lacking in Aotearoa New Zealand; second, there is no one with experience who understands the phenomena of a prolonged critical illness and recovery actively caring for the patient and managing the process as they move through the system; third, there is no one involved in the care of this cohort that understands the whole journey that the patient and family are on. What is needed is firstly, recognition that prolonged critical illness is an ongoing phenomenon that profoundly impacts survivors and their families long after discharge from the ICU. At all phases of the journey, this cohort needs nursing leadership and a person-centred navigated model of care. After hospital discharge, long-stay ICU patients need ongoing rehabilitation. Both the patient and family need ICU follow-up and support for PICS and PICS-F.

8.2 Strengths of the Study

There are several strengths of this study. A key strength is the rich, in-depth understanding of participants' experiences that has been achieved. The method of inquiry, specifically having multiple, in-depth, and unstructured conversations with each participant, coupled with the longitudinal feature of data collection allowed for the collection of rich, detailed data about the experience of prolonged critical illness and ICU survivorship. The total number of interviews (40) generated an extensive data set, which is a strength of this study. The willingness and openness of participants to take the time to share detailed stories of their experiences of being critically ill, of recovery, of healthcare, and of navigating life after their illness is another strength of this study. All participants spoke earnestly. Patient participants stated that talking about their experiences with someone who could relate to the ICU experience and what they were having to deal with in the present moment was therapeutic. Family participants stated that the process of periodically sharing with the researcher the personal narratives and stories of their ongoing journey offered numerous benefits: It provided a space to debrief after hospital; a space to reflect on their experiences; a space to process emotions, to voice their struggles and challenges; and a space where they were met with empathy and so, the conversations were considered therapeutically validating highlighting a strength of the chosen methodology. Because the study participants felt heard and understood, there was a richness and depth to their stories and therefore the data collected.

Another strength of this study is that it has provided contextualised insights. Dewey (1938/1963) suggests that to understand people, the researcher needs to understand not only an individual's personal experiences, but also their interactions with other people and with the environment in which those experiences take place

and how their experiences change over time. By considering the dimensions of time, sociality, and place and how they relate to research participants' storied experiences, narrative inquiry provides a more complete picture of participants' experiences bringing to light the characteristics of the experience. This is important as it provides context, gives meaning, and offers greater insight to participants' narratives of the research phenomenon.

Another strength of this study is that it is inclusive of people from diverse backgrounds. Inclusion and diversity in research are essential for public health progress. Cultural diversity of research participants is important as different groups bring different perspectives and experiences. Actively seeking and exploring these ensures that research benefits all society and does not perpetuate existing inequalities, in the end leading to a more just society (Willis et al., 2021). Participants in the current study included people of various ethnicity, age, and educational backgrounds. Māori, Pacific, and New Zealand European people participated in this study, which reflects the Aotearoa New Zealand population. Participants were included from a wide range of ages (40s to 70s). The qualification levels ranged from high school to Doctorate.

Including diverse voices has enriched the research by ensuring that the study captures a broad range of experiences, insights, and perspectives. This in turn has added richness to the data and led to more nuanced and insightful research findings. Additionally, the diversity of participants supports ethical research practice, specifically, the principle of inclusion.

Another strength of this study is that using the narrative inquiry methodology has humanised the research. This study has truly given voice to study participants, and the final research texts have amplified their voices. This is important as these

groups are underrepresented in the literature. Additionally, the final research texts have been written with an intended audience in mind thus, making the research more relatable and understandable to readers. Through reading the final research texts, nurses involved in the care of long-stay ICU patients and their families have the opportunity to understand more fully these groups, especially their experiences of illness and healthcare, nurse-patient relationships, and other nursing issues (Wang & Geale, 2015) and thus, shift their practices in relation to care of them.

8.3 Limitations of the Study

There are several limitations of this study. First, the findings and conclusions about experiences during and after a prolonged critical illness are limited to the study participants' lives and experiences and cannot be generalised to larger populations of ICU patients and survivors or considered to provide a common experience about experiences during and after a prolonged critical illness. Narrative inquiry aims to bring to light the meanings of study participants' experiences, revealing subjective truths for the participants within their social context as opposed to objective, decontextualised truths (Wang & Geale, 2015).

Second, the storied experiences of the study participants are fluid and their stories of being critically ill and narrative accounts of experiences across the first year following the illness reflect their thoughts in the present context of the study, reflecting the temporality commonplace. What participants have shared is their narrative truth at the time they were interviewed. With time, their story and the meaning they ascribe to their storied experiences may change. As Connelly and Clandinin (2006) write, "Events under study are in temporal transition" (p. 479).

A third limitation is that that some findings have been withheld because of the need to preserve confidentiality and anonymity of participants and the hospitals that

participants were cared for in. This mainly related to the presentation of personal information that may have made people and places identifiable. Also withheld due to the need to protect participants' couple relationship were a small number of personal thoughts and feelings from some of the participants regarding the couple relationship post-ICU.

A fourth limitation is that while the group of participants was in some ways diverse, another limitation of the study was that the participants only included male patients and female family members. This was not intentional, but the result of only male patients meeting the study inclusion criteria during the recruitment period. It is understood that illness and chronic illness affects individuals differently based on gender and this is influenced by biological and societal factors. Furthermore, acknowledging that gender plays an important role in shaping peoples understanding of caregiving, future studies might explore the perspectives and experiences of patients and family members of other genders.

A fifth limitation is that, while this research included Māori participants, the findings were not interpreted through an Indigenous lens. As a result, Māori experiences, perspectives, and cultural meanings may not have been fully represented. Research is needed for Māori ICU survivors and their whānau that is informed by an Indigenous lens and interpretive framework because meaning is culturally situated. How experiences are interpreted and what is considered meaningful from a Māori world view differ to non-Māori.

A final limitation is the interpretive boundary of the study as it only captures those who successfully transitioned home. Research is also needed for survivors who transition from the ICU to long-term rest-home care.

8.4 Recommendations for Practice, Education, Research, and Policy

Recommendations will now be presented as a *Post-ICU Framework* for Aotearoa New Zealand designed to bridge the *Systemic Gap* identified in Chapter Two and the *Continuum of Vulnerability* identified in the findings.

Post-ICU Framework

Practice

National virtual/telehealth ICU follow-up service for long-stay survivors and their families: Setting up a virtual/telehealth service for this group is an approach that potentially could work well and is worthy of further research. Several factors make virtual/telehealth follow-up a better option than physical/in-person including, Aotearoa New Zealand has a small population, geographic challenges limit access for rural patients, long-stay patients only account for 5% of the ICU patient population, and there are chronic staff shortages.

A model of person-centred navigated care: A model of person-centred navigated care is needed, led by an experienced nurse practitioner with expertise in prolonged critical illness. This nurse practitioner would guide care delivery for this cohort during their hospital stay and provide ongoing support to the patient and family as they transition home. Acting as a liaison between the ICU and step-down units or wards, the nurse practitioner would help improve patient safety, ease the transition for patients, families, and ward nurses, and contribute to better outcomes. Their role would also include providing education and mentorship to step-down and ward nurses, thereby supporting the development of knowledge and skills in caring for former long-stay ICU patients and their families. The value of an experienced nurse practitioner who understands the phenomenon of prolonged critical illness and leads care for this cohort beyond the ICU warrants further research.

Screening for psychological distress: A screening/assessment tool needs to be adopted that supports ward nurses to recognise early if the patient is not coping with the trauma of the critical illness and/or showing signs of psychological distress.

Structured psychological support be provided for long-stay patients and their families across the entire care continuum – from admission to the ICU, through subsequent hospitalisation, and into reintegration within the community: There is a need for patients and their families to discuss their experiences. This ongoing support should address the cumulative emotional and psychological impact of critical illness, fostering recovery and resilience for both patients and their families.

Collecting and disseminating survivors' stories: Individual ICUs need to develop a process for collecting former long-stay patients' and their families' stories of their critical illness experience and of recovery as a mechanism of service evaluation and staff education. Hearing survivors' stories provides an avenue for nurses to think critically about their practice, to reflect on how they care for long-stay patients and families, and has the potential to help nurses to form more effective relationships and partnerships with these groups, driving person-family centred care.

Person-centred practice: This study has revealed that there is a need for embedding person-centredness as a philosophy of nursing practice for long-stay patients. All nurses caring for this cohort across the continuum of care must understand what person-centred care for the long-stay patient means and they must understand how to achieve it. Applying Kitson's (2016) Fundamentals of Care Framework would support this.

Education

Mandatory *narrative-based* education for ICU, ward, and rehabilitation nurses on the long-stay ICU journey. There needs to be education and raised awareness for

nurses on the phenomena of prolonged critical illness and the long-stay patient and families' journey. This must include the therapeutic role of the nurse and the needs of the patient and family at the different phases of the illness/recovery trajectory. Also, there needs to be education and raised awareness of PICS and PICS-F among these nurses. This knowledge and awareness will facilitate an understanding of why former long-stay ICU patients and their families are complex; give ward nurses insight into what the long-stay patient and family have been through; and enable nurses to meet the individual needs of the patient and family.

Delirium education and provision of information: There needs to be education for nurses on delirium. This will support nurses to develop the knowledge and skills needed to provide evidence-based delirium care and better support the patient and family through delirium.

Policy

Establishment of a National Professional Working Group for ICU Survivorship: The establishment of a National Professional Working Group that focuses on the long-term recovery and well-being of ICU survivors and their families is needed. Because recovery is a complex process and the needs of patient and their families are diverse and multifaceted, it is essential that the group is interprofessional (clinicians, researchers, educators) and adopts a multidisciplinary approach. It is also important to include patient and family advisors to ensure that the voices of these people are always held at the centre of discussions.

Infrastructural

The establishment of ICU follow-up services: Follow-up should screen and provide support for PICS and PICS-F; offer symptom advice; information provision; reassurance; and an opportunity to debrief. Additionally, follow-up services can be

used as a mechanism of data collection and service evaluation; data on health status, outcomes, and patient and family experiences can be used to monitor and improve the quality of care.

Integrated Post-ICU Recovery Road Maps and Passports for patients and families: There needs to be the provision of information and education for survivors and their families on recovery after a prolonged critical illness. This needs to include information about PICS and PICS-Family, recovery expectations, and when and where to seek help if needed. Delirium information is also greatly needed.

The establishment of specialised post-critical illness rehabilitation services: To support survivors to reach their recovery potential.

Research

Further research of long-stay patients unable to be discharged home: This study recruited participants who had been discharged from hospital to home following a prolonged critical illness. Survivors who were unable to be discharged home from hospital, such as those who required long-term hospital-level care (such as a rest home) were not part of this group of study participants and their voices are still to be heard. There is limited research that focuses on these patients' experiences after prolonged critical illness, but as they could be considered to have less favourable outcomes and arguably less quality of life, hearing their stories is important. As medical advancements continue, so too will the number of ICU survivors. This raises important ethical questions such as what is a good outcome after a prolonged critical illness, who defines what a good outcome is, who should be saved, and who makes these decisions. Quality of life for the survivor should be a key part of decision making and it is imperative that all patients' voices are at the centre of these conversations.

8.5 Concluding Statement

Building on the only other study conducted in Aotearoa New Zealand and internationally to explore the ICU experience of a prolonged critical illness from both the patient and family's perspective (Minton, 2017), this narrative inquiry charters new territory by exploring long-stay ICU patients' and families' experiences across the next phase of their journey. Critically, this study has identified that this cohort experience a continuum of vulnerability as they move through the healthcare system from hospital to home and this vulnerability endures across time and place because currently in Aotearoa New Zealand there is a lack of understanding and effective supportive services to meet their specialised needs. This highlights the big picture where no one is with them on their journey.

It is troubling that in Aotearoa New Zealand there is a scarcity of formal policy, systematic follow-up care, and specialised rehabilitation for ICU survivors and their families. The lack of aftercare is now unacceptable and I hope this research contributes to the work that is beginning to emerge in Aotearoa New Zealand that seeks to fill this gap. The problem is huge and it cannot be solved alone, so those who have the clinical and research expertise in this space, and key stakeholders and decision makers must work together to address the challenges Aotearoa New Zealand faces and figure out how Aotearoa New Zealand can do better for ICU survivors and their families. The continuum of vulnerability for the long-stay patient and family must be recognised because while the ICU stay is in the past, the experience and its effects remain very much present and ongoing.

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Appendices

Appendix A: Ethics Form (HDEC Approval Letter)

Health and Disability Ethics Committees

Health and Disability Ethics Committees
Ministry of Health
133 Molesworth Street
PO Box 5013
Wellington
6011
hdec@health.govt.nz

Ethics reference: 2022 EXP 12583

9 September 2022

Miss Amy Best

[redacted]

Tēnā koe Miss Best

APPROVAL OF APPLICATION

Study title: A Narrative Inquiry Exploring the Experiences of Survivors and Support People of Long-term ICU

I am pleased to advise that your application was **approved** by the Northern B Health and Disability Ethics Committee (the Committee). This decision was made through the expedited pathway.

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:

- Before the study commences at *any* locality in New Zealand, all relevant regulatory approvals must be obtained.
- Before the study commences at *each given* locality in New Zealand, it must be authorised by that locality in Ethics RM. 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.

After HDEC review

Please refer to the SOPs for HDEC requirements relating to amendments and other post-approval processes.

Your next progress report is due by 9 September 2023.

Participant access to compensation

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 trialed. 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.

Further information and assistance

Please contact the HDECs Secretariat at hdecs@health.govt.nz or visit our website at www.ethics.health.govt.nz for more information, as well as our General FAQ and Ethics RM user manual.

Nāku noa, nā

Ms Kate O'Connor

Chair

Northern B Health and Disability Ethics Committee

Appendix B: Chapter 2 Statement of Contribution

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GRADUATE RESEARCH SCHOOL

STATEMENT OF CONTRIBUTION DOCTORATE WITH PUBLICATIONS/MANUSCRIPTS

We, the student and the student's main supervisor, certify that all co-authors have consented to their work being included in the thesis and they have accepted the student's contribution as indicated below in the Statement of Originality.

