Intensive Care Survivors' Perspectives and Post-Intensive Care Syndrome

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A Dissertation presented to the Graduate Faculty of the University of Virginia in Candidacy for the degree of Doctor of Philosophy

School of Nursing

University of Virginia

December, 2020

Abstract

Critical care medicine was developed in the 1950s when physicians created hospital units offering close monitoring of patients with life-threatening illnesses (Vincent, 2013). During the intervening 70 years, critical care medicine evolved to the point that fewer than 20% of intensive care unit (ICU) patients succumbed to their illnesses (Garland, Olafson, Ramsey, Yogendran, & Fransoo, 2014). Improved survival rates have encouraged researchers and providers to examine the consequences of critical illnesses and ICU stays for involved patients. Post-intensive care syndrome (PICS) is a group of new or worsening symptoms and debilities experienced by ICU survivors related to critical illness and ICU stay (Jutte, Erb, & Jackson, 2015; Needham et al., 2012). PICS can include decreased functional, cognitive, neurological, and psychological functional status. While PICS's description has improved the management of many issues experienced by the ICU patient population, the definition of PICS is medically-derived. This study addresses a knowledge gap of PICS, the "lived experience" of ICU survivors with self-reported PICS. A constructivist grounded theory approach was used to examine social media posts of twenty ICU survivors with PICS. The posts were written by self-reported adult ICU survivors with PICS symptoms at varying lengths of time after hospital discharge for their inciting critical illness. The resulting 325 posts were transcribed verbatim. Comparative methods and inductive analyses provided categories based on relationships between focused codes and emerging themes to allow for the development of a grounded theory to explain the process of recovery for ICU survivors with PICS. The GT approach allowed for an examination of differences between provider- and patient-perspectives of PICS and facilitated examination of facilitators and barriers experienced by ICU survivors throughout their recovery period. The resulting GT model was then used to compare patient-focused experiences versus the accepted provider-driven definition of PICS. An explanatory matrix (EM) was developed to collate the themes collected from the ICU survivors' posts and summarized as the *'Journey to a New Normal'*. The EM provided a resource for expanding the definition of PICS to include a more patient-centric perspective of the related health issues experienced by intensive care survivors. As the central process, the *'journey to a new normal'* represents the course of recovery for ICU survivors with self-reported symptoms of PICS as they recuperate from their recent critical illness. Many patients experience an eventual plateau in recovery representative of their *'new normal'*. The contributing processes affecting the *'journey to a new normal'* included separating nightmares from reality, individualizing the process of recovery, and determining the consequences of survival. Consequences of the journey to a new normal state included dealing with false memories related to delirious episodes, changes to overall health and functional status, new survival needs, evolving definitions of life's value after ICU, and engaged versus absent support systems (Chapter 4, Figure 1). In 2020, many ICU survivors have expressed unprecedented anxieties surrounding media coverage of the COVID-19 pandemic. The public information about COVID-19 has prompted some intensive care survivors to adjust or write new advance directives precluding readmission to an ICU, intubation, or advanced life-support measures. This study provided an examination of patient-focused experiences with recovery after critical illness and added patient-driven perspectives to augment the provider-focused definition of PICS for the overall goal to improve patient recovery and health outcomes.

Acknowledgements

My sincerest thanks go to my dissertation chair and advisor, Dr. Ken White, and additional committee members, Dr. Susan Kools, Dr. Kyle Enfield, and Dr. Katrina Debnam, for their guidance and support throughout this challenging process. They have provided great insight and direction in my development as a researcher as well as my development as a nurse practitioner.

To my wife, Anna, for her unfailing support and love throughout this endeavor. I look forward to celebrating this accomplishment and spending more time with you. To my father, Robert Kelleher, who allowed me to experience the ICU from a family member’s perspective. I am ever grateful that your ICU stay was quick and that you have recovered so well. Also, to my mother, Cindy Kelleher, who has offered unfailing support in all my endeavors. And to all my family, thank you so much for all your support, I look forward to spending more time with you all now that I’ve completed this educational hurdle.

This dissertation is dedicated to the anonymous ICU survivors who were central to the study and to all the critical care nurses and staff who work tirelessly to deliver the best care possible to a complex patient population. Your experiences and stories continue to inspire me and enrich my professional experiences, encouraging me to continue advancing my understanding of critical care and PICS management.

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Chapter 1 – Introduction

Dissertation Overview and Organization

This dissertation encompasses a series of academic work focused on the study of intensive care survivors with Post Intensive Care Syndrome (PICS). Most research on this topic consists of studies that have been limited by medical subspecialty, population size, or timeframe. The author is unaware of other studies that have attempted to utilize a large population of ICU survivors discussing their symptoms and recovery process through social media platforms over an extended period. The qualitative data obtained through analysis of participant posts provides rich information with detailed patient perspectives of PICS and the process of recovery after an ICU stay.

The format of this dissertation complies with the University of Virginia's School of Nursing dissertation manuscript option. This dissertation is made up of six chapters. Chapter one introduces the dissertation and the specific aims for the included studies. Chapter two contains the revised proposal reflective of changes recommended by the dissertation chair and committee members. Chapters three through five will be turned into manuscripts ready for peer review. Chapter three provides a knowledge gap analysis of PICS. Chapter four is a grounded theory analysis of ICU survivor social media posts describing the process of recovery for participants with self-reported symptoms of PICS. Chapter five offers a comparison between the accepted definition of PICS and patient perspectives of associated symptoms to facilitate an expansion of the PICS definition. Chapter six provides the final discussion and conclusion for this dissertation.

Introduction to the Topic

Recent research defines critical illness as any primary diagnosis requiring admission into an intensive care unit (ICU) and length of stay (LOS) in the ICU of greater than 96 hours (Modrykamien, 2012). Patients who suffer a critical illness requiring treatment in an intensive care unit and survive through to hospital discharge are considered ICU survivors (Davidson, Hopkins, Louis, & Iwashyna, 2013). Patients who required more than 96 hours of care in an ICU, admitted for a primary diagnosis of sepsis, ARDS, or other illnesses requiring ventilator support, vasoactive medication, or antibiotic treatment, and whose stay was complicated by the development of delirium are at the greatest risk of developing post-intensive care syndrome (PICS) (Higgins, Stollings, Jackson, & Sevin, 2015). This sequelae of issues related to critical illness and prolonged ICU stays includes decreased physical, neurocognitive, and psychological function and often leaves ICU survivors with serious debilitations including post-traumatic stress disorder (PTSD), anxiety, muscle weakness, shortness of breath, and a host of other new chronic issues (Davidson et al., 2013; Jutte et al., 2015; Needham et al., 2012).

Critical care medicine has evolved greatly over the last 70 years from a survival rate less than 60% for all ICU patients and less than 20% for patients requiring mechanical ventilation to mortality rates less than 20% for overall ICU populations (Berthelsen & Cronqvist, 2003; Garland et al., 2014). By improving mortality rates, ICU providers have facilitated the development of a growing population of ICU survivors with approximately 4 million new ICU survivors in the United States each year (Barrett, Smith, Elixhauser, Honigman, & Pines, 2014). More than 2 million of these ICU survivors will suffer from significant functional impairment over the three years following their ICU stay (Iwashyna, Cooke, Wunsch, & Kahn, 2012). 29% of ICU survivors are unable to return to work and continue to require more than $10,000/year of healthcare support compared to patients with similar diagnoses who did not require an ICU stay (Collie et al., 2019; Hodgson et al., 2018). Some of the most common conditions experienced by ICU survivors include memory loss, anxiety, muscle weakness, neurocognitive dysfunction, and decreased activity tolerance (Davidson et al., 2013; Needham et al., 2012).

Ten percent of ICU survivors develop chronic cognitive, physical, and/or neurological impairments related to their recent ICU stays (Davidson et al., 2013). However, fewer than 20% of ICU survivors participate in PICS follow-up care to receive treatment for their new significant impairments (O. Ranzani & Jones, 2015). Because of poor follow-up and management of their new health conditions, more than 30% of ICU survivors are readmitted to a hospital within 6-months of their initial hospital discharge (Hua, Gong, Brady, & Wunsch, 2015). Despite an apparent understanding of the medical needs of ICU survivors and the many symptoms encompassed by PICS, the ICU-survivor population continues to have poor follow up clinic attendance and increased utilization of medical facilities after their hospital discharge compared to patients with similar diagnoses who did not require an ICU stay (Barrett et al., 2014; Needham et al., 2012; Ranzani & Jones, 2015).

Specific Aims

The overall purpose of this program of research is to enable better understanding of the recovery experience for ICU survivors with PICS and facilitate improved follow-up care for this patient population. Management of PICS has evolved during the intervening eight years since the syndrome was initially described (Needham et al., 2012). ICU survivors who required mechanical ventilation represent an even more vulnerable subset of ICU survivors experiencing up to a 72% one-year mortality rate (Needham, Feldman, & Kho, 2011). Patients with primary diagnoses most commonly requiring ICU management (including sepsis, myocardial infarction, and congestive heart failure) have approximately a 20% 30-day readmission rate. Treating these patients costs more than $400 million/year of state funding (Chang, Tseng, & Shapiro, 2015).

ICU survivorship also has a much more personal cost that often has a prolonged effect on the lives and social roles of patients. It is essential for us to have a better understanding of ICU survivors' experiences after their initial hospital discharge. While we have data describing functional, neurological, and cognitive changes experienced by ICU survivors with PICS, much of the post-discharge research is disjointed and focused on specific, individual complications rather than the entire sequalae of issues, including the emotional and quality of life issues often experienced by these patients. The available literature is also lacking in research that examines how ICU survivors interact with their new debilities and how they deal with them. The aims of this dissertation are:

1. Examine the available literature focused on ICU survivors with PICS and present knowledge gaps for future research
2. Describe the process of transition from ICU to a new long-term functional state and possible recovery plateau for ICU survivors
3. Identify facilitators and barriers to achieving the nearest approximation to ICU-survivor's previous functional state prior to their initial inciting illness
4. Examine the differences between the published medical definition of PICS and the lived experience from the ICU-survivor's perspective
5. Provide insight into the process of recovery and journey to a new normal state for ICU survivors with PICS

Critical care research provides an important role in guiding management of ICU-patients. Similarly, outcomes studies for this patient population led to definitions and descriptions for post-intensive care syndrome (Colbenson, Johnson, & Wilson, 2019; Jutte et al., 2015; Needham et al., 2012). A professional consortium of critical care providers and researchers defined PICS based on multiple studies of ICU survivors who developed the included sequelae of symptoms. However, patient experiences are often different than clinical descriptions would suggest. By examining the knowledge gaps surrounding ICU survivors and PICS from the patient perspective, this dissertation emphasizes the need to further study post-intensive care syndrome from the ICU-survivor's viewpoint.

The ground work for the dissertation focuses on the ICU-survivor's process of recovery and personal experiences, including facilitators and barriers, throughout the process of recovery from PICS. The examination of PICS from the patient's perspective provides a greater understanding of their needs for optimizing recovery and facilitating their integration into their lives before the inciting illness occurred. Additionally, the dissertation compares the clinical definition and the patient experiences of PICS. By emphasizing the differences between these two parallel perspectives, we can better understand opportunities to improve care and support for this patient population.

Reflexive memo

This dissertation is derived from my experience as a critical care provider and nurse scientist. In one of my previous lives, I was a bench researcher during a three-year period when I worked with two different research groups focused on HIV vaccine research and later examining characteristics of pituitary cancer therapies. Several professions later, I made my way into nursing and now nursing research. My current profession combines a background in microbiology, bench research, education, and nursing in a unique way—affording me a broad knowledge base from which to approach clinical research questions. As a nurse with more than ten years' experience in critical care with six years as a nurse practitioner in a medical intensive care unit, I have seen many of the complications related to prolonged/serious ICU stays. I have also interacted with many ICU survivors as they face the challenges related to their preceding ICU stay. Unfortunately, most of my interaction with survivors is when they return to the hospital for subsequent admissions to deal with the same or new health issues. Every patient has a different experience during their ICU stay depending on the reason for the admission, comorbidities, and the state of their health and functional/cognitive level prior to hospitalization. The level of social support is also important at the time of admission, during the hospital stay, and at time of discharge. Social and family support can often affect the degree and the ICU survivor's ability to return to their pre-ICU admission functional states. However, as providers, we have a certain focus when we look at our patients. We tend to concentrate on significant health issues or problems that affect physical and cognitive function. It is easy to overlook health problems that are not life-threatening but may affect ICU survivors on a much more personal level.

As a family member with a father who spent several days in an ICU for acute structural heart failure related issues and surgery, I recognize that our clinical focus may miss the mark in addressing issues that seem less important to us but may be as important, or even more important to our patients. Knowledge, support, control, self-image, and a clear memory of significant events as well as other issues may play a significant role in patient recovery but be less emphasized in follow-up visits and after-care for ICU survivors. While critical care has evolved greatly over the past 70 years, we are still very new at dealing with the fallout of ICU stays. As someone whose professional career has also focused on education, I believe it is important to achieve greater understanding of the issues, facilitators, and barriers to ICU survivors' recovery, and to ensure the information and education is provided to patients and families, and also to health care providers who are able to improve quality of life outcomes.

Theoretical influences

This study utilizes the theoretical underpinnings of Meleis's health transitions theory as a conceptual foundation in exploring the health transitions experienced by a ICU survivors with PICS (Meleis, 2018; Meleis et al., 2000). Healthy people adapt to changes in their health status through anticipation and adjustments to their lifestyle. People's abilities to adjust to changes in their health status are affected by their underlying health, ability to care for themselves, and preventative actions to maintain their current health status (Meleis, 2018). However, ICU survivors with PICS are frequently unable to anticipate or adapt to the changes to their health status resulting from recent hospitalization. This study seeks to determine facilitators and barriers to rehabilitation for ICU survivors with symptoms of PICS. This study also highlights differences between the provider-definition and patient-driven experience for PICS.

This study utilizes a constructivist grounded theory approach to examine publicly available social media posts from ICU survivors with self-reported symptoms of PICS (Charmaz, 2014). Through this grounded theory (GT) approach, this study developed a model explaining the process of recovery for ICU survivors with PICS (Glaser & Holton, 2004; Glaser & Strauss, 1967). The model was developed through coding, thematic analysis, abstraction, and categorization of emerging themes. Resulting themes were organized based on relevant relationships as evidenced by interactions between the research participants. The conclusions and assumptions inherent in this model are based on the theoretical foundations of symbolic interactionism (SI) (Blumer, 1969; Charmaz, 2014). Through SI, this study developed explanations of behaviors, shared terminology, and expressions within a population of ICU survivors as they discuss and interact with their symptoms of PICS and recovery from recent critical illnesses (Blumer, 1969). ICU survivors all have different experiences with their critical illnesses and subsequent recovery after hospital discharge. However, they share many overlapping experiences, expressions, thoughts, and behaviors. These experiences vary slightly depending on degree of functional loss, severity of symptoms, and the effect their recent illnesses and new symptoms have on their overall life. Constructivist grounded theory utilizes the input of these study participants in addition to the researcher's interpretation of the participants' interactions with each other to co-construct a model that explains the process of recovery for ICU survivors with PICS (Charmaz, 2014).

Glossary of terms and abbreviations

Intensive Care Unit (ICU): Hospital ward with close observation/intensive treatment of critically ill patients (Berthelsen & Cronqvist, 2003).

ICU survivor: Patients with recent critical illness requiring treatment in an intensive care unit who survive through to hospital discharge (Davidson et al., 2013).

Acute Respiratory Distress Syndrome (ARDS): A sudden inflammatory process resulting in a change in gas exchange within the lungs, diffuse multifocal infiltrates seen on radiography, and hypoxia (Rawal, Yadav, & Kumar, 2016).

Post – Intensive Care Syndrome (PICS): Sequelae of symptoms including physical, neurocognitive, and psychological changes related to recent critical illness and prolonged ICU-stay (Needham et al., 2012).

Post-Traumatic Stress Disorder (PTSD): (Substance Abuse and Mental Health Services Administration., 2014)

ABCDEF Critical Care Bundle: Preventive bundle of ICU interventions targeted at minimizing delirium in the in-patient setting and PICS in the out-patient setting (Marra, Ely, Pandharipande, & Patel, 2017).

This chapter introduced the dissertation and the specific aims of this research. The chapter provided definitions for key terms and explanations of predominant theoretical influences. The subsequent chapter discusses the evolution of critical care and development of PICS as a description for common issues experienced by ICU survivors. Chapter two describes the conceptual framework and knowledge gaps addressed by this dissertation. It will also present the methods for the addressing the specific aims of the dissertation.

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Chapter 2: Revised Proposal

Introduction to the Problem

Changes in critical care medicine over the last 20 years have improved disease management so that approximately 80% of patients admitted to intensive care units (ICU) survive to discharge from the hospital (Garland, Olafson, Ramsey, Yogendran, & Fransoo, 2014). United States hospitals admit over 5 million people to ICU each year (Barrett, Smith, Elixhauser, Honigman, & Pines, 2014). According to Iwashyna and colleagues (2012), 66% of these patients had persistent functional impairment three years after their initial critical illness. Improved mortality rates for ICU survivors have led clinicians to focus on ways to better provide follow-up care for this population. Critical care medicine researchers identify ICU survivors as people who have experienced a critical illness requiring admission to an intensive care unit having survived their hospital stay to discharge (Davidson, Hopkins, Louis, & Iwashyna, 2013).

The healthcare industry's management of aftercare for ICU survivors affects the overall populations health, economics, and social wellness. Members of this patient population often have a long road to recovery affected by pre-existing illnesses, health literacy level, and healthcare access in addition to their critical illness (Lone et al., 2016). Patients who experienced an ICU stay for a recent illness have higher one- and five-year morbidity and mortality rates when compared with similar patients who did not require an ICU-stay during their hospital admission (Lone et al., 2016). The average five-year healthcare utilization cost for ICU survivors is 51% higher than matched patients without an ICU stay resulting in approximately $10,000 more spent on each ICU patient in the 5 years after their hospital stay (Lone et al., 2016). The United States spends approximately $82 billion yearly of its gross domestic product on critical care (Sjoding, Prescott, Wunsch, Iwashyna, & Cooke, 2016). Within the first six months after hospital discharge, 34% of ICU survivors require readmission due to unplanned events (Hua, Gong, Brady, & Wunsch, 2015). Greater emphasis should be placed on improving aftercare for ICU survivors.

Care for ICU patients after hospital discharge (after-care) is an evolving area of clinical practice and recommendation can vary depending on the patient's functionality, severity of inciting illness, and level of debilitation after hospital discharge. Various methods for aftercare include clinic follow up, home or in-patient rehabilitation, and various combinations of all of these. While there are many ICU aftercare clinics in Europe, United States based ICU aftercare clinics remain relatively rare. This is partially related to a lack of professional recommendations and, until recently, a poor definition of the comorbidities involved in post intensive care syndrome. In 2012, the Society for Critical Care Medicine (SCCM) defined the cluster of morbidities frequently experienced by ICU survivors as Post Intensive Care Syndrome (PICS) (Needham et al., 2012).

The sequelae related to ICU survival include physical, mental, or cognitive impairment that may last months after a critical illness (Needham et al., 2012). PICS may also include pulmonary, psychiatric, neurocognitive complications, and decreased quality of life (Fonsmark & Rosendahl-Nielsen, 2015). One of the more serious complications common to ICU patients is delirium. Delirium is an acute alteration of mental status resulting in memory loss, hallucinations, agitation, anxiety, which often results from acute illness, various medications, and changes to sleep/wake cycle experienced during an ICU stay (Siddiqi, House, & Holmes, 2006). 60 to 80% of ICU survivors develop delirium during their hospital stay. With as low as a 33% detection rate, there is a significant population of ICU survivors whose delirium remains undetected but will still suffer the same neurologic and cognitive delays experienced by those with recognized delirium that is a major component of PICS (Girard et al., 2010; Siddiqi et al., 2006). Patients who experience delirium, one of the major complications contributing to PICS, in the hospital have increased mortality beyond their hospital stay and suffer from prolonged debilitations that complicate their transition back to functional society (Abraham et al., 2014). While ICU after care in the United States is gradually improving, this patient population continues to have follow up clinic attendance as low as 20% (Ranzani & Jones, 2015). Direct discharges to home (DDH) from ICUs have increased dramatically during recent years across the United States from 3% to 12.5% (Lau, Priestap, Lam, & Ball, 2018). Direct discharge from intensive care may also decrease the overall survival rate of ICU-patients (Senaratne et al., 1999). Thus, it is not surprising that ICU survivors have readmission rates up to 34%, with increased mortality for patients needing hospital readmission (Hua et al., 2015).

Purpose

Meleis and colleagues (2000) developed the theory of health transitions in nursing. Patients experience health transitions at different rates depending on illness severity, social support, health literacy, complicating comorbidities, and personal resiliency (Meleis et al., 2000; Schumacher & Meleis, 1994). Efforts to improve the follow-up care of ICU survivors should meet the patients' needs as they recover from their recent illness and strive to return to some approximation of their baseline functional and health status (Meleis et al., 2000). ICU survivors follow a general trajectory of illness process. Typically, there is an inciting event that leads to a hospital admission and eventually to a stay in the ICU for those with severe illnesses and any development of delirium with variations in severity, duration, and number of delirious episodes. Beyond the ICU stay, patients may be transferred to a lower acuity level of care and then eventually discharged from the hospital. At discharge, patients may go to long-term care facilities, rehabilitation facilities, other acute care centers, or home. Because of the various consequences of their recent illness and resultant comorbidities, many patients never return to their previous cognitive, neurocognitive, or physical function.

The author will use the term “new normal” to describe the participants’ plateau in recovery and their new health status. Recovery after ICU stay is often a long process requiring extensive rehabilitation depending on the acuity of their inciting illness and the severity of their co-morbidities as well as the severity and duration of delirium episodes. Many elderly patients with multiple co-morbidities are unable to return to their previous state of health. They often find their recovery plateaus into a “new normal” state where they function better than during their hospital stay but at a decreased functionality compared to their abilities prior to the hospital stay. The length of time for recovery and obtaining a “new normal” may vary depending on the severity of associated comorbidities, social support, rehabilitation, clinical follow up, and many other variables. The purpose of this study is to explore the transition from ICU and in-hospital care to outpatient care for patients with PICS, including long-term care, rehabilitation facilities, other acute care centers, and patients discharged directly to home. For this purpose, the proposed study will focus on adult ICU survivors with PICS who have posted about their recovery experience on freely accessible social media platforms. By examining patient social media posts, this study will seek to describe the process of transition to a “new normal” baseline. With deeper insight into the needs of this population, the long-term goal of this program of research is to develop a patient-centric after-care approach to improve morbidity and quality of life for ICU survivors with PICS.

The specific aims of this study were updated to reflect the summary of recommendations from the dissertation chair and key committee members as discussed at the proposal defense. The resulting research goals reflect the consensus of these recommendations:

a. Examine the available literature focused on ICU survivors with PICS and present knowledge gaps for future research
b. Describe the process of transition from ICU to a new long-term functional state and possible recovery plateau for ICU survivors
c. Identify facilitators and barriers to achieving the nearest approximation to ICU-survivor's previous functional state prior to their initial inciting illness
d. Examine the differences between the published medical definition of PICS and the lived experience from the ICU-survivor's perspective
e. Provide insight into the process of recovery and journey to a new normal state for ICU survivors with PICS

Research Strategy

Significance. Approximately 80% of ICU survivors experience decreased physical and cognitive abilities that persist years beyond their initial ICU stay (Harvey & Davidson, 2016). Up to 50% of these patients also experience post-traumatic stress symptoms related to their ICU stay and recent illness for up to 8 years beyond their initial illness (Harvey & Davidson, 2016). Despite an apparent understanding of the medical needs of ICU survivors and the many symptoms encompassed by PICS, the ICU-survivor population continues to have poor follow up clinic attendance and increased utilization of medical facilities after their hospital discharge compared to patients with similar diagnoses who did not require an ICU stay (Barrett et al., 2014; Needham et al., 2012; Ranzani & Jones, 2015). The poor follow up attendance for ICU survivors is largely unexplained by the currently available literature but will be better illuminated through an improved understanding of the ICU-survivor experience after hospital discharge in the proposed study.

Costs of ICU survivorship. Improved survival rates for patients requiring intensive care treatment has highlighted the impact of critical illnesses on ICU survivors and society. ICU survivors have 51% more healthcare expenses during the 5-years after their initial hospital stay compared to matched patients with similar illnesses who did not require intensive care treatment (Lone et al., 2016). ICU survivors who required mechanical ventilation represent an even more vulnerable subset of ICU survivors experiencing up to a 72% 1-year mortality rate (Needham, Feldman, & Kho, 2011). Patients with primary diagnoses most commonly requiring ICU management (including sepsis, myocardial infarction, and congestive heart failure) have approximately a 20% 30-day readmission rate. Treating these patients costs more than $400 million/year of state funding (Chang, Tseng, & Shapiro, 2015).

ICU survivorship also has a much more personal cost that often has a prolonged effect on the lives and social roles of patients. It is essential for us to have a better understanding of ICU survivors' experiences after their initial hospital discharge. The purpose of the following research is to examine knowledge gaps in the literature for ICU survivors with symptoms of PICS, the process of recovery, and variations between the survivor and provider perspectives of PICS.

Literature Review

A brief review of available literature regarding ICU survivors, PICS, and Post Intensive Care Syndrome demonstrated 71 articles related to the search terms. Of these, only one study focused on patient experience with PICS after hospital discharge (Kang & Jeong, 2018). Kang & Jeong (2018) performed semi-structured interviews with 13 ICU survivors with PICS. These interviews resulted a grounded theory framework that described the feelings of vulnerability experienced by many ICU survivors and their process of dealing with these new issues (Kang &

Jeong, 2018). Kang & Jeong (2018) focused on coping mechanisms utilized by ICU survivors and how these impacted their acceptance of new limitations related to their recent illnesses. This study will build on Kang & Jeong's (2018) results by examining ICU survivors their transition from ICU to a "new normal" state through their social interactions in online support groups. Multiple interactions and engagement from participants in the online support groups over time will facilitate the development of a theoretical model for the process of recovery for ICU survivors.

Other studies found during the literature review focused on 1-2 symptoms within PICS, such as delirium, muscle weakness, post-traumatic stress symptoms, and Health Related Quality of Life (HRQOL) for ICU survivors with PICS (Abraham et al., 2014; Chaboyer & Grace, 2003; Jones et al., 2010). Marra and her research team (2018) examined incidence of PICS symptoms and occurrence frequency of multiple symptoms within each patient. Only one study focused on the patient experience with PICS and the true meaning of this conglomeration of symptoms for ICU survivors (Kang & Jeong, 2018). Further research into the experiences with PICS will aid in developing patient-centered interventions to manage the sequelae of related symptoms. Understanding psychosocial interactions between ICU survivors will aid in managing symptoms related to PICS (Kang & Jeong, 2018). The different recovery trajectories and varieties in social interactions will also provide insight into differing levels of recovery for ICU survivors.

Theoretical underpinnings

For healthy people, transitions in their lives start with anticipation of change and adaptation to their environment (Meleis et al., 2000; Meleis, 2018). Their ability to adapt to these changes is affected by their overall health, ability to care for themselves, as well as any preparation and preventative actions taken to increase the likelihood of the best possible outcome to each transition (Meleis, 2018). This study will utilize the theoretical underpinnings of Meleis's health transitions theory as a foundation for understanding health transitions in a patient population experiencing vast health changes in a short period of time with many of those changes inhibiting their ability to adapt (Meleis, 2018). Much of Meleis's theory focuses on gradual transitions and often addresses the experiences of healthy or relatively healthy individuals who will eventually regain full functionality (Meleis, 2018). This study focuses on the survivors' experiences with the changes in health caused by their recent ICU stay. The study also examines the participants' transitions back to some semblance of health and their adaptation to a "new normal." The affect PICS symptoms have on ICU-survivor recovery can provide insight into the various characteristics of their environment and healthcare follow up that act as facilitators and barriers to optimal recovery.

Key terms. Recent research defined critical illness as any primary diagnosis requiring admission into an intensive care unit (ICU) and length of stay (LOS) in the ICU of greater than 96 hours (Modrykamien, 2012). This study defines ICU survivors as patients requiring greater than 96-hours in the ICU for a primary diagnosis of sepsis, ARDS, or other illness requiring ventilator support, vasoactive medication, or antibiotic treatment whose stay was complicated by the development of delirium or other sequelae of PICS (Higgins, Stollings, Jackson, & Sevin, 2015). These patients must survive their hospital stay through to discharge to be considered ICU survivors (Davidson et al., 2013). This study defines a "new normal" state as the point when the patient's clinical recovery and functional ability plateaus to the nearest approximation of their functional and neurocognitive ability prior to their recent ICU stay. This study includes adult patients over 18-years of age who have posted about their critical illness experience on a freely accessible social media platform.

Approach

Design. This study will utilize a constructivist grounded theory approach to examine first-hand descriptions of ICU survivors and their experiences during and after their hospital stay as they recover from critical illness (Charmaz, 2014). The Grounded Theory (GT) approach facilitates the development of a model to explain an observed process (Glaser & Strauss, 1967; Glaser & Holton, 2004). Models developed using GT are made up of a series of hypotheses and interactions between events based on the researcher's observations of various data sources.

Grounded theory is based on the theoretical foundation of symbolic interactionism (SI) (Blumer, 1969; Charmaz, 2014). Blumer (1969) believed that communications between people and the value or definitions they ascribed to various terms defined the world as they saw it. Symbolic interactionism is an analysis of the meaning research participants place on social behaviors, shared terminology, and expressions. SI examines shared meanings co-constructed between the researcher and the study participants to develop a framework that describes behaviors and interactions of interest (Blumer, 1969). By observing research participants' behaviors with other participants, spoken language, symbols, and objects around them, we can infer much of the evolution of the participants' defined role. These roles in participant social circles demonstrate how their recent illness has changed their views and interactions with common symbols (Blumer, 1969; Charmaz, 2014).

Constructivist grounded theory utilizes the input of the researcher, study participants, and target audience to co-construct frameworks that explain the subject of research (Charmaz, 2014). This form of GT accepts the subjective nature of qualitative research and all research in general as an interpretation of the author's conclusions from analysis of related data (Charmaz, 2014). In contrast, objectivist GT focuses on what is thought to be empirical data and passive observation with a neutral observer. However, it also assumes that there is one reality experienced and shared by all that will be discovered through the research process (Glaser, 1992). Each ICU-survivor has a different experience with their critical illness and subsequent hospital stay. Their recovery and interaction with PICS symptoms also differ depending on the degree of functionality loss, severity of symptoms, and the effect of those symptoms on their life. Providers, medical professionals, ICU survivors, and survivor family members all assign different meanings to the definition of survivor and PICS symptoms as well as how the patients are affected by the overall experience. Each person's definition and understanding of these terms and experiences are their personal symbolic interactions. Overlaps of symbolic interactionism between ICU survivors and their experiences with PICS symptoms will offer insight into their recovery experience.

Sample. Purposive sampling will provide the initial group of participant posts based on details provided by the participants, severity of illness described, duration of ICU-stay, and PICS symptoms experienced after hospital discharge. Theoretical sampling, maximizing variation in levels of severity for initial illness and subsequent PICS symptoms, will allow refinement and provide greater depth for major theoretical categories as they develop. This study will sample 20 to 30 participants and their social media posts. Research content will include any associated videos, pictures, reposts, and responses posted by ICU survivors, their family members, or primary caregivers on free-to-access websites such as YouTube and Facebook. Analyzing social media provides a view into the lives of the participants from their own perspectives in which the study population develops all interactions. Through multiple small group discussions (posts and responses) and participant self-identification, researchers can observe interactions, lingo adoption, common experiences, facilitators, barriers, participant-vouched remedies, and shared successes and frustrations of after care for PICS.

Social media posts and reposts, written by ICU survivors over an extended period, will provide longitudinal insight into the experiences of ICU survivors as they recover from their recent illness. While approximately 20-30 participants will be identified for data extraction, this process will include multiple posts, reposts, responses, video interviews, and other input for the abstraction of conceptual categories and development of the overarching theory of this transition from illness, through recovery, to a plateau in physical, cognitive, and neurologic improvement in the closest approximation to the participants' functional state prior to the inciting illness.

Posts included for analysis in this study will consist of adults over the age of 18, who self-report a recent illness with more than 96-hour stay in the intensive care unit and with discussions of their experience of recovery after ICU stay and statements consistent with symptoms included in PICS. Posts written in languages other than English will be excluded. Participants will be excluded based on self-report of trauma or elective surgical procedure leading to ICU stay, lack of description of ICU stay and recovery experience in their profile or posts, or participants with a single or minimally detailed posts. Patients who are unable to post and likely those who suffer the most debilitating effects of their recent illnesses and resulting PICS, and those who do not post on social media will be excluded by their lack of posts and this is a limitation that cannot be addressed in this design.

Data sources for this study include ICU-survivor posts on social media sites including Facebook and freely accessible, public ICU-survivor sites. Individuals participating on the social media sites will represent the population of participants while responses and reposts will offer an opportunity to examine symbolic interactions through social exchanges. Videos and pictures will also provide detailed illustrations of ICU survivors' lives and interactions with their PICS symptoms after hospital discharge. Analysis of the pictures and videos will be reflected in verbal descriptions within the related transcribed post data.

IRB approval. The University of Virginia Social and Behavioral Institutional Review Board (UVA IRB-SBS) approved this research protocol with exempt status as the participants will not be contacted in any by the researcher. As there will be no contact with the participants, there is minimal risk of harm. The social media posts are publicly available and only contain information voluntarily submitted by the blog authors and not elicited through any requests by the researcher. Videos and pictures with identifying images will not be included for privacy purposes. However, images blurred to prevent recognition or without identifying information may be included for reference and context.

Data gathering. Publicly available blogs and videos posted on various free-to-access websites found via an internet search for blogs/videos about ICU survivors who experienced Post-Intensive Care Syndrome and their experience during the transition from hospital to a "new normal" state will provide qualitative data for examination. Twenty to thirty participants and their social media posts will aid in further understanding the experience, facilitators, and barriers encountered by ICU survivors and their interactions with these factors as they transition from hospital to home and a "new normal" functional state. Passive data gathering offers information regarding patient experiences unaffected by interaction with a researcher or associated healthcare professional. The knowledge of critical illnesses and their consequences inherent in each post will represent information available to most ICU survivors used as they adapt to physical, psychological, and cognitive changes resulting from their illness. While this information is all publicly available, analyzing it for facilitators, barriers, and an overall process of transition from hospital to a "new normal" will aid in future research and development of follow up care for ICU survivors.

The posts for this study are available through a Facebook and Google text searches with the terms "ICU-survivor," "sepsis survivor," "post sepsis syndrome," "post ICU syndrome," "post intensive care syndrome," and "sepsis survivor." These search terms are identifiers used by ICU survivors as they share their recovery experiences through social media. Participant posts will continue to be gathered over a 24-month period until theoretical saturation of the data is reached (Glaser & Strauss, 1967; Glaser, 1992). While the included posts were from the specified time period, the ICU stays referenced by the participants may have been from months to years prior to this study. The point at which no new ideas, properties, or interactions arise from further posts will be considered theoretical saturation (Charmaz, 2014). At the point of saturation, several further posts will be analyzed to confirm saturation and ensure that all ideas and categories are fully developed.

Analysis

Participant posts will be transcribed verbatim into Dedoose v 8.0.35 for coding and data abstraction (Dedoose development team, 2018). An in-depth review of the available participant interactions and experiences, combined with professional experience, available literature, and expert input, facilitates a triangulated approach to the development of a framework to explain the process of transition to a "new normal" for ICU survivors. Initial coding will entail direct extraction of central ideas and context analysis to develop codes that are relevant to multiple participant posts. Theoretical sampling will fill out evolving codes and categories of participant experiences, facilitating the development of a grounded theoretical model to explain the process of transition from ICU to home and a "new normal" state from the patients' perspective. Each post will be read and reread multiple times after transcription. Initial, direct coding will offer the foundation for categorization and eventual abstraction of the available data (Strauss & Corbin, 1998). Focused coding, in conjunction with further theoretical sampling will highlight the most salient emerging categories and flesh out the related themes and relationships within the data (Charmaz, 2014).

Visual and audio data, including pictures, interviews, and audio clips, will also contribute to the available wealth of data provided by participant posts. Like any observational data, videos and photographs are interpreted by the viewer's personal cultural and symbolic interactions (Ball & Smith, 1992). While inferences may be drawn from images and video clips, reflexivity must provide a contextual frame through which the target audience can understand any inherent biases reflected in the author's interpretation of the visual data. To provide more objective analysis of the available visual data, this study will provide three objective factors for each picture or video: content, referent, and context (Ball & Smith, 1992). The content of the visual data includes any objects physically present in the picture or video. The referent describes the photographer's or videographer's expressed intent for the media. The context of the visual data includes the photographer's or videographer's location of display and original purpose of the media. Ethnomethodology, procedures people use to contextualize their daily experiences, will provide a framework for analysis of the visual media available in ICU survivors' social media posts (Ball & Smith, 1992). An examination of the ICU-survivor's comments for each picture and corresponding responses will provide social context for each picture or video and allow for coding, categorization, and data abstraction from the visual media.

Comparative methods and inductive analysis will aid in the development of categories based on relationships between initial and focused codes. Further theoretical sampling and selective coding will facilitate additional data to refine emerging categories and their relationships. This process will lead to an over-arching, core category that describes and explains the process of recovery and transition to a "new normal" state for ICU survivors with PICS as they leave the hospital and return to their lives (Charmaz, 2014).

Rigor, credibility, reflexivity, representativeness/transferability. The social media posts will be coded and evaluated throughout the study in an ongoing fashion. Data triangulation will ensure rigor and credibility through multiple sources of data. These sources will include patient social media posts, video and picture thematic analysis, responses, reposts, and memoing (Borbasi, Jackson, & Wilkes, 2005). Throughout the study, data will be expanded through initial coding, followed by the determination of the relative importance of emerging themes. Comparisons between different posts will be used to develop abstractions that allow application of higher-level themes across multiple social media authors.

Theoretical verification will occur throughout the study through discussions with healthcare professionals, an ICU-survivor consultant, and the researcher's personal experience and training as a critical care provider. This verification process will assist in the co-construction of findings. As higher-level themes emerge, substantive and clinical experts in critical care and will be consulted to verify the products of analysis. Methodological verification will be established through subject-expert verification, participation in a qualitative analysis group with other doctoral students, and consulting with a grounded theory methods expert at every phase of the research to ensure the rigor of the analytic process.

Findings

This study will facilitate an analysis of the experience of ICU survivors after hospital discharge as they recover from their recent illness and struggle with the debilitating effects of

PICS. Through qualitative, grounded theory analysis, the participant social media posts utilized in this study will provide a theoretical model to describe the process of recovery for ICU survivors, common themes and experiences, as well as facilitators and barriers encountered throughout the recovery phase after hospital discharge. The model will also seek to explain why some patients do better than others. The resulting grounded theory offers potential areas of intervention targeted at improving and hastening recovery as well as limiting long-term effects of PICS symptoms. This study will also provide insight into positive and negative factors affecting ICU survivors' hospital stays and opportunities for improvement and prevention that could be implemented prior to hospital discharge and even during the earliest phases of ICU patients' hospital stays. Efforts to ensure transferability will include the use of constant comparative methods throughout the analysis phase within the evolving categories and themes and validation through literature review and consultation with clinical experts and an ICU-survivor consultant with first-hand experience.

Limitations

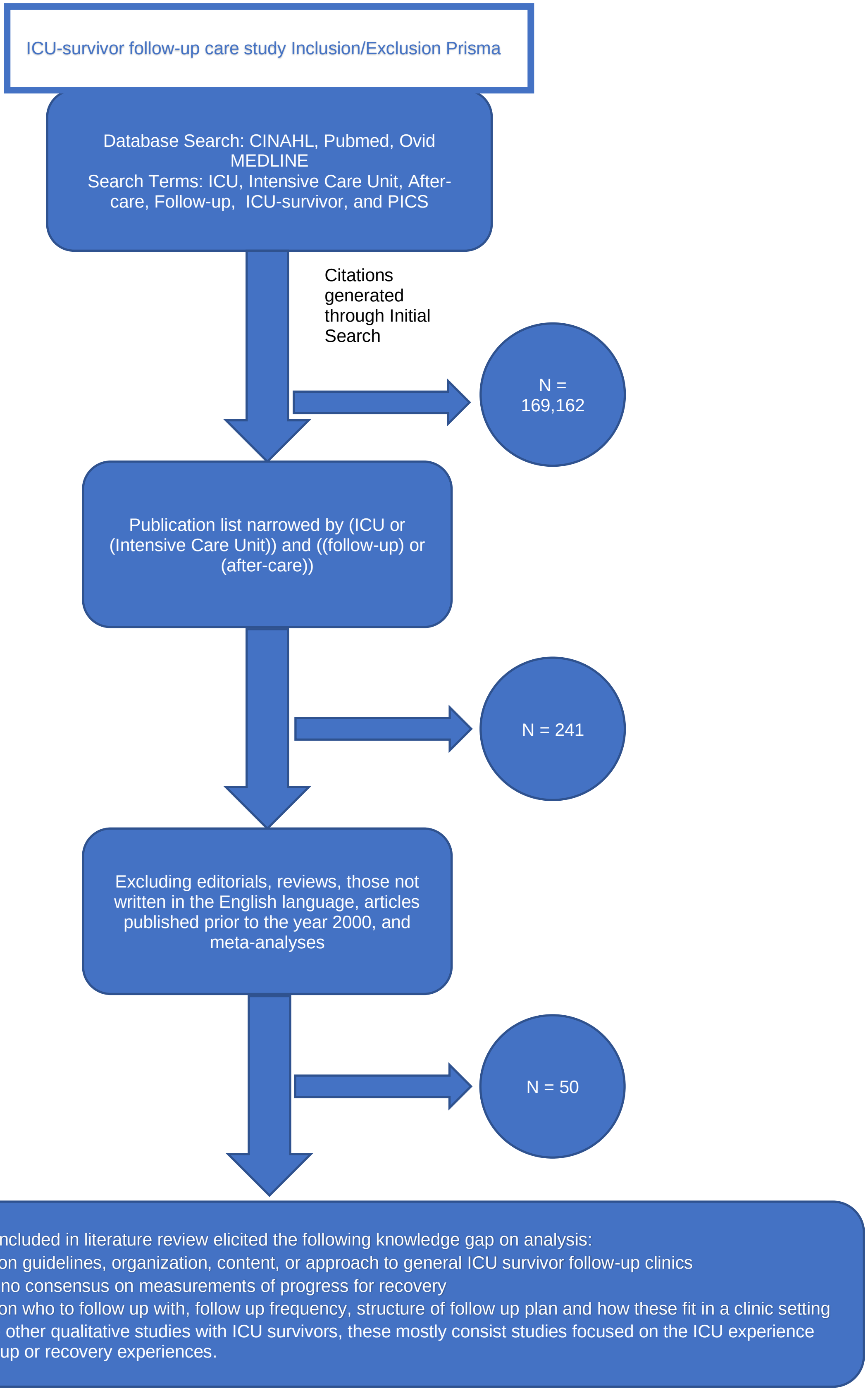
Qualitative studies utilizing social media can offer the opportunity to investigate social interactions, participants, and phenomena that would otherwise be limited by access, distance, or participant availability. However, this approach has limitations as well. This study will utilize an observational approach and exclude interactions with any of the participants. While this facilitates an uncontaminated observation of the social interactions and opinions of ICU survivors as they discuss their experiences and challenges faced after their recent illness, posts will be limited to those naturally available on each site. The content of each post will consist of native language shared by ICU survivors and developed through common experiences. Unfortunately, this approach precludes interaction with any of the participants and therefore, it is not possible to query for clarification or elaboration. The available information is limited to the topics naturally discussed by the participants. To minimize the limitations inherent in this observational approach, an anonymous ICU-survivor will serve as a consultant to review and verify concepts, categories, and conclusions throughout the analysis period.

The research method for this study is also limited by selection bias. The data sources are restricted to online social media posts, reposts, responses, videos, and anonymous pictures. This will automatically select for a certain level of education, desire to disclose personal experiences publicly, and access to the internet. While many ICU survivors have access to the internet, there is a population of ICU survivors who are generationally less likely to be computer literate. There are also patients who are homeless or marginally housed and may not have regular access to the internet or social media. The patients in these populations may have a different hospital and post-discharge experience than those observed in this study, so the transferability of findings is limited to survivors who use social media to process their experiences. This study will also only include ICU survivors who are functionally able to write social media posts and will exclude patients who suffer from the most debilitating illnesses and comorbidities. Further research could focus on the specific experiences and challenges experienced by other populations, using the more traditional approach of in-depth interviewing and participant observation. Similarly, this study focuses on English language social media posts available on internet servers in the United States and excludes discussions in other languages. Verification studies may be carried out to compare the experiences of ICU survivors in other countries or who do not speak the primary language of their home countries.

Importance of the Knowledge to be Gained

Critical care medicine has made great strides and improved survival rates for sepsis and other diagnoses resulting in an ICU stay. The number of Americans over the age of 65 will double over the next 40 years as baby boomers progress towards retirement age (Mather, Jacosen, & Pollard, 2015). The average age of ICU patients in the United States is 64.5 years old with most ICU patients falling between ages 40 to 80 years old (Garland, Olafson, Ramsey, Yogendran, & Fransoo, 2013). While mortality rates for ICU survivors have improved greatly over the last 20 years, their follow-up continues to present a challenge to the current healthcare industry. ICU follow-up clinics are one method of coordinating and providing care for these complex patients. However, the results of research on such clinics have been mixed and may or may not show significant improvements in patient quality of life or re-admission rates. Part of this may be caused by a disconnect between provider expectations and patient/caregiver needs as far as clinic organization and content. By exploring the process of recovery and transition from critical illness to “new normal” from the patients’ and caregivers’ viewpoints, we may be able to provide personalized care to the ICU survivors attending the ICU follow-up clinic.

Figure 1. Literature Review Prisma



The final articles included in literature review elicited the following knowledge gap on analysis:

1. No consensus on guidelines, organization, content, or approach to general ICU survivor follow-up clinics
2. Many tools but no consensus on measurements of progress for recovery
3. No consensus on who to follow up with, follow up frequency, structure of follow up plan and how these fit in a clinic setting
4. While there are other qualitative studies with ICU survivors, these mostly consist studies focused on the ICU experience and not on follow up or recovery experiences.

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Chapter 3: Manuscript #1 Literature Review

Long-Term Outcomes of Post-Intensive Care Syndrome from Providers' and Patients' Perspectives: A Review of the Evidence and Knowledge Gaps

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Target Journal: *Critical Care Medicine*

Abstract

Objectives: To review the literature and identify potential knowledge gaps in the management of intensive care unit (ICU) survivors with post-intensive care syndrome (PICS) across the care continuum.

Data Sources: A review of the literature was conducted using CINAHL, MEDLINE, and PubMed with the search terms: 'ICU', 'intensive care unit', 'after-care', 'follow up', 'ICU survivor', and 'PICS or Post-Intensive Care Syndrome'.

Study selection: Studies were selected based on discussion of symptoms related to PICS. Editorials, meta analyses, non-English articles, and publications written prior to 2000 were excluded from the final analysis. The article pool was further narrowed by focusing on studies related to follow up or aftercare management.

Data Extraction: The resulting 50 articles were narrowed further by excluding studies not related to patients with primary medical indications for ICU admission resulting in nine studies selected for evaluation.

Data Synthesis: Nine articles provided information relevant to PICS management in ICU survivors. Of the nine articles, seven were focused on researcher-developed patient reported outcomes (PROMs) and quality of life (QoL) measures. Two studies focused on patients' perspectives of PICS.

Conclusions: Researchers utilized various QoL surveys and other PROMs that have limited validation in ICU survivor patient populations. There was no consensus in QoL and PROM measures applied to the PICS patient population. Two qualitative studies provided rich descriptions of ICU survivor experiences with PICS. However, they were limited in scope and duration. Larger sample sizes and serial participant interactions would provide more detailed information of the patient perspective in recovery for ICU survivors with PICS.

Key words: Post Intensive Care Syndrome, PICS, ICU survivor, Intensive care survivor, knowledge gap

Introduction

In the United States, more than five million patients are admitted annually to intensive care units (ICUs) for treatment of a variety of life-threatening illnesses or conditions (Society of Critical Care Medicine, 2020). In the midst of the Covid-19 pandemic, that number has drastically increased and continues to surge to meet the rising demand globally (Stam, Stucki, & Bickenbach, 2020). In the first two decades of the 21st century, advancements in critical care medicine have improved ICU patient outcomes with an overall in-hospital ICU mortality rate of fewer than 20% (Garland et al., 2014). With a decrease in ICU mortality rates, there is a concomitant increase in the numbers of patients discharged or "ICU survivors" by more than four million per year (Barrett et al., 2014). Ten percent of ICU survivors will develop chronic cognitive, physical, and/or neurological impairment related to their initial ICU stay (Davidson et al., 2013).

For many ICU survivors, the symptoms of PICS significantly affects quality of life and the ability to resume pre-admission roles in society (Barrett et al., 2014; Davidson et al., 2013; Garland et al., 2014). The sequelae of PICS symptoms often persist months to years after the initial illness. ICU survivors often experience significant changes to quality of life related to new debilitations. Up to 29% of the survivors are unable to return to work or participate in pre-ICU admission social roles up to six months after their initial illness and 20% of them were unable to return to work four years after their ICU discharge (Collie et al., 2019; Hodgson et al., 2018). ICU survivors also have higher health care utilization and financial burden than patients with similar diagnoses who did not require intensive care stays. Each ICU survivor spends an average of $10,000 more on health care, resulting in a total of $82 million of the United States' gross domestic product spent on critical care (Sjoding, Prescott, Wunsch, Iwashyna, & Cooke, 2016). With a 34% six-month hospital readmission rate, improved patient care follow-up in this population would reduce healthcare costs, improve patient outcomes, and raise health-related quality of life for ICU survivors (Hua et al., 2015).

Needham *et al.* (2012), in their initial report from a stakeholders' conference examining PICS, created a symptomatic grouping of the most common sequelae that were described by ICU survivors after hospital discharge. Other researchers have added to the initial description of PICS in the outpatient setting (Davidson et al., 2013; Jutte et al., 2015; McPeake & Mikkelsen, 2018) and patient management approaches have improved. While researchers have examined the nature and management of contributing symptoms that comprise PICS, there are relatively few studies that examine outcomes of long-term management of PICS after hospital discharge. This article reviews the literature to describe the post-discharge symptoms associated with PICS from the provider's and patient's perspective, as well as the evidence supporting the long-term management of PICS, while also identifying gaps in our knowledge.

Background

Intensive care units and the management of critically ill patients have progressed greatly since the inception of this specialty in 1952 where patients were ventilated by hand via tracheostomies as they received treatment for polio (Berthelsen & Cronqvist, 2003; Kelly, Fong, Hirsch, & Nolan, 2014). From bloodletting, iron lungs, and leeching to extracorporeal membrane oxygenation (ECMO) and modern-day mechanical ventilators, there have been great strides in critical care medicine over the last 65 years. In that time, mortality of ICU patients has decreased from more than 85% to approximately 20% depending on the reason for admission (Kelly et al., 2014; Zimmerman, Kramer, & Knaus, 2013). With the high level of mortality in the early 1950s, there was very little known about follow up care for ICU survivors. More recently, the ICU survivor population has grown significantly, with more than four million survivors each year (Garland et al., 2014).

Critical care medicine improved drastically between 1952 to present day. With the utilization of modern-day mechanical ventilation, evidence-based care, ultrasound guided procedures, targeted antibiotic therapy, improved nurse staffing ratios, volume resuscitation and standardized sepsis management, as well as various other improvements to critical care, patients have a greater likelihood of surviving through to hospital discharge. Because various medical subspecialties have their own interests in follow up care for ICU survivors, research on ICU survivors has historically been divided into silos of knowledge. Because of these focused approaches, the literature surrounding ICU survivors and their recovery process is fragmented, managed by various subspecialties.

Needham et al. (2012) developed a holistic description of common symptoms and deleterious effects most frequently noted in ICU survivors. These symptoms were grouped into categories: psychological, neurocognitive, physical, and functional. Acute Respiratory Distress Syndrome (ARDS) and sepsis are separated out below as these represent a large subpopulation of ICU patients that may end up with PICS with symptoms that may not be represented in the larger population of survivors. The literature parallels specialties in medicine and research although from the patient’s experience, a holistic perspective of the symptoms needs to be managed. During the hospital admission, the patient was likely treated by a team of intensivist and specialist medical teams. Upon discharge, the patient may be referred to their primary care physician for follow-up care, with specialty physicians providing consultation with focused symptoms.

Post-discharge symptoms of PICS

Given that PICS is a relatively newly-defined syndrome, the tendency for researchers is to describe post-discharge symptoms in particular patient populations. This section is organized by the three main issues that are addressed in the literature: (1). acute respiratory distress syndrome (ARDS) and sepsis; (2). neurocognitive and psychological symptoms; and, (3). physical and functional symptoms.

1. Acute respiratory distress syndrome and sepsis

Sepsis and acute respiratory distress syndrome (ARDS) are two of the more severe and common diagnoses often requiring prolonged ICU stays and frequently resulting in respiratory failure necessitating mechanical ventilation. Sepsis is the result of a severe inflammatory response to infection resulting in organ dysfunction. Sepsis is one of the more common illnesses that result in prolonged ICU admission and leaves ICU survivors with symptoms of post-traumatic stress, anxiety, new functional limitations, and cognitive impairment (Prescott et al., 2019). Sepsis can result from many types of infections and may result in various long-term changes to survivors' overall health, cognition, and functional status. Many studies examined complications experienced by sepsis survivors eventually leading up to the development of the designation PICS (Needham et al., 2012).

The varying causes and complications related to sepsis have resulted in a multitude of approaches to studying the survivor experience after hospital discharge. One of the purposes in developing the term PICS was to combine and organize the research related to ICU survivors including sepsis related survival. Historically, poor survival and high one-year mortality have limited development of long-term outcome studies. Other research limitations are common to many medical specialties including limited research involving lower income populations and countries. Poor follow up participation and high morbidity/mortality after hospital discharge have also limited any research focus on post-discharge follow up interventions targeted at improving long-term survival (Prescott et al., 2019). Research targeted at optimizing mobility, cognitive and physical rehabilitation, peer support, and coping with new permanent functional or cognitive limitations would provide great benefit to understanding optimal management of this population (Prescott et al., 2019).

ARDS is a severe lung injury often causing acute respiratory failure requiring admission and prolonged stays in an intensive care unit for treatment (Chiumello et al., 2012). Acute lung injury (ALI), pneumonia, influenza, lung inhalation injury, and various other pulmonary inflammatory diseases can result in respiratory failure requiring mechanical ventilation, sedation, chemical paralytics, and prolonged ICU stays (Chiumello et al., 2012). Most ICU survivors with ARDS recover to the point where their pulmonary symptoms largely resolve after the first 12-months after hospital discharge (Herridge et al., 2003). However, many survivors remain limited in their physical function and activity (Chiumello et al., 2012). Optimal rehabilitation, societal integration, and peer support remain topics of minimal research that could have a great impact on quality of life for ICU and ARDS survivors contributing to the overall population of PICS patients.

Many ICU survivors experienced sepsis or ARDS and share new chronic symptoms and limitations after hospital discharge related to PICS. Much of the available research focuses on individual health issues and should be addressed independently for the sake of a thorough literature review. Research topics addressing PICS are often broken down into psychiatric, neurocognitive, and physical limitations, patient recovery, follow up care, and focused assessments of outcomes related interventions.

2. Neurocognitive and psychiatric symptoms

Neurocognitive and psychiatric symptoms are closely interrelated and often affected by many medications initiated during ICU stays. Antidepressants, antipsychotics, anxiolytics, and atypical antipsychotics are often utilized in ICUs to manage psychiatric symptoms. These medications are often inappropriately continued long after hospital discharge (Wang, Kheir, Allen, & Khan, 2018). Sedatives used for anxiety and agitation often contribute to prolonged immobility and delirium affecting neurocognitive and psychiatric function beyond hospital stay (Stollings et al., 2018). While recent trends focus on minimizing anxiolytics and other deleriogenic medications, many ICU survivors are still treated with benzodiazepines and anticholinergics that increase chances of recurrent delirium and long-term cognitive impairment (LTCI). The long-term results of these medications and frequency that they are continued beyond initial hospital stays is still poorly described in ICU survivor and PICS literature. Antipsychotics, frequently used to treat delirium in the ICU, may also contribute to LTCI and should provide the focus of future long-term studies examining neurocognitive function in ICU survivors (Wang et al., 2018).

Some medications started in the ICU may be appropriate beyond hospital discharge to help manage depression and anxiety that persists after hospital discharge (Haines et al., 2017). However, many medications continued after hospital discharge are no longer relevant to the survivor after they leave the ICU and may cause many side effects and complications (Stollings et al., 2018). In a study with 307 ICU survivors, pharmacists participating in ICU recovery follow up clinics made an average of four interventions per participant including stopping medications, changing doses, providing education, and starting new medications.   Many primary providers are unaware of the need to review various medications started during an ICU stay for conditions related to an acute illness creating barriers to patient recover after hospital discharge (Wang et al., 2018).

Post-traumatic stress symptoms occur in up to 50% of ICU survivors (Harvey & Davidson, 2016). Delirium, anxiety, and depression are some of the most common symptoms to contribute to post-traumatic stress after an ICU stay (Svenningsen et al., 2014). Delirium is experienced by more than 80% of ICU patients during their hospital stay, while depression, anxiety, and PTSD-symptoms are experienced by approximately 20% of ICU survivors during the first 6 months and up to 10 years after their initial hospital admission (Svenningsen et al., 2014). More than 25% of ICU survivors demonstrated depression up to 2-years after hospital discharge while more than 40% continue with prescriptions for antidepressants started during their initial ICU visit (Haines et al., 2017). Research focused on antidepressant use in the ICU and ICU-related depression, as well as long-term outcomes for patients started on antidepressants during their initial ICU admission, would help providers better understand ICU-related depression and the best management approaches (Haines et al., 2017).

Age is an independent risk factor for developing delirium during an intensive care unit admission and critical illness. Increased age also raises patient risk for developing post-traumatic stress symptoms related to ICU admission (Wang et al., 2018). Visual and hearing impairments also increase risk for decreased neurocognitive recovery after ICU stay for older adults. Pharmaceutical choices including the use of antipsychotics, anticholinergics, opioids, benzodiazepines, and other deleriogenic medications result in greater frequency and severity of delirium in this population. A research focus on geriatric psychiatry would facilitate better understanding of the cost of an ICU-stay for older adults as well as aid in development of evidence-based approaches to improve recovery and manage new cognitive impairments experienced by many elderly ICU survivors (Wang et al., 2018). A focus on geriatric psychiatric research in ICU survivors would also encourage the development of standard approaches to medication monitoring, duration of these prescriptions, and follow-up after hospital discharge for patients at greatest risk of poor outcomes related to these medications and recent ICU stay (Wang et al., 2018).

3. Physical and functional symptoms

The frequency of patients discharged from hospitals after an ICU stay with severe functional or physical impairment is difficult to determine. Many patients find themselves treated by a hospital system unfamiliar to them because of the severity of their illness and a requirement for higher levels of care than their local hospitals can handle. Because they may be treated in a new hospital system, their functional and physical baselines are difficult to obtain and compare to their eventual status at hospital discharge and during the recovery phase of their treatment. ICU survivors with the greatest physical or functional limitations after their critical illness are also frequently excluded from research studies. These complications limit the ability to evaluate the number of new functional and physical debilities experienced by ICU survivors (Ohtake et al., 2018). However, while determining the true severity of new symptoms experienced by ICU survivors is nearly impossible, the types of new debilities are well documented in the available literature and include chronic pain, dysphagia, fatigue, sensory loss, sleeping disorders, sexual dysfunction, shortness of breath, and muscle weakness. Researchers have noted varying degrees of impact of these limitations on quality of life indicators creating further difficulty in evaluating the follow-up needs for ICU survivors (Craik, Ohtake, Strasser, & Needham, 2012). Standardized outcome measures that show statistical significance for physical and functional impairment of ICU survivors would aid in determining the impact and severity of new symptoms on this patient population.

Current Study

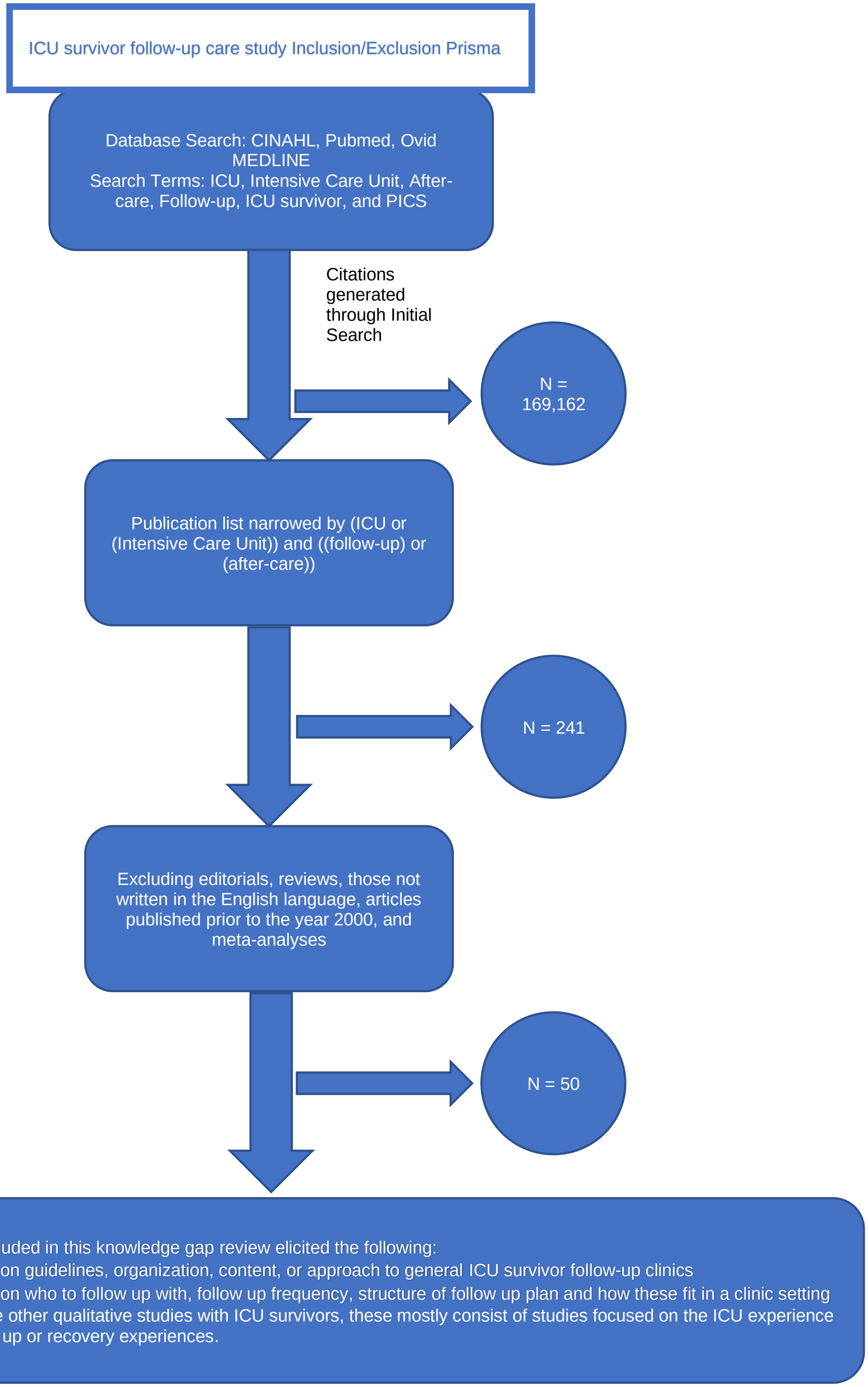
A knowledge gap analysis was engaged to explore key areas of the long-term management of PICS by assessing literature in the field, identifying related work since the initial description of the symptomatic grouping by Needham, *et al.* (2012), and to add to what is known about the management of PICS for the end goal to standardize clinical practice.

The relatively new designation of PICS, while useful in grouping symptoms shared by patients with similar hospital courses, creates some difficulty in database searches. Much of the previous research results exist under historic terms, diagnoses, or groupings including intensive care unit (ICU), acute respiratory distress syndrome (ARDS), and sepsis survivors. Other studies separate PICS symptoms and study them on an individual basis depending on the interest and focus of each research group. A literature review focused on ICU survivors with PICS should examine the parts as well as the whole to provide a thorough assessment of the knowledge available on this topic.

Method

The literature search for this review was conducted using three main databases: CINAHL, OVID (MEDLINE), and PubMed using the search terms: ‘ICU’, ‘intensive care unit’, ‘after-care’, ‘follow up’, ‘ICU survivor’, and ‘PICS’. A total of 50 articles were filtered by English language, abstracts, and scholarly or peer-reviewed articles in academic journals and publication dates limited to the most recent 10 years (2008- 2018). (See Figure 1.) The rationale for the time selection is that the Needham, *et al.* (2012) definition was among the first to describe a “bundle” of symptoms that were labeled as “post intensive care syndrome.” Four years prior to the 2012 publication provided an opportunity to search for related articles.

Figure 1. Knowledge Gap Review Prisma



The 9 articles included in this knowledge gap review elicited the following:
1. No consensus on guidelines, organization, content, or approach to general ICU survivor follow-up clinics
2. No consensus on who to follow up with, follow up frequency, structure of follow up plan and how these fit in a clinic setting
3. While there are other qualitative studies with ICU survivors, these mostly consist of studies focused on the ICU experience and not on follow up or recovery experiences.

Table 1. Literature on PICS from providers' perspectives

AUTHOR & YEAR	PURPOSE	SAMPLE/ SETTING	METHODS	RESULTS	DISCUSSION & LIMITATIONS
Clinical Utility of a Structured Program to Reduce the Risk of Health-Related Quality of Life Impairment after Discharge from Intensive Care Unit: A Real-World Experience (Venni et al., 2018)	Pre/post cohort study to evaluate the effectiveness of a structured program to prevent PICS	ICU survivors admitted to a 6-bed ICU in Florence, Italy given SF-12 questionnaire and brief questionnaire regarding ICU stay experience	70 pre-cohort retrospective chart review patients and 159 post-cohort participants -Intervention included minimized sedation protocol c/w daily SAT and minimizing RASS; adequate analgesia protocol based on VAS or Behavioral Pain Scale (BPS); delirium prevention; and 6-month follow-up for all patients	- 10% w/nightmares - 20% required sleep aids after ICU stay - 20% showed evidence of PICS as determined by results of SF-12 questionnaire	- Many studies have difficulty linking HRQoL changes to PICS symptoms so this may not be a valid definition of existence of PICS in a population - Those who demonstrated more frequent or more prolonged delirium had worse functioning and decreased HRQoL at follow-up
A Retrospective, Pilot Study of De Novo Antidepressant Medication Initiation in Intensive Care Unit Patients and Post-ICU Depression (Haines et al., 2017)	Evaluate if antidepressants started in the ICU affect post-ICU depression and if patients remain on Rx after discharge	- Retrospective chart review to identify patient population with a total of 27 patients participating in the study. - Patients were from mixture of ICUs including surgical, general, and cardiac ICUs.	Telephone survey to determine if participants were still on their ICU prescribed antidepressants and if they were still depressed (per PHQ-2)	-26% of patients were positive for depression at time of study up to 2 years after ICU stay -48% were still on the antidepressants started while in the ICU -18.5% on antidepressants and still depressed	-Time after hospital discharge to participation in the study varied greatly (study done in 2017 with participants from ICU stays during 2015 through 2017) -Did not examine reason patients were still on antidepressants (poor med recs?) -Small study population from a single center
Resilience in Survivors of Critical Illness	Identify facilitators and barriers to	2 site mixed method telephone survey	- Telephone interview - Cognitive questions (Health Utilities Index-HUI-3)	-84% were discharged form hospital directly to home	- No time relation between ICU stay and gen/med stay prior to discharge

in the Context of the Survivors' Experience and Recovery (Maley et al., 2016)	recovery for ICU survivors	-Included pts > 48 hr ICU stay -Excluded hospice DCs -43 participants completed telephone survey - Contacted participants median of 8-months post discharge	- HADS - EuroQoL 5D-5L - PTSD-10 question questionnaire - Describe mental and physical health, and memory as better, worse, or same compared to before ICU stay - Open-ended ?s re-challenges experienced in ICU, transitioning to gen/med, and going home - Connor-Davidson Resiliency 10-item scale	-Average hospital stay was 14 days -Physical debility, cognitive changes, mental health symptoms, dysphagia, difficulty communicating -Also, dependence on others and disease related symptoms -Limited ability to perform ADLs, scheduling/organizing follow-up -Family, community, and belief system support, provider encouragement, follow-up services, and optimistic outlook	-PICS identified by results of cognitive, mental health, and physical function questions – thus far, survey questions and self-reporting of PICS have proved unreliable
A feasibility study of functional status and follow-up clinic preferences of patients at high risk of post intensive care syndrome. (Farley, Eastwood, & Bellomo, 2016)	-Determine prevalence and degree of PICS symptoms experienced by participants requiring prolonged ventilation Describe participant opinion about	-Single center cohort study in Melbourne, Australia -N=48 -Included patients ≥18 y/o, ventilated for ≥7 days, survived to hospital discharge Excluded patients who were non-English speaking,	-Scripted Telephone interview -EQ-5D and HADS questionnaires -Also asked for participant's opinion regarding benefit of ICU follow-up clinic - Included participant hospital/health demographics, APACHE III, ventilator days, and discharge destination	- 4% declined interview d/t traumatic experience in the ICU and reluctance to re-live that - Interviews conducted approximately 20 months after ICU discharge - 30% noted moderate problems in ≥ 1 dimension of EQ-5D; 37% with ≥2 and 30% ≥ 3 dimensions	- Single center study - Small population size - Unable to determine how much of described impairment was related to ICU stay vs. other causes - Follow-up done at 20 months so may have missed some of the initial debility related to ICU stay as patients recover over time - Also excluded the most severely debilitated patients who would probably be

	follow-up clinics	died prior to interview, unable to participate in telephone interview		- 22% described their health at 50% of previous - 22% demonstrated anxiety and depression for HADS with 30% showing only depression and 30% showing only anxiety -60% of eligible patients died prior to	unable to participate in conversations on the phone

Table 1. Literature on PICS from providers' perspective (continued)

AUTHOR & YEAR	PURPOSE	SAMPLE/ SETTING	METHODS	RESULTS	DISCUSSION & LIMITATIONS
Symptoms experienced by intensive care unit patients at high risk of dying (Puntillo et al., 2010)	Determine the impression of ICU patients with high APACHE II scores in regards to common symptoms experienced by ICU survivors with delirium (compared to without)	-Study performed in 2 ICUs within tertiary hospital in U.S. -Included patients > 18 y/o -APACHE II score >20 on admission -ICU LOS> 72 hours -Included diagnosis of: acute heart or pulmonary failure, cirrhosis, MODS with sepsis, or cancer causing any organ failure -Total of 245 patients (with APACHE II score of 30.4 ± 6.5 enrolled with 69.8% able to respond to survey	-Edmonton Symptom Assessment Scale with addition of tiredness and thirst measured by 3-point Likert scale to describe intensity of symptom - Pain - Tired - SOB - Restless - Anxious - Sad - Hungry - Scared - Thirsty - Confused	- Up to 75% participants reported thirst, anxiety, or fatigue - Anxiety was more prevalent for ventilated patients - Thirst was the second most common symptom - Pain was noted less frequently and typically noted to be mild to moderate (compared to moderate to severe thirst and anxiety) - However, those who did have pain found it to be moderate to severely distressing - 30% participants noted fear and or sadness and fear was more common in ventilