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Life After ICU: The patient experience with ICU and after hospital discharge

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Life After ICU: The patient experience with ICU and after hospital discharge

by

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A THESIS

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Abstract

ICU can be a life-altering experience for patients and their families. ICU survivors may face a multitude of complications after their hospital stay that have been collectively termed Post Intensive Care Syndrome (PICS). In the current global environment of the COVID-19 pandemic, ICUs across the world have seen a drastic increase in ICU patients.

It has been recognized within the ICU community that a better understanding of the post-ICU population is needed as there is a lack of understanding about what the ICU survivor experiences after hospital discharge and what resources may support them to manage best or avoid PICS. To examine the experience of former ICU patients, the qualitative method of Interpretive Description was utilized. Patients who participated in the ICU recovery clinic in Alberta, Canada, were invited to participate in a 45-minute interview about their experience with ICU and their life after hospital discharge. Three former ICU patients were interviewed virtually to share their experiences.

The results of this study found themes in data analysis that include communication challenges, living with uncertainty, and post-ICU fallout. These themes do not occur in isolation but are interconnected and can impact the other themes, which ultimately can impact ICU survivors' recovery. Participants expressed frustration with various communication challenges they experienced both during and after ICU, and the impact of visitation restrictions on their experience. Participants also expressed emotion about the uncertainty they face after an ICU admission, including uncertainty about what happened in ICU and uncertainty with their present and future. Finally, participants discussed their experience of living with the fallout of an ICU admission and the benefit of attending the ICU recovery clinic.

The results of this study highlight the need for broader awareness and education for health professionals on the potential complications faced by ICU survivors after discharge. This study also shows support for specialized follow-up services, like the ICU recovery clinic. Specialized follow-up allowed each of the participants to be viewed holistically, beyond their medical diagnosis or physical impairment, and for the first time each had their experience normalized.

Keywords: Intensive care, Post ICU Syndrome, ICU survivor, ICU follow-up

Preface

This thesis is original, unpublished, independent work by the author, Catherine A. McIntyre. The interviews reported in Chapters 4-5 were covered by Ethics Certificate number, REB19-1279 issued by the University of Calgary Conjoint Health Ethics Board for the project “Life After ICU: The patient experience after hospital discharge” on FEB 19, 2021.

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List of Abbreviations

AHS – Alberta Health Services

GP – General Practitioner

HRQoL – Health Related Quality of Life

ICU – Intensive Care Unit

MD – Medical Doctor

PICS – Post Intensive Care Syndrome

PPE – Personal Protective Equipment

PTSD – Post Traumatic Stress Disorder

RN – Registered Nurse

RRT – Registered Respiratory Therapist

WHO – World Health Organization

Chapter 1: Introduction to the Topic

A hospital's Intensive Care Unit (ICU) is generally a mysterious entity in any medical setting. ICUs are highly specialized areas in acute care hospitals that provide care to critically ill or injured patients. This care requires a specialized interdisciplinary team (physicians, nursing, respiratory therapists, pharmacists, dieticians, and physiotherapists) to provide advanced medical care to sustain life during a life-threatening time when an organ(s) may be failing to function adequately (Marshall et al., 2017). It is this ability to either temporarily or even permanently replace the function of multiple-organ systems in response to critical illness or injury with the view to help patients return to their preadmission lifestyle, and functional status is the core of critical care medicine (Kelly et al., 2014; Morgan & O'Connor, 2018).

History of ICU

Intensive care medicine was first developed in 1952 in response to the polio epidemic in Denmark (Kelly et al., 2014), making critical care a relatively new branch of medicine. The idea of providing this level of care to the sickest quickly spread to other areas of the world like such as the U.K. and U.S.A by the 1960s (Kelly et al., 2014). By the 1980s, many larger hospitals had these specialized units where patients would receive technologically advanced therapies and specialized monitoring (Kelly et al., 2014). In 2022, critical care is no longer limited to larger centres and may be found in rural settings. ICU care is in high demand in most developed countries. From 2013-2014, approximately 230,000 Canadians were admitted to an ICU during their hospital stay (Canadian Institute for Health Information, 2016). This number is expected to increase exponentially with further advancements in medical therapies leading to people surviving illnesses that they would have succumbed to previously.

During the infancy of ICUs there were high rates of mortality and poor outcomes for patients. Today, with the advancement of modern medicine, technology, and medical therapies, more patients survive critical illnesses and are discharged from the hospital setting to home. Traditionally, most of the research surrounding ICU care focused on more short-term goals; improving treatments within the ICU for immediate survival and improving care within the ICU setting to help minimize iatrogenic complications. With these short-term improvements in care, a growing population of ICU survivors emerged, leading to an increased research focus on the long-term outcomes of ICU survivors (Moran & O'Connor, 2018).

Introduction to Post Intensive Care Syndrome (PICS)

ICU survivors may face unique challenges after hospital discharge. Some of the challenges they may face include: pronounced muscle weakness, anxiety, depression, cognitive dysfunction, and sleep problems, to name a few (Morgan & O'Connor, 2018). This group of symptoms is now known as Post Intensive Care Syndrome (PICS), a collective term to describe common health disorders that afflict those who survive critical illness (Morgan & O'Connor, 2018). As defined by Harvey and Davidson (2016), "PICS is defined as a new or worsening impairment in physical, cognitive, or mental health status arising and persisting after hospitalization for critical illness" (p.381). PICS is not limited to a particular age group, gender, or group with a specific pre-existing condition; all ICU survivors are at risk of developing this syndrome after an ICU admission (Harvey & Davidson, 2016; Makic, 2016). Despite the recent influx of research on this population, ICU survivors face higher morbidity and mortality rates after hospital discharge and increased utilization of the health care system. However, the reasons for this are not clearly understood (Bryant & McNabb, 2019).

The overall goal of much of the past and current research is to help identify risk factors in developing PICS to inform practice changes within ICUs that may help reduce patients' risk. Researchers have focused primarily on the prevalence of PICS, the long-term outcomes of patients, potential interventions to help reduce PICS, and patient/family experiences with ICU and life after ICU. One key area of research in the study of ICU survivors is ICU delirium (previously termed ICU psychosis). The results from this research brought about broad changes in the administration of sedation, appropriate pain management, and early mobilization, and all are showing benefits to ICU patients' outcomes (Ely, 2017). Additionally, ICUs have opened up to families and friends, encouraging their presence and partnership with the care of their loved ones (Davidson et al., 2007; Ely, 2017). All of these changes are significant steps forward in providing excellent patient care, yet so far, the solution to PICS remains elusive. However, it remains unclear what the ICU survivor finds beneficial for them personally once they have left the hospital and what their personal experience is as they navigate the health care system from inpatient to outpatient treatment. Through this understanding, we might better be able to support this population after hospitalization.

With this research I aim to understand the ICU experience from the survivor's perspective, and also to understand the impact of that experience on their life as a way of better meeting this particular population's needs. Unfortunately, on March 11, 2020, a global pandemic was declared by the World Health Organization (WHO) in response to the novel Coronavirus SARS-CoV-2, more commonly known as COVID-19, adding another layer of complexity for this population.

This pandemic has directly impacted the specific population I had planned to research, and it is an essential factor to acknowledge when researching the ICU survivor population.

Initially, my research question was, “*What are the experiences of patients discharged from ICU in Calgary, Alberta, who are at risk of developing Post Intensive Care Syndrome.*” The province of Alberta initially shut down for almost eight weeks, with various levels of restrictions in place for the duration of the pandemic, with all restrictions being lifted by early 2022.

Recognizing this was a unique time; the research question was modified to acknowledge the evolving environment of the COVID-19 pandemic. Life is very different from usual: How we work, interact socially, and spend free time was directly impacted, contributing to a heightened sense of anxiety. By adding the complexity of hospitalization during this time, removing or restricting the support of friends or family in-person visitation, limitations of outpatient programs (moving to a more virtual manner), and then having to contend with a global pandemic, all patients during this time have faced many challenges during their illness and recovery. It is unclear what the impact of the pandemic will have on ICU survivors, but one cannot deny that there will be one. The average population has noted a change in how our everyday lives occur; therefore, ICU survivors will likely face new and unique challenges.

Why the Post-ICU Population?

I have spent most of my nursing career in the intensive care environment, where a nurse may routinely face extreme stress or emotional situations in helping patients and their families as they encounter life-altering situations. As a nurse, I would tell myself that hard work and extreme stress are worth it as you are most often helping someone survive and go back to their everyday life. I had always assumed that what I did in the ICU benefited the patients I cared for and never realized the impacts an ICU stay can have over the longer term. ICU is a fast-paced environment for nursing; you move to your next patient with the next shift or new admission with no real idea of what happens to your former patients. An education session about post ICU

syndrome and the follow-up clinic in Calgary, AB, was an eye-opening experience. It was the first time I even began to understand the full implications of what an ICU stay means to a survivor and what they must face. Additionally, by chance, I happened to see a former patient out in the community, and this was a monumental moment for me personally in how I viewed my professional practice as a registered nurse in ICU. This former patient was plagued with ongoing issues well after hospital discharge, and this was the first time I had ever faced this reality. It seemed like surviving was the easy part. The fact is, these patients are forever changed, not only physically but also psychologically.

The realization of what former ICU patients encounter made me question what kind of life patients are returning to and what help is available after hospital discharge. As a nurse, it is terrifying to imagine that what I was doing at the bedside may potentially cause lifelong damage. This thought left me with the feeling of questioning my career choice as a nurse. I reflected on “what am I doing to these people?” because at the core of my nursing practice is to help. This time coincided with the beginning of graduate school, which further challenged my views regarding my practice as a registered nurse. Graduate school provided a new lens to view my practice and solidified the decision to look at this population. The intention was to learn more about this population to help improve the outcomes of patients I care for in the ICU. After careful reflection, I decided that the ideal way to learn more about the post-ICU population is to ask former ICU patients, “what is it like?” and, more importantly, “what can we be doing better to help you?”

Purpose of the Study

The primary goal of this study initially was to better understand the experience of former ICU patients during hospitalization and after discharge home. The goal was later changed to

include the experience of hospitalization and discharge home during the COVID-19 pandemic. Listening to those directly impacted by an ICU stay gives a voice to those affected by this care. This study adds to the current literature on ICU survivors, their overall experience, and areas for improvement that former patients recognize. With the recent influx of ICU patients worldwide primarily related to the pandemic, it is recognized within the critical care community that a better understanding of the ICU survivor population is required. Early data shows that COVID-19 survivors display PICS-type symptoms in addition to what is known as “long-COVID”. An increase in research on this population will help better inform practice at the bedside. On a larger scale, this research may help better inform policy to improve care during the remainder of this pandemic or in the future for other public health emergencies.

Research Question

What are the experiences of patients discharged from ICU in Calgary, Alberta, who are at risk of developing Post Intensive Care Syndrome during the COVID-19 global pandemic?

Research Aims

1. To better understand the ICU experience of ICU survivors in Calgary, Alberta, during the COVID-19 global pandemic.
2. To better understand the post-discharge experiences of ICU survivors in Calgary, Alberta, during the COVID-19 global pandemic.

Research Approach

A qualitative approach was used to conduct this study. This decision came about after consultation and reflection on the knowledge I hoped to gain from this study. Inherent in the research question posed above is the generation of knowledge based on a human experience.

Moving to a quantitative approach to ICU survivors could be misleading as there is still so much unknown about this population, making a qualitative approach the ideal way to answer the research question. Further, who better to gain a better understanding of the experience of an ICU survivor than from the survivor? Once we settled on a qualitative approach, I discussed on multiple occasions with my supervisor and other faculty what would be the best methodological approach to my question. I was very fortunate when a nursing faculty member offered the idea of Interpretive Description (ID). It offered a way to answer my question and my initial curiosities “is there anything that I can change in my practice to help make things better for former ICU patients?” One of the things that initially drew me towards ID was the ability to take a real-world question and use it to study a phenomenon for the generation of knowledge to improve clinical practice rather than focusing on theory development (Thorne, 2016).

The study design was developed in consultation with my supervisor and supervisory committee. My supervisory committee reviewed and approved a proposal of the study design and approach, during which time they provided valuable feedback regarding the guiding questions for the participants. The proposal was then submitted to the University of Calgary Conjoint Health Research Ethics Board, which approved this study (REB19-1279). An amendment to the ethics application had to be done as a pivot was made to undertake virtual interviews only due to the COVID-19 related social distancing guidelines at the time. The interviews were designed to explore the experiences of ICU survivors, with guiding questions to help facilitate responses that might help conversationally answer my question, thereby allowing each participant to tell their own story.

Outline of the Thesis

A total of three participants were enrolled in this study. This sample size is smaller than desired, but each participant provided a rich, emotionally raw account of their experience from hospitalization to how their current life is progressing at the time of the interview. Due to time limitations for completing this thesis, restrictions related to the ongoing COVID-19 pandemic, and in consultation with my supervisor, we determined to proceed with this small sample size. As a qualitative study using ID methodology, the concept of data saturation was not applicable. Further justification for the number of participants will be provided in Chapter 3 (methodology).

A pseudonym was used for each participant in this thesis for ease of reading and to provide a layer of humanness to the data. The participants of this study are Sam, a 48-year-old male who suffered a severe, potentially life-ending or altering C-spine injury requiring ICU during the “second wave” of the COVID-19 pandemic (for a timeline of each “wave” see Appendix D). George, a 65-year-old male, suffered from a respiratory infection that progressed to requiring mechanical ventilation for support and suffered multiple complications during his lengthy hospital stay. He was hospitalized during the “first wave” of the COVID-19 pandemic. The final participant in this study is Sarah, a 32-year-old female admitted to the ICU with COVID-19 requiring mechanical ventilation. She was hospitalized during the “second wave” of the COVID-19 pandemic. Each participant shared with me their unique raw experiences of hospitalization and recovery after an ICU stay. Each continues to have gains and setbacks as they move forward in their lives. The data I was able to extract from each of the interviews illuminates the raw personal emotion of a very vulnerable time.

The structure for this thesis follows a traditional thesis format. Chapter 2 will delve into the literature review of PICS in the ICU population. This review has been lengthy and updated

multiple times due to the time it has taken for completion and the rapidly changing information available about ICU patients during the COVID-19 pandemic. For instance, in the initial literature review, there was no mention of COVID-19, as it was not in existence during that period but was later included due to its impact directly on the population under study. Chapter 3 will examine the methodology used for this study, interpretive description (ID). This chapter includes a background of the methodology, justification of use, and how it was implemented in this study. This chapter includes ethical considerations, the process of data collection and details on the mechanisms used during data analysis, with an explanation of how interpretation occurred using this methodology. Chapter 4 is the findings chapter in which I provide a deeper description of each participant. This description is to better understand each individual outside of the label of a former ICU patient. In this chapter, I present the interpretation data for the first time, grouped into themes. The themes derived from the interpretation of the data are communication, uncertainty and post-ICU fallout. Finally, Chapter 5 is the discussion chapter, and this is the chapter where I further discuss my interpretations and situate those interpretations within the current literature. I have provided a diagram of the themes in the findings because it was during the interpretation that a more profound understanding came forward that each theme is interconnected for each participant. Each theme impacts the next, which elicits the experience of ICU survivors as an ongoing continuum that is not static. Finally, I provide the limitations of the study, areas for future research, what the findings mean for nursing practice and a conclusion of this study.

Summary

ICU survivors are a complex patient population that may face many complications after discharge. It is unclear how the global pandemic of COVID-19 will add to the complexity of this

population. Additionally, they do not have a traditional pathway through the hospital system. At a minimum, ICU patients transition through three different attending services before being discharged home; it is not routine or standard practice for an intensivist to ever follow up with a patient after hospital discharge. The multiple transitions in care highlight a lack of continuity of care for a complex, vulnerable population, which may contribute to potential gaps in aftercare for this population.

Additionally, during this time, all patients within the hospital environment were moving through the system in an unfamiliar way. From restrictions on visitation to not seeing a care provider in-person after discharge, how health care is provided and experienced has changed in response to the pandemic. However, it remains unclear as to the impact of these changes. Before the COVID-19 pandemic, the post-ICU patient population lacked a robust network of outpatient resources, and this remains an area of concern. This study will provide information about the experience of ICU survivors during the COVID-19 pandemic in Calgary, Alberta.

Chapter 2 - Literature Review

This study aims to better understand ICU survivors' experiences in ICU and after hospital discharge during the COVID-19 pandemic. The literature search started with gathering what is currently known about ICU survivors which led to further investigation of Post Intensive Care Syndrome (PICS). Reviewing the literature allows for the appropriate focus to identify themes, patterns, and gaps that may help identify areas for further research (Polit & Beck, 2017).

This study employs interpretive description as a methodology to understand complex experiential clinical phenomena that are relevant and useful to applied professional practices such as nursing (Thorne, 2016). As mentioned, reviewing the literature is essential to any research study as it helps ground the research in what is known and missing. The literature review with an interpretive description study is no different. Within an interpretive description study, the literature review is essential to a study's *theoretical scaffolding* (Thorne, 2016). This theoretical scaffolding positions the study within scholarly literature that will ultimately influence the direction of my research (Thorne, 2016).

This literature search was conducted using academic databases: Cumulative Index to Nursing and Allied Health Literature (CINHAL), EBSCO Academic Search Complete, and reference lists from articles selected. Key search terms were used: *Post Intensive Care Syndrome, ICU Recovery, ICU Survivorship, and Intensive Care*. Filters were set for scholarly articles in the English language, from 2008 to 2022, from peer-reviewed sources, and limited to the age group of ≥ 18 years. Titles and abstracts were reviewed to determine if the articles were pertinent to the research question "What are the experiences of patients discharged from ICU in Calgary, Alberta, who are at risk of developing Post Intensive Care Syndrome during the COVID-19 global pandemic?" Searches were conducted over 36 months as this chapter was

developed. The themes identified in the literature developed around PICS, patient outcomes, the patient experience, and post-ICU follow-up.

Considering the global pandemic of COVID-19, I also wanted to expand my literature search to better understand the current situation that ICU survivors may face during and after their ICU admission. Academic databases: Cumulative Index to Nursing and Allied Health Literature (CINHAL), EBSCO Academic Search Complete, MEDLINE, PubMed, and reference lists from articles selected. Key search terms included: *Novel Coronavirus, COVID-19, ICU, and Family Presence in ICU*. The settings for filters remained the same and were set for scholarly articles in the English language, from 2008 to 2022, from peer-reviewed sources and limited to the age group of ≥ 18 years. Searches were conducted over a period of 24 months. A PRISMA diagram was completed in the early phases of this literature review as a part of the required coursework. However, in light of the iterative nature of the literature review process and in keeping with Thorne's (2016) caution to ID researchers to reflect on why articles are excluded, it was decided to do a narrative review of the topic as an emerging area of research. In keeping with a narrative-style literature review, the PRISMA diagram was abandoned. Themes of the available literature were developed to explore what was known about intensive care survivors' experiences and the impact of the COVID – 19 pandemic on post-hospitalization care. Thorne (2016) noted that undertaking literature reviews in this way will help researchers better understand themselves before moving on to data collection/analysis and will give insight into decision-making in the future (Thorne, 2016).

The themes identified from the literature reviews include PICS, patient outcomes, patient experiences, and post-ICU follow-up. The literature surrounding these themes in relation to my question is discussed below. Additionally, literature regarding COVID-19 and family presence in

ICU were added as they help provide background and context to the current environment of critical care during this pandemic.

Post ICU Syndrome

ICU survivors frequently face complications that are directly attributable to their critical illness (Herridge et al., 2011). These complications are diverse and can impact all aspects of a person's life including cognitive dysfunction, physical weakness, sexual dysfunction, anxiety, depression, post-traumatic stress disorder (PTSD), exercise intolerance, and early-onset dementia (Heydon et al., 2019). This myriad of complications that persist after hospitalization have been grouped into a syndrome or cluster of symptoms known as post-intensive care syndrome (PICS) (Heydon et al., 2019). The official definition set out by the ICU community is "the new or worsening impairment in physical, cognitive, or mental health status arising and persisting after hospitalization for critical illness" (Harvey & Davidson, 2016, p.384). Fifty to 70% of ICU survivors may face ongoing impairment in their physical, cognitive, or mental health status, suggesting a large number of patients may be left with potential chronic, life-long health issues following ICU discharge (Myers et al., 2016; Makic, 2016). Recovery from critical illness can be a lengthy process that is not straightforward or linear as all aspects of a person's life may be impacted, such as family dynamics, employment, health, cognition, and psychological well-being (Pattison et al., 2015).

No single isolated factor puts a patient at risk for developing PICS; however, researchers have identified associations between certain factors and the development of PICS (McPeake et al., 2017). Early on, it was recognized that length of stay within the ICU and number of days of mechanical ventilation were predictors of identifying at-risk patients, but it has since been shown that these were overly narrow indicators (Harvey & Davidson, 2016; Herridge et al., 2011;

Makic, 2016; Needham et al., 2012). Current evidence suggests that there are other vital factors to take into account when identifying patients at risk. Some of these factors are related to ICU care and procedures, such as heavy sedation practices, immobilization, disruption of the sleep-wake cycle, and use of mechanical restraints (Harvey & Davidson, 2016; Makic, 2016; Needham et al., 2012). Other factors that may put patients at risk include physiologic issues involved in their illness such as hypoxia, hypotension, hyperglycemia, delirium during their ICU stay, or nutritional deficiencies (Makic, 2016; Needham et al., 2012). Additionally, there is a link between the development of PICS and gender (female), lower socioeconomic status, and mental health status (history of depression/anxiety) pre-hospitalization (Biehl & Sese, 2020; Griffiths et al., 2013; Lee et al., 2020). It is clear from the literature that many potential factors may put ICU survivors at risk of developing PICS; therefore, all patients should be screened for this potential complication if possible. Nevertheless, there is a lack of clarity on the exact criteria to use in the diagnosis and further assessment of PICS making this a challenging diagnosis for clinicians (Lee et al., 2020; Vrettou et al., 2022).

Patient Outcomes

Patient outcomes can be considered from multiple perspectives; they can be described by metrics such as survivability or patient-centred metrics such as Health-Related Quality of Life (HRQL). For this literature review, I have included both types of patient outcomes.

Patient survival was once the gold standard metric used in critical care medicine to determine the value of an intervention or therapy. Traditionally, the parameter for ICU survival was transfer from the ICU to the ward. Over the last 20 years, however, researchers have questioned how long ICU survivors live after hospital discharge (Herridge et al., 2011). As

mentioned previously in the short term, with the advancement of medical therapies, many ICU patients now survive their critical illness and there is an increased number of patients surviving to hospital discharge (Nakanishi et al., 2021). Still, once out of the acute care environment, their risk of mortality in the longer term is higher when compared to the general population or with other types of patients discharged from the hospital (Hill et al., 2016). For example, the mortality rate at 5-years post-hospital discharge was between 40-50% for post-ICU patients, with the highest risk of mortality within the first year of hospital discharge (Cuthbertson et al., 2010; Hill et al., 2016; Hofhuis et al., 2015; van Sluisveld et al., 2017). There is not one isolated factor explaining why ICU survivors have an increased rate of mortality. However, increased ICU length of stay, the number of days requiring mechanical ventilation, age at ICU admission, pre-hospital co-morbidities, and severity of illness upon admission to the ICU have all shown to increase the mortality risk of a patient after hospital discharge (Cuthbertson et al., 2010; Hill et al., 2016; Hofhuis et al., 2010).

Another strategy to examine patient outcomes is to examine ICU survivors' health-related quality of life since there is more complexity to patient outcomes than merely surviving the ICU stay. Examining a patient's health-related quality of life allows a better understanding of how a person is coping in their everyday life beyond their medical diagnosis.

Health-Related Quality of Life (HRQoL) is both a concept and a measure and has multiple dimensions related to a person's physical, mental, emotional, and social functioning (US Department of Health and Human Services, 2018). The concept focuses on how health status impacts the overall quality of life (US Department of Health and Human Services, 2018). HRQoL is a central concept for PICS researchers as it identifies the domains of life that PICS impacts. Most patients who survive ICU will have an altered health status at hospital discharge,

as shown by 50-70% of ICU survivors exhibiting at least one symptom of PCIS (Bigas & Hough, 2016; Nakanishi et al., 2021).

As a measure, HRQoL is evaluated through reliable and validated survey tools. The survey tool most frequently used to measure HRQoL for ICU survivors is the 36-item Short Form Health Survey (SF-36). The SF-36 is reliable (Cronbach's $\alpha=0.85$) and has been validated specifically in the critically ill population (Chrispin et al., 1997; Cuthbertson et al., 2010; Farley et al., 2016; Hofuis et al., 2010; McPeake et al., 2017; Steenbergen et al., 2015).

ICU Survivors and Quality of Life

ICU survivors have decreased quality of life when compared to the general population or even non-ICU patients discharged from the hospital; this is consistent across all the studies that examined HRQoL as a patient outcome metric (Cuthbertson et al., 2010; Farley, et al., 2016; Hofuis et al., 2010; McPeake et al., 2017; Steenbergen et al., 2015). This is perhaps not surprising given the widespread impact that PICS may have on ICU survivors' lives. PICS symptoms are most often grouped within three domains: mental or psychological, physical, or cognitive status (Nakanishi et al., 2021). Most often, ICU survivors are affected in only one of the domains, however, some patients are known to have two or more domains involved, highlighting the complexity of ICU survivorship (Rasulo et al., 2021).

Depending on the study, approximately 30% (10-50%) of ICU survivors experience mental health symptoms, including anxiety, depression, PTSD, or nightmares, and these symptoms do not dissipate with time alone (Harvey & Davidson, 2016; McPeake & Mikkelsen, 2018; Rattray & Hull, 2008). Patients may also have persistent physical issues such as muscle weakness, breathlessness, or decreased neuromuscular function (Harvey & Davidson, 2016;

Morgan & O'Conner, 2018). These issues can lead to a patient's inability to perform tasks of everyday living independently. In multiple studies, 20-25% of survivors required extra support with activities of daily living (ADLs) at six and 12 months post-ICU, when they were previously independent pre-hospitalization (Cuthbertson et al., 2005; Griffiths et al., 2013; McPeake & Mikkelsen, 2018; Morgan & O'Conner, 2018). The impact of increased dependence may be profound and include increased costs associated with care (outside help or family member), changes in relationships between family members, and loss of independence, among other things (Morgan & O'Conner, 2018). Another aspect of quality of life is employment; this also links with other social aspects of everyday life. There is a discrepancy within the literature regarding ICU survivors returning to work. Depending on the study, 40-70% of patients return to work within five years (Cuthbertson et al., 2005; Griffiths et al., 2013; Herridge et al., 2011). A potential reason for this variation may be due to the social system where the studies took place, for example, in Denmark versus the United States. In Denmark, the health care system is publicly funded, and non-retired residents are eligible for up to one year of their usual salary during rehabilitation after an ICU stay. This is covered by the national social system, while in the United States, health care is not publicly funded and there is no public funding for salary adjustment while on sick leave; it is dependent on third-party insurance which is usually provided through an employer (Agard et al., 2014). In the Canadian study by Herridge et al. (2011), reported that 77% of participants returned to work within 5 years after hospital discharge with the majority returning to work within 2 years. This leads to the question: Are patients returning to work because of necessity, or are they ready? PICS can impact all aspects of a patient's life, which is something beyond measurability. To truly understand what an ICU survivor must face a better understanding of how PICS impacts their everyday lives is required.

Post-ICU Consultation

In response to the poor long-term outcomes that patients face upon hospital discharge, various programs have been developed to help patients and their families post ICU. Following ICU patients after hospital discharge first developed in the United Kingdom in response to the King's Fund panel (Park, 1989) which was mandated to explore the cost-effectiveness of intensive care programs and determine the clinical outcomes of patients as a measure of the effectiveness of ICUs (Park, 1989). The first post-ICU clinic was opened in the United Kingdom and followed post-ICU patients at two, six, and 12-month intervals (Modrykamien, 2012). This service helped develop an understanding of the factors that ICU survivors experience after hospitalization and raised the alarm worldwide about the sometimes grim reality survivors face. This ultimately led to a global consensus among the critical care community that follow-up services were necessary to help ICU survivors manage the after-effects of ICU admission.

Since the initial inception of post-ICU clinics, various models of post-ICU follow-up have been trialled mainly in Europe, the United Kingdom, and Australia; however, to date, an accepted model for ICU follow-up care remains elusive (Modrykamien, 2012; Van Der Schaaf et al., 2015). Post-ICU clinics are rare in North America; in Canada, there are only six such clinics across the country. Some clinics are nurse-led, physician-led, or a combination of both. All clinics have a multidisciplinary model, but the health disciplines included vary between clinics (Modrykamien, 2012; Van Der Schaaf et al., 2015). Some clinics require in-person visits; others involve email or telephone follow-up. This variation between clinics makes it very difficult to compare outcomes between the models. Clinics generally invite patients based on length-of-stay (LOS) and the number of days of mechanical ventilation. During follow-up, patients complete several questionnaires regarding quality of life, depression, anxiety, sleep, and cognition. It is the

results of the questionnaires that relays to the clinical team how their recovery is going and if the patient is showing any early signs of developing PICS (Griffiths et al., 2006). Additionally, it is the results of these questionnaires that determine the potential benefit of the intervention or clinic (Griffiths et al., 2006). So far, follow-up clinic visits do not consistently show benefits for patients based on the metrics collected (Cuthbertson et al., 2009; Jonasdottir et al., 2018; Sevin et al., 2018). The inconsistency in findings could be attributed to the difference in healthcare systems between Europe and North America (Sevin et al., 2018). The discrepancies make it difficult to secure funding for expanding post-ICU clinics in today's fiscally tight healthcare environment (Modrykamien, 2012).

Although evaluation is essential, it may be possible that critical factors are being missed by only using quantifiable metrics to guide clinic or intervention efficacy/usefulness. Patients and their families find value in having a conversation, either in person or by phone or email, with a care provider from ICU (Griffiths et al., 2006; Jensen et al., 2015; Schandl et al., 2011; Lasiter et al., 2016). Patients and families find it highly beneficial to have conversations with any provider who can give context/education for their ICU stay and recovery (Griffiths et al., 2006; Jensen et al., 2015; Schandl et al., 2011; Lasiter et al., 2016). Each patient has a different experience within ICU, and how a person perceives and feels about this experience is highly individual; therefore, how a person recovers from such an experience is also likely to be unique (Griffiths et al., 2006; Jensen et al., 2015). Answering questionnaires alone is not directly helpful to the recovery process, and these questionnaires are primarily useful for data collection and quality improvement initiatives. Despite the lack of evidence, the potential impact of follow-up with ICU survivors is profound. Follow-up by PICS-trained staff allows for early identification of potential problems (Griffiths et al., 2006; van Mol et al., 2018).

Patient Experience

An experience is highly personal; our life experiences shape who we are, and our individualities shape our experiences. Understanding the patient experience is beneficial in health care as it facilitates moving beyond treating the illness toward treating the person. The study of patient experience has been examined across all health disciplines as it has been shown that improvement in patient experience improves outcomes and reduces associated healthcare costs (Chung et al., 2020). It is clear from previous studies that patients struggle after critical illness, but it remains unclear why. A logical place to start gaining a better understanding is to ask the patients about their experiences. Through an account of their experience, clinical practice will be better informed.

Patient Experience with ICU

Understanding the patient experience in ICU itself is essential as it remains unclear how much of the care/therapy provided within the ICU contributes to their poor outcomes. Many survivors of critical illness face memory impairment during their recovery. It is also not uncommon for ICU patients to experience delusions or hallucinations during and after hospitalization (Löf et al., 2008). This can make it challenging to appreciate the experience of ICU survivors fully. Many studies have been conducted to better understand the ICU survivor's experience, and patients have reported the experience across the spectrum from comforting to extremely distressing (Löf et al., 2008). It is not surprising that some studies report patients' experiences of aloneness, vulnerability, and the transformation of time and space (Agard et al., 2012; Kang & Jeong, 2018; Papathansoglou & Patiraki, 2003). ICU patients may experience delirium, potentially altering their cognitive and verbal perceptions (Carr, 2007). This finding was not unexpected as ICU patients face potential death, with multiple organ systems not

functioning correctly, in addition to the many medications/therapies used that may alter perception/cognition.

Alternatively, some patients reported that their ICU experiences were positive. Patients who reported their ICU experience as positive still dealt with traumatic events but reported different ways of viewing and coping with them (Agard et al., 2012; Olsen et al., 2017; Papathansoglou & Patiraki, 2003). Interestingly, one study identified those with pre-existing health conditions or disabilities prior to ICU and found their ICU hospitalization as a positive transformation or a “second chance” (Olsen et al., 2017). It remains unclear why some find ICU a positive experience/second chance while others view the experience as negative. One possible explanation for this contrast in experience between patients could be due to recent practice changes across ICUs around the world, such as minimizing sedation and restraint use and increasing family presence and mobilization (McPeake & Mikkelsen, 2018). The contrast of experience could be related to these practice changes, but it is unclear if these practices were in place when the different studies were conducted. It could be as simple as the relationship between the health care team and patient, as that has been shown to heavily influence patient experience; specifically, nursing staff are frequently thought of as a source of comfort for patients (Olsen et al., 2017). The results of experiences from qualitative studies are not generalizable. Still, they are essential to better understand the patient’s perspective as they can help highlight needed changes.

Patient Experience with Post ICU Follow-up Clinics

Understanding the patient’s experiences with follow-up services will help improve the services offered to meet the needs of the target population (Clay & Misak, 2016). It remains unclear who the target population for attendance at an ICU follow-up service should be. All

patients who have been in an ICU for any length of time should be offered the service, but this is cost-prohibitive (Griffiths et al., 2006). There is no practice standard on the implementation of follow-up services for ICU survivors or even what qualifies as a diagnosis of PICS as there is not a consensus on the assessment tools used for diagnosis and further evaluation (Svenningsen et al., 2017; Vrettou et al., 2022). Of the limited number of studies conducted examining the patient's experience with ICU follow-up, the overwhelming consensus was that patients find follow-up useful for education and validation of their experience (Agard et al., 2014; Hanifa et al., 2018; Haraldsson et al., 2015; Svenningsen et al., 2017; Williams & Leslie, 2008). Patients usually do not remember their admission to an ICU, or much of their stay, due to a combination of medical therapies (sedatives) and disease processes that render their memories disjointed and sometimes delusional (Hanifa et al., 2018; Williams & Leslie, 2008). Follow-up allows a patient to open up about their stay, to talk with someone who understands the complexities of ICU and validates their experience.

Patients who leave the ICU receive education on what to expect in recovery from a pathophysiological / disease trajectory perspective. Still, there is little education given to patients and families on what to expect when recovering from their ICU stay. Validating the bad dreams, constant fatigue, and breathlessness as a regular part of recovery has meaning to patients and helps normalize their experience (Hanifa et al., 2018). All studies in this review on the patient experience with follow-up took place outside Canada, and no studies exploring the Canadian perspective were identified. Unfortunately, there is currently no intervention that has clearly shown to benefit ICU survivors in their recovery from critical illness in reducing PICS symptoms (in all domains) or future health care utilization (Lasiter et al., 2016). This highlights the lack of understanding of ICU survivors' needs and expectations after hospitalization (Vlake et al., 2020).

This may be further compounded by the recent COVID – 19 pandemic which has shifted both the function and experience of ICU and health care since 2020. The background of COVID-19 and how it may directly impact ICU patients will be explored further.

Novel Coronavirus (COVID-19) and the ICU Population

Coronaviruses are a family of RNA viruses that can lead to infections in humans and animals (World Health Organization [WHO], 2020). Most commonly in humans, the infection is of the respiratory system, and infections may range from symptoms similar to that of the common cold to a severe infection of the respiratory system, as is the case in SARS-CoV-2 (better known as COVID-19) (Singhal, 2020; WHO, 2020). The particular strain of coronavirus that caused COVID-19 was discovered in December 2019 and originated in Wuhan City in Hubei Province, China (Singhal, 2020). COVID-19 is transmitted from an infected individual (either symptomatic or asymptomatic) via respiratory droplets (usually generated from coughing or sneezing), prolonged close contact, and a non-infected individual touching a contaminated surface then touching the mouth or eyes (Government of Canada, 2020; Singhal, 2020). For most people, COVID-19 leads to a mild to moderate upper respiratory infection that requires no further intervention beyond supportive care at home (fluids, rest, and over-the-counter medication for symptom management). Unfortunately, COVID-19 may lead to a more severe infection in some; those with advanced age, co-morbidities, and immunocompromised are at the highest risk of developing a more severe infection (Government of Canada, 2020; WHO, 2020). In its most severe form, COVID-19 may progress to respiratory failure, multiorgan dysfunction, and death (Singhal, 2020; WHO, 2020). Currently, the mortality rate of the virus is between 2-3% (Singhal, 2020).

During the early emergence of COVID-19, it was clear that this virus could spread quickly and globally. With no vaccine available at the time and no definitive treatments available, the concern worldwide, and here in Alberta, was the limitation of resources in the health system (Niederman et al., 2020). Before the pandemic, there were 293 ICU beds in Alberta, and every ICU in the province increased their bed capacity in preparation for a potential COVID-19 spike to 1374 ICU beds in the province (Alberta Health Services [AHS], 2020). There was additional concern about the availability of personal protective equipment (PPE), medications essential for ICU, and healthcare workers (RNs, RRTs, and MDs). To limit the spread of the virus and not overwhelm the fragile balance of available resources within ICUs, many restrictions and limitations were put in place to “flatten the curve.” Restrictions included the closing of schools, daycares, universities, gyms, pools, movie theatres, in-person dining, malls, and in-person hospital visitation (Government of Alberta, 2020). Restrictions began to ease in Alberta on May 14, 2020 while the city of Calgary was held back until June 1, 2020 due to the number of active cases (Government of Alberta, 2020). Restrictions were implemented again in December 2020 in response to rising case numbers and hospitalizations. Fortunately, a vaccine became available in late December 2020; In addition, new variants of SARS-CoV-2 within the community are known to spread more easily. It is clear that COVID-19 may potentially affect ICU patients during and after their ICU stay in multiple ways (see next section). As of late, all COVID restrictions have been lifted within the community, but restrictions still exist within the hospital system in Calgary, AB.

Impact of COVID-19 on ICU Patients

The most obvious way COVID-19 might impact an ICU patient is having the virus and requiring ICU care. Throughout this literature review, specific disease processes have been

avoided so as not to stereotype the ICU survivor. I believe it is worth speaking of COVID-19 survivors based explicitly on the number of patients seen in the ICU. So far, emerging data reports that COVID-19 survivors face more pronounced challenges. This has been largely attributed to PICS, with as many as 90% of former ICU patients showing signs of PICS, an increase from pre-pandemic data (Tingey et al., 2020; Weidman., 2022). Reducing the risk of developing PICS requires a reduction in the number of ICU days, minimization of ventilator days, and reduction of unnecessary over-sedation (Kotfis et al., 2020). Unfortunately, all patients with COVID-19 admitted to ICU have acute respiratory failure which generally requires a lengthy ICU stay, potentially a prolonged course on a mechanical ventilator, and heavy sedation with the use of paralysis for the patient to tolerate modes of mechanical ventilation that are of benefit to them (Tingey et al., 2020). Currently, there is no cure for COVID – 19; it is a viral illness that requires supportive care.

In addition to heavy sedation and paralytic practices, patients often receive at least one course of high-dose steroids; this is well documented to contribute to ICU delirium (Kotfis et al., 2020). Many of the strategies that have been developed and proven to help minimize the risk of developing PICS have been abandoned due to the specific challenges of the pandemic. For example, restrictions on family visitation/presence, shown to help minimize stress and anxiety of patients, was halted to help protect patients/staff/families from the transmission of COVID-19. Patients are all treated by care providers in extensive personal protective equipment (PPE) who are busy tending to multiple sick patients, which can hinder communication and be frightening (Murray et al., 2020). It is well established that as a result of this pandemic, daily life has changed. The ICU environment is not excluded from many of the social distancing practices in place to help curb the spread of the virus. Unfortunately, these practices may further exacerbate

post-ICU complications of PTSD, anxiety, fear, and a sense of isolation, which are some of the defining characteristics of PICS (Kotfis et al., 2020). It is a delicate balance to limit the spread of the virus and minimize the risk of harm to those providing care (health care workers, family, and other patients) for patients within the ICU while providing care to help reduce PICS.

Family Presence in ICU

The definition of family is “the basic unit in society traditionally consisting of two parents rearing their children. Also, any of various social units differing from but regarded as equivalent to the traditional family” (“Definition of family,” 2020). Health care today most often accepts that ‘family’ is who the patient/client identifies as their family and is not limited to those under legal or genetic definitions (Gerritsen et al., 2017).

Visitation policies within an ICU remain diverse even within Canada. The idea of extended, open family visitation is relatively new within the ICU environment. In the past, it was common for ICUs to have highly restrictive visitation policies, only allowing families to visit for one to two hours per day and at designated times (Gershengorn & Garland, 2016). The traditional view was that families could negatively impact patient care by adding stress to the patient and staff (Gershengorn & Garland, 2016). Within the last twenty-five years, progress has been made to make families an integral part of the care provided, as research has shown many benefits to having family present (Gershengorn & Garland, 2016). Many ICU patients are in an altered mental state or unconscious during their ICU admission, and the family melds into a partnership with the health care team to make decisions about care (Gerritsen et al., 2017). The presence of family helps provide a sense of support and security during the stressful time in ICU (Olsen et al., 2009). The family also provides an invaluable resource for healthcare providers by

humanising patients in what is an overwhelming technological environment (Gerritsen et al., 2017; Gershengorn & Garland, 2016).

In Calgary, Alberta, family presence within the ICU is highly encouraged by all levels of the ICU team. The provision of “excellent patient and family-centred care” is a part of the vision of the Department of Critical Care Medicine in Calgary (Department of Critical Care Medicine [DCCM], 2022). However, on April 4, 2020, all in-person visitation was prohibited due to the pandemic. Every attempt was made to connect families via other technological methods, such as video conference. These restrictions were relaxed officially on July 2, 2020, allowing for 1-2 designated visitors at some of the sites within Calgary, AB, but all visitors must first pass through screening (AHS, 2020). This is inconsistent across the city and is unit/hospital dependent leading to further confusion for families. Early research has indicated that this contributes to a patient feeling isolated and withdrawn (Cutler et al., 2013). As more patients move through the ICUs, the full impact of these decisions will become more clear.

Positioning my Study Within the Current Literature

The literature review clearly shows that ICU survivors are a complex, multifaceted population. Despite the abundance of research conducted on PICS and related subjects, it is evident that ICU patients during COVID-19 are at higher risk of poor outcomes related to their ICU stay, regardless of the reason for admission. Additionally, the COVID-19 pandemic has added another potential risk for an already vulnerable population. Through my study, I hope to develop a more comprehensive understanding of the perspectives and experiences of ICU survivors in Calgary, Alberta, during the COVID-19 pandemic. This understanding will help better inform the services currently offered to patients following discharge from ICU and clinical care within the ICU.

Chapter 3: Methodology and Methods

The methodology of a study describes how a researcher approaches the topic or question asked (Davey, 2017; Vasilachis de Gialdino, 2009). In qualitative work, it is the phenomenon that is being examined which determines the methodology used. The methodology determines how the question is thought about, how to engage with participants, and the generated data (Bloomberg & Volpe, 2019). The phenomenon being examined in this study is the experience of former ICU patients after hospital discharge during the COVID-19 global pandemic with the research question “*What are the experiences of patients discharged from ICU in Calgary, Alberta who are at risk of developing Post Intensive Care Syndrome during the COVID-19 pandemic ?*” PICS and the patient experience with ICU is a newly recognized area of study and is heavily rooted in the clinical realm of ICU. A qualitative approach was selected to answer the research question and inform an understanding of the experiences of former ICU patients in Calgary, AB. The methodology used for this study is Interpretive Description (ID). In this chapter, I will provide some background to ID, justification of ID as my choice for method, the philosophical underpinnings of ID, study methods, ethical considerations, and issues of credibility.

Background of Interpretive Description

ID was developed initially in 1997 by Sally Thorne and two of her graduate students, Sheryl Remer Kirham and Janet MacDonald-Emes, in response to the distinct need within applied health fields to answer questions driven by clinical phenomena (Hunt, 2009; Thorne, 2016). There is an underlying tension in using many of the more traditional methodologies in qualitative research when answering questions generated from the clinical realm in health research, as there is a high risk of method “slurring”, especially for a novice researcher such as

myself (Thorne, 2016). ID was initially developed to answer questions within applied nursing practice and has been taken up by various other disciplines such as education, social work, and medicine (Thorne, 2016).

Justification of Methodological Choice

The development of my question was derived from my clinical practice as an RN in the ICU in Calgary, AB. The decision to study this population developed from reflection on my practice. I discussed methodological approaches with my supervisor and other faculty, and ID was proposed by a nursing faculty member as a way to answer my research question and also to answer one of my initial curiosities “is there anything that I can change in my practice to help make things better for former ICU patients?” One of the things that initially drew me towards ID was the ability to take a real-world question and use it to study a phenomenon for the generation of knowledge to improve clinical practice rather than for theory development (Thorne, 2016).

Moving past this initial phase, I had to ensure that my question would be one that worked well with this methodology. Thorne (2016) stated that for ID to be the most appropriate methodology for a study, three criteria should be met: (1) My question is a real-world problem generated from my actual clinical practice. Understanding what ICU patients go through during and after hospitalization could help highlight areas for improvement in inpatient and community care; (2) My literature review developed my understanding of what is known and not known about the topic (Chapter 2); (3) There is an broader interest in the knowledge generated beyond my own curiosities. The experience of former ICU patients is still a relatively new topic and I believe it is of interest to those involved in critical care and post ICU care. Having met the three criteria set out by Thorne (2016), I then moved forward in developing my ID study. In

developing the study, an understanding of the philosophical roots of ID was undertaken to ensure I was building a study that maintained the essence of ID.

Philosophical Roots of ID

ID is rooted in the three main qualitative research methods: phenomenology, ethnography, and grounded theory (Thorne et al., 1997). The philosophical underpinnings of ID align with constructivist and naturalistic inquiry (Hunt, 2009; Thorne, 2016). Thorne et al. (2004) stated that the three truths of naturalistic inquiry research described initially by Lincoln and Guba (1985) are:

- (1) Multiple constructed realities can only be studied holistically; thus, reality is considered to be complex, contextual, constructed, and ultimately subjective;
 - (2) The inquirer and the "object" of inquiry interact to influence one another; indeed, the knower and known are inseparable;
 - (3) No *a priori* theory could possibly encompass the multiple realities that are likely to be encountered; instead, research outcomes must emerge or be grounded in the data.
- (p.3)

Within these three assumptions of naturalistic inquiry, the ontological and epistemological foundation for interpretive description is uncovered (Thorne, 2016). The first assumption indicates a relativist ontological stance. Relativism is the view that people have their own unique “world” or reality in which they live, and it is relative to the people involved, and the specific context that they are in, or simply, that reality is subjective to each individual and is context-dependent (Crotty, 1998; Lincoln & Guba, 2013). The second assumption indicates an epistemological stance of constructivism. Constructivism is the idea that an individual’s experience is constructed upon is based on the world around them (i.e., social, historical and

cultural influence); therefore, multiple realities can exist depending on the where/when/how of an individual's particular experience (Appleton & King, 1997). With the ontological position of relativism and epistemological position of constructivism, ID acknowledges that an individual participant's experiences are shaped by their own 'world'; therefore, multiple different realities exist as each person's world is unique, and so is how the ways in which they experience the world around them (Thorne, 2016).

Additionally, Thorne (2016) considered that the multiple realities we construct surrounding an experience as human beings that may be contradictory to one another. However, my role as a researcher is to recognize that multiple realities may co-exist without necessarily trying to separate or evaluate the truth claims. Knowledge about a problem or phenomenon is generated through the interaction between the participant and researcher, who influence each other to co-create an understanding of the phenomena in question together (Hunt, 2009).

ID aims to generate knowledge relevant to the clinical context of related health disciplines (Hunt, 2009). It is another way of trying to address a complex experiential question. At the same time, any knowledge gained will be used to help better inform clinical knowledge and practice, not to develop theory (Thorne, 2016). I will now describe how this study was constructed based on the philosophical roots.

Building an ID Study

As with many types of qualitative methods, there is not one specific manner to conduct an ID study. Though there are various design approaches to an ID study, they all start similarly. Before beginning, Thorne (2016) recommended scaffolding the study appropriately to avoid issues later in the analysis phase. Thorne (2016) referred to this scaffolding as "Theoretical

Scaffolding” and is the starting point of all ID studies. According to Thorne (2016), theoretical scaffolding has two essential aspects: (1) The literature review, which allows the researcher to come to know the current state of the applied problem and gain valuable insight into the problem, how others have researched it, and the challenges they have encountered; and (2) The identification of what I (the researcher) will bring into the study beyond my thinking about the problem and positioning the study within a disciplinary orientation of nursing.

Literature Review

For a literature review to support an interpretive description study, Thorne (2016) stated that it must include the following three components. A literature review:

(1) Grounds the study within the existing knowledge, (2) offers a critical reflection on what exists and what does not, and (3) offers interpretive commentary on the strengths and weaknesses within the overall body of knowledge. (p. 67)

In my initial literature review, I found many articles describing PICS, patient outcomes, and studies attempting to reduce the incidence within the post-ICU population. However, I found very little literature about the patient experience. Additionally, with the global pandemic of COVID-19 adding a new layer, I could only find a few articles on how this may impact patients within the ICU at that time, thus reinforcing the need to understand the perspective of former ICU patients once they return home.

Theoretical Forestructure

The second aspect of scaffolding an ID study is the development of a theoretical forestructure, melding the clinical and theoretical positions that I take as a researcher. Three elements to a theoretical forestructure require careful reflection before beginning any research. It

is important for the researcher to 1) locate theoretical allegiances, 2) locate the disciplinary orientation, and 3) locate personal relationships of the researcher to the ideas held (Thorne, 2016,p.70). Within ID, it is acknowledged that the researcher and participant will interact and influence one another.

In my reflection on the theoretical forestructure for an ID study I first started with my theoretical allegiances. As a non-traditional methodology, ID does not follow the more traditional view that a specific theory should be explicitly acknowledged (Thorne, 2016). Indeed, Thorne (2016) cautions researchers to be mindful of the language used as it can indicate to readers a theoretical position.

I combined the final two elements of disciplinary orientation and personal relationships to hold ideas in a reflection on my practice as an RN in ICU. I am mindful that my experiences are from a care provider's perspective, specifically in nursing. I always viewed a patient surviving their ICU stay as a win or a good thing and held the belief that patients went on to live their normal lives after hospital discharge. This changed one day when I happened to see a former patient at a local mall, which was my first experience running into a former patient, and they recognized me. This patient was a young 25-year-old woman who was in the ICU for an extended period of time with H1N1 influenza. Prior to her hospital admission, she was a happy, healthy young woman, but the young woman I saw in that mall was anything but happy or healthy. Physically she appeared gaunt and weak, requiring the help of mobility aids. She had patches of hair loss and appeared unwell. Her voice was nothing more than a whisper when speaking with her. I asked her “how are you doing?” and she was honest with me and stated “awful”. Walking away from that interaction with the former patient, I began to question, “is there anything that I can be doing as a nurse to help patients after ICU is over?” because even as

a health care provider, I had no idea that patients could face such debilitating complications after ICU, especially given that this was a previously healthy young woman. During this reflection, I found it essential to recognize that I understand the operation of an ICU and its specific language or terminology, but in no way do I know what it is like to be the person on the receiving end of this care or living life after ICU. This recognition was essential for me as I believe it helped me better prepare patients and families (pre-pandemic) for the potential complications after ICU. The clinical experience of caring for ICU patients will help me understand what some participants relay in my research.

Methods

There are multiple ways to conduct data collection and analysis for an ID study. I will now describe the method that I used.

Sampling and Recruitment

In an ID study, there is not one specific way to sample, and one must orient the findings to the sample they came from (Thorne, 2016). In my study of former ICU patients, I wanted to gain knowledge from the people who have experienced an ICU stay and were at risk of developing PICS post discharge during the COVID-19 pandemic. Therefore, I was looking for a population with a particular experience and participants were recruited through purposive and convenience sampling via the post-ICU recovery clinic offered through Alberta Health Services (AHS) at Foothills Medical Centre and South Health Campus in Calgary, Alberta. All former ICU patients invited to the clinic had been discharged from an adult ICU within the Calgary Zone of Alberta Health Services and were deemed at risk of developing PICS, based on a minimum of three days in the ICU with at least three days of mechanical ventilation.

Before attending the ICU recovery clinic, all former ICU patients received a letter inviting them to participate in the recovery clinic. I included an invitation (Appendix A) to participate in this study with that letter. A consent form and background information on the study were included (Appendix B), as well as my contact details. For this study, inclusion criteria were those who were patients in a Calgary ICU for a minimum of three days requiring mechanical ventilation for those three days, the age range of 18-99 years old. Exclusion criteria included individuals discharged from the hospital less than three weeks before attending the clinic, inability to communicate in English, or unwilling to give informed consent.

I enrolled three respondents who met inclusion/exclusion criteria into the study. Participants were a mix of males and female with different ages and reasons for ICU admission. Although the sample was small, this number is considered adequate for an ID study of this kind to support a meaningful clinical description and gain an in-depth understanding of the issues (Thorne, 2016). Furthermore, three participants were considered feasible given the challenges of post-ICU recovery and COVID-19 pandemic restrictions and limitations. The three participants offered rich and detailed stories and insights into the experience of post-ICU recovery during the COVID-19 pandemic.

Within an ID study, a smaller sample size is acceptable as the goal with ID is not to achieve “saturation”, with the caveat of explicitly stating that there will always be variation with human experience and more to study (Brudine et al., 2020; Thorne, 2016). Additionally, with such a small sample size, it is clear that the sample is not representative of the entire post ICU population. Thorne (2016) recommended acknowledging that the goal is to keep representation in mind while recognizing that it is ultimately unachievable with this type of study. However, she stated that an ID study: "...will reflect a certain kind of perspective built from an auditable

set of angles of vision whose nature and boundaries we can explicitly acknowledge and address" (Thorne, 2016, p.97-98). The stories that each participant shared were rich and powerful within each of their unique experiences.

Data Collection

In an ID study, data collection and analysis occur concurrently as an iterative process (Brudine, Thorne & Sandhu, 2020). Before beginning data collection, Thorne (2016) suggested acknowledging and documenting ideas and biases about the phenomenon under study. Participating in this reflective process before beginning data collection allowed the opportunity for reflexivity and to document what happened to me as the researcher throughout the data collection and analysis process (Thorne, 2016). This is not considered part of the data itself and is not included as a part of the study. However, this reflection allowed me to better understand the implications of my role as a researcher during data collection and analysis (Thorne, 2016). I completed this process before beginning my data collection via journaling and meeting with my supervisor to ensure reflexivity. Before starting my data collection process, I wrote down my expectations for each interview and what I thought I would learn.

The overarching goal of any data collection is to get as close as possible to the subjective experience to gain the information or material necessary to answer the study's research question (Thorne, 2016). I used semi-structured interviews as my data collection method based on my research question. Interviews are ideal for generating knowledge to answer my proposed research question, as those who have lived a particular experience are often the best source of those experiences (Thorne, Kirkham & MacDonald-Emes, 1997). Thorne (2016) "cautions the researcher to be aware that human subjectivity exists and to be humble regarding uncovering experiences as they reflect a specific relationship to time and place" (p. 139). To enhance the

quality of the interview and the data obtained, I followed further guidance from Thorne (2016) to have careful planning before entering the interview to ensure appropriate attitude and communication are used to build rapport (Thorne, 2016). This rapport is essential as it allows for an easy conversation with the participant, providing a sense of respect and safety (Thorne, 2016).

Initially, I had intended for data collection to occur via semi-structured interviews after the participants' visit at the ICU recovery clinic (South Health Campus or Foothills Medical Centre) or at a time of convenience for each participant. Each of the interviews was to occur within the clinic/hospital and was to be conducted in a private office to help minimize noise or interruptions and ensure confidentiality or in an area with reduced noise if the participant preferred to meet in another public setting. Unfortunately, due to social distancing guidelines related to the COVID-19 pandemic, all interviews were conducted via audio/video calls at a time of convenience for each participant. The time frame for each interview ranged from 35 to 120 minutes. This length of time allowed the participants to feel comfortable with the process and allowed them time to expand on their responses. Verbal consent was obtained from each participant before the interview commencing, and an electronic consent form was provided to each participant. There were a few guiding questions to get the interview started, such as "*Tell me about what brought you to this point,*" "*How has your life changed after ICU?*" and "*Tell me about your life at home now*" (Appendix C), however, questions varied between interviews. In ID the interviews are not fully structured but are a conversation with each participant. All interviews were digitally audio-recorded, and field notes were written immediately following each interview. The interviews were transcribed verbatim for further analysis after the interview had concluded. To further ensure reflexivity, I spoke with my supervisor after each interview via

phone or email. Data collection and analysis were done concurrently, which is essential to ID methodology (Thorne et al., 2004).

Data Analysis

During the data analysis phase of ID research, the focus is to illustrate the patterns and themes that emerged from the data and present them in a relevant way to the discipline of origin (Thorne, 2016). When first beginning data analysis in a qualitative study it can become onerous and easy for the researcher to become overwhelmed with the vast amount of data, especially for a novice researcher such as myself. To help manage this, Thorne (2016) recommends four strategies: 1) remain true to the purpose of your study; 2) enter the data broadly at the beginning to gain a true understanding; 3) borrow from other qualitative techniques to aid in analysis; and 4) ongoing reflection throughout the analysis process, not only to prevent premature findings but to explore ongoing questions.

The initial step when reading the transcripts was first to remember my study aims to help situate myself. Then I read and re-read the transcript to understand what was occurring throughout the interview, keeping a broader view of the interview and to understand the participant's story as a whole (Thorne, 2016). Each transcript was read several times to move through the many layers to immerse myself within the data before beginning any re-organizing of the data (Teodoro et al., 2018). Additionally, the field notes collected during each interview were added to each interview on the margins of the transcript. The field notes are considered as essential to ensure the essence of each interview is maintained and consistent among interpretations. Field notes also may help highlight reactions, and non-verbal cues, which are equally important during analysis (Thorne et al., 1997).

At this stage, I started to pick up on critical quotes from the interviews that resonated; I returned to the question, ‘what is going on here’ and would refer back to my overall question. I was concerned that I was not seeing beyond the obvious and prematurely jumping to conclusions. After consultation with my supervisor, it was decided that I should consider writing a narrative of each participant's story as a way of seeing the whole picture in order to provide a description of what each individual’s experience had been in ICU and their life after. I then began to work with each participant's narrative from the whole story rather than just selected quotes to maintain a broader view of what was occurring within the data. This broader view with immersion in the data is essential with ID to ensure a holistic understanding of the phenomenon in question and adds to the validity of the interpretation (Teodoro et al., 2018). This narrative that acts as the descriptive portion of ID is included at the beginning of Chapter 4.

With the narrative in hand, I felt I had immersed myself in the data and allowed for a better understanding in moving forward with analysis. Commonly in the analysis phase of a qualitative study is the use of coding in order to help organize the data for the researcher. Thorne (2016) cautions researchers against using traditional coding methods of line-by-line in ID as this rigidity can negatively impact good interpretive thinking. Instead, Thorne (2016) advocates a more creative approach by using colour schemes or note-taking during analysis to help group segments of data. I employed this method in consultation with my supervisor using colour-coded post-it notes to help organize my key quotes. The use of post-it notes allowed the freedom to move quotes and data segments around easily to see things from different perspectives. The data was then organized into flexible patterns to see the interrelationships between and among the patterns (Thorne, 2016).

At this data analysis stage, I borrowed from the Grounded Theory method, and applied constant comparative analysis within and between the transcripts and narratives to find common themes/concepts (Thorne et al., 2004). Constant comparative analysis ensures that premature themes or concepts are not brought forward (Thorne et al., 1997). The resulting concepts and themes are further analyzed with an ID lens to assess relationships or the impact of sequence (Thorne, 2016). I began to notice commonalities across interviews about family importance, communication barriers, dealing with the new reality after ICU and normalizing the post-ICU experience. For example, a quote that was colour coded from an interview was, “ I wasn’t really understanding very much, so every single day, they would have to keep reminding me where I was telling me where I was because I couldn’t figure it out.” This quote was coded under the health care-patient needs. It was also brought up across interviews about barriers to communicating or understanding. I sought to understand the common thread among the participants in relation to how do these barriers, and patient understanding fit together. After further discussion and reflection with my supervisor, it became clear that the interpretation of the data showed that communication challenges was a key theme across all participants in the experience of patients after ICU. The final product is not a new concept or framework but a thematic summary. This thematic summary illustrates to readers the resulting concepts within the phenomena that can be viewed through an ID lens as a means to advance knowledge of the phenomena under examination (Thorne, 2016). This thematic summary acts as the interpretive portion of ID in this study, which is presented in Chapter 4, as the themes identified have come from my interpretation of the data. A discussion of the interpretation of the themes in the context of the current literature can be found in Chapter 5. The key themes identified from the data analysis were *Communication Challenges; Living with Uncertainty; and Post ICU Fallout*

Through the use of ID, I was able to further build upon what was already known about the experience of ICU survivors from the literature review (Chapter 2) and highlight areas for improvement to bring back to clinical practice, which I will discuss further in Chapter 5.

Ethics

Ethical approval is an essential requirement of all research that involves human subjects (Gearing et al., 2006). This study received supervisory committee approval and ethical approval from the University of Calgary Conjoint Health Research Ethics Board (CHERB) (REB19-1279). Approval was also obtained from Alberta Health Services (AHS) before commencing the study. The study's potential ethical issues were confidentiality, privacy, patient complaints/concerns with care received, and the discovery of imminent harm to self or others.

To ensure that confidentiality and privacy were maintained, all information obtained or transcribed electronically was stored on a password-protected server, and the files were encrypted. All written and printed data were stored in a locked filing cabinet. Specific identifiers were removed and replaced with more generic identifiers; for example, all participants are identified by a pseudonym in all written work. There may be instances where a participant's story may be recognizable despite best efforts to remove specific information, and participants were made of aware of this possibility in the consent form before the interview commenced. In one instance, concerns were raised during the interview regarding care received, and information about the patient advocate service was provided. Recognizing that reliving these experiences can be difficult if the participants' experience of ICU was emotional or anxiety inducing, a list of free mental health services was available to all participants. When faced with a concern about one participant experiencing a difficult time during the interview, I spoke with my supervisor about the situation to discuss if further action should be taken; ultimately, it was determined that no

other action was to be taken. Following the University of Calgary Ethics guidelines, all documents related to the study will be destroyed five years after completion of the study. Finally, the ethics application was closed, with the research ethics board informing them of the completion of the study.

Credibility

The credibility of a qualitative research study is akin to the validity of a quantitative study; that is to say, the study results are not merely the researcher's opinion (Thorne, 2016). It is essential to maintain credibility with any study but since ID studies may inform future practice or policy they must present as a credible source of information. To maintain credibility within an ID stud, the researcher must adhere to four criteria described by Thorne (2016), which are not limited to ID studies but are required across all qualitative work. According to Thorne (2016), "a study must: have epistemological integrity, representative credibility, analytic logic, and interpretive authority" (p.233-235). I will go through each of the four criteria to provide evidence of the credibility of this study.

The first criterion for credibility is that a study must show that it has epistemological integrity (Thorne, 2016). Thorne (2016) advises, "the research process must reveal a research question that is consistent with the stated epistemological standpoint and an interpretation of data sources and interpretive strategies that follows logically from that question" (p.233). The epistemology of ID was discussed earlier in this chapter, and the research question is consistent with the epistemological standpoint for ID of constructivism. I have previously justified my data sources of interviews as former ICU patients are the best source to answer the research question. The interpretive strategies used are logical from the data generated.

The second criterion is that of representative credibility, which is that the findings of a study align with the sample or that a researcher does not make claims in findings that overstep the given sample (Thorne, 2016). To ensure representative credibility Thorne (2016) provides steps that the researcher can take, such as prolonged engagement with the phenomena, data triangulation/multiple sources of data or obtaining various views of the phenomena under study. In this study I ensured representative credibility as I have had a prolonged engagement with the topic and the data over the last 5 years throughout my Master in Nursing program. While the sample size for this study is small, each of the three participants provided very diverse experiences of the ICU and their experiences after hospitalization. Also, I do not claim the findings of this study to be generalizable to the broader post ICU survivor population; ICU survivors may recognize some elements of their experience reflected in the findings, and health care providers working with this population may find value in reflecting on their practice in light of these findings.

The third criterion is that of analytic logic in which the researcher must articulate decisions made throughout the study (Thorne, 2016). To achieve this, I kept a research journal throughout the study where I would reflect on stages and note biases and decisions made about aspects of the study. Additionally, I discussed my self-reflection with my supervisor throughout my data collection/analysis stage to ensure reflexivity. Key decisions are also supported by links to data to provide an audit trail between themes and data.

Finally, the fourth criterion is interpretive authority, that is, ensuring the results or interpretations of a study are trustworthy and do not simply reveal the researchers' views or biases (Thorne, 2016). I took steps within this study to increase interpretive authority by having guiding open-ended guiding questions for each interview only. Additionally, I practiced

reflexivity and reviewed data analysis with my supervisor to ensure that my biases were not influencing my interpretation of the data.

Summary

A qualitative research approach via ID methodology was used to guide the research of this study in the generation of knowledge about the experience of former ICU patients at risk of developing PICS during the COVID-19 pandemic. The rationale for the choice of interpretive description was the improvement of current clinical practice for post ICU patients, as the improvement of clinical practice is one of the defining features of an interpretive description study. Data was collected via interviews and analyzed for themes and patterns across them using constant comparative analysis. Ethical approval for this study was obtained via the University of Calgary Conjoint Health Research Ethics Board (CHERB) (REB19-1279) and operational approval was obtained from Alberta Health Services. I will now move into Chapter 4 which will begin with a descriptive narrative of each of the participants and then move into the thematic summary developed from interpretation of the data. The themes identified from the data are *Communication Challenges; Living with Uncertainty; and Post ICU Fallout.*

Chapter 4: Research Findings

In this chapter, I present the research findings from interviews with three participants about their ICU experience and life after hospital discharge. The participant age range was 32-65 years, with two males and one female. All participants met the inclusion criteria of at least three days of mechanical ventilation and admittance to a Calgary ICU. The three main themes from data analysis are Communication Challenges, Living with Uncertainty, and Post ICU Fallout. Before discussing the themes, there is a description of each participant's stories. This description helped to give a better perspective of each participant as people in their everyday lives and allowed me to immerse myself in the data. From each of these detailed descriptions of participant stories and multiple reads of the transcripts with additions of reflections and field notes, I was able to apply my interpretation of the data in conjunction with some of the broader literature to develop a thematic summary of the participants' experience with ICU and life after hospital discharge.

Participant Stories

Sam's Life-Changing Experience

Participant 1, "Sam", was a 48-year-old male, married with university-aged children. Sam responded to the invitation letter via email to set up a time to meet. Sam and I met virtually via video conferencing to conduct the interview. This interview was easy to arrange, and I found Sam was eager to participate. He had been home from the hospital for approximately five months. When asked about his background and life before ICU, Sam was very strict with the details he provided in almost a robot-type fashion. He is employed full-time and is the primary financial support for his family; his employment requires that he work away from his family's primary residence in Saskatchewan for long periods, and it is physically demanding work that he

performs. Before his hospitalization, Sam had never been hospitalized for any extended period and was otherwise healthy. He was in the ICU during the beginning of what has been referred to as the beginning “second wave” of the COVID-19 Pandemic during the fall of 2020.

I started the interview by asking about what brought him to the ICU, and the interview followed a chronological timeline from his ICU stay to the present day. Sam was brought into the ICU in early October of 2020 due to a traumatic injury requiring eight days of mechanical ventilation and approximately twelve days in one of the adult ICUs in Calgary, Alberta, based on his recollection of the experience. He spent an additional twenty-one days in the trauma ward in Calgary, Alberta. After this period, he was required to remain in the Calgary area for a few follow-up appointments before returning to his primary residence in Saskatchewan; all further follow-up was conducted via video conferences and with his primary care physician (family doctor) in Saskatchewan.

Regarding his memories of the ICU, Sam does not remember much and what he does remember is very patchy. During the discussion of his memories of the ICU, those of his wife's presence seem to bring the most comfort, as exhibited by his smiles during the interview. Sam has no direct memory of what brought him to the ICU. He went to work one day and woke up in the ICU with “lots of stuff attached to me.” Having the presence of his wife during this period brought about a sense of comfort for Sam as initially he did not believe that anything was wrong and did not understand the gravity of his situation. “And I think it was either Sunday night or Monday that she told me what happened. I didn’t believe her. Oh, no, I didn’t. And then finally, I realized that I was not in good shape.” I was curious about this experience for Sam and if receiving this information brought about greater meaning for him when coming from his wife instead of a healthcare provider.

...I would think mentally just with a healthcare provider, there's no personal relationship, none, and it is in one ear and out the other. I guess depending on the relationship; it's your wife or your spouse; she starts talking and telling me how bad it is. Yea, no, I would think it was for me. It was better to have my wife explain what happened.

I could tell this was very important to Sam, that his wife was a source of comfort and safety for him. I had the distinct impression that his wife was one of the few people he felt safe being vulnerable with, and I made a point to note this during our interview. As we further discussed his hospitalization, I asked Sam when he started to remember, and he reported his last day in ICU and transfer to the trauma ward. "No, for the most part in trauma, I remember probably most everything because once I got transferred to trauma, I was on my own." The statement "I was on my own" stuck out for me as it conveyed feelings of isolation and fear. I decided to explore this further with Sam. As evident from earlier questions, his primary support person was his wife, who will be referred to as Jane. Jane was allowed visitation while in the ICU. Still, during his hospitalization, there was a spike in COVID cases in Calgary, and visitation to the hospital was limited once he was transferred to the trauma unit. Therefore, he was no longer allowed in-person visitation with his wife, making him feel as though he was on his own while on the ward.

That was horrible. It wasn't the hospital's fault; it was just, no, it was terrible. I never saw my wife for 21 days when I was in the hospital; I couldn't. She was there in Calgary like we live out in Saskatchewan, so she was there in Calgary and never left, and we had video calls every day, but it wasn't the same.

This was one of the significant moments in our conversation. Sam's voice cracked while describing the experience of not having his wife present, and his eyes became glassy, giving the

impression of tears. Adding further to the distress of not having the presence of family, Sam described a situation to me regarding his understanding of further surgery required.

Here is a fine example for you. The doctor told us I had to have a fusion between C1 and C3. Okay, fine. And then I'm so drugged up on hydromorphone, and he says you're going to lose what I thought he said you'll lose 20% of your movement from side to side. Well, it comes out, and we decide to go ahead with the fusion as a family. And then, after the fusion was done, I told my wife I said well, it's not that bad. I'm only going to lose 20%, and she said no, you're only going to have 20%. Yeah, so that was, I mean, I had to have the fusion 100%, but I mean, I was just not in a clear mental state, you know, because of the drugs; it wasn't ideal.

Jane was present virtually via video conference during the discussion for surgery, but not having her at his bedside during those major decisions was "horrible" for Sam. I had the distinct impression that underlying for Sam was a sense of anger with himself for not clearly understanding the conversation regarding surgery at the time. Yet during our conversation, he held no ill feelings toward the system and regarded himself as "lucky" that things turned out well in his favour. Though it should be noted that his hospitalization was not straightforward, he did have a few complications related to his initial injury and other complications related to interventions to save his life. For example, he had to relearn how to swallow post-tracheostomy and developed a secondary infection related to his requirement for a ventilator.

During our interview, there were no examples of PICS-type symptoms brought up by Sam during his description of ICU or hospitalization. When asked questions about the classic symptoms of PICS, Sam initially denied having any issues with sleep, nightmares,

breathlessness, or fatigue. On reflection, he identified that he did, for a short period, have problems with nightmares or hallucinations, but he related them to the drugs he was receiving.

That did happen, but I just, I didn't relate it to the incident or accident; I related it to the drugs, but I did have dreams where my stepdad he's passed, but I remember him. I knew I had to go get a CT scan, and I had a vision of him standing there, holding my hand and taking me to the CT scan.

These hallucinations of a loved one provided him with comfort. He also reported some fatigue but felt lucky to be alive with minimal long-term physical impairment. He denied having any issues with PTSD-type symptoms, low mood, anxiety or depressive-type symptoms. While in the hospital at points of transition, Sam received information about expectations on recovery from his physical issues related to his injury. However, he didn't recall receiving any information regarding potential problems with ICU care or possible things to look out for after going home. "Oh, no, I don't remember that specifically no. They explained stuff about the infections, but there was nothing specifically said to me".

Sam eventually returned to his primary residence in Saskatchewan. Since returning home, his care has been primarily under his family doctor, although he did have a few follow-up appointments with his surgeon in Calgary via video conference. Sam also had a follow-up through the ICU Recovery Clinic in Calgary via video conference with the physician lead. Sam highlighted the benefit of having a follow-up with the ICU recovery clinic as he felt reassured.

"I'm new with this. I've never been hospitalized before. He asked relevant questions about my experience outside of the whole hospital or tracheostomy or fusion". As mentioned previously, Sam did not recall anyone explaining the potential side effects of ICU, specifically

during his hospitalization. He further said that his one-time virtual visit to the ICU recovery clinic “was probably one of the most useful and sincere conversations we had after leaving the hospital.” He said he had declined further follow-up as he felt better. When asked how things were going since returning home, Sam told me that he was returning to work shortly, returning to his previously held position with the same hours and denied any issues post ICU.

When asked if COVID had any impact on him personally while hospitalized, Sam denied any issues related to COVID and had no fear of being hospitalized during the pandemic. However, he did note that limitations to family visitation had an impact on him related to his wife's inability to visit.

To wrap up the interview, I asked Sam what he would like to see for others in a similar situation as himself, a former ICU patient navigating our hospital system at an unusual time. His response was

You know, a mental health physician would have been nice. When you're getting ready to get discharged, a mental health physician would have probably been an asset. Not that I had, um, like I keep saying that I ever had, I don't as of to date have that. Um, but yeah, that would have helped for sure.

Sam did not elaborate further on why he thought it would be helpful when I attempted to probe further. As evident by the quote, Sam did not feel he had any mental health concerns related to his ICU stay or injury.

Reflecting on my interview with Sam and the raw data, it was clear he was a person who did not like to dwell on things, and it was clear he wanted to move past this experience as quickly as possible. He was a willing, eager participant in the interview, but I had the distinct

impression that answering questions beyond the pathological made him uncomfortable. This was evident by frequently clearing his throat and shifting in his seat when asked about “feelings” or difficult situations. In my initial review of the video recording of our virtual interview, transcribing the interview was challenging at points. I had to check my initial disappointment as I felt that Sam did not elaborate much when discussing his feelings. Two aspects of Sam’s experience resonated with me as I further immersed myself in the transcript/field notes and began making my early interpretations of the importance of having his wife present and the confusion around his conversation with the surgical team regarding his spinal fusion. These resonated with me profoundly as an RN because I never fully appreciated the impact of a patient not understanding what I was trying to convey. As an ICU nurses, we deliver what feels like millions of pieces of information daily to patients and their families, and Sam’s experience reminded me of how impactful our words are. The final thing from Sam's interview that stuck out for me was his recommendation for future ICU survivors to have mental health support. This struck a chord with me for Sam because, throughout our interview, I had the distinct impression that Sam is not one to complain or voice issues related to feelings; additionally, Sam denied any ongoing issues related to his hospitalization or any problems at all; therefore, this statement left me thinking – what did I miss during this interview.

After my initial workings with the raw data, I met with my supervisor to discuss how things went and what was emerging for me from the data. I discussed my initial interpretations and the things that stood out for me. My supervisor reminded me to be cautious not to let this early uncovering sway my perception of future interviews and to write in a reflective journal about the experience.

Retirement is Rewritten for George

George and I started communicating after he responded to my recruitment letter asking for participants. I had the distinct impression that he was initially hesitant to participate in this study. Booking the time for our interview was a challenge as I had left the timing open to George, but he insisted that I select the date and time. Going into this interview, I was nervous as I felt I may have started on the wrong foot, so to speak, with George. I met George virtually via video conference, and he reminded me of a friendly older neighbour, smiling from ear to ear. From the outset of our interview, it was clear that he was a “talker” and loved to discuss things. George is a 65-year-old male married with grown children and young grandchildren, and he and his wife primarily reside in Calgary, Alberta. Two of his adult children also live in the Calgary area. At the time of the interview, he had been out of the hospital for approximately ten months. Both George and his wife are retired and live independently. George reported that he and his wife previously shared a very socially active lifestyle and were active within the community and with their family. When talking about the activities he and his wife once enjoyed, George had a giant smile on his face. At the time of our interview, George had never faced such a potential life-limiting experience or had experienced such a lengthy hospitalization. George shared that he has pre-existing comorbidities of hypertension, COPD, obesity, and a skin condition that required treatment with biologic medications before his hospitalization.

During his hospitalization, George was ill with what he thought was a respiratory illness. He had sought care from his primary care physician, but ultimately, he required further care and sought emergency help via ambulance. From his recollection, George was admitted to a Calgary area adult ICU in April 2020 for approximately 49 days, with about 35 days of mechanical ventilation. George required another 43 days in the hospital in the medicine ward before being

discharged home. George was hospitalized during the initial or “first wave” of the COVID-19 pandemic in 2020. George continues to have follow-ups with various healthcare professionals, some related to his hospitalization and others associated with managing his pre-existing conditions. These appointments are both in-person and via video conference. This is something that he found exhausting at the beginning. “It was pretty trying in the beginning. Okay, like I said that every doctor that ever took a piece of me away wanted to see me within about a month after me getting out.” I found this difficult to hear that a patient felt like just a bag of parts and needed to jump through the hoops of the system. Another potential interpretation of the statement was that George felt the pieces taken away made him feel like he was left as a shell of a person. My background is entirely in acute care; therefore, I don’t completely understand what the outpatient world looks like for patients. George's description was upsetting for me that someone could be made to feel like that. When I asked George for further elaboration on that statement, he became slightly angry, as noted by his change in facial expressions and posture.

George reports not remembering anything about his ICU stay and most of his hospitalization. All of his knowledge about the lead-up to what brought him to the hospital and what occurred during his stay has been told to him by his wife from the notes she kept throughout his stay. Georges’ wife is his primary support person. As he was admitted to the hospital during the “first wave,” there was no visitation allowed in ICU at that time, and due to technical issues, George’s wife was unable to have a video conference to see George during his time in ICU. George reports that his wife did receive regular updates via phone from the medical team while he was in ICU. When questioned whether this was a source of stress, he simply replied “no.” Initially, this stood out as it was the opposite of the previous interview. Still, I

began to question if George didn't find this stressful as he had no memories of his hospitalization.

Once George was transferred to the ward for further management, his wife could visit in person. I made a mental note of how this was the opposite experience of Sams'. George remembers being taken outside by his wife to visit with family outdoors; he mentioned that this was a "neutral" experience for him, and being away from family did not bring him personally any additional distress. George had multiple complications during his hospitalization, as evidenced by his lengthy hospital stay. Some complications were related to his initial injury, and some were related to being so sick for so long. For example, George stated that his recovery memories are "foggy" even at our interview, which was almost a year after hospital discharge. He has memories of what he attributes to dreams/hallucinations, none of which he found distressing. He frequently refers to his hallucinations/bad dreams as his "craziness". The only thing that was a source of stress for George while hospitalized was when he realized the length of his hospital stay. "I do remember the doctor telling me how long I've been in, and I got quite distressed, but I think that's probably the biggest stressor I had."

It was evident throughout the interview that without explicitly asking about PICS-type symptoms, George exhibited many of the "classic" symptoms of PICS, from his fragmented memories and hallucinations while hospitalized to physical and cognitive impairments that continued well into his discharge home. Throughout the interview, George frequently referred to living as "craziness", "brain fog", or "hallucinations". "Really, the first couple or three weeks that I was at home, almost all of my functioning brain time was reliving my hallucinations." George did not appear distressed about discussing his hallucinations or "craziness" as he frequently referred to them. He referred to this experience in almost a detached or cold fashion.

I further asked about his functioning upon returning home and at what point he felt he had returned to being independent. “I would say it took me five weeks before I was really independent.” Again, George did not appear bothered by this experience; it was more a matter of fact for him. He seemed accepting of his situation concerning his cognitive impairment and physical issues after discharge, utterly unbothered by either. I asked if gaining his independence back was an emotional boost for him as a sign that things were moving in the right direction. He replied that it was more helpful for his wife than him personally as “I was no longer a baby anymore.” Though he put on a brave front that the cognitive impairment didn’t bother him, he did mention that he reached out to one of the physicians who took care of him during his hospital stay to ask if he had suffered any brain damage. “I was so far out of it, and I’m usually so well into it.”

Regarding the COVID pandemic and its impact on him during his hospitalization, George denied any personal issues for himself or his family. But further questioning how the pandemic impacted George was surprising, as it affected his care beyond family visitation. Like many ICU patients, George faced limitations in his physical function. He was well enough to no longer require an acute care facility, but his healthcare team deemed a rehab facility beneficial. Unfortunately, just before his transfer, an outbreak was declared at the rehab facility, and the facility was no longer accepting patients.

Okay, it was very clear to me that I was discharged because they did not see any more surgeries. Okay, we’re going to move me to a rehab facility, and just before they could make that arrangement, a COVID outbreak happened there. So what really happened, in a nutshell, is we got home, and I began to understand how limited my physical abilities were. It took about two weeks for my head to clear. I had quite a bit of conflict with my

wife. She wanted me doing rehab exercises, and I just wasn't there; my brain wasn't there for sure.

Two things emerged for me from that statement from George. First, he conveyed that he felt he was disposable from the system as he did not require further surgeries and the impact this experience has had on his relationship with his wife. George appeared more upset about the effects of his illness on his wife now that she now had to become a primary caregiver without additional support. The tone of his voice changed, and his body posture changed when discussing how this experience impacted his wife rather than him personally. This illness had significantly impacted the dynamics of their relationship not only in the hospital but also during his recovery period at home.

It was evident that George had suffered from PICS, as demonstrated by his cognitive impairments and physical issues after discharge. I was curious about his experience with the ICU recovery clinic. He first had a video conference with the clinic a month after returning home. He frequently referred to the appointments as refreshing and helpful. George described multiple situations where the physician he saw at the clinic would directly advocate for further support for him and his wife. When discussing his experience with the clinic, his posture relaxed, and his tone of voice lightened. Upon my reflection, I had the distinct impression that George felt seen as a whole human rather than his parts during his visits with the clinic staff.

As in the previous interview, I asked George what he would like to see for others in a similar situation as himself, a former ICU patient navigating our hospital system. He mentioned more support for his wife. Throughout the interview, it was clear that this hospitalization and recovery had been a strain for George and his wife, with facing possible death and changing roles within the household all taking a toll on the couple. I further asked George if he thought

counselling or mental health support would have been of benefit to him, but he did not believe so directly.

Reflecting on my interview with George and reviewing the raw data of transcripts with field notes and reflections was lengthy. George's interview was long, and I found it challenging to see what he was trying to tell me about his experience. Like Sam, George was an eager participant in the interview, and his willingness to share his experience was abundant. After multiple replays of the interview and during my reflection, it was clear that George took a clinical approach in how he viewed his PICS-type symptoms and the difficulties he faced after ICU, which felt cold. I had a visceral reaction to his complete ease with this experience. This caused me to reflect further as to why. Why did this bring about such a strong reaction in me? The frequent use of the term *craziness* as the description of his hallucinations and other cognitive impairments was uncomfortable for me to hear. For me, the term *crazy* has a negative connotation. I'm not sure what the purpose of this was or if he did this as a protective mechanism. The other vital areas from George's interview that stuck out for me in my initial analysis were: how George was discharged from the hospital. This has multiple facets for me as he was made to feel like an object rather than a person, and he was discharged with little preparation for himself and his wife despite having high needs. At multiple points during the interview, George mentioned he was discharged "because they didn't see any more surgeries," which is saddening that he felt the system saw him as just a surgery. It is heavily drilled into nurses in nursing school that the patient is more than their illness, and unfortunately for George, the system did not deliver for him. On his discharge, George felt ill-prepared to return home, something he said he and his wife didn't fully appreciate until he was home. Once home, he was unsure where to turn to for help, so he and his wife "made do." The final area that stood out for

me from the interview with George is the impact the hospitalization and recovery have had on the relationship between George and his wife. George shared a lot with me, but the tension regarding changing roles within his relationship with his wife was palpable.

Sarah's Life-Changing Experience

Participant 3, “Sarah,” and I began communicating after she also responded to the recruitment letter provided to her by the ICU recovery clinic. She agreed to a date and time that worked for her, and we met virtually via video conference, during which the interview was conducted. I found this interview the most challenging to conduct and analyze, as ICU was a horrible experience for her. Sarah exhibited raw emotion throughout the experience, and I found much of what she had to say challenging as an ICU nurse. Sarah was a 32-year-old female who was married with no children. When the interview was conducted, Sarah had been home from the hospital for approximately six months. Before her hospitalization, Sarah was employed full-time. She was admitted to the hospital during the height of what has been referred to as the “second wave” of the COVID-19 global pandemic in December 2020. Before her illness that brought her to the hospital and ICU stay, she denied any previous health concerns, had no real medical history, and had never been hospitalized.

Sarah was admitted to the ICU in mid-December 2020 for respiratory illness related to COVID. She was in the ICU for approximately two weeks, per her recollection of events. She knew she had COVID before being admitted to the hospital and struggled at home for a few days before requiring transfer by ambulance to the closest hospital. Attempts were made to avoid mechanical ventilation but failed, and Sarah had a breathing tube placed for approximately ten days. She was transferred to the medical unit after ICU for an additional 1.5 weeks for further

recovery. After discharge from the hospital, Sarah's aftercare has been conducted with her primary care physician and other allied health specialties (primarily physiotherapy).

Sarah does not remember the first part of her hospitalization in the ICU but has vivid memories of the last half of her stay. On her memory of the first time she realized she was in ICU, a nurse first explained this to her. In the explanation of what happened and where she was, Sarah describes the experience as "I wasn't really understanding very much, so every single day, they would have to keep reminding me where I was telling me where I was because I couldn't figure it out." Although she described the experience of the explanation as "good," she noted the conversation was one-sided as she still had the breathing tube in, making verbal communication impossible for her. As she relived this experience, it was clear that this memory was still strong for Sarah, and she began to cry when talking about this memory. I gently asked what would have been more helpful, and she replied, "I don't think there was anything else that could have really been said or done." Unfortunately, all of Sarah's experiences and memories in the ICU are very negative, as she initially described her overall experience as "horrible" even as she reflected during our interview, it was clear these memories were painful for her. She remained teary throughout our interview, and despite my offers to stop the interview or reschedule, she was clear that she wanted to press on and talk about her experiences.

For Sarah, her poor experience was partly driven by conflict with staff and memories of medical procedures that caused her distress in recounting her experiences. Sarah explains her experience in ICU: "I just remember being super happy to get out of the ICU because it was just horrible, and I felt like I just couldn't stop crying while I was in the ICU." I asked Sarah to further elaborate on what made her experience so poor if she felt comfortable, and she recounted

a situation that had occurred in the ICU about a conflict with a staff member around her decision-making in her care:

I just couldn't speak at all really except for whispers, and they [staff] couldn't really hear me. I wanted to tell them that I didn't really understand what the mask was, but I didn't think I really wanted the fishbone [nebulizer], so I just kind of put my head up in the middle. The one nurse she just kinda [sic] chose it for me. I think it was that and the fact that they didn't really get my family involved either with the decision because I couldn't speak for myself.

During her recount of this memory in the interview, Sarah was visibly upset, crying, and having difficulty discussing this specific scenario. Her lack of being made to feel a part of the discussion or having her family involved significantly impacted Sarah even to this day. This, again, was challenging to hear from the perspective of someone who provides care for those in the ICU, as not being made to feel a part of her own decision-making had a significant impact on Sarah.

I was curious about how Sarah felt about visitation, which resonated with her. Recognizing Sarah had a different scenario concerning visitation because she was admitted for COVID, I asked about how visitation worked for her and communication with her family. Her husband was also COVID-positive at the time and was in quarantine during most of her ICU admission. Once she was transferred to the medical ward, she was not allowed visitors due to her COVID-positive status. Her father-in-law could come to the ICU and see her but could only visit once and did not return due to the overwhelming nature of the experience for him. "He just saw me in the room behind the glass, but he couldn't get access to me; he just saw me from behind the glass. He was there for a little bit, and then he left, and that was about it". This is not

something Sarah remembered, but her father-in-law told her the account. It was clear that she felt immense emotion about not having a family member present to help support her during this time of vulnerability.

Even before I had asked about PICS-type symptoms, it was apparent that Sarah was still contending with issues related to her ICU stay. I asked explicitly about PICS-type symptoms like bad dreams/brain fog/anxiety/depression/physical limitations. Sarah described multiple instances where she exhibited many PICS symptoms that were still ongoing at the time of the interview. I believe her descriptions of each of her ailments are profound and give meaning to each of these symptoms for a former ICU survivor.

On her bad dreams:

Umm, bad dreams aren't as often anymore. I'm not dreaming as vividly as I used to. For a while there, I did have issues with even going to sleep because I was scared to go to sleep over my dreams and also the fear of not being able to breathe in my sleep.

On brain fog:

I do still have quite a bit of brain fog. So, for example, when I first got out of ICU, I couldn't remember simple things like what is my password for my bank account, what I was doing the other day, little stuff like that.

On her mental health:

I did have anxiety and depression; I had suicidal thoughts and panic attacks. I first experienced my first panic attack and anxiety attack in my entire life a month after I got out of ICU. I was having anxiety about my health and also depression about my health.

Umm, the suicidal thoughts were also because of my health because I just felt like it was impossible because my body felt so...it's like that mentality that I'm 32, and I should be able to do all this stuff, but I can't. You know my mind says I can do it, but my body is saying no.

She further described her issues with mental health and when she sought help.

So after the first panic attack and anxiety attack that lasted about two days, and that's when I first ended up calling the 811 where you can talk to the nurse. So I ended up calling there because I didn't know what to do because I had never experienced this before, and I kept having difficulty breathing because the panic attack just kept happening. I started begging my husband to take me out. I didn't want to be home because that was the only way for me to get over that was to get out of the house. I was scared I was going to end back up in bed, so I rather just sit in the car all day and drive around. Umm, for all those issues, I thought I could get over it, but I just couldn't. So about a week later, I started talking to a psychologist. I talked to her for almost three months. I also started seeing another nurse about all the issues as well because I found that the psychologist was so expensive.

Regarding her physical limitations, Sarah still reports having many limitations and has not returned to her baseline or pre-hospital level. "I think my physical limitations are the biggest source of my depression." She required a walker and aids in the bathroom during her initial stages after returning home. I further asked if anyone had mentioned anything about recovery after ICU and what to expect; Sarah recalled that information was given about the physical aspects, but information about the potential mental health challenges she would face was absent

from any conversation during her hospitalization. “So whether it was the physical therapists or the doctors, a lot of it was more talked about with the physical, not the mental.”

I then moved the discussion toward the ICU recovery clinic. The clinic initially contacted Sarah about six weeks after returning home. She was and continues to be followed by the physician lead of the clinic. On her experience with the clinic:

I think it’s been really good. First, I was going to decline it because I felt like I’d been over this a million times with my family doctor, but there was no solution. I really found some of the things my family doctor wasn’t able to tell me or talk to me about; he was able to explain it to me in better detail.

I further asked if she felt that the clinic had helped her with her mental health at all;

I think it was both the psychologist and the clinic. With the psychologist, she explained to me what it was and once I got the awareness and understanding of it, more that really helped. There are some things that I found the other therapists or doctors couldn’t help me with, but he was able to explain in more detail. It was that made me understand it better, rather than just kind of brushing me off kind of thing. He actually sat down and said, “Oh, you went through all of this,” and I’m like, “what happened?”

As per previous interviews, I asked Sarah what she would like to see for others in a similar situation as herself, a former ICU patient navigating our hospital system. Her primary concern was increased mental health support for former ICU patients like herself. She articulates that:

I would want to be more therapists available to those people, like even at a more or less costly rate probably or even just like more support even at the hospital. They could have

some sort of program where people could get help without having to worry about the financials because I know that even right now, during the pandemic, many people are having problems. I was in that situation a couple of months ago where both my husband and I weren't working, and we had to figure out how we were going to pay for all this health. Right. And I know others in the same situation might not have been able to make that as much available to them. So I would try to set something up for that program for people who can't afford it.

Before beginning the data transcription from the interview with Sarah, I immediately reached out to my supervisor as I felt this interview was emotional and raw for me. My thoughts were flooded with guilt and worry that I had potentially stirred things up, and I was concerned that I had caused harm somehow. I reviewed the interview with my supervisor and discussed how the interview closed. Sarah denied any immediate thoughts of self-harm; she recognized that remembering this experience had been difficult, but helpful to have someone else hear her story. A list of support services and resources was provided to Sarah, but she noted that she had her own therapist. An additional offer was made to reach out to the ICU recovery clinic to see if it was possible to get an expedited appointment, but she declined this. After consultation with my supervisor, it was decided that despite the intense emotion of the interview, Sarah was not in immediate danger and could access support services as required.

I found immersing myself in the raw data from this interview with Sarah challenging. The pain she was feeling was palpable and heart-wrenching. Throughout our discussion, I was reminded why I wanted to research the topic of PICS and that being in an ICU is a life-changing experience for many people. Still, hearing Sarah's powerful interview and her willingness to be open and honest about her experiences made me realize the potential ramifications of an ICU

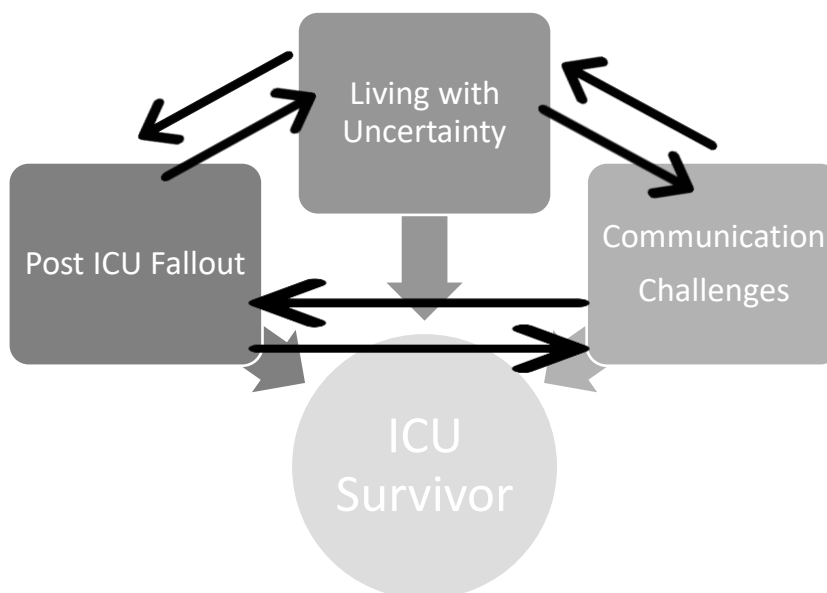
admission for post-ICU survivors. Some of the areas of Sarah's interview that were brought forward during multiple read-throughs of the transcripts with field notes were: the impact of being unable to be an active decision-maker for herself or have family act as a substitute affected her long after hospitalization, the impact that ICU has had on all levels of her life to the point of feeling suicidal, and the positive effects that post-ICU follow up can have for those in profound moments of despair.

Interpretation of the Findings

From the individual experiences and initial sorting of the data, I moved into the interpretation of the findings. I began to look across all three interviews to see similarities and differences between each. After many weeks of immersion in the data, I became focused on three main themes that emerged during the interviews: communication challenges, living with uncertainty, and post-ICU fallout. I have developed a figure to visually represent the findings (Figure 1). This figure provides a visual representation of how each theme is not a discrete entity but rather that each theme is dynamic and interrelated in the way that they may impact ICU survivors' experiences.

Figure 1

Factors that impact the experience of the ICU Survivor



During the interpretation of the data, it was clear that each of the themes contained subthemes. The theme of “communication challenges” includes two sub-themes: communication between patients and health care providers; and communication between patient and family. For the theme of “living with uncertainty,” sub-themes are “when will this get better?”, “is this my life now?” and “what happened to me?”. Finally, post-ICU fallout has sub-themes of struggling for help, normalizing PICS – post-ICU follow-up and benefits of specialized follow-up: general practitioner vs ICU recovery clinic.

Communication Challenges and Their Impact During and After ICU

Communication is essential to everyday life, and how communication is managed during times of fear and stress can have lasting impacts. I did not ask questions specifically about communication during the interviews (interview guide Appendix C); however, participants reflected on numerous occasions when messages were conveyed and either forgotten or misunderstood and the impact this had on them. As I explored the challenges of communication,

it became evident that there were two subthemes of communication: between patients and healthcare providers; and between patients and families.

Communication With the Healthcare Team

All three participants reported barriers and challenges in communication with their healthcare team. In some instances, the ICU interventions acted as a barrier, such as an endotracheal tube or medications, creating missed communication opportunities and confusion. Communicating with a patient in an ICU can be challenging. Patients routinely have mechanical barriers, potent sedatives, or paralytics in place, which may hinder their ability to understand or self-advocate. Patients in ICU may be unable to participate fully in decision-making or be aware of the consequences and impact of decisions made on their behalf. Additionally, during the pandemic, there has been an increase in the use of Personal Protection Equipment (PPE), which creates a further communication challenge between patients and providers. Reflecting on my practice as an ICU nurse, I find it challenging to understand my colleagues through masks due to muffled voices and find it difficult to ensure I have articulated myself correctly.

Specific examples of the impact of communication challenges on participants were evident throughout all three interviews. This was evident in Sam's discussion with his surgical team regarding a spinal fusion. Sam made a potentially life-altering decision without a clear understanding of the consequences. In another example, Sarah found the experience of being unable to act or speak for herself as a source of frustration and stress. Sarah was given a choice of how she wanted to be repositioned, but she didn't feel like she had any choice "I just couldn't speak at all. I had a tube down my throat. I didn't even fully understand what they were asking, but no one understood what I was trying to say." This experience remains an upsetting memory of her ICU stay. This inability to speak for yourself also highlights that ICU care is often

provided to patients with very little input from them directly, which can lead to painful memories in the future. Concerning the use of PPE, George mentioned that he felt like he was treated as infectious and separated from those around him. “So it kind of put a level of separation and loneliness. I can’t remember anyone because all of their faces were covered.”

Communication Between Patient and Family: Visitation Restrictions

A second communication challenge for participants was not having their family present during this stressful time. All three participants faced limitations or restrictions with family visitation during their ICU stay related to the COVID pandemic, making communication with family challenging. Family helps provide the bridge between patient and health care (Boulton et al., 2021). Patients routinely look to their families to advocate on their behalf, and when unable to be present, a disconnect between the team providing care and the patient may occur (Drapeaux et al., 2021; Istanbulian et al., 2022). The absence of family showed up in multiple instances for participants of this study.

Two specific examples of this communication disconnect for participants in this study were evident in Sarah and Sam’s stories. For Sarah, not having her family to advocate and act as alternate decision-makers left her with feelings of powerlessness and that her care was happening without consent leading to ongoing anxiety about what occurred while in the ICU. For Sam, who had a family member present for part of his ICU stay, the benefit of his wife keeping notes and sharing the difficult news regarding his injury was significant. I believe both of these instances highlight the importance of family communication for ICU patients as they help provide context and a sense of safety for ICU patients.

Alternative means of communication using available technology were attempted in an effort to fill the gap for both patients and their families. George had a particular example of how this attempt fell short for him personally. He recognized his impairment and inability to operate the necessary equipment: “I was really stoned and had no voice at the time, but we tried to get the Zoom [video conference] happening, and it just didn’t work. So it didn’t happen. I had a lot of trouble with it.” While reflecting on my time as an ICU nurse during this period, the technology required was in short supply, and the internet connections would frequently drop. Done with the best intentions, advanced technology was a suboptimal substitute for actual family presence.

Living with Uncertainty

Former ICU patients may face a highly variable future outside their initial illness. Throughout the analysis, various concerns arose from having to live with a degree of uncertainty that impacted participants’ expectations of recovery and future life and their understanding and ability to process what happened to them during their ICU stay.

What Happened to Me?

For each person who has undergone a life-altering event, the memory of the event can help to provide a context and narrative to the situation that helps people understand and process what has happened (Cypress, 2016). It is common for former ICU patients to have no memory or fragmented memories of the experience of their ICU stay. All three participants reported no memory or fragmented memories of their ICU stay. Those who could remember had memories ranging from comforting to terrifying experiences that continued to cause issues for the participants during the interview. The lack of memory of the event can further add stress, as it

leaves the survivor with a lack of understanding of what they have gone through (Cypress, 2016).

When Will This Get Better?

Former ICU patients often face an unpredictable recovery. Some of this is directly related to their initial injury or disease, while others are from their ICU stay. Recovery from ICU is unique, and ICU survivors may have little information about what to expect during their recovery process (Vogel et al., 2021). This lack of knowledge can impact patients' expectations of their recovery process. Progress can be non-linear and slow physically and psychologically for former patients, leading to uncertainty about their recovery and feelings of *when will this get better?*

George described living with delirium/cognitive impairments for approximately three weeks after he was discharged from the hospital. With no forewarning that this can be a regular part of recovery, he was left wondering if and when he would return to his pre-hospitalization level of functioning.

My wife was very concerned that I might have had some cognitive damage from this situation. Now I asked the doctor directly if I ever lost blood flow to the brain and he said no. There is no brain damage or anything, but because I was so far out of it and I'm usually so well into it. Especially once I got home I was still in a fog.

For Sarah, the youngest of the three participants, the psychological and physical limitations post-ICU have continued to limit her recovery, leaving her yearning for her life before hospitalization. I think it is also essential to highlight the stage of her life that Sarah is in as the youngest of the three participants. At the age of 32, most young adults start to establish

their careers, they might consider having children or may further their education. It is not common for a young adult to face chronic conditions. “ I really just want to heal and get better faster. Going back to work has been a struggle, but like I’ve told my work, I want to be at work. It just helps me mentally, like, it’s a mental health thing right now”.

Each former ICU patient in this study had frustrations with their recovery. Although there was a preconception that they had survived the hard part (i.e., ICU), the lack of knowing what might come next left them feeling that their survivorship and recovery were unstable. With no timeline or understanding of the potential progress or outcome of recovery, each is left uncertain about their future.

Is This my Life Now?

All three participants faced challenges with what their lives looked like moving forward. Each participant was at various stages of acceptance of this new life. They were across the spectrum in where their lives were at approximately six months after ICU/hospitalization. Sam was returning to work at his previously held position with the same hours. He self-reported no ongoing issues related to his injury or ICU stay. George was slowly returning to his “old self”; he self-reported some ongoing limitations but stated, "I got sick, and I got better. I am better, maybe 70% of what I was, but I am 65, I am kind of use to it". George faces the additional challenge of changing his body image since his ICU admission. He was the only participant whose physical appearance had changed since his ICU admission. "You know, it is quite a shock. I am not very self-conscious, I am too old, but everyone who saw me would stare," Sarah reported having ongoing physical and psychological issues with brain fog, anxiety, depression and physical limitations. These complications have led Sarah to feel further isolated. Additionally, Sarah faced the challenges associated with her identity being shifted due to her age and stage of life

when this event occurred. As mentioned previously, she was 32 years old when admitted to ICU, which is an age for many women when they consider having children, advancing their education, or exploring career advancement opportunities. These impacts affected her personally and professionally and may have changed how she identifies in the world.

All have had changes in employment, relationships and abilities. How they conduct their daily lives has changed, and each was at a different stage of finding their new normal. How each faced this new uncertain life is different depending on the individual, as evidenced by the three different experiences among participants.

Post ICU Fallout

After hospital discharge, the three participants all faced a disconnect between their life before ICU to their current reality. Each faced a future for which they had not previously considered or prepared. The opportunity to interview these individuals allowed me to develop a more holistic understanding of the impact of an ICU admission and PICS on people's lives. Post-ICU fallout included the sub-themes: struggling for help, normalizing PICS through post-ICU follow-up, and benefits of specialized follow-up.

Struggling for Help

Each individual was profoundly affected by their ICU stay. The more profound understanding of PICS is in the struggle each faces in returning to their daily lives. The psychological and physical difficulties each have dealt with have a more significant toll on their daily functioning, something they were not ready to manage. It was common for the participants to mention snippets of how the ICU has impacted their financial situation and their close relationships. For both George and Sarah, the impact is felt in their relationships with their

spouses. George appeared more upset about the effects of his illness on his wife. She now had to become a primary caregiver without additional support or preparation. As mentioned previously in the narrative, their relationship changed from a partnership to more of a parental-type relationship. "My wife had to make all my meals, shower and wash me. She basically had to do everything except dress me. She had to do all that with no support." Sarah found comfort in being close to her husband and extended family to the point of never wanting to be alone, which she recognized as a loss of independence but something she needed. She felt she needed the constant reassurance of having family close by and was afraid to be alone.

I still needed somebody to be with me because I had those panic attacks before and had anxiety of being alone and scared. I think being around family, even though I go there, I would be like, I need you to talk to me constantly, so I'm not thinking about my own issues. It would get my mind off of being sick.

The financial burden that ICU survivors face is only sometimes examined. For example, from lost household income to increased costs for hospital parking, there is a burden placed on the patient and inadvertently on their family. It can be challenging to navigate what financial support is available to ICU survivors. Those seeking additional mental health support face a further increase in household costs. Sam can return to work at his previously held job. However, Sarah is only working a fraction of what she was pre-hospitalization, increasing her family's financial hardship. Sarah mentioned

I wish there was more support or program where people could get help without having to worry about the financials because I know even right now, during the pandemic, a lot of people are having problems. I was in that situation a couple of months ago where both

my husband and I weren't working, and we had to figure out how we were going to pay for all of this health.

Normalizing the Experience of PICS: Attending the ICU Recovery Clinic

It is common for ICU survivors to face side effects of the treatment they received in the ICU (McPeake et al., 2021). For the participants of this study, it is clear that both George and Sarah have ongoing sequelae directly attributable to their ICU stay. All three participants had the opportunity to participate in the ICU recovery clinic, and all found this support beneficial. They described their interactions with the clinic as “refreshing” and “great” and felt they were “finally heard.” Even Sam, who appeared to have minimal issues after hospitalization, found his visit with the clinic useful, stating, “talking to the clinic was one of the most useful conversations and sincere conversations that I’ve had after leaving the hospital.” George found the clinic helpful in his discussions with clinic staff “he's a joy to talk to. I find it refreshing.” Sarah reported on her discussion of what she went through and described the benefits as they “explained it in more detail and in a way that made me understand it better, rather than just kind of brushing me off kind of thing.” It is the opportunity to have a deeper understanding of what happened and feel understood about the complex individual experience.

How ICU patients recover is complex and when to educate a patient/family about what happened to them is just as complicated. Frequently, patients are delirious or have brain fog or even a certain level of cognitive impairment at the point of transfer to other hospital areas, making education challenging and potentially anxiety-provoking. In other units or wards, the staff may not have an understanding of what happened in the ICU to be able to provide additional education. Having a place where patients and their families can ask questions and somewhat normalize the experience each is going through is of benefit, from experiences of

advocacy to being seen holistically as a person or even reassurance that each participant found utility in participating in the ICU recovery clinic. Sam, George, and Sarah all have multiple care providers and endless appointments, yet they found the most benefit for themselves personally to have this visit with the ICU recovery clinic.

Benefits of Specialized Follow-Up: General Practitioner versus ICU Recovery Clinic

Routinely patients will follow up with their primary care physician or General Practitioner (GP), as was the situation for all three participants. However, all three participants reported that it was of little utility as it became a further source of frustration of not being heard and limited insight into what happened to them and what to expect in the recovery period. This is not to say that GPs do a terrible job at this, but more to highlight the benefit of having a clinic that provides this specialized and individualized aftercare to members of this population.

Sarah had a specific example she shared about her experience of frustration when dealing with her GP. She approached her GP with a concern she had concerning her one leg after discharge. Unfortunately, she left that appointment feeling rejected and ignored. “When I talked to my doctor about it, she just said oh, it will be fine and shrugged me off. At the clinic, they explained to me what happened and how this issue is connected to my overall ICU stay.” This difference in experience is multifaceted. GPs face time constraints on their appointment timing; therefore, they likely need to prioritize the most urgent issues first. ICU survivorship is an increasingly growing area, and GPs may not have the direct knowledge base to pull from to guide this complex patient population. Additionally, specialized clinics like the ICU recovery clinic have the luxury of seeing the patient holistically, not just as their surgical procedure or diagnosis; this is something that GPs are often not afforded. For Sam, it appeared that this provided him with a certain level of comfort “The clinic was very thorough and asked relative

questions about my overall experience, not just about my tracheostomy or fusion. I think everybody should have that experience one hundred percent”. Despite numerous other medical appointments, all three chose to attend this voluntary clinic and each participant found utility in attending.

Summary

My research has identified that ICU patients experience communication challenges, living with uncertainty, and issues related to post-ICU fallout. Communication is an essential tenet of quality health care; unfortunately, communication between the patient and the health care team can break down despite best efforts. This is further complicated in ICU because of patients’ level of illness, medication and sedation effects, and medical and mechanical interventions, which make communication difficult at best. Fragmented communication can profoundly impact the patient and lead to ongoing issues related to anxiety and depression in former patients months to years later (Drapeaux et al., 2021). Additionally, not having family present or having decreased family presence during the COVID-19 pandemic may have contributed further to the communication breakdown. Additional PPE requirements during COVID may have added to patients’ communication challenges. In the theme “living with uncertainty,” participants reported various levels of uncertainty associated with their illness experience, expectations and looking forward to their future life, and understanding what they endured in the ICU. This uncertainty seemed to play a role in participants’ stress and anxiety as there are no concrete timelines for rehabilitation or return to baseline. Post-ICU fallout was the final theme of the findings chapter. Participants had difficulty making sense of and normalizing their experience of the ICU until attending the ICU recovery clinic, where they felt understood

and heard regarding their lengthy recoveries. These findings will be discussed further in Chapter 5 and positioned within the literature.

Chapter 5: Discussion

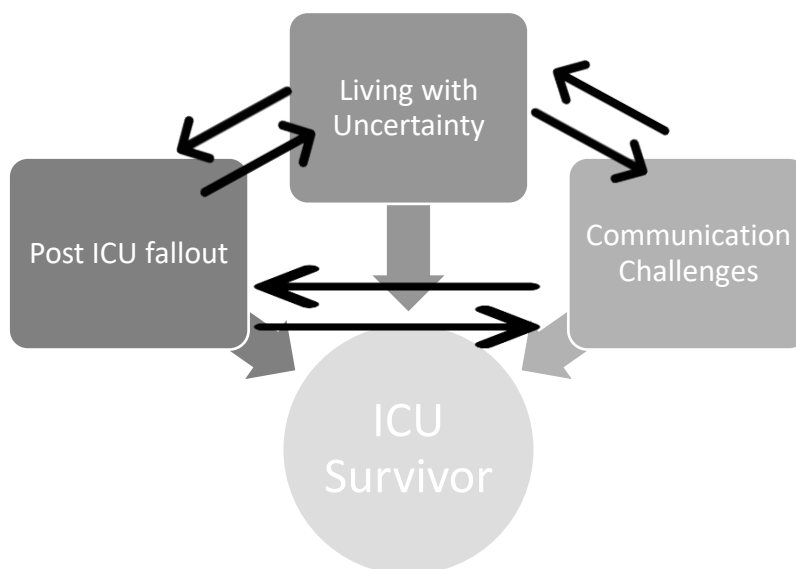
The purpose of this Interpretive Description study was to better understand former ICU patients' experience during the COVID-19 global pandemic. The research aimed to address the question, “*What are the experiences of patients discharged from ICU in Calgary, Alberta, who are at risk of developing Post Intensive Care Syndrome during the COVID-19 global pandemic?*” In this study, there were two research aims:

1. To better understand the ICU experience of ICU survivors in Calgary, Alberta, during the COVID-19 global pandemic;
2. To better understand the post-discharge experiences of ICU survivors in Calgary, Alberta, during the COVID-19 global pandemic.

Those who experience ICU have a unique experience of the health care system both during and after their hospital stay. The experiences reported by the three participants in this study highlight the particular needs of former ICU patients. While some of these can be attributed to their ICU stay, it is clear that the COVID-19 pandemic exacerbated existing challenges and created additional issues for ICU survivors. Three main themes emerged from the interviews and narratives outlined in Chapter 4: communication challenges, living with uncertainty, and post-ICU fallout. I have included the visual diagram of these themes (Figure 1) as a reminder that what each ICU survivor endures is not discrete issues. Rather a complex interplay between a myriad of post-ICU challenges. In this chapter, I will further discuss the interpretation of these themes and situate these findings within the current literature. I will also discuss the implications for practice, the limitations of the study, and recommendations for future research.

Figure 1

Factors that impact the experience of the ICU Survivor



Communication Challenges and Their Impact During and After ICU

Communication is one of the basic needs we require as humans; it is how we interact with the world around us (Shin et al., 2021). Communication is “a process by which information is exchanged between individuals through a common system of symbols, signs, or behaviour” (“Definition of communication,” 2022). How individuals communicate is generally in one of three ways: verbal, non-verbal, or visually, though there are a variety of other subsets beyond those general three. Communication within health care is considered a cornerstone of excellent, safe care for many reasons. It is frequently highlighted as an area of improvement within healthcare systems worldwide (Rider et al., 2014). Communication can influence patient adherence to the prescribed treatment plan, thus improving patient outcomes, but it is also a direct contributor to patient safety (Vermeir et al., 2015).

Within the ICU, communication between the patient and the health care team may be impaired due to mechanical ventilation, pathophysiological conditions, or the use of sedatives. When a patient requires mechanical ventilation, an endotracheal tube is placed, which blocks airflow across the vocal cords, leaving the patient voiceless; during specific disease processes, communication can be impaired, for instance, with stroke or brain injury, or they are so breathless that speaking is too much of a burden on their system (Karlsen et al., 2018). Being left without a voice has been reported frequently as a significant stressor for ICU patients, leaving them feeling like they are an object rather than a person (Karlsen et al., 2018). The COVID-19 pandemic added additional barriers to communication. For example, restricted visitation, use of extensive PPE by visitors and health care professionals, and prolonged use of sedatives/paralytics may have contributed to the extra stress on ICU patients.

Communication Between Patient and Healthcare Team

The presence of barriers in communication between the patient and their healthcare team found in this study aligns with findings reported in previous studies (Magnus & Turkington, 2006; Tembo et al., 2015). Participants expressed fear, isolation, and anxiety about not being an active participant in their care or fully understanding what was happening to them as a person or what they agreed to. This loss of control and feeling of powerlessness may develop into feelings of anxiety and stress for countless ICU patients. This type of response is not uncommon among former ICU patients. It is well documented within the literature that communication barriers may leave former patients with feelings of stress, anxiety, fear, sense of imprisonment, and depersonalization and may contribute to long-term sequelae such as depression or PICS (Karlsen et al., 2018; Leung et al., 2018; Magnus & Turkington, 2006; Tembo et al., 2015). The loss of voice is so profound that it has been described as *vocal imprisonment* by Tembo et al. (2015).

Added to this loss of voice are additional measures taken by the healthcare system to help mitigate the further spread of COVID-19 through the use of multiple layers of Personal Protective Equipment (PPE) for healthcare workers. Although essential to reduce viral transmission, they further impaired other aspects of communication between participants and their healthcare team; team members were always masked and generally wearing a face shield, making their care team members unrecognizable.

Additionally, the voices of healthcare workers are muffled through the mask, making their speech even more difficult to understand. Participants reported that these barriers increased their feelings of isolation and loneliness, despite protecting healthcare workers and other patients (Drapeaux et al., 2021). These feelings align with the literature where patients have reported feeling they lacked autonomy and were not treated humanely while hospitalized in an ICU during the COVID-19 pandemic (Drapeaux et al., 2021; Istanbulian et al., 2022; Schitteck et al., 2021). The importance of quality communication cannot be overlooked with ICU patients and their healthcare team, despite barriers present, as it has a profound impact not only during their hospitalization but also in their life moving forward.

Communication Between Patient and Family: Visitation Restrictions

Family members are a core part of care in the ICU environment (Vester et al., 2021). Family presence within the ICU pre-pandemic was highly encouraged as it is strongly linked to positive outcomes for ICU patients (Greenberg et al., 2021). Some positive effects of family presence are reduced delirium and; decreased stress and anxiety. These symptoms are all known to contribute heavily to an ICU patient's development of PICS (Drapeaux et al., 2021).

Unfortunately, due to the COVID-19 pandemic, families could not be at the bedside of their loved ones for much of their entire hospitalization, including the ICU portion, to limit the further spread of the Coronavirus. Visitation was restricted to end-of-life situations at specific points throughout the pandemic, leaving families unable to see their critically ill loved ones and communicate via distant means (video conferencing or telephone). The literature has primarily focused on the family perspective and experience of this situation, as former ICU patients may have difficulty recalling their ICU stay (Boulton et al., 2021; Lopez-Soto et al., 2021; Valley et al., 2020). In this study, two out of three participants found the absence of their family devastating, with the third participant feeling it had no impact. For Sam, the delivery of news regarding a life-altering injury was more meaningful coming from his family. In contrast, Sarah reported that the lack of family presence added to her sense of isolation and further exacerbated her feelings of fear of the whole situation. Both Sam and Sarah highlighted the increased vulnerability they felt without their family present to help them advocate for themselves. This aligns with the literature as it is reported that family presence help eases anxiety and provide an individualistic approach to communicating with their loved one that healthcare providers cannot achieve in the same way (Drapeaux et al., 2021; Istanboulian et al., 2021).

All three participants reported that distant communication methods were used during their hospitalization via phone or video conferencing. All three reported various levels of dissatisfaction with these means of communication. Their dissatisfaction stems from multiple reasons, such as issues with understanding advanced technology, not physically being able to participate in conversation due to disease processes (e.g., breathlessness), and the lack of physical presence. There are multiple perspectives within the literature regarding the use of alternative forms of communication for ICU patients with their families, with the majority

highlighting patient satisfaction in the use of telephone or video conferencing in communicating with their family and understanding of the reasoning for restrictions on visitation (Boulton et al., 2021; Venturas et al., 2021). Although initiated with the best intentions to facilitate communication, the primary use of distant means, such as video conferencing or even telephone, may exacerbate disparities unintentionally (Valley et al., 2020). It is always a possibility that there may be disabilities present, a family is unfamiliar with certain aspects of technology, or financial constraints where those forms of communication are not viable solutions. As for PPE, visitation restrictions were done for sound reasons and with the best intentions; however, they impacted the patient experience during hospitalization. They may also play a role in the emotional toll on survivors moving forward for former ICU patients, as is the situation with two participants in this study.

Living with Uncertainty

We, as humans, like a certain level of predictability to our everyday life; when thrown into situations that are unknown or unfamiliar, this raises our stress response to a problem, and the level of intensity of that stress response is highly individual (Flahault et al., 2022). Having the course of your life change in a moment to face potential death and the rehabilitation that follows, a former ICU patient's description of feeling various levels of uncertainty is not surprising. Adding another layer to the complexity of this level of uncertainty is that symptoms or sequelae of PICS are not well known within the medical community outside of ICUs and are virtually unheard of in mainstream culture. This may contribute to the uncertainty felt by former ICU patients as there is no sense of normalization of their experience.

Uncertainty in illness is not something unique to the former ICU population. There have been countless studies regarding this topic, including within the former ICU population (Babrow

& Stone, 2021). A middle-range nursing theory first described by Mischel (1988) is frequently cited as the primary key to understanding how patients understand the uncertainty related to their illness (Babrow & Stone, 2021; Cypress, 2016). Uncertainty is described within the literature as “the mental state of perplexity, doubt, undetermined or unknown question ableness, obscurity, inconclusiveness and indeterminateness” (Cypress, 2016, p. 43). In this study, the theme of uncertainty was broken down into three subthemes of questions that each of the participants, in a roundabout way, proposed during their interview that contributed to their experience of uncertainty: what happened to me? When will this get better? and is this my life now?

What Happened To Me?

Understanding a distressing event may help those who experience it give meaning to the experience and thus accept/accommodate their experience. It is not uncommon for former ICU patients to report either no memory or fragmented memories of their ICU stay (Cypress, 2016). They rely heavily on their care team and loved ones to convey the experience to give some chronological continuity to their life and help identify hallucination versus reality (Olsen et al., 2017; Vogel et al., 2021). In the current COVID world, participants did not necessarily have family present as there were restrictions on visitation. All three participants had visitation impacted by the constraints related to the COVID-19 pandemic, which was previously mentioned in this chapter.

For some patients, understanding what they went through is necessary to give meaning to the experience. In contrast, others choose not to reflect and dwell on their memories as they found remembering uncomfortable or painful. This was the case for two of the participants in this study. Sam intentionally decided not to engage or share his memories of ICU, though he did not mention that this was done to avoid unpleasant memories; it was more about how he was

moving on with his life—while for Sarah, having the pieces of fragmented memories has led to added stress and anxiety about the situation as she does not fully understand what she went through and cannot bring meaning to her experience. This variation in experience is documented within the literature. For someone like Sam, the lack of memories is beneficial, while for Sarah, the lack of memories is a problem as she is left to fill in the gaps on her own, which is known to occur in delirium (Löf, 2008). This has been described within the literature as a situation where a person has no point of reference when evaluating their experience of ICU, thus leading to the experience of uncertainty because what they do remember might be painful or frightening (Cypress, 2016). The inability to make sense of the experience of the ICU doesn't allow the ICU survivor to take ownership of it and may lead to feelings of anger and frustration (King et al., 2019). The difference in the management of how Sam and Sarah have experienced the uncertainty related to what happened during their ICU stay has also been documented within the literature; for some, the memories of ICU and the act of remembering are somewhat of a burden (Flahault et al., 2022). Though there is a difference in perspective on the necessity of remembering, I believe this again highlights that the care of the post-ICU patient must be highly individualized as each has their own needs or priorities; therefore, subjecting Sam to a discussion about memories may be triggering for him, while for Sarah understanding her experience may lead to a greater sense of certainty as knowing what happened may bring her comfort and a sense of control about a situation that she had no control over.

When Will This Get Better?

It is commonplace for anyone to want to know how long and what it will take to recover from illness or injury. What recovery looks like for each person is highly individual, as each person has their unique perspective on what this will look like for them. Unfortunately, in

situations where a person has required an ICU stay, this is not always straightforward, with no clear answer. Former ICU patients generally do not have a linear trajectory in their recovery as usually what brought them into ICU in the first place is complex. Former ICU patients can face ongoing issues related to their initial illness or injury, which may be directly attributable to their ICU stay. Still, they may face many years of continuing recovery or long-term limitations after they have left the hospital (King et al., 2019; Vogel et al., 2021; Wubben et al., 2022). With no clear understanding or expectations communicated to former ICU patients at the time of hospital discharge, they may see multiple providers regarding their recovery, which may further dilute or confuse their expectations or make the potential recovery trajectory more challenging to understand (Schorr & Gill, 2021). This may create feelings of uncertainty as former ICU patients are left questioning what their future may hold. From the interviews in this study, the sense of uncertainty related to recovery is multifactorial. Participants recognize the areas of their lives that have changed since their ICU admission, including physiological or physical issues, changing roles within the family, and financial considerations.

Wanting to know the endpoint of the illness phase or when life will return to normal is something that all participants experienced. Concerning their illness uncertainty, those interviewed for this study frequently reported that the slow-moving recovery related to physical and psychological symptoms was a source of stress, which is common in this population (Olsen et al., 2017). One of the participants, Sarah, recognizes that this uncertainty has led her to persistent feelings of depression and anxiety. All participants had unknown expectations after ICU on what recovery may look like. All reported that there was no discussion on what to expect during their recovery period at their discharge or early in their follow-up visits with their family doctors. Any expectations of timelines related to recovery were discussed from a strictly surgical

perspective and only for those participants who had surgical procedures during their hospitalization.

Family relationships can be some of the most important in a person's life. Any change to how those relationships function can be highly debilitating and further exacerbate feelings of hopelessness. Both George and Sarah described how their relationships with their partners had changed, moving from a partnership to a caregiver or parental relationship. This shift in relationships and roles within the family is not uncommon within the population of former ICU patients, frequently reported within the literature as a source of stress for everyone involved (Vester et al., 2022). The uncertainty related to the expectation of the return to previously held roles or duties within the household has also been shown to cause additional strain not only on the former ICU patient but also on the family as a unit (Vester et al., 2022). This is something that all three participants voiced concern about, as their previously held roles within their families were somewhat tied to their identities.

Another aspect of one's identity is work, which was an issue for two participants. Sam and Sarah mentioned not only the financial strain of not working but also that employment was an inherent part of their sense of self. Each was returning to work, with Sam returning to his previously held position. At the same time, Sarah still required reduced hours/adjustments to her schedule to accommodate her ongoing post-ICU struggles. Both had mentioned in their interviews that returning to work was another indicator that life was returning to "normal," providing a sense of security (financial) and helping boost their self-worth or self-esteem. This aspect of uncertainty related to return to work as not only a source of stress for economic reasons but also for psychological reasons is something that aligns with what is known within the literature (Olsen et al., 2017; Sutton et al., 2022; Vester et al., 2021). Working adults frequently

report their job or career as a source of validation for their self-worth and self-esteem.

Uncertainty related to the period of convalescence and recovery after ICU is something that all three participants of this study experienced and aligns with what is known in the literature.

Is This My Life Now?

Coming to terms with a new normal and the uncertainty surrounding it is something that all three participants highlighted as a stressor. Additionally, all three stressed uncertainty about this new normal as it is unclear what their future may look like. Their feelings are not unfounded, as many ICU survivors face a much different life after their ICU experience (Sutton et al., 2022). Changes in familial relationships, memory gaps, employment status, and vague timelines for recovery require many ICU survivors to start over in some ways. Previous studies have documented that physical and psychological sequelae of PICS can last many years after hospital discharge (Olsen et al., 2017; Schorr & Gill, 2021). This may make the recovery process challenging as it is frequently changing, and ICU survivors are left wondering what sequelae of PICS might be permanent.

Several studies have highlighted uncertainty in a “new” life as an essential aspect of recovery from critical illness as it signifies a level of acceptance and optimism in moving forward (Vester et al., 2022; Vogel et al., 2021). I believe this is the case for two participants: George and Sam. Sam had recovered to the point where he denied any ongoing concern related to his ICU stay or illness. In contrast, George had a level of acceptance related to his ongoing issues, as he stated in the interview, “I got sick, and I got better. I am better maybe 70% of what I was, but I’m 65, I’m kind of use to it.” The third participant, Sarah, did not seem to be at this level of acceptance at the time of the interview; she was still comparing her “new” life to her “old” life pre-ICU. This is not uncommon, as re-establishing oneself in a new life and accepting

an uncertain future can be anxiety-provoking (Olsen et al., 2017; Schorr & Gill, 2021). The participants' stories in this study highlight the necessity of individualized aftercare. As with any illness recovery, survivors will respond differently depending on multiple factors, including their gender and family roles, age, and circumstances.

The experience of uncertainty for ICU survivors is debilitating, further impacting their physical recovery and mental well-being as they're unsure of what happened to them, what to expect, and what life will look like in the future. All three participants had differing views and coping with uncertainty after hospitalization, highlighting the necessity of a highly individualized approach in this population.

Post ICU Fallout: Life After Hospital Discharge

PICS sequelae affect up to one-third of all former ICU patients, contributing to ongoing issues for ICU survivors (McPeake & Mikkelsen, 2018). All three participants in this study displayed various challenges faced by those recovering after ICU admission with varying degrees of severity, which are also common symptoms of PICS. There is currently no standardized method for the diagnosis of PICS. By moving beyond a list of symptoms and moving to the experience, I believe this study highlights the massive impact that PICS can have on ICU survivors as it is known to affect the three important domains of life: physical, mental, and cognitive function (McPeake & Mikkelsen, 2018). All three participants exhibit varying levels of issues across the domains. Despite the sizeable potential population, there is little information available to those who survive ICU, and survivors are often left struggling independently. There is recognition within the ICU community of how large a problem PICS is for the population of ICU survivors. Three subthemes were identified within the post-ICU fall-

out theme: Struggling for help, normalization of PICS through post-ICU follow-up, and benefits of specialized follow-up.

Struggling for Help

All three participants faced struggles after hospital discharge. This is not uncommon for ICU survivors, as it is well documented in the literature that they may have mental health symptoms, including anxiety, depression, PTSD, or nightmares (Harvey & Davidson, 2016; McPeake & Mikkelsen, 2018; Rattray & Hull, 2008). It has also been noted that it is not uncommon for patients to have persistent physical issues such as muscle weakness, breathlessness, or decreased neuromuscular function (Harvey & Davidson, 2016; Morgan & O'Conner, 2018). PICS has a wide range of symptoms that vary in severity, and the time to recovery is inconsistent (Daniels et al., 2018). This was the scenario for both George and Sarah as both faced issues related to mental health and ongoing physical problems after hospital discharge. George reported initial issues with cognitive function in his early days after hospital discharge, as well as physical impairments, while Sarah struggled with ongoing mental health concerns and physical limitations.

At the time of follow-up in the community, Sam denied having ongoing issues related to his ICU stay, while both George and Sarah did. Both struggled tremendously on where to turn for help, with the additional financial stress on their recovery as they reported their family doctor was unaware of other available resources. All three did not attend the ICU recovery clinic until approximately three months after hospital discharge. All three participated in the clinic in a non-traditional manner, as their appointments were via telephone or video conference due to strict social distancing guidelines due to the COVID pandemic. Despite this, all three still found their experience with the clinic helpful.

The healthcare system is challenging to navigate, even for those well-versed in it. For those experiencing issues post-ICU, determining whom to see or where to turn for help may be difficult. This was the case for both George and Sarah, who struggled to find the appropriate resources without causing further financial hardship or burden on their families. George frequently mentioned the increased workload on his wife to manage his recovery and the day-to-day operation of their family household. This added further worry and anxiety to George during his recovery. Sarah still routinely struggled with mental health concerns at the time of the interview; she sought out help from mental health professionals at the additional expense to her household, which further caused her to worry. This is not an uncommon concern as PICS is known to increase the burden on families/informal caregivers economically and emotionally (Angus & Carlet, 2003). When asked directly what they would like to see for those in a similar situation in the future, all three participants unanimously reported “mental health services or counselling that is free,” while there were mentions of additional financial support for families during this period. The request for help in the mental health domain is not surprising given the high rates of Post-Traumatic Stress Disorder (PTSD), anxiety and depression among ICU survivors, with reported rates as high as 30% (Wallen et al., 2008). Yet, mental health services such as counselling are not routinely covered in the public health care system and are instead primarily covered via employer benefits, and the degree of coverage is highly variable. The recovery process of ICU survivors is a unique time in their lives as they struggle to return to their ordinary lives while learning to live in a changed body/mind (King et al., 2019).

Normalization of the Experience of PICS: Attending the ICU Recovery Clinic

As mentioned previously, ICU survivors frequently face lingering sequelae related to their ICU admission (Kean et al., 2021; McPeake et al., 2021). This was the case for both George

and Sarah, as they faced challenges well after hospital discharge. As discussed above, both were left to navigate a complex world of recovery and rehabilitation after hospital discharge. This may leave ICU survivors with unmet needs during their recovery period.

All three participated in the ICU recovery clinic, and each benefitted from this visit. Through the clinic, participants found someone understood what they were going through for the first time, thus helping normalize their experience. For example, Sarah felt the level of explanation and education she had received from the clinic went above and beyond what her family doctor had explained. This level of description has helped Sarah tremendously as it has helped her normalize her experience and the difficulties she has faced after ICU. Sam and George found the visits sincere, and the clinic helped validate their experience of the ICU and the challenges they frequently faced as ICU survivors. This validation and normalization are regarded as highly beneficial to ICU survivors within the literature (Kean et al., 2020; Wallen et al., 2008). It helps survivors recognize that others face the same challenges and are not restricted to them alone (Kean et al., 2020; Wallen et al., 2008). This has been shown to provide comfort to some survivors, to know that they are not alone in their struggles after ICU and that others have faced similar challenges (Kean et al., 2020; Wallen et al., 2008).

Benefits of Specialized Follow-Up: General Practitioner versus ICU Recovery Clinic

Post-ICU clinics around the world have been designed to fill in the gaps in care faced by countless ICU survivors and reduce the incidence of PICS (Lasiter et al., 2016). All three participants in this study had the opportunity to visit the ICU Recovery Clinic in Calgary, Alberta. This clinic is a unique feature of the health care system in Calgary, AB, and is not commonplace. These clinics are considered somewhat controversial in the ICU community as they are expensive in an already fiscally tight environment. The evidence of benefit is lacklustre

in the literature on the direct reduction of PICS. Countless studies have not shown a statistically significant benefit in these types of clinics when looking at quantitative metrics in the reduction of PICS symptoms or quality of life after ICU (Bohart et al., 2018; Cuthbertson et al., 2009; Lasiter et al., 2016; Rai et al., 2019). These findings are inconsistent with the participants' reports in this study. All three participants found usefulness and necessity in a clinic such as the ICU recovery clinic.

All three followed the traditional pathway within the Canadian health system and initially followed up with their GP after hospital discharge. Each participant noted that it was at the ICU recovery clinic the first time a member of their healthcare team provided information regarding the potential consequences of being a patient in the ICU. Sarah's experience of struggling to have her concerns taken seriously by her GP is not isolated, as it is noted in the literature as a source of frustration for many ICU survivors (Kean et al., 2020). This is not surprising as the number of ICU survivors a GP may see is likely small, limiting their knowledge of the topic (Kean et al., 2020). In contrast, within the clinic, all three participants reported a strong sense of satisfaction with attending the clinic. For example, George found advocacy in being referred to additional physical rehabilitation resources and group counselling, both of which were only offered to George via the ICU recovery clinic. Even Sam, who had minimal ongoing issues after hospital discharge, found the appointment valuable as the clinic doctor asked questions outside of his surgical procedures and more towards a holistic approach to him personally. Recent literature has highlighted areas like peer support groups for further research that have preliminarily shown utility for ICU survivors and their benefit during their recovery period (McPeake et al., 2021). There is recognition that ICU survivors face a unique situation of reintegrating multiple aspects of their lives together after an ICU stay. That rehabilitation needs

to focus on the physical and social aspects of recovery, with direct support for mental health services a key priority, as identified by countless ICU survivors (Heydon et al., 2019).

The post-ICU fallout felt by countless ICU survivors is not unique to the participants in this study. The experience felt by the participants of this study in the struggle to find the appropriate resources while yearning for validation and normalization of their experience is widespread across the ICU survivor community. Although controversial and costly, ICU follow-up clinics have been shown to benefit ICU survivors in non-metric ways through normalization and validation of their experience (Lasiter et al., 2016). Though the COVID-19 pandemic has highlighted calls for further funding for these clinics, many COVID survivors also require care within an ICU, placing an increased strain on the healthcare system. There is currently no standardized framework for a clinic due to the recognized variable resources available and the complexity of the patient population. Still, each clinic should be multidisciplinary and use screening tools to identify patients most likely to benefit from the clinic (Butcher et al., 2022). King et al. (2019) developed a support needs assessment tool using the “Time it Right” framework, which identified critical time periods during recovery when an ICU patient should be offered support (p. 2). The purpose of developing this assessment tool was to help guide practitioners to support this patient population (King et al., 2019). There are no clear answers yet on what ideal follow-up looks like but a tool like this can be highly beneficial as it is the first step for an individual approach to determining the needs of each patient (King et al., 2019).

The COVID pandemic has highlighted that delivery of such clinics in non-traditional methods via phone, or video conferencing benefits certain individuals (Nakanishi et al., 2021). In-person visits are always highly preferred as things may be missed virtually (i.e. physical exam or the ability to test strength/endurance). Still, there may be a benefit to offering visits virtually

for those unable to travel or live a distance from the clinic, such as Sam. All three participants did not attend an in-person clinic due to social distancing guidelines at the time.

Recommendations

Although, this small qualitative study does not seek to generalise findings beyond the experience of these three ICU survivors, the findings do highlight some areas for improvements both within and outside the ICU. I will approach the implications on three different levels. First from a direct care provider standpoint within the ICU and outside the ICU; second, recommended improvements to the health system to improve outcomes for ICU survivors; and finally to recommendations for future health care policy.

From the findings of this study, I want to highlight the importance of clear communication practices, both written and verbal, which are of the utmost importance to ICU survivors. Communication breakdown has been shown to have severe and lasting implications for the participants of this study. Although a challenging task, made even more difficult with the pandemic-related increase in PPE use further impairing communication, every effort should be made to find a way to give ICU patients a voice during their stay and to support them to be active participants in their care. There is no easy solution, but highlighting the importance of communication is the first step, as many nurses may not recognize its lasting impacts. Many do not realize that communication impairments leave ICU survivors feeling like they were in a period of imprisonment and the long-term consequences felt by survivors (Karlsen et al., 2018; Leung et al., 2018). Another important implication of this study is the education of healthcare providers both within and outside the ICU on PICS. Much of the teaching and normalizing of the experience of the ICU was left to the ICU recovery clinic. This left two participants feeling anxious and stressed regarding their progress during recovery. All three participants noted that

the first time they had heard of ICU complications was at the recovery clinic. This delay in information for ICU survivors may contribute to anxiety and depression and further exacerbate their symptoms of PTSD. I don't believe practitioners within the system are choosing to withhold information. There are multiple potential reasons for the delay in education, as there is uncertainty about when it is best to deliver this education and who should be delivering the instruction. Alternatively, it might be a lack of information on their part regarding the importance of knowledge translation regarding the impact PICS has on ICU survivors. Regardless, the findings of this study highlight the necessity of further education to all healthcare practitioners about PICS and the need to help ICU survivors in their journey through recovery.

Areas of recommended improvement from the standpoint of the overall healthcare system are multifaceted. First, how PICS is viewed within the health care system should be re-examined. ICU survivors with PICS may experience long term, on-going challenges that transcend health care silos (cross medical specialties and health care services) that suggest PICS has more in common with chronic illness models. Thus, PICS should perhaps be more accurately be viewed as more of a chronic disease rather than an acute illness. As reported throughout this thesis and in reports from the study participants, PICS is a unique diagnosis that is not well understood, from how ICU survivors move through the hospital system while in acute care, to how patients engage with the healthcare system after hospital discharge. The long ranging effects of PICS highlights the need for a robust network of resources for this population that is often seen in other areas of healthcare like Cardiology, or Stroke for example. Having a network of healthcare providers that includes Physicians, Nurses, and Physical Therapists who are specialized in ICU and the after-effects of an ICU stay would go a long way in supporting ICU survivors from acute care through to the community. This network of healthcare providers highlights an area for collaboration in

developing a discharge pathway for ICU survivors who have been identified as at risk of PICS. This could include a pre-clinic visit to pre-emptively educate patients and their families before going home. Hence, they know help is available and where to reach out, as this study's participants identified this as an area for improvement. Additionally, enhancing community support for this specific population would be of benefit to them as findings from this study do suggest there is a need for further support when in the community as the system as it currently functions does not meet the unique needs of this population once they have left the acute care environment. Finally, the expansion of an ICU recovery clinic would allow for the potential of further areas of improvement and supports like the development of ICU diaries, debriefing ICU visits (in person or virtual), or an ICU survivor support group which have all shown benefit within the literature to ICU survivors (King et al., 2019; Lasiter et al., 2016)

Areas for recommended improvement within future health policy is a further understanding of the family's role during and after an ICU admission is also vital in ensuring a partnership between the patient and care team, leading to optimal outcomes for both sides. The involvement of families is essential in bridging the gap between seeing the patient beyond their diagnosis and bringing a level of humanity to the situation. The patient is no longer viewed as merely a diagnosis but as a human with a life they had before ICU with likes/dislikes, hope and aspirations. Additionally, the family provides comfort and safety to the ICU patient. Therefore, there should be a better effort in policy-making regarding family visitation and visitation restrictions. How family is viewed needs to change within health policy as they are a part of the healthcare team, and to leave them out has lasting impacts, which was experienced by some of the participants of this study. There is an understanding that certain limits may need to occur, such as related to a global health emergency (e.g.:COVID-19 pandemic), but in the future, better

engagement needs to occur with family to find a better solution to the problem. The participants of this study all recommend a clear communication and visitation plan should be in place to help minimize the impact on both patient and the family.

Limitations of the Study

A limitation of this study was the small sample size. The decision was made to proceed with the three participants based on feasibility issues in recruiting during a global pandemic and in consideration of time as a limiting factor for the completion of this thesis. Additionally, this study only provides a snapshot in time and does not reflect an overall timeline of experience throughout the pandemic. It should be noted that the participants interviewed were hospitalized during the earlier “waves” of the pandemic. Both public and healthcare restrictions were at their highest, individuals were limited in their ability to carry on their daily lives, and there was minimal access to healthcare facilities outside of urgent or emergent situations related to the strain on the healthcare system from the pandemic. Additionally, restrictions within the hospital at that time were unclear and frequently changing, which may have impacted the participants’ overall experience.

Another limitation of this study was the lack of diversity among participants. There was only one female and two males who participated, limiting potential gendered considerations. Additionally, cultural or spiritual practices were not explored during the interviews, so this study cannot comment on how these practices may shape participants’ experiences with the healthcare system or how they coped with PICS symptoms post-ICU. Also, all three participants were English-speaking and appeared to have a firm grasp of the language; understanding the

perspective of those where English is not the primary language will be beneficial to help improve the experience of all who enter the ICU in Calgary, AB, not just those for whom English is the primary language.

I would also consider my experience as a novice researcher a limitation of this study. Specific ques given by the participants during the interview were not picked up until much later during the analysis phase. For example, in Geroges' interview, he said, "Okay, like I said, every doctor that ever took a piece of me away wanted to see me within about a month after me getting out." I attempted to explore further but could not delve further with this participant. Reflecting, I recognize that maybe reframing the question or shaping it differently may have produced a different response.

Finally, the participants of this study were restricted to former ICU patients only and not their family members or support persons. Gaining family and former patients' experiences can help capture the overall picture of the ICU experience here in Calgary, Alberta.

Recommendation for Future Research

As mentioned in the limitations section, this study involved participants who were hospitalized during the initial "waves" of the pandemic; therefore, recruitment of participants who were hospitalized during subsequent waves would be beneficial to gain a broader understanding of the impact of the pandemic on ICU patients here in Calgary, Alberta. These participants were hospitalized when the strictest public health measures were in place when there was still so much unknown, and there was confusion regarding the restrictions in place. It would be of value to see if anything changed with the experience since the downgrading of restrictions and increased knowledge about COVID.

Expanding the sample size would help generate possible differing viewpoints while gaining perspectives from a variety of sources, including those who do not have family, are unhoused, and those with pre-existing mental health concerns, in addition to cultural/spiritual diversity. Having a diverse participant group would be essential to ensure that future programs or policies are not limited to the viewpoint of one group but foster inclusiveness for the broader ICU survivor population.

Future research should also include the perspective of families within Calgary, Alberta, to understand how ICU impacts the survivor and the overall family. Additionally, understanding families' experiences with a loved one hospitalized in ICU during the pandemic would garner valuable information. This would help inform future policy and practice for the healthcare system if faced with a similar situation. There is a growing body of research on the perspective of families of ICU survivors. However, having a local perspective would help further enrich knowledge to improve the experience for the ICU survivor community in Calgary, Alberta.

Additionally, I believe future research should include ascertaining healthcare providers' understanding of PICS. All three participants highlighted that they were only provided with any information regarding the potential issues related to an ICU stay at the ICU recovery clinic. With the pandemic, the number of post-ICU patients is increasing exponentially; patients should be able to receive information regarding the potential complications related to ICU from multiple sources, for example, potentially at ICU transfer or during hospitalization on the ward. Some education should be offered, and a part of their discharge teaching, this education should not only be provided at a specialized clinic.

Finally, future research should include an examination of the cost of healthcare utilization for former ICU patients to understand how and where ICU survivors are using the healthcare

system in Calgary, AB, after hospital discharge. This will highlight a metric that does not necessarily look at the reduction of PICS but may provide economic data to justify reallocating healthcare dollars to support this vulnerable population.

Conclusion

This thesis is an inquiry into the experience of ICU survivors with hospitalization and after discharge during the global COVID-19 pandemic in Calgary, Alberta. The findings from this study expand on the current literature on the experience of former ICU patients and give a unique perspective on the experience of patients in Calgary, Alberta. While some findings align with previous research, the study identifies areas for change and improvement within our health system. Additionally, this study bolsters information about the experience of former ICU patients and helps illustrate what it means to experience Post Intensive Care Syndrome (PICS).

The study highlights communication challenges, living with uncertainty, and post-ICU fallout, with associated suggestions for improvement. This study highlights the importance of communication throughout hospitalization with both the patient and family and the importance of family presence to the patient. The family presence or lack thereof was a source of stress for some participants, and the lack of family made participants feel exposed and vulnerable. The poor communication that participants experienced is shown to have a ripple effect on the patient that follows them well beyond their hospital stay and has a lasting impact on their recovery.

This study also highlights the importance of ICU follow-up for ICU survivors. All three participants in this study have varying degrees of PICS sequelae, as demonstrated through descriptions during their interviews. For the participants of this study, the ICU recovery clinic

serves as a profound advocate and normalizes the process of ICU recovery for those participants. This highlights the necessity of these types of clinics and provides further evidence of support.

Future research should include larger sample sizes and have multifaceted diversity (i.e., cultural, spiritual, unhoused, and those with addictions) to ensure future policies are inclusive of all ICU patients. I also recommend educating all healthcare providers about PICS as the population of ICU survivors continues to increase. Furthermore, future qualitative studies should include families to help understand the ICU experience for patients and their families. This will help ensure that future policies or programs will support the patient and the entire family.

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APPENDIX A: STUDY INVITATION



Faculty of Nursing

Dear Patient,

Re: Research Study: Life After ICU: The patient experience after hospital discharge

We are writing to inform you of a study involving former ICU patients in Calgary, Alberta to hear about your experience during your hospital stay and since going home.

The principal investigator of the research study, Dr. Lorraine Venturato is an associate professor with the University of Calgary, Faculty of Nursing.

The research team is trying to gain a better understanding of the experiences of patients discharged from ICU in Calgary, Alberta. We are looking to know more about what it was like for you during your hospital stay and since going home.

For more information about the study or to arrange for your participation, contact Catherine McIntyre

Participation in the study is voluntary. If you choose not to participate, your care will not be affected in any way.

Sincerely,

Catherine McIntyre

Graduate Student

University of Calgary, Faculty of Nursing

APPENDIX B: CONSENT FORM

STANDARD CONSENT FORM

TITLE: Life After ICU: The patient experience after hospital discharge

INVESTIGATORS: Catherine McIntyre (MN-Student)

Supervisor: Dr. Lorraine Venturato

This consent form is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, please ask. Take the time to read this carefully and to understand any accompanying information. You will receive a copy of this form for your records.

BACKGROUND

An ICU stay is a major life event for patients and their families. ICU survivors may face a many different complications after their hospital stay. It is not clear how an ICU stay affects people after they have returned home. This study will help gain a better understanding of ICU survivor experiences. This may help in the planning of future services for ICU survivors like yourself.

WHAT IS THE PURPOSE OF THE STUDY?

ICU survivors may face problems once returning home. This study will provide more information about the experience of ICU survivors. It will help understand the resources required for ICU survivors.

WHAT WOULD I HAVE TO DO?

Take part in a 45-minute Zoom video interview. Answer questions about what your experience has been with ICU and after hospital discharge.

WHAT ARE THE RISKS?

Talking about your experience of ICU may bring up bad memories, or trigger emotions. If you are at risk of harming yourself or others during this interview clinic staff will be notified.

Your privacy is very important. All identifying information about you will be removed. But your story is unique, therefore there is a chance it could be identifiable.

DO I HAVE TO PARTICIPATE?

Voluntariness and Withdrawal of consent

Participation in the study is voluntary and you may withdraw from the study at any time without jeopardizing your health care.

Withdrawal of Study Data

The data that you provide in the interview can be withdrawn up until the data analysis phase has commenced. To have your interview withdrawn please contact **Catherine McIntyre**.

WILL I BE PAID FOR PARTICIPATING, OR DO I HAVE TO PAY FOR ANYTHING?

There is no compensation for your participation in this study.

WILL MY RECORDS BE KEPT PRIVATE?

To ensure that confidentiality and privacy are maintained, all information obtained or transcribed electronically will be stored on a private password protected computer. All data collected in this study will be de-identified. Any written, printed, or recorded data will be stored in a locked filing cabinet that only myself and my supervisor will be able to access. Additionally, the University of Calgary Conjoint Health Research Ethics Board will also have access to the records for quality assurance purposes.

SIGNATURES

Your signature on this form indicates that you have understood to your satisfaction the information regarding your participation in the research project and agree to participate as a participant. If you are unable to provide a signed copy verbal consent will be accepted. In no way does this waive your legal rights nor release the investigators or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time without jeopardizing your health care. If you have further questions concerning matters related to this research, please contact:

Dr. Lorraine Venturato

If you have any questions concerning your rights as a possible participant in this research, please contact the Chair, Conjoint Health Research Ethics Board, University of Calgary at 403-220-7990.

Participant's Name

Signature and Date

Investigator/Delegate's Name

Signature and Date

Witness' Name

Signature and Date

The University of Calgary Conjoint Health Research Ethics Board has approved this research study.

A signed copy of this consent form has been given to you to keep for your records and reference.

APPENDIX C: INTERVIEW GUIDE

Research Question: *What are the perspectives and experiences of patients discharged from ICU in Calgary, Alberta at risk of developing Post Intensive Care Syndrome to better inform our practice of discharge support needs.*

Questions:

Can you tell me about what happened from your ICU stay till now? (looking for timeline of events)

When was the first time someone explained to you why you were in ICU and explained what happened to you? Would you want this handled differently?

What was your experience when you were transferred from ICU to the ward? Then with discharge from the hospital?

From the literature it has been reported that people can sometimes have bad dreams, feel tired, have trouble sleeping, or have muscle weakness. Would you say this has happened to you?

- Looking for PICS type symptoms: Nightmares, delirium, anxiety, depression, breathlessness, poor cognition, etc.

If you were in charge of the health care system and had no limits what would you have for people in your situation?

Is there anything that we haven't talked about today that you would like to talk about?

APPENDIX D: TIMELINE OF COVID-19 PANDEMIC IN ALBERTA, CANADA