Student name:	Amy Eyre
Name and title of main supervisor:	Professor Clare Harvey
In which chapter is the manuscript/published work?	Chapter Two

Describe the contribution that the student and members of the supervisory team have made to the manuscript/published work:[1]

In conducting this review, I was responsible for devising the purpose and research question, collecting, and analysing the data, interpreting the results, and drafting the paper. This publication was written by me, and my contribution amounted to 80%. Professor Clare Harvey and Dr Claire Minton both contributed to formulating the research question and reviewing the draft of the paper. Their contribution was 10% each. Associate Professor Rachel Forest was not a member of the supervisory team at the time this literature review was conducted.

Please select one of the following three options:

○ **The manuscript/published work is published or in press**

Please provide the full reference of the research output:
Best, A., Harvey, C., & Minton, C. (2023). The experiences of family of former long-term ICU patients after the patient has been discharged home: An integrative review of the literature. Nursing In Critical Care, 28(4), 596-607. DOI: 10.1111/nicc.12886

○ **The manuscript is currently under review for publication**

Please provide the name of the journal:

○ **It is intended that the manuscript will be published, but it has not yet been submitted to a journal**

Student's signature:		Main supervisor's signature:	Clare Harvey Digitally signed by Clare Harvey Date: 2026.02.02 17:04:47 -08'00'

This form should be placed at the beginning of each relevant thesis chapter.

[1] Refer to the Massey University Publishing and Authorship guidelines (OneMassey for staff, Stream for students) and/ or Contributor Roles Taxonomy (CRediT) guidelines for guidance.

Appendix C: Best et al., 2023

Received: 7 February 2022 | Revised: 26 November 2022 | Accepted: 6 January 2023
DOI: 10.1111/nicc.12886

LITERATURE REVIEW

BACCN Nursing in Critical Care WILEY

Experiences of families of prolonged critical illness survivors that are discharged home: An integrative review of the literature

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Clare Harvey RN, PhD, Deputy Head of School[1] |
Claire Minton RN, PhD, Senior Lecturer and Director of the Bachelor of Nursing[3]

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Abstract

Background: Within the context of the increasing prevalence of prolonged critical illness, a situation intensified by the COVID-19 global pandemic, advancing understanding of the experiences of families of survivors that are discharged home is important in understanding the complexity of life for these people.

Aims: To examine research related to the experiences of families of survivors of prolonged critical illness that are discharged home.

Study design: This review was conducted using the Whittemore and Knafl framework for integrated literature reviews. A literature search was conducted using the electronic databases of Web of Science, CINHAL, Scopus, and PubMed for English language studies published between January 2002 and October 2021. Article titles and abstracts were screened in view of finding a selection of articles that focussed on the experiences of families of people who have survived a prolonged intensive care stay that are discharged home. Study quality was assessed using the CASP (Critical Appraisal Skills Programme) tool. Data analysis of nine peer-reviewed articles was informed by the Braun and Clarke approach to thematic analysis. The PRISMA guidelines were used to report the review process.

Results: Nine articles were included in the review. Three major themes were identified, namely, (i) the negative impact on family caregiver health and well-being, (ii) caregiver burden, and (iii) unmet support needs.

Conclusions: Families of prolonged critical illness survivors that are discharged home face complex challenges that make their experience difficult and demanding. Family support needs once patients are discharged home are largely unrecognized in this population.

Relevance to clinical practice: This review evidences the need to investigate further the experiences of families of survivors of prolonged critical illness. Further qualitative research has the potential to help inform service provision and support for these people.

KEYWORDS
chronically critically ill, critical care nursing, family experiences, intensive care, long-term intensive care

Appendix D: Double Entry Reflexive Log: The Clinical Observation (Expert) and the Narrative "Lived Truth" (Learner)

Clinical Observation (Expert Lens)	Narrative "Lived Truth" (Learner Lens)	Reflexive Action
Patient 3 described scary animals in the ICU and, specifically around his bedspace, "chimpanzees" and "meerkats" and restlessness and agitation; matches hyperactive delirium subtype (CAM-ICU positive). Likely due to hypoxia, pain or metabolic factors. As a nurse I would prioritise oxygenation, pain relief, antipsychotics and family presence to keep patient safe and calm.	Patient 3 described scary animals: "there were chimpanzees coming towards me" and "meerkats came crawling through the ceiling". He remembers "being frozen, watching these meerkats running around the hospital room, yeah, that was that was pretty scary at the time. Yeah, it was terrifying." His world/his reality: He describes animals as being invaders and a threat; amplifies his experience of existential threat, feelings of helplessness and vulnerability, not merely delirium as a pathophysiological state.	Re-read transcripts focusing on lived experience of delirium – participants narrative truth. What they saw, heard, felt, thought, believed to be true. Coded transcript initially via "participants imagery" (animals, dimensions of place – "ceiling coming down on angles"), rather than impulse of clinical lens, which is to categorise "clinical manifestations" of delirium as a pathophysiological disease. Focused on "embodied fear" and "existential threat" theme. Common thread of the "continuum of vulnerability emerging". Journaled my urge as an ICU nurse to "fix" the problem pharmacologically.
Patient 3 described himself as being "really paranoid", accusing staff of "wanting to harm me" and mistrust, "what drugs are you giving me?" He describes trying to remove his IV lines, "trying to rip the needles out of my arms." The confusion, high agitation, combative state and delusions he describes matches hyperactive	Patient 3 recounted "I started accusing everyone of wanting to harm me or wanting to do something to me. I was really paranoid. 'What kind of drugs are you giving me?' Trying to rip the needles out of my arm, ah there was one, one of the nurses jumped on my back. Not jumped on my back, but she was holding me to try	Re-read transcript focusing on prioritising sensory and embodied experience. Shifted analysis to centre relational terror and survival instinct. Foregrounded "embodied fear" theme. Journaled my urge as ICU nurse to "fix" via medication. Also journalled my urge as an ICU nurse to "control", which in this case

delirium subtype (CAM-ICU positive). Likely triggered by hypoxia or pain or other metabolic factors. As a nurse I would prioritise oxygenation, pain relief, consider antipsychotic, sedation (e.g., dexmedetomidine, propofol) to keep patient physically safe, reduce risk of lines being removed, and family presence as this may help to re-orientate and keep patient emotionally safe.	and stop me from doing what I was about to do. It was all about self, self-preservation type. Survival." His world/his reality: Staff as a relational threat, medication as a threat; not just brain biochemistry; family role as protector amid fear and helplessness.	is around controlling the environment (risk management and mitigation) and the patient (biomedical influence on the ICU nurses work)".

Appendix E: Study Information Sheet (Patients)

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PARTICIPANT INFORMATION SHEET – PATIENTS
A study exploring the experiences of former long-stay intensive care unit patients and support people

My name is Amy Best, and I am a nurse at Wellington Intensive Care Unit (ICU). I am also undertaking research as part of a PhD through Massey University and am seeking participants for a study.

What is the study about?

I am undertaking research investigating the experiences of people and their support people who have spent a long time in the ICU (more than eight days). This research is focused on peoples' experiences after ICU, i.e., in hospital and at home. It aims to learn survivors' and their support peoples' stories. There is very little Aotearoa New Zealand research on the experiences of people who have spent a long time in the ICU, particularly once they have been discharged home from hospital.

What type of participants are being sought?

The research will have two participant groups:

- People aged over 18 years who have spent eight days or more as a patient in the ICU
- Primary support people (aged over 18 years) of someone who has spent eight days or more in the ICU

What will the study involve?

You will be invited to participate in multiple interviews (up to four) with the researcher (Amy Best) in the first year after you have been discharged home from hospital. The interviews will range in length from 60-120 minutes. They will be audio recorded. The interviews will occur at a time and location of your choice (for example your home, a café). However, in circumstances where the researcher is unable to travel, interviews may be facilitated via phone or video-call. If at any stage you feel uncomfortable during the interview or wish to not answer a question, you may decline and choose not to continue. There will be no consequence or disadvantage to you should you choose to not answer a question or discontinue the interview. You may always have a support person of your choice present.

If you are a former ICU patient, you will be asked to share your story of your life and experiences after the ICU experience.

You will also be asked if you would like to keep a diary and write down your thoughts and experiences as they come up over the following months. However, keeping a

diary is voluntary and entirely your choice. At each interview, your diary entries will be read and discussed with the researcher to clarify stories of your experiences.

Can I withdraw from the study?

Yes. This is a voluntary study, and you may withdraw at any time.

What information will be collected, and how will it be used?

Your participation in the study would involve:

1. Reading and signing a consent form. If you wish to not sign the consent form, you may give verbal consent which will be audio recorded.
2. Being interviewed about your experiences after ICU. Interviews will be loosely structured and intend to flow like a natural conversation. Interviews will take place in the first few weeks of you getting home from hospital, then at various time points in the next 12 months.
3. Writing or recording a diary of your experiences and then talking about your diary entries with the researcher (optional).
4. Allowing the researcher to access your ICU discharge summary and hospital clinical notes. Note these will be read only. No copies will be taken.
5. Having the opportunity to read a summary of your story, or if you prefer talk about your story to ensure it has been accurately captured.
6. You will need to have access to a telephone or mobile phone and the internet. Your interviews, diary entries and our conversations will be recorded. To protect your confidentiality, during the first interview you will be asked to choose a pseudonym (made up name) that will be used when talking about and recording the stories of your experience. This pseudonym will be used throughout the entirety of the study and in the final report.

Data storage and confidentiality

Interviews will be transcribed by a professional company who will not have access to your personal details (e.g., your name, contact details) and they will be required to sign a confidentiality agreement.

Data (tapes, interview documents, notes, and diary copies) will be stored in a secure location. Only the researcher will have access to data. Data will be kept for five years then will be disposed of as confidential waste.

Should you choose to withdraw from the study, you may request the audio recording of your interview and be assured that it is the only copy.

What if I have questions?

If you have any questions about this study or would like more information, please contact:

Amy Best (PhD Student): [redacted]
Claire Minton (Supervisor): [redacted]
Clare Harvey (Supervisor): [redacted]

Appendix F: Study Information Sheet (Family)

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

PARTICIPANT INFORMATION SHEET – SUPPORT PEOPLE
A study exploring the experiences of former long-stay intensive care unit patients and support people

My name is Amy Best, and I am a nurse at Wellington Intensive Care Unit (ICU). I am also undertaking research as part of a PhD through Massey University and am seeking participants for a study.

What is the study about?

I am undertaking research investigating the experiences of patients and their support people who have spent a long time in the ICU (more than eight days). This research is focused on peoples' experiences after ICU, i.e., in hospital and at home. It aims to learn survivors' and their support peoples' stories. There is very little Aotearoa/New Zealand research on the experiences of people who have spent a long time in the ICU, particularly once they have been discharged home from hospital.

What type of participants are being sought?

The research will have two participant groups:

- People aged over 18 years who have spent eight days or more as a patient in the ICU
- Primary support people (aged over 18 years) of someone who has spent eight days or more in the ICU

What will the study involve?

You will be invited to participate in multiple interviews (up to four) with the researcher (Amy Best) during the first year of your whānau member being discharged from the ICU. The interviews will range in length from 60-120 minutes. They will be audio recorded. The interviews will occur at a time and location of your choice (for example the hospital if your friend/whānau member is in hospital, your home, a café). However, in circumstances where the researcher is unable to travel, interviews may be facilitated via phone or video-call. If at any stage you feel uncomfortable during the interview or wish to not answer a question, you may decline and choose not to continue. There will be no consequence or disadvantage to you should you choose to not answer a question or discontinue the interview. You may always have a support person/people of your choice present.

If you are a support person of someone who survived a long -stay in ICU, you will be asked to share your story of your life and experiences after the ICU experience.

You will also be given the choice of keeping a diary and writing down your thoughts and experiences as they come up over the following months. However, this is voluntary

and entirely your choice. At each interview, your diary entries will be read and discussed with the researcher to clarify stories of your experiences.

Can I withdraw from the study?

Yes. This is a voluntary study, and you may withdraw at any time.

What information will be collected, and how will it be used?

Your participation in the study would involve:

1. Reading and signing a consent form. If you wish to not sign the consent form, you may give verbal consent which will be audio recorded.
2. Being interviewed in person about your experiences after ICU up to four times in one year. Interviews will be loosely structured and intend to flow like a natural conversation. The first interview will take place when your whānau member is close to being discharged from hospital. Then at various time points in the following year.
3. Writing or recording a diary of your experiences and then talking about your diary entries with the researcher (optional).
4. Having the opportunity to read a summary of your story, or if you prefer talk about your story to ensure it has been accurately captured.
5. You will need to have access to a telephone or mobile phone and the internet.

Your interviews, diary entries and our conversations will be recorded. To protect your confidentiality, during the first interview you will be asked to choose a pseudonym (made up name) that will be used when talking about and recording the stories of your experience. This pseudonym will be used throughout the entirety of the study and in the final report.

Data storage and confidentiality

Interviews will be transcribed by a professional company who will not have access to your personal details (e.g., your name, contact details) and they will be required to sign a confidentiality agreement.

Data (tapes, interview documents, notes, and diary copies) will be stored in a secure location. Only the researcher will have access to data. Data will be kept for five years then will be disposed of as confidential waste.

Should you choose to withdraw from the study, you may request the audio recording of your interview and be assured that it is the only copy.

What if I have questions?

If you have any questions about this study or would like more information, please contact:

Amy Best (PhD Student): [redacted]
Claire Minton (Supervisor): [redacted]
Clare Harvey (Supervisor): [redacted]

Appendix G: Consent Forms

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

Consent Form (Patient)

Study Title: Experiences after a long stay in Intensive Care

1. I understand that a support person/whānau members can be present at any time during my participation in this study.
2. I have read (or had someone read to me) the Information Sheet and had details of the study explained to me.
3. I understand that my participation in the study will involve being interviewed about my experiences after ICU; that the first interview will take place within the first few weeks of me getting home from hospital; then a further three interviews will take place over the next 12 months.
4. I understand interviews may be up to two hours in duration (though this will be guided by me) and that they will occur at a time and location of my choice to support my comfort. I understand that if the researcher is unable to travel for interviews, they may be facilitated via phone or video-call.
5. I have had sufficient time to consider whether I wish to take part.
6. My questions about the study have been answered to my satisfaction, and I understand that I may ask further questions at any time.
7. I also understand that my participation in this study is entirely voluntary, I may withdraw at any time and decline to answer any question in the study.
8. I understand the potential risks and benefits to participating in this study.

Benefits:

9. I am aware there while are no specific benefits for me taking part, I may find it helpful to talk to someone about my experiences and know that my recommendations will contribute to future improvements in care.

Risks:

10. I understand that this research involves open questioning and conversations about my experiences in and after ICU. If the questions make me feel uncomfortable, I can decline to answer and can withdraw from the project without any disadvantage of any kind. If sharing of my story causes me any mental/emotional distress or physical discomfort, I understand that I may pause the interview and recommence when I feel I am able or discontinue the interview. I understand that should any of these situations occur, the researcher will support me to access support from either my General Practitioner (GP), identified support people or any of the following support services:

    - **Atareira Mental Health Support** – Mental health support for whānau Ph: 04 499 1049 https://www.atareira.org.nz/family-whanau-support/
    - **Healthline** – Free general health advice and information Ph: 0800 611 116
    - **Helpline** (free mental health support) Ph or text: 1737
    - **The Depression Helpline** Ph: 0800 111 757 or text 4202
    - **Puāwaitanga** – A phone and web-based service to support people with their emotional wellbeing through a Te Ao Māori lens. Trained counsellors. Te Reo Māori language supported. Ph: 0800 782 999 https://whakarongorau.nz/puawaitanga

11. I agree to provide information to the researcher under the conditions of confidentiality set out in the Information Sheet.

12. I understand that a professional transcription service may be used to transcribe my interviews and they will be required to sign a privacy and confidentiality agreement.
13. I understand that I will receive a koha as a gesture of appreciation for my participation.
14. I would like a copy of the study results sent to me Yes / No

I agree to take part in this study

Participant's name (please print) _____

Signature of participant _____

Contact details _____

Date _____

Researcher's name _____

Researcher's signature _____

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

Consent Form (Whānau/Support Person)

Study Title: Experiences after a long stay in Intensive Care

1. I understand that a support person/whānau members can be present at any time during my participation in this study.
2. I have read (or had someone read to me) the Information Sheet and had details of the study explained to me.
3. I understand that my participation in the study will involve being interviewed about my experiences after ICU; that the first interview will take place before my family member is discharged home from hospital; then a further three interviews will take place over the next 12 months.
4. I understand interviews may be up to two hours in duration (though this will be guided by me) and that they will occur at a time and location of my choice. I understand that if the researcher is unable to travel for interviews, they may be facilitated via phone or video-call.
5. I have had time to consider whether I wish to take part.
6. My questions about the study have been answered to my satisfaction, and I understand that I may ask further questions at any time.
7. I also understand that my participation in this study is entirely voluntary, I may withdraw at any time and decline to answer any question in the study.
8. I understand the potential risks and benefits to participating in this study.

Benefits:

9. I am aware there while are no specific benefits for me taking part, I may find it helpful to talk to someone about my experiences and know that my recommendations will contribute to future improvements in care.

Risks:

10. I understand that this research involves open questioning and conversations about my experiences in and after ICU. If the questions make me feel uncomfortable, I can decline to answer and can withdraw from the project without any disadvantage of any kind.
11. If sharing of my story causes me any mental/emotional distress or physical discomfort, I understand that I may pause the interview and recommence when I feel I am able or discontinue the interview. I understand that should any of these situations occur, the researcher will support me to access support from either my General Practitioner, identified support people or any of the following support services:
    - **Atareira Mental Health Support** – Mental health support for whānau Ph: 04 499 1049 https://www.atareira.org.nz/family-whanau-support/
    - **Healthline** – Free general health advice and information Ph: 0800 611 116
    - **Helpline** (free mental health support) Ph or text: 1737
    - **The Depression Helpline** Ph: 0800 111 757 or text 4202
    - **Puāwaitanga** – A phone and web-based service to support people with their emotional wellbeing through a Te Ao Māori lens. Trained counsellors. Te Reo Māori language supported. Ph: 0800 782 999 https://whakarongorau.nz/puawaitanga
12. I agree to provide information to the researcher under the conditions of confidentiality set out in the Information Sheet.

13. I understand that a professional transcription service may be used to transcribe my interviews and they will be required to sign a privacy and confidentiality agreement.
14. I understand that I will receive a koha as a gesture of appreciation for my participation.
15. I would like a copy of the study results sent to me Yes / No

I agree to take part in this study

Participant's name (please print) _____

Signature of participant _____

Contact Details _____

Date _____

Researcher's name _____

Researcher's signature _____

Appendix H: Confidentiality Agreement (Pacific Transcription)

PACIFIC Transcription

Australia and New Zealand's On-line, on-time, and on-call transcription services

Terms and Conditions

1. General

1.1. Wherever these Terms and Conditions differ from an existing contract or service agreement, the conditions of the contract or service agreement take precedence.

1.2. Governing law and jurisdiction: The terms of this agreement shall be governed and constructed in accordance with the law of Queensland, Australia, and the parties submit to the jurisdiction of the Courts of Queensland and the Commonwealth of Australia.

2. Definitions and Interpretation

2.1. 'Pacific Transcription[1]/we/us' means Pacific Solutions Pty Ltd ABN: 67 100 292 171, any employees, agents or subcontractors of Pacific Transcription.

2.2. 'Rates brochure' refers to any of Pacific Transcription's pricing brochures and individual client rates letters as applicable in the current calendar year.

2.3. 'Client/you' means anyone by whom Pacific Transcription has been engaged in the provision of services.

2.3.1. 'Research clients' are clients to whom the research rates brochure applies, that is, clients who utilise Pacific Transcription's services for the transcription of research or other interviews or focus groups.

2.3.2. 'Professional dictation clients' are clients to whom the professional rates brochure applies, that is, clients who utilise Pacific Transcription's services for transcription of professional dictation, whether it be medical, legal, or otherwise in nature.

[1] Pacific Transcription is a registered trading name of Pacific Solutions Pty Ltd, a company incorporated in Australia. (ABN 67 100 292 171)

2.4. 'Transcript' means the type-written version of audio either provided by the client to Pacific Transcription or recorded by Pacific Transcription. Transcription means the production of a transcript by Pacific Transcription.

2.5. Manager refers to a duly authorised manager of Pacific Transcription.

2.6. 'Personal information' means the information or an opinion (including information or an opinion forming part of a database) whether true or not, and whether recorded in a material form or not, about an individual whose identity is apparent or can reasonably be ascertained from the information or opinion.

2.7. 'Confidential information' means information that:

2.7.1. is by its nature confidential;

2.7.2. is identified (whether in writing or not) as confidential by the client to Pacific Transcription;

2.7.3. Pacific Transcription knows or ought to know is confidential.

2.8. Words importing a gender include the other; words in the singular number include the plural and vice versa; and references to legislation or to provisions in legislation include references to amendments or re-enactments of them and to all regulations and instruments issued under the legislation.

3. Supply of Service

3.1. Pacific Transcription provides transcription, typing, and document-production services for businesses, institutions, and individuals.

3.1.1 Pacific Transcription is also a supplier of digital audio recording equipment and qualitative analysis software programs.

3.1.2 Pacific Transcription also provides stenography, minute taking and live and remote captioning services

3.2. Pacific Transcription may be engaged in the provision of services explicitly, by verbal and written negotiation, or implicitly, by the provision of audio to Pacific Transcription by a client for the purpose of transcription.

3.3. You acknowledge that by:

3.3.1. uploading a file to the Pacific Transcription website;

3.3.2. submitting a request to Pacific Transcription for the provision of services (whether as an order form or otherwise); or

3.3.3. otherwise communicating to us your acceptance of these Terms and Conditions,

you agree to be bound by the Terms and Conditions set out herein. If you do not agree to these Terms and Conditions please do not proceed to request our services.

3.4. Pacific Transcription reserves the right to decline to engage in the supply of services to any client. This will usually be as a result of very poor-quality audio. If Pacific Transcription declines to engage in the supply of services to a client, the client will be notified.

3.5. Supply of services may be carried out by either a Pacific Transcription employee or an authorised Pacific Transcription subcontractor.

3.6. Pacific Transcription may from time to time include clients' company logos on promotional material. If you do not wish to have Pacific Transcription use your company logo on promotional material, please notify us.

3.7. We reserve the right to amend these Terms and Conditions or any information or material appearing on the Pacific Transcription website at any time, without liability or further notice to you. By placing an order with us following an amendment to our Terms and Conditions, you are accepting the amended Terms and Conditions.

4. Rates

4.1. Rates brochures are available either:

4.1.1. in the client login;

4.1.2. in a separate rates letter/client agreement; or,

4.1.3. in the case of prospective clients, by email.

4.2. Upon providing Pacific Transcription with audio for transcription, it is deemed that you have read, understood and accepted all information contained in the rates brochure, and are liable for all subsequent transcription costs incurred by us.

4.3. Itemised quotations for cost of services are provided in good faith and are an approximation of anticipated charges based on information provided by a client. A precise assessment of final charges will be made once the audio has been received and typed, and other factors relevant to the transcription of the audio are known. Pacific Transcription reserves the right to alter the final charges made to clients, in line with the rates brochure, where circumstances change.

4.4. For research clients, pricing is based on a rate per audio minute, dependent on audio quality.

4.4.1. 'Audio minutes' refers to the total minutes of transcribed audio per file, with each file rounded up to the nearest whole minute.

4.4.2. 'Audio quality' is rated from low through to high, with 'low' audio charged at a higher rate in line with our standard rates.

4.5. For professional clients, pricing is based on a rate per line, or per audio minute depending on the negotiated agreement.

4.5.1. 'Per line' has the meaning attributed in our rates brochure, namely: every 65 characters with spaces (i.e. 65 keystrokes), but not white space. This can be audited against the Microsoft Word character count. Part lines are rounded up to the nearest whole line.

4.6. For stenography clients, pricing is based on a rate per hour of attendance, and the number of pages of transcript produced. Minimum hourly rates apply to both on-site attendance and remote attendance.

4.7. In special circumstances, Pacific Transcription is able to provide an enforceable pricing agreement with a client. To do so, the entirety of audio subject to the pricing agreement needs to be provided by the client in order for Pacific Transcription to make an assessment of anticipated costs.

4.8. The decision as to whether or not the discount is applicable is at the discretion of the Pacific Transcription manager and is determined on a case-by-case basis, however this will be confirmed with the client prior to any costs being incurred.

4.9. All audio is automatically deleted from the client's online account once the completed transcript has been returned to the client.

5. Invoicing

5.1. An invoice for work completed is issued monthly for professional clients, approximately fortnightly for research clients (unless other arrangements have been made), shortly following completion of each event for stenography or minute taking clients.

5.2. Pacific Transcription reserves the right to require credit card details at the time of booking, to require pre-payment, to require payment before release of a transcript, to issue invoices more frequently to new clients, and also to require payment of outstanding invoices before continuing to provide services.

6. Payment

6.1. Any client residing within Australia has the obligation to pay GST upon any service provided by Pacific Transcription.

6.2. Pacific Transcription reserves the right to charge late fees on overdue amounts at a rate of 10% of the outstanding balance or $25 whichever is greater, per month.

6.2.1. Late fees will be charged after an invoice remains outstanding for 60 days from the date of invoice.

6.3. Pacific Transcription retains ownership of all transcripts until the invoice for those transcripts is paid and reserves the right to take reasonable measures to recover costs from invoices outstanding greater than 60 days.

6.4. In the event of a cheque from a client being refused by the bank, or a refund being made by the credit card, the client will be responsible for all bank charges resulting from the returned cheque/credit card refund.

6.5. In the event of invoices that remain unpaid, Pacific Transcription has the right to commence legal proceedings to recover the debt.

6.6. Pacific Transcription reserves the right to charge stenography client's credit card where payment has not been received within 10 days of completion of work.

6.7. Clients residing outside Australia should note that whilst invoices are issued in local currency, credit cards are debited in Australian dollars (AUD). When reviewing credit card debits by Pacific Transcription, clients should allow for small price differences caused by short term currency exchange rate fluctuations.

6.8. Prepayment for transcription is available at the discretion of the manager, and such funds provided to Pacific Transcription with this purpose in mind remain in your credit until the credit is either exhausted by payment for services, or the period of two years from the date of prepayment has lapsed.

6.9. Surcharges apply for all payments made by credit card.

6.10. Invoice payment is to be made in full and without deduction or offset of fees or charges levied by the client's financial institution.

7. File Retrieval/Archiving

7.1. For security and confidentiality purposes, unless archiving is requested by a client, Pacific Transcription purges all client transcripts and audio files from client accounts approximately one month after completion of the transcript.

7.2. Pacific Transcription's archiving service keeps completed transcripts (and, by negotiation, audio) on Pacific Transcription's server for as long as the archiving fee continues to be paid by the client.

7.2.1. Where a client fails to pay the archive service fee, Pacific Transcription reserves the right to purge documents and/or audio in line with usual security and confidentiality policies as outlined in clause 14.

7.3. Unless agreed otherwise, a secure offline backup of completed work is maintained. Where possible, files may be retrieved from this secure site for a small retrieval fee outlined in the rates brochure.

8. Turnaround

8.1. Except where another arrangement exists, turnarounds detailed in rates brochures operate as guidelines only and may vary depending on audio quality and volume of work. Turnarounds are not enforceable in any way. Pacific Transcription endeavours to meet all reasonable requests for specific turnaround times, and the client may add notes via their secure client login at the time of audio file upload or by emailing the Operations Team prior to commencement of the transcription job, detailing a specific turnaround request to any audio uploaded. Pacific Transcription will notify the client if any reasonable deadline specified in a note is unlikely to be met.

9. Style

9.1. Pacific Transcription's standard style (sometimes known as "intelligent verbatim") will be used for all transcripts of interviews/focus groups (and other multi-speaker recordings) unless otherwise agreed. In order to improve the readability of the transcript, the standard Pacific Transcription style excludes false starts, repeated words, verbal acknowledgements (when not pertinent to the meaning of the transcript), repetitive speech habits, over-speaking and trailing off.

9.2. Unless instructions are given to the contrary, dictations will be transcribed using the exercise of reasonable care, skill and discretion by the typist, with regard to punctuation, capitalisation, and spelling of words. This applies to all Professional Transcription.

10. Trials

10.1. Where requested, and at the discretion of the Managing Director, Pacific Transcription may offer a free trial of services for 10 minutes of audio for the purpose of confirming template, style and quote specifications.

11. Cancellation

11.1. Where a file booked for standard turnaround is cancelled and work has not yet commenced, there is no fee charged for cancellation.

11.2. Where a file booked for any turnaround faster than standard turnaround is cancelled and work has not yet commenced, a cancellation fee may apply.

11.3. Where transcription of a cancelled file has been commenced, the client will be charged for the audio minutes transcribed at the time of cancellation.

11.4. Where transcription of a cancelled file has been completed, the full amount for transcription of the file is payable.

11.5. Where the service provided by Pacific Transcription involves urgent turnaround files or the attendance of stenographers/court reporters/minute takers, cancellation less than five business days prior to the attendance date will incur loss of deposit/attendance fees, and/or any other term specified in a letter to the client regarding this service, unless this is explicitly waived at the discretion of the manager.

12. Dispute Resolution

12.1. Although all transcripts are quality assured prior to return to client, it must be noted that the final checking of transcripts is the responsibility of the client.

12.1.1. Pacific Transcription will comply with any reasonable request for correction of typing without charge, but does so at the manager's discretion, taking into account quality of audio, nature of transcript, and types of errors.

12.1.2. A request for the correction of a transcript must be made within 14 days of issuance of invoice for the transcript.

12.1.3. Pacific Transcription is not liable for any charges the client might incur correcting a transcript.

12.2. Pacific Transcription endeavours to resolve all disputes to the satisfaction of a client and aims to do so in a peaceable and amicable manner. If any dispute or difference arises out of, or in connection with, these Terms and Conditions which are unable to be resolved by negotiation, then Pacific Transcription and the client agree that the dispute

shall be submitted to an independent mediator appointed by agreement between Pacific Transcription and the client. Any disputes regarding the quality of a transcript should be assessed by a mediator familiar with the nature and standard practices of the industry. Each party is to bear its own costs for mediation. In the event that either Pacific Transcription or the client should fail or refuse to agree to, or participate in, this dispute resolution procedure, then either party shall be free to seek to resolve matters by obtaining independent legal advice.

12.3. Pacific Transcription will provide appropriate avenues for clients to state and resolve any grievances about the service received without fear of penalty or victimisation.

12.4. All grievances will be handled according to Pacific Transcription's Terms and Conditions, Risk Management, Privacy and Confidentiality policies.

12.5. Consumers of Pacific Transcription services are able to lodge complaints in the following ways:

Via email: To the Enquiries Teams, enquiries@pacifictranscription.com.au or enquiries@pacifictranscription.co.nz.

Via post: PO Box 2340, Milton QLD 4064 Australia.

12.5.1. Complaint details will be recorded, including: date of the complaint, name and contact details of the complainant (this information will be kept confidential), a record of the investigations undertaken, the nature of the complaint (including subject and details of the matter), final action taken and the date and manner in which the complainant was informed of the outcome.

12.5.2. The complainant will be notified within 10 working days from the notification of the complaint as to the process being undertaken to reach a resolution and will be informed as to the final outcome and/or updated as appropriate. Company representatives will be given the opportunity to answer any complaint.

13. Warranties and Liability

13.1. Pacific Transcription warrants that services will be provided using reasonable care and skill, and that all typists are subject to strict confidentiality agreements, have appropriate experience and have undergone a rigorous quality review process.

13.2. Sale of goods and services

13.2.1. Where Pacific Transcription supplies in connection with the provision of the services any goods supplied by a third party, such as the sale of merchandise, Pacific Transcription does not give any warranty, guarantee or other term as to their quality, fitness for purpose or otherwise, but shall, where possible, assign to the client the benefit of any warranty, guarantee or indemnity given by the party supplying the goods to Pacific Transcription.

13.2.2. Refunds for sale of goods such as digital audio recorders or software are dealt with in accordance with the manufacturer's standard refund policies and Australian Consumer Law.

13.2.3. Refunds for transcription will only be considered after a mediation assessment.

13.3. Pacific Transcription shall not be liable for any loss, damage, costs, expenses or other claims for compensation arising from:

13.3.1. any breach by a client of these conditions;

13.3.2. any client material or instructions supplied by the client which are incomplete, incorrect, inaccurate, illegible, out of sequence or in the wrong form, or arising from their late arrival or non-arrival, or any other fault attributable to the client;

13.3.3. any use by the client of the transcribed or typed material for illegal or libellous purposes;

13.3.4. the production by Pacific Transcription of any transcript, or the use by the client or anyone else of any transcript.

13.4. Pacific Transcription recommends that any client material sent to Pacific Transcription through the postal services is sent via Express Post.

Pacific Transcription shall not be liable for any loss, damage, costs, expenses or other claims arising from any client material which is lost or damaged through the postal system or of which the client has not retained a copy.

13.5. Pacific Transcription will not be liable for any loss or damage to any cassettes/discs or other portable storage media, or due to any mechanical failure of a cassette/disc or other form of portable storage media. For this reason, we recommend that clients maintain a duplicate copy of any material provided to us.

13.6. Force Majeure

13.6.1. Pacific Transcription does not accept liability for failing to supply services due to Acts of God, fire, flood, electrical or telecommunications problems or any other reason beyond our control.

13.7. All incoming emails, discs, CDs or other media will be scanned for viruses. Pacific Transcription will not open unsolicited emails or email attachments which do not have an accompanying explanatory message.

13.7.1 Pacific Transcription will endeavour to scan all email attachments sent to customers. However, it is the responsibility of all recipients to check attachments prior to opening the file as no responsibility or liability will be accepted by Pacific Transcription.

14. Confidentiality

14.1. The client warrants that it has the right to disclose any confidential information which it discloses to Pacific Transcription.

14.2. The client agrees to save, protect, defend, indemnify and hold Pacific Transcription harmless from and against any and all claims and/or financial losses of any type whatsoever arising from any third-party claim that use of the information disclosed to or by Pacific Transcription hereunder in accordance with these Terms and Conditions violates or infringes any third party's property or proprietary rights of any kind.

14.3. Pacific Transcription and its operations will at all times adhere to the letter and spirit of the Australian Privacy Principles as set out in the *Privacy Act 1988* (Cth) (Australia) and the *Privacy Act 1993* (New Zealand). Pacific Transcription's Privacy Policy is available upon request from Pacific Transcription and is also available for download as a PDF via Pacific Transcription's websites.

14.4. Pacific Transcription at all times acknowledges that confidential information remains the exclusive property of the client and this Agreement does not convey any proprietary or other interest in the confidential information to Pacific Transcription, except in circumstances where clause 6.3 applies.

14.5. Pacific Transcription will use the confidential information provided by the client only for the purpose of providing the services to the client.

14.6. Pacific Transcription agrees that during and after the provision of services:

14.6.1. It will only disclose the confidential information on a 'need to know' basis to its directors, employees, agents or subcontractors for the purposes of providing the services.

14.6.2. It will inform its directors, employees, agents or subcontractors of their obligation under these Terms and Conditions and will ensure they sign any confidentiality agreements which are necessary to ensure their compliance with these Terms and Conditions and the standards required by the *Privacy Act 1988* (Cth) (Australia) and the *Privacy Act 1993* (New Zealand).

14.6.3. Confidential information will be kept in a secure location where it cannot be accessed by any third party.

14.7. The obligations of Pacific Transcription under these Terms and Conditions will not be taken to have been breached where the confidential information:

14.7.1. is legally required to be disclosed, provided the client is notified promptly in order to contest such a disclosure;

14.7.2. is or becomes generally available to the public through no wrongful act, omission or breach of these Terms and Conditions by Pacific Transcription;

14.7.3. was in Pacific Transcription's possession prior to the time it was acquired from the client free from any obligation as to confidentiality and was not acquired, directly or indirectly, from the client;

14.7.4. has been independently developed or acquired by Pacific Transcription;

14.7.5. forms part of a transcript that falls under the conditions set out in clause 6.3 retaining ownership of the transcripts until the invoice for those transcripts is paid.

14.8. Term and Termination:

14.8.1. Obligations as to the non-disclosure of confidential information are ongoing and will survive the expiration or termination of the provision of the services.

14.9. Waiver and Variation:

14.9.1. a provision or obligation under these Terms and Conditions may not be waived except in writing signed by the party granting the waiver.

14.9.2. a provision or obligation under these Terms and Conditions may not be varied except in writing signed by the parties.

15. Signing

15.1. All clients are taken to have read, understood, accepted and agreed to Terms and Conditions set out above. For clients who require a signed agreement for their own administrative purposes, please refer to the signing page overleaf.

Signing is optional unless clients require a formal agreement.

IN WITNESS WHEREOF, the parties have read, understood, accepted and agreed to all of the Terms and Conditions contained in this document.

For Amy Best, PhD candidate, Massey University.
(Client name) (Company/Institution)

of [redacted] WTN, NZ
(Address)

Signature: [signature] Signature of Witness: _____

Name: Amy Best Name of Witness: _____

Position: Researcher Date: _____

Date: 2/06/23

for **PACIFIC SOLUTIONS PTY LTD**, ABN 67 100 292 171

Signature: [redacted] Signature of Witness: [redacted]

Name: [redacted] Name of Witness: KYM VINEY

Position: DIRECTOR Date: 02/06/23

Date: 07/06/2023

Appendix I: Confidentiality Agreement (Capital Transcription)

Transcriber Confidentiality Agreement

A Narrative Inquiry Exploring Patient and Family Experiences Following Prolonged Critical Illness

This research is being undertaken by Amy Best, PhD candidate in the School of Nursing, Massey University, Wellington. The purpose of the research is to explore the lived experiences of people and their family who have experienced a prolonged critical illness, across the first year following discharge home. As a transcriber of this research, I understand that I will be hearing recordings of confidential interviews. The information on these recordings has been revealed by interviewees who agreed to participate in this research on the condition that their interviews would remain strictly confidential. I understand that I have a responsibility to honour this confidentially agreement. I agree not to share any information on these recordings, about any party, with anyone except the Researcher of this project. Any violation of this and the terms detailed below would constitute a serious breach of ethical standards and I confirm that I will adhere to the agreement in full.

I, Melissa Kate Harsant of Capital Transcription agree to:

1. Keep all the research information shared with me confidential by not discussing or sharing the content of the interviews in any form or format (e.g. audio files, transcripts) with anyone other than the Researcher.

2. Keep all research information in any form or format (e.g. digital/audio files, transcripts) secure while it is in my possession.

3. Return all research information in any form or format (e.g. digital/audio files, transcripts) to the Researcher when I have completed the transcription tasks.

4. After consulting with the Researcher, erase or destroy all research information in any form or format regarding this research project that is not returnable to the Researcher (e.g. information stored on my computer hard drive).

Transcriber: (print name) Melissa Harsant (signature) [redacted]
(date) 13/4/2023

Researcher: (print name) Amy Best (signature) [signature]
(date) 13/4/23

This study has been reviewed and ethically approved by the New Zealand Health and Disability Ethics Committee.

Appendix J: Study Risk Management Plan

The key ethical considerations in the proposed study relate to participant vulnerability, informed consent, the balance of risks and benefits, and the protection of confidentiality. Potential risks to the study, participants, and the researcher are identified below, together with strategies to mitigate these risks and detailed procedural steps to follow in the event of specific situations arising.

Risk of study not complying with ethical codes: Prior to commencing research, this study will obtain ethics approval from NZHDEC. The researcher will read and comply with the following:

- HRC Research Ethics Guidelines 2021
- Guidelines for Researchers on Health Research Involving Māori (2010)
- The Pacific Health Research Guideline (Health Research Council, 2014)
- Code of Health and Disability Consumers' Rights.

Inadequate information about study given to potential participants: A participant information sheet has been developed for both participant groups. It can be printed in a larger font size for ease of reading if required.

Risk of participants becoming unwell with COVID-19: Pre-interview covid screens will be performed by the participants and researcher. Two days before the interview the researcher will phone the participants and conduct a covid screening questionnaire. These questions will be revisited on the day of the interview. Additional participants will be recruited if this becomes an issue.

Risk of COVID-19 transmission between participants-researcher: For in-person interviews, two days prior to interviewing, the researcher will contact the participant via telephone and conduct a covid screen. She will also ask if any household or close contacts have recently been unwell. If the researcher/participants have signs and symptoms of a respiratory illness (or any other illness) the interview will be postponed until well. During

interviews public health measures will be adhered to minimise risk including physical distancing and hand hygiene.

Risk of research practices not being culturally safe in interviews with Māori: I have consulted with a Māori cultural advisor, Dr Bevan Erueti, Kaiarataki Māori/Associate Dean Māori, Pūkenga Matua/Senior Lecturer, Te Kura Hauora/College of Health, Massey University. Should the participant exhibit and/or verbalise signs of cultural discomfort, I will reassure them and say that the interview can be stopped if they wish. I will then seek advice from the study Māori Cultural Advisor on how to address this further. Consideration will be given as to whether Dr Erueti feels it is necessary to have a Māori cultural advisor present during interviews.

Risk of research practices not being culturally safe in interviews with Pacific peoples: I have consulted with a Pacific cultural advisor. Should the participant exhibit and/or verbalise signs of cultural discomfort, I will reassure them and say that the interview can be stopped if they wish. I will then seek advice from the study Pacific Cultural Advisor on how to address this further.

Participant tiredness or health issues impacting on interview duration: Early in the interview process the researcher will ask the participant how they are feeling today including their energy/fatigue levels and ask them how long they feel they will be able to talk for. They will be informed that should at any point, they wish to take a break, have a rest, or stop the interview for the day, that is okay and will be supported. If during interviews patients verbalise or demonstrate tiredness, the researcher will pause the interview and ask if they would like to take a break. Participants will be asked whether they would like to resume the interview after a break or reconvene at another time.

Risk of emotional/psychological trauma of survivors: Participants re-storying of their experiences has the potential to be upsetting and traumatic. Participants emotional safety is paramount; they can have support people with them in all meetings and

interviews, and this is explained in the Study Information Sheet and Consent Form. It will also be stated at the beginning of each interview. Should re-storing of an experience cause emotional or psychological upset, the researcher will acknowledge this and ask the participant if they wish to take a break, talk about something else or stop the interview. Participants will also be provided with an information sheet containing the contact details of local pastoral and mental health support services.

Participant observed to have ongoing medical issues/health problems that while not urgent, do require timely medical attention (for example a wound that looks infected, a recent fall that requires attention or further investigation). Or patient or support person asks the primary researcher for her professional opinion or help with a non-urgent medical issue: In this case, duty of care would indicate that should participants demonstrate or express ill health of any form, their health and safety is paramount. As an experienced ICU nurse, I will be able to conduct a patient assessment and offer professional support. However, this is where boundaries are extremely important. My role as the researcher means I will not be able to provide direct care to the participant, however, what I can and will do, is inquire whether the individual is receiving treatment for the problem, guide them on who to contact for further help and advise them what to say. In this instance it is anticipated that the first recommendation will be to contact their General Practitioner (GP). If they would like assistance with doing this, I will collaborate with them to call the GP and make an appointment. Following this, I will also advise them on how to contact Help Line. Then I will provide them with a pamphlet that contains the names and contact details of local professional pastoral and mental health clinicians. I will make sure this written information is printed in large font to accommodate those with visual impairment. This list will be inclusive of Māori and Pacific healthcare organisations.

Participant found to be in distress with unmanageable physical or psychological symptoms at time of interview: In this case, safety will be prioritised over

the research process. Consent will be sought to collaborate with the support person to call an ambulance. I will stay with the patient and support person until help has arrived.

Participant readmitted to hospital: The researcher will remain in contact with the participants and when the patient has been discharged home again, interviews will resume if the patient is well enough. I will liaise directly and sensitively with the patient and their support person to determine their health status and ascertain whether the patient has recovered sufficiently to continue with interviews.

Participant death: Consent will be obtained to use data up until the point no further data is able to be collected. As an ICU nurse, I have extensive experience with death and dying and am skilled in sensitive communication in these circumstances. I will navigate this territory sensitively and gently.

Participant safety issue: Any participant safety issues will be managed by the primary researcher in conjunction with the research team and a response/action plan will be followed and documented in the study notes.

Risk to researchers' safety when going into people's homes for interviews: I have developed a safety plan in the event of interviews being conducted in the homes of participants. First, it needs to be noted that I will have met with participants in person and communicated with them multiple times before the first interview, so I will have made an initial assessment on whether I feel it is safe for me to be alone with individual participants. The safety plan includes:

- Prior to the interview taking place, I will ask participants whether there will be any dogs on the property and ask that they be tied up for the duration of the interview.
- Letting my PhD supervisors know the date, time and location of the interview as well as expected duration.
- Letting my supervisors know my phone number and ensuring that my phone is fully charged and functioning and with me during interviews.

- Upon completion on the interview, I will phone my supervisors immediately to confirm my safety.
- If they do not hear from me by the agreed upon time, they will phone me and take appropriate action to confirm my safety.
- If at any time during the interview, I have concerns for my safety or wellbeing, I will stop the interview and ask that it be resumed later. If I have serious concerns for my safety that are unable to be mitigated, then the participants involved will be withdrawn from the study.

Participant expressing strong views on taking legal action against the healthcare system or services within it as unhappy with care experiences: In this situation, the risks to the study and myself are significant and so the participant will be withdrawn from the study.

Participants not having access to a telephone or virtual meeting platforms: The need for access to these will be explained in the information sheet. If participants do not have access to these and wish to be involved in the study, a conversation will be had around the possibility of using a support persons device.

Inability to complete interviews in-person: At this stage in the current COVID-19 climate, it is likely that interviews will be able to be conducted in person. Consideration to conducting interviews on the phone or via virtual meeting platforms such as Zoom will be given when in-person cannot occur.

Participants not being competent/confident with using virtual meeting platforms: Participants will be asked if they would like an education session on how to use the Zoom app. The teach back method will be used to ascertain those participants are comfortable and competent in using the app. If participants do not feel comfortable with Zoom, interviews can be conducted via telephone.

Technology/equipment failure (Zoom, internet): Written and verbal instructions will be provided to participants regarding equipment use. If Zoom or internet fails, interview/meeting will be rescheduled.

Risk of emotional upset to researcher: Hearing participants stories of their experiences may potentially be confronting and upsetting: I have set myself up with a strong support network. I will debrief after participant interviews with my PhD supervisors; both are experienced ICU nurses and experienced nurse researchers who have experience interviewing vulnerable groups.

Appendix K: Interview Question Guide

Question Guide for Patient Interviews (Time, Place, Interaction)

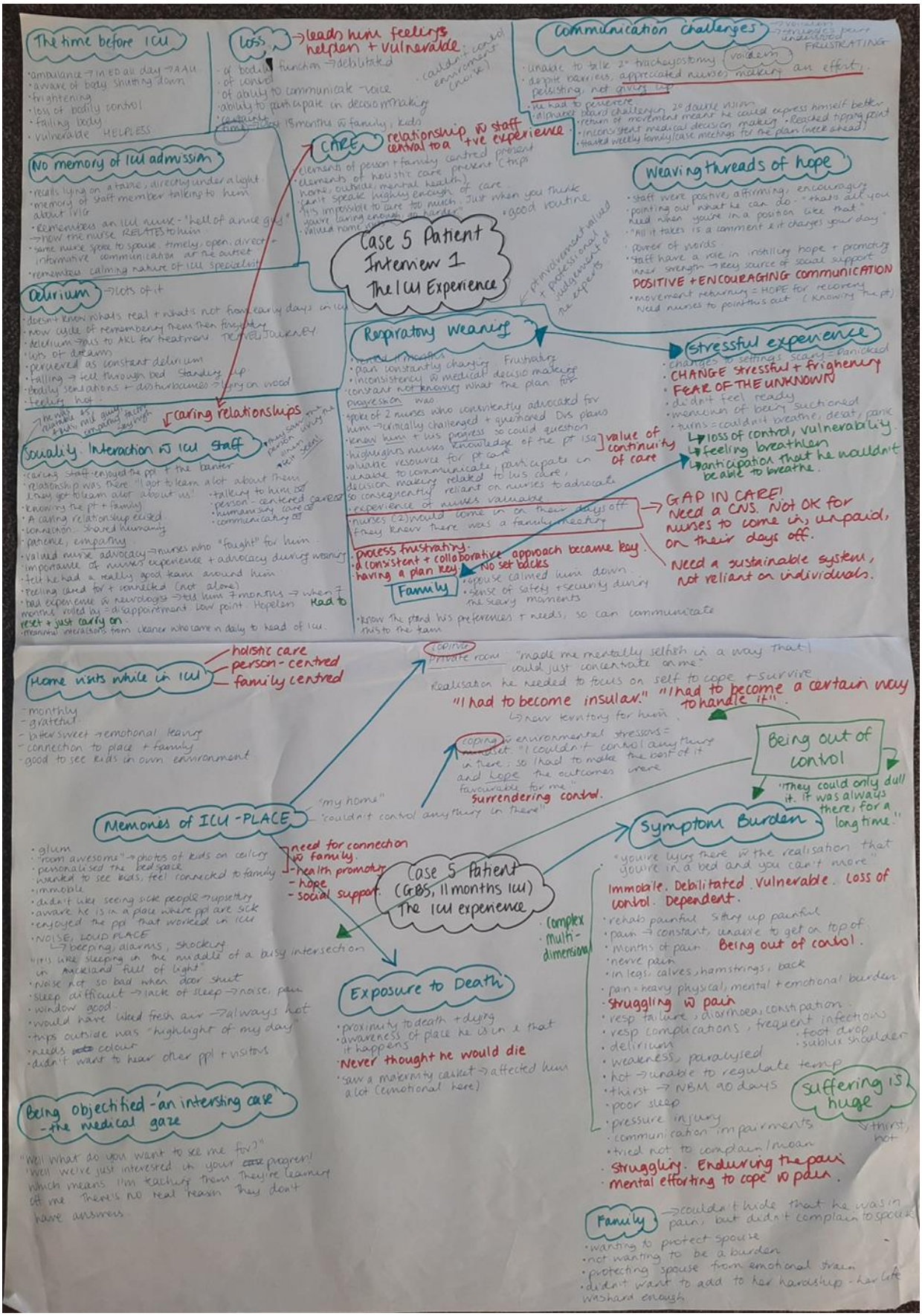
- Tell me about your experience of becoming critically unwell
- Tell me about your experience of the time in ICU
- Tell me about your experience of the time on the general hospital wards and at rehabilitation
- Tell me about your experiences coming home from hospital
- What has changed for you since the last interview?
- Can you tell me about the impact of this experience on you and your life?

Appendix L: Example of Coding Process

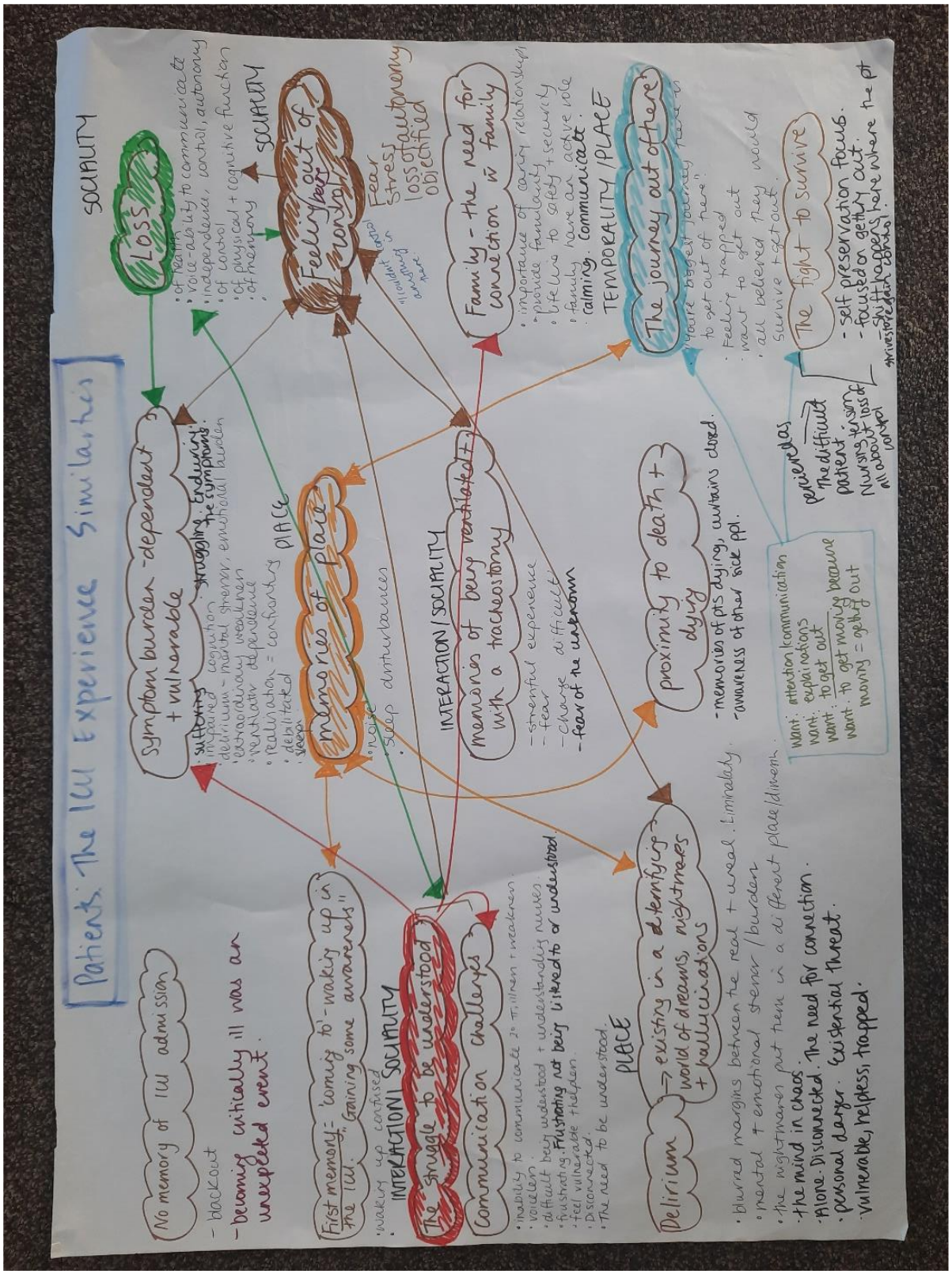
Field Text	Code	Category	Theme(s)
But also for me, the biggest difficulties are still, well there's the relationship, but is the cognitive difficulties. Because he's really quite a different kettle of fish in that regard. You know, like he was an intelligent, capable man.			
"But also for me, the biggest difficulties are still, well there's the relationship"	Ongoing challenges	Carer experience Relationship strain	Navigating a different us
"the cognitive difficulties"	Ongoing challenges	PICS Cognitive impairment	A prolonged struggle
"Because he's really quite a different kettle of fish in that regard."	Changed personality (Patient) Identity changes	Loss of identity Recognising **a different person** Adjusting to changed person	Adjusting to changes over time
"He was an intelligent, capable man."	Memory and identity Comparing past and present self	Grieving the person before Loss	Navigating a different us
Perhaps the most difficult bit is his memory because I'll tell him something and then he won't remember. That's problematic. But so is the not being able really to conceptualise things. Like if I say something that's quite big or say a bit of a scenario, he just can't hang onto it all at once and so he can't understand it. He says what do you mean, [de-identified]? So, like I can't have the same conversations, if you know what I mean? Like, there's a lot of things now I just don't bother bringing up. For example, my work.			
"Perhaps the most difficult bit is his memory because I'll tell him something and then he won't remember."	Memory loss	PICS Cognitive impairment Ongoing challenges **Everyday struggles**	Adjusting to a changed person
"That's problematic."	Everyday challenges Everyday cognitive challenges	Care burden Work around the patient Constant patient management	A prolonged struggle

"But so is the not being able really to conceptualise things. If I say something that's quite big or say a bit of a scenario, he just can't hang onto it all at once."	Inability to conceptualise	PICS Cognitive impairments	Adjusting to a changed person
"I can't have the same conversations, if you know what I mean?"	Loss of communication Loss of connection Loneliness within the relationship	Relationship changes Adjusting to a changed person Loss	Navigating a different us Adjusting to change over time
I didn’t kind of – I knew it was going to be difficult, but I hadn’t realised in what senses quite. That's really hard.			
I knew it was going to be difficult, but I hadn’t realised in what senses quite.	Anticipated challenges The unknown/the unexpected Multi-dimensional impact	**Unmet informational support needs** (systemic failure) **Expectation versus reality** Lack of preparedness for reality Adjustment and adaptation process	Navigating new realities alone and in the dark
That's really hard	Emotional strain of caregiving	Emotional labour	Carer burden

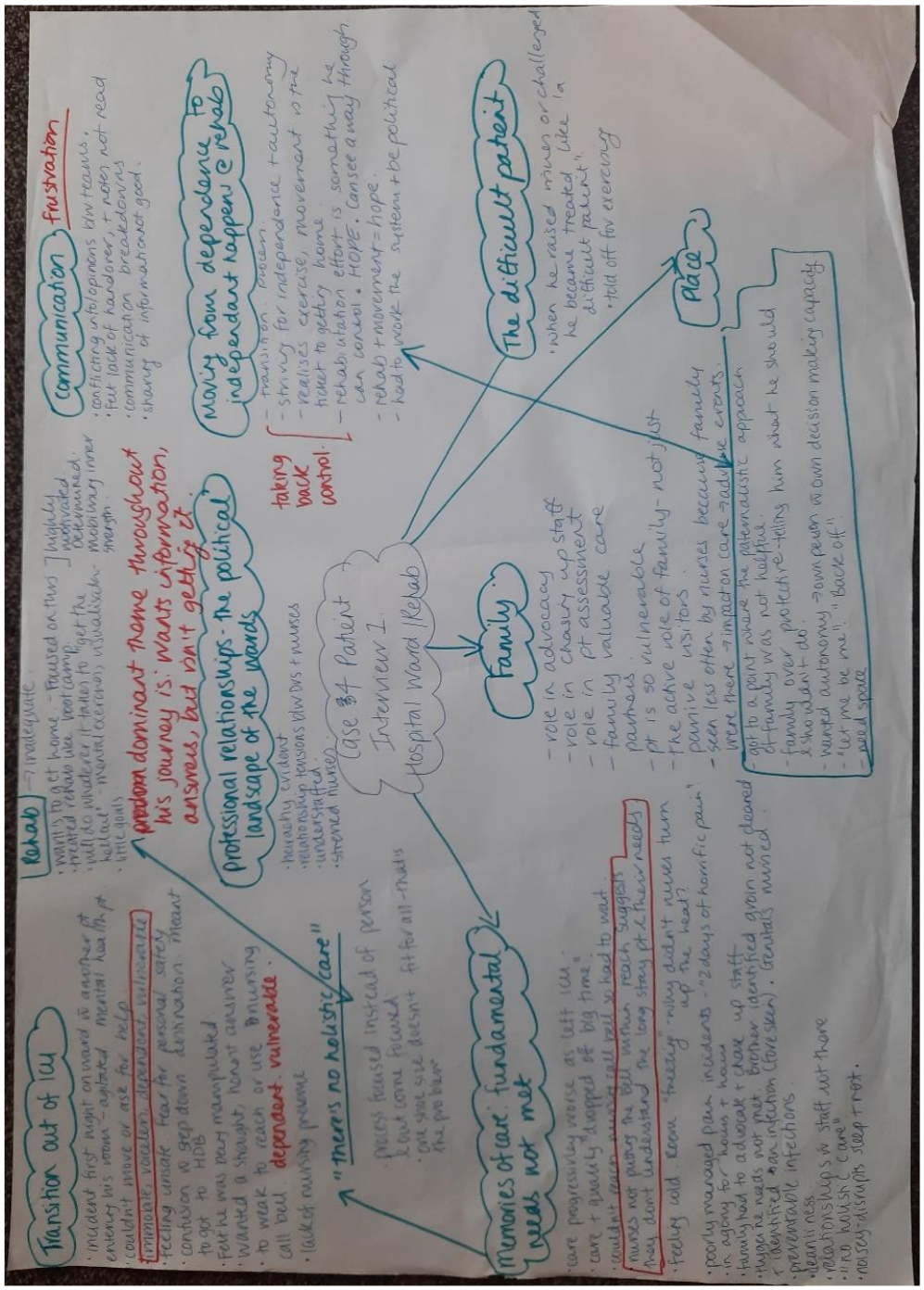
Appendix M: Messy Map of a Patient's Experience of the ICU



Appendix N: Messy Map of Patients' Experiences of the ICU – Similarities

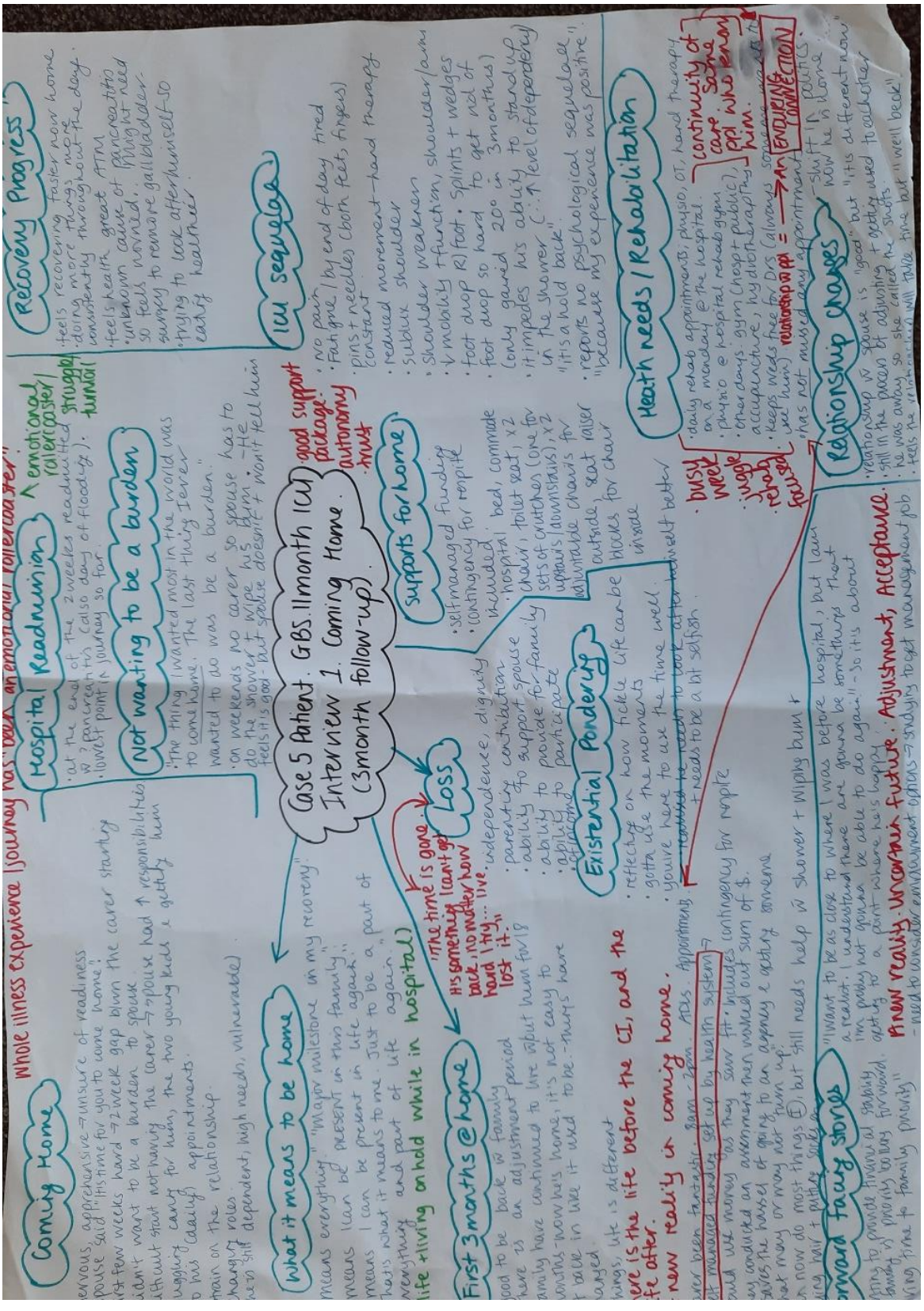


Appendix O: Messy Map of a Patient's Experience of the General Wards/ Rehabilitation

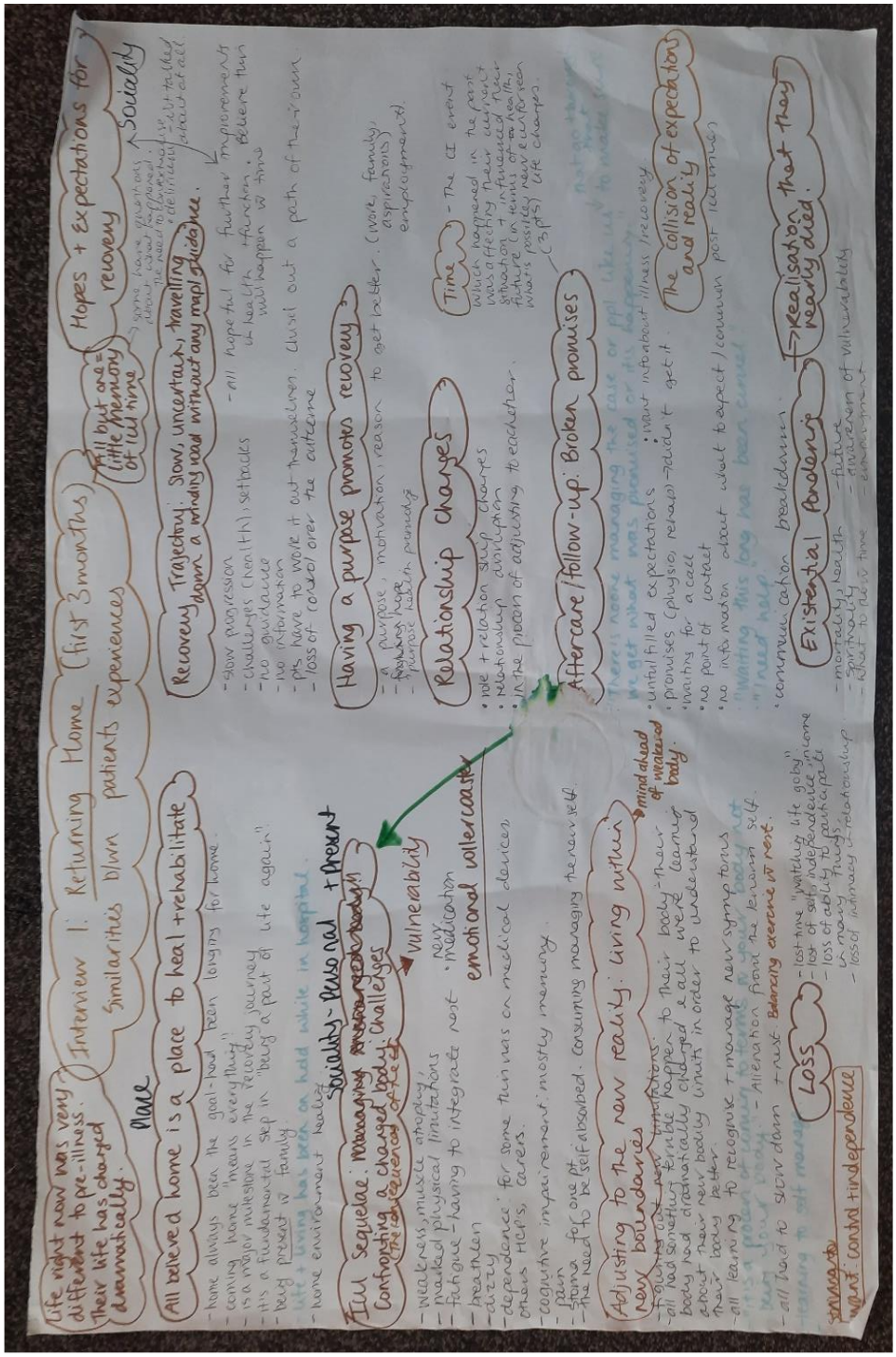


Appendix P: Messy Map of Patients' Experiences on the General Ward/ Rehabilitation – Similarities

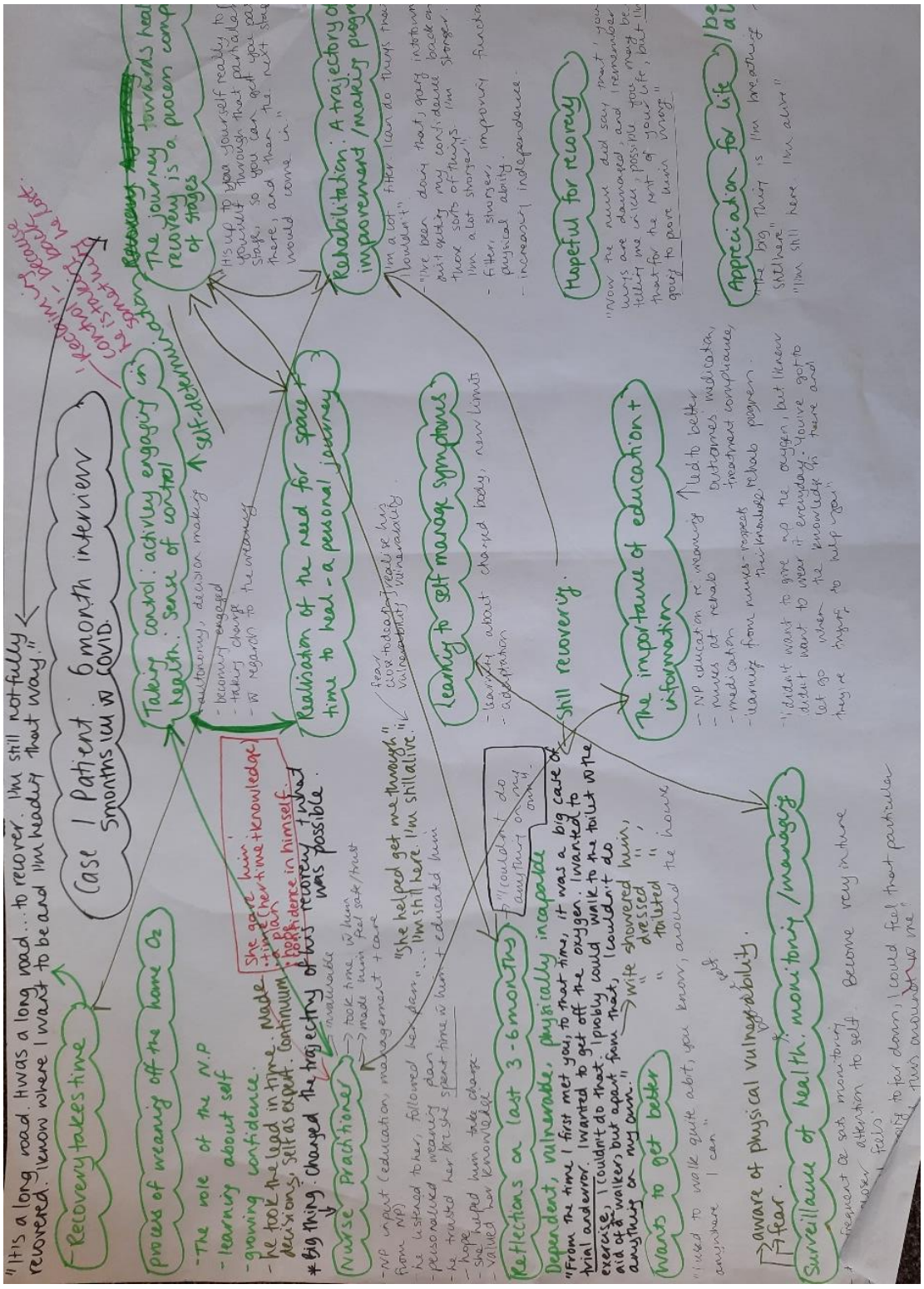
Appendix Q: Messy Map of a Patient's Experience of Coming Home

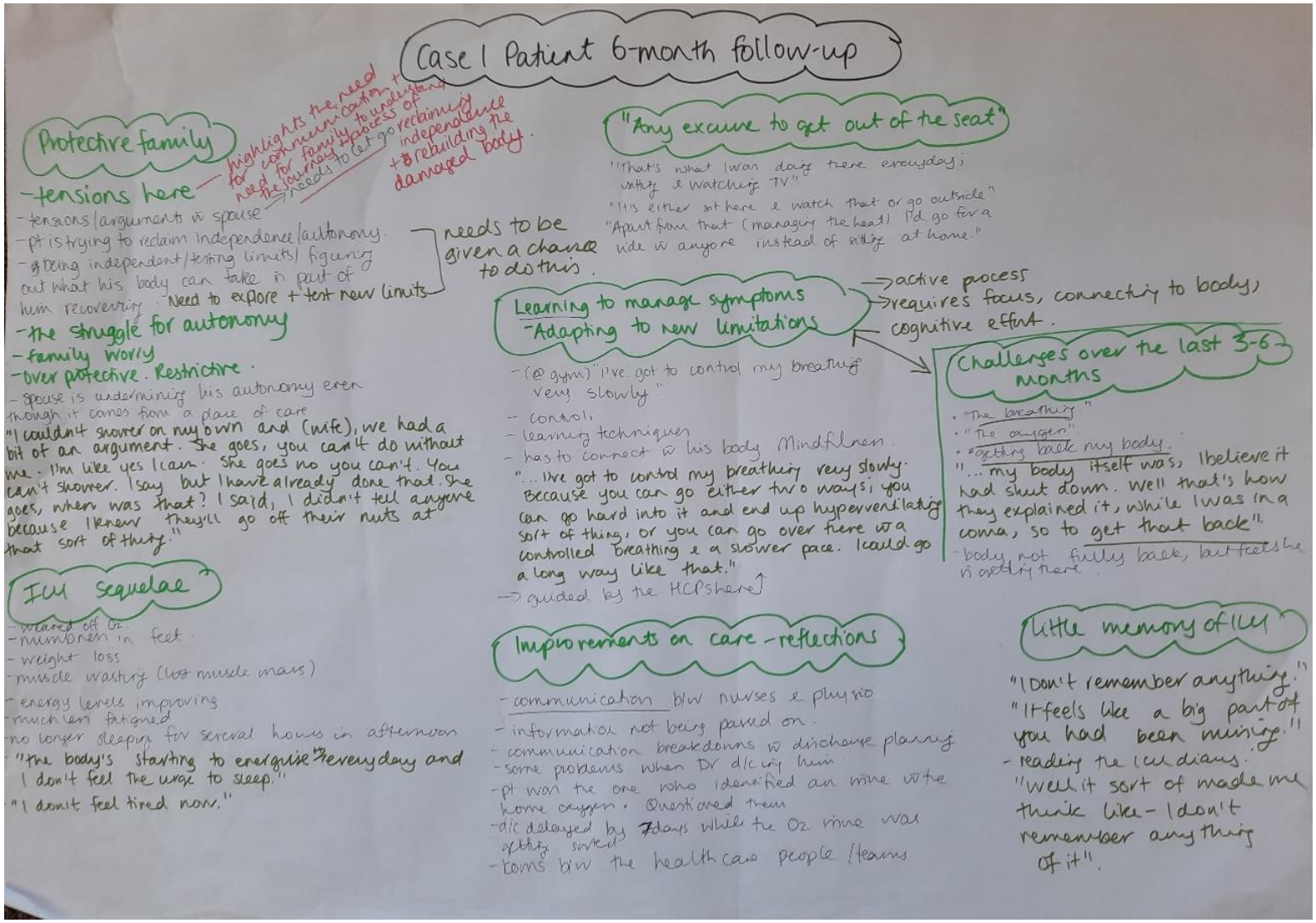


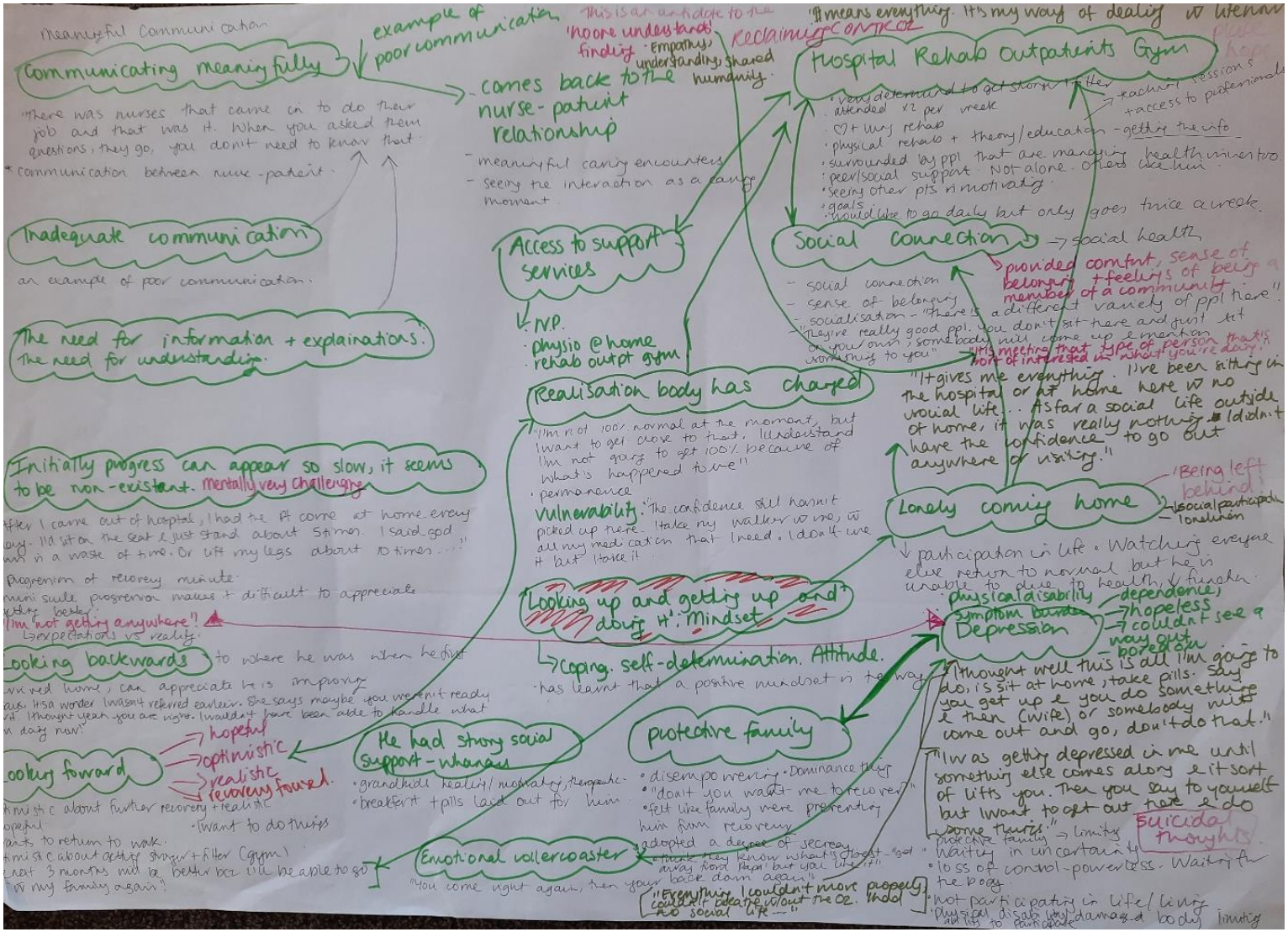
Appendix R: Messy Map of Patients' Experiences of Coming Home – Similarities



Appendix S: Messy Map of a Patient's Experience 6-months

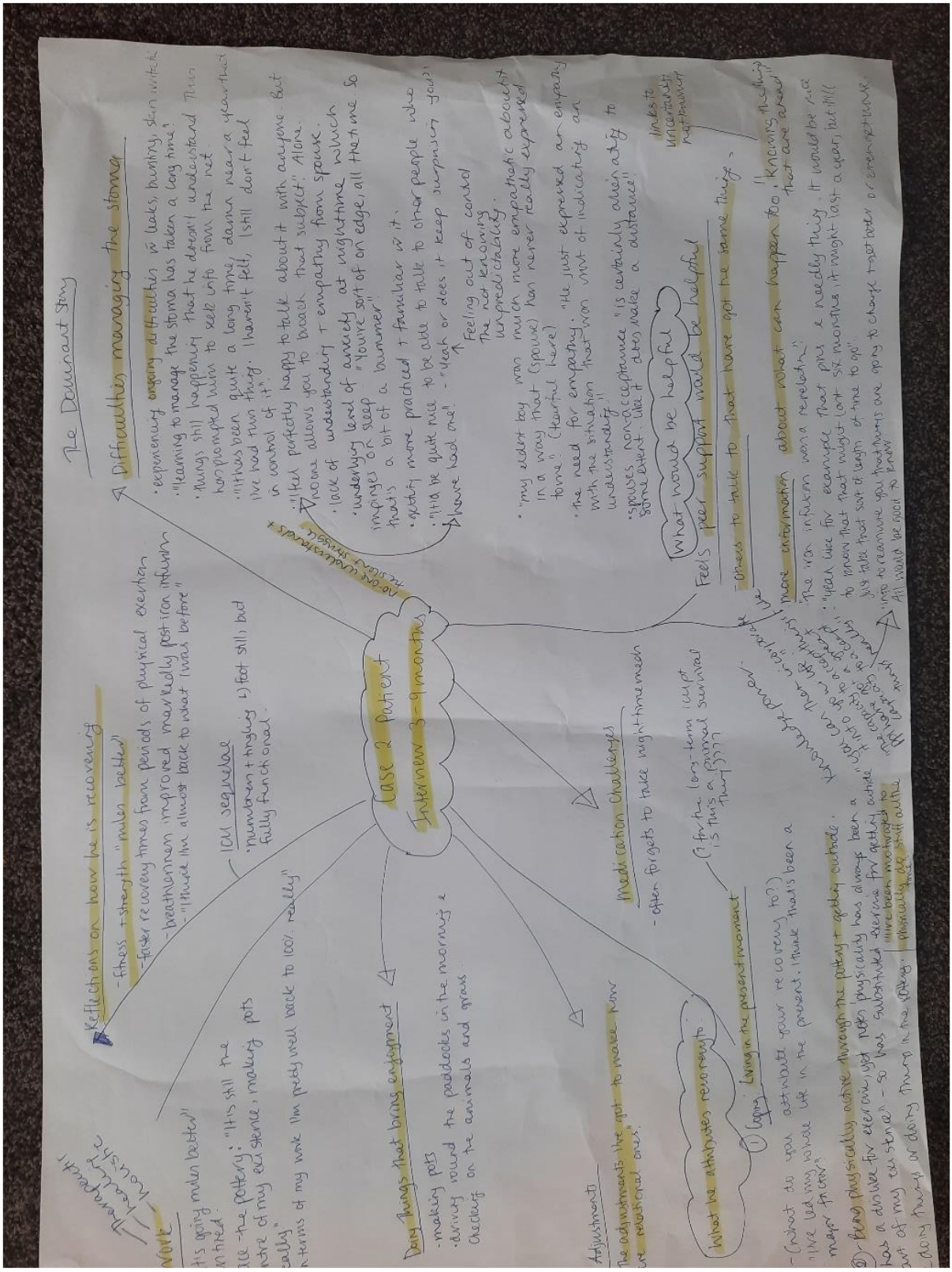



Case 1 Patient 6-month follow-up
Protective family
highlights the need for continuing education + need for family to understand the journey + process of needs to let go reclaiming independence + rebuilding the damaged body.
-tensions here
- tensions/arguments in spouse
- pt is trying to reclaim independence/autonomy
- ↑ being independent/testing limits/ figuring out what his body can take is part of him recovering. Need to explore + test new limits
needs to be given a chance to do this.
-the struggle for autonomy
-family worry
-over protective. Restrictive.
- spouse is undermining his autonomy even though it comes from a place of care.
"I couldn't shower on my own and (wife), we had a bit of an argument. She goes, you can't do without me. I'm like yes I can. She goes no you can't. You can't shower. I say but I have already done that. She goes, when was that? I said, I didn't tell anyone because I knew they'll go off their nuts at that sort of thing."
"Any excuse to get out of the seat"
"That's what I was doing there everyday; sitting & watching TV".
"It is either sit here & watch that or go outside"
"Apart from that (managing the heat) I'd go for a ride or anyone instead of sitting at home."
Learning to manage symptoms
-Adapting to new limitations
→ active process
→ requires focus, connecting to body, cognitive effort.
- (@ gym) "I've got to control my breathing very slowly"
- control.
- learning techniques
- has to connect w his body. Mindfulness.
"... I've got to control my breathing very slowly. Because you can go either two ways; you can go hard into it and end up hyperventilating sort of thing, or you can go over there w a controlled breathing & a slower pace. I could go a long way like that."
→ guided by the HCPs here
Challenges over the last 3-6 months
• "The breathing"
• "The oxygen"
• "getting back my body."
"... my body itself was, I believe it had shut down. Well that's how they explained it, while I was in a coma, so to get that back".
- body not fully back, but feels he is getting there.
ICU sequelae
- weaned off O2
- numbness in feet
- weight loss
- muscle wasting (lost muscle mass)
- energy levels improving
- much less fatigued
- no longer sleeping for several hours in afternoon
- "The body's starting to energise itself everyday and I don't feel the urge to sleep."
- "I don't feel tired now."
Improvements on care - reflections
- communication b/w nurses & physio
- information not being passed on.
- communication breakdowns w discharge planning
- some problems when DR d/c'ing him
- pt was the one who identified an issue w the home oxygen. Questioned them
- d/c delayed by 7 days while the O2 issue was getting sorted
- issues b/w the healthcare people / teams
Little memory of ICU
"I don't remember anything."
"It feels like a big part of you had been missing."
- reading the ICU diary.
"Well it sort of made me think like - I don't remember anything of it".

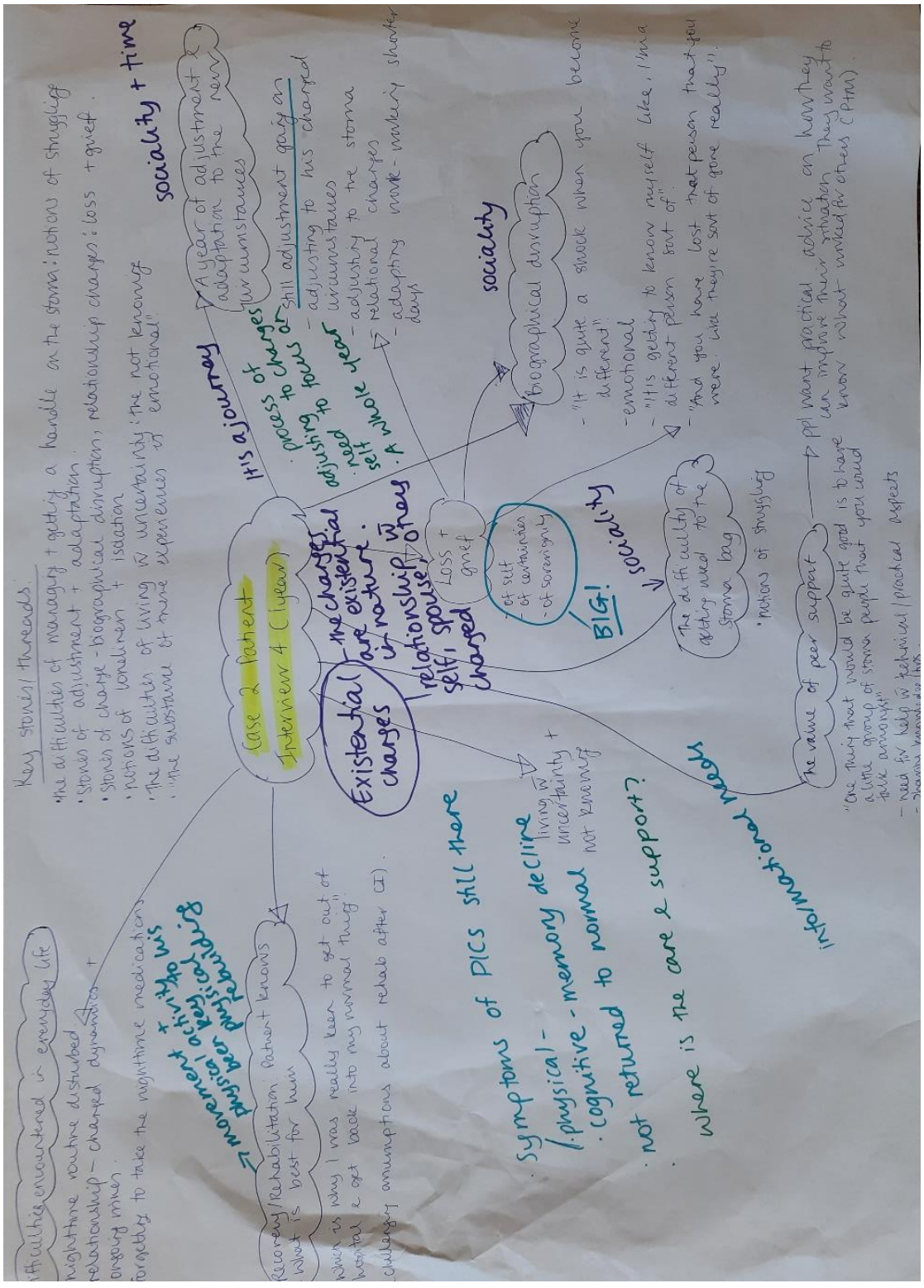

Meaningful Communication
Communicating meaningfully
example of poor communication
comes back to the nurse-patient relationship
- meaningful caring encounters
- seeing the interaction as a caring moment
"There was nurses that came in to do their job and that was it. When you asked them questions, they go, you don't need to know that."
* communication between nurse-patient
Inadequate communication
an example of poor communication.
The need for information + explanations.
The need for understanding.
"This is an antidote to the 'no one understands' finding" - Empathy, understanding, shared humanity.
Reclaiming CONTROL
"It means everything. It's my way of dealing w illness"
Hospital Rehab Outpatients Gym
• very determined to get stronger & fitter
• attended x2 per week
• ♡+ lung rehab
• physical rehab + theory/education - getting the info
• surrounded by ppl that are managing health issues too
• peer/social support - Not alone. Others like him
• seeing other pts is motivating
• goals
• would like to go daily but only goes twice a week
reactivation sessions
access to professionals
Access to support services
N.P.
physio @ home
rehab outpt gym
Social Connection
→ social health
- social connection
- sense of belonging
- socialisation - "there's a different variety of ppl there"
"You're really good ppl. You don't sit there and just let it on your own, somebody will come up & mention something to you"
provided comfort, sense of belonging + feelings of being a member of a community
"I'm meeting that type of person that's sort of interested in what you're doing"
"It gives me everything. I've been sitting in the hospital or at home here w no social life... As far a social life outside of home, it was really nothing. I didn't have the confidence to go out anywhere or visiting."
Realisation body has changed
"I'm not 100% normal at the moment, but I want to get close to that. I understand I'm not going to get 100% because of what's happened to me"
• permanence
vulnerability: "the confidence still hasn't picked up there. I take my walker w me, & all my medication that I need. I don't like it but I take it."
Lonely coming home
'Being left behind'
social participation
loneliness
participation in life. Watching everyone else return to normal but he is unable to due to health & funding.
Initially progress can appear so slow, it seems to be non-existent. mentally very challenging
After I came out of hospital, I had the PT come at home every day. I'd sit on the seat & just stand about 5 times. I said god, this is a waste of time. Or lift my legs about 10 times..."
Progression of recovery minute.
minuscule progression makes it difficult to appreciate
getting 'lost'
"I'm not getting anywhere!"
Looking up and getting up and doing it: Mindset
Coping. self-determination. Attitude.
- has learnt that a positive mindset is the way
physical disability
dependency
symptom burden
Depression
hopeless
I couldn't see a way out
boredom
"I thought well this is all I'm going to do, is sit at home, take pills. Say you get up & you do something & then (wife) or somebody will come out and go, don't do that."
"I was getting depressed in me until something else comes along & it sort of lifts you. Then you say to yourself but I want to get out there & do some things."
Looking backwards to where he was when he first arrived home, can appreciate he is improving
says his wonder I wasn't referred earlier. She says maybe you weren't ready at that point. I thought yeah you are right. I wouldn't have been able to handle what I'm doing now.
Looking forward
hopeful
optimistic
realistic
recovery focused.
optimistic about further recovery + realistic
hopeful
wants to return to work.
optimistic about getting stronger + fitter (gym)
next 3 months will be better b/c I'll be able to go
for my family again."
He had strong social support - whanau
• grandkids reality/motivating, therapeutic
• breakfast + pills laid out for him
protective family
• disempowering • dominance thing
• "don't you want me to recover"
• felt like family were preventing him from recovery
adopted a degree of secrecy
• made they know what's good for him but you live it"
Emotional rollercoaster
"You come right again, then you're back down again"
"Everything I couldn't more properly model"
could not take me out. No social life —"
protective family → limiting
• waiting in uncertainty
• loss of control - powerless. Waiting for the body
• not participating in life/living
Suicidal thoughts
physical disability damaged body limiting

Appendix T: Messy Map of Patients' Experiences 6-months – Similarities

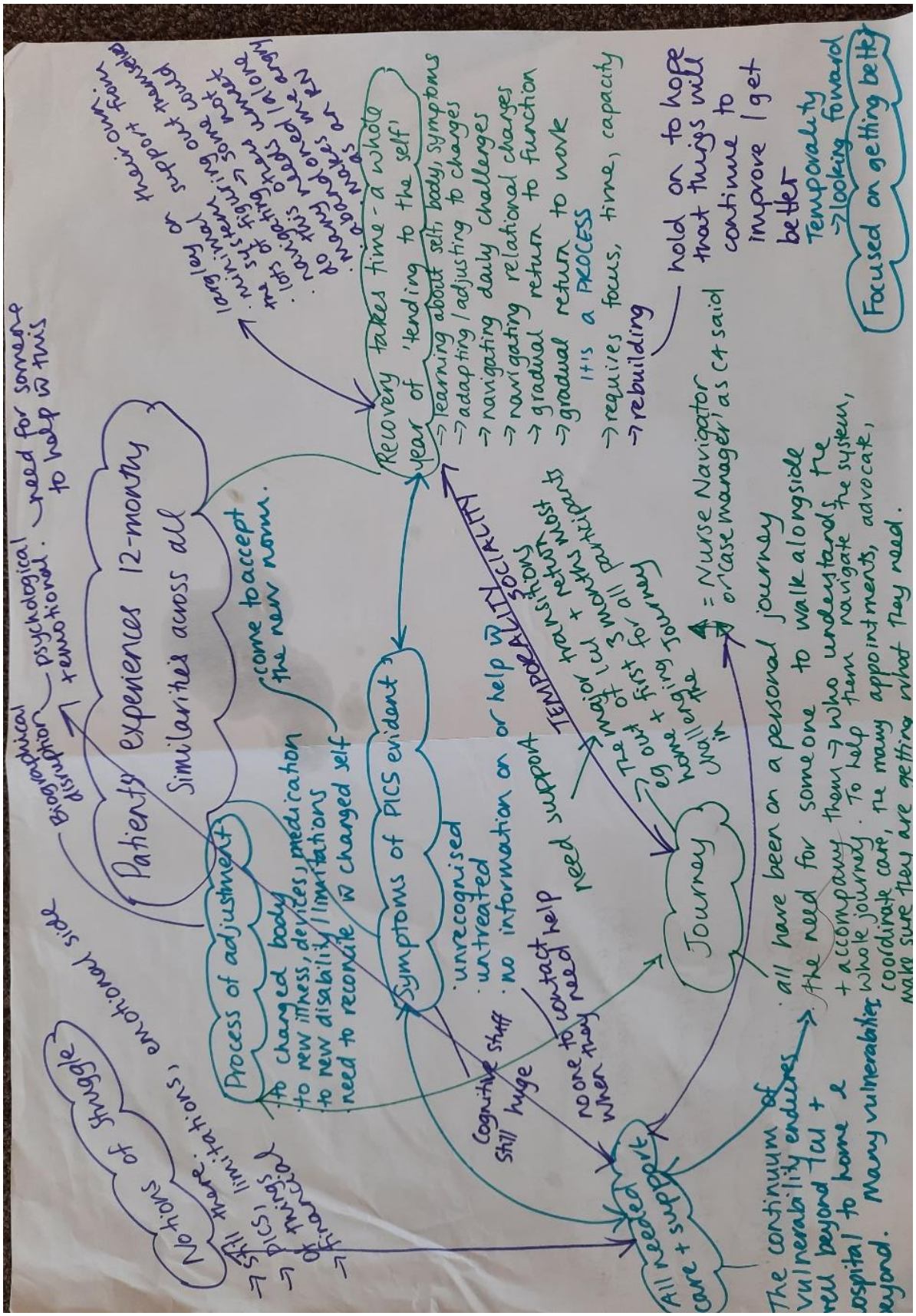
Appendix U: Messy Map of a Patient's Experience 9-months



Appendix V: Messy Map of a Patient's Experience 12-months



Appendix W: Messy Map of Patients' Experiences 12-months – Similarities



Appendix X: Messy Map Combining Patients and Families Across Time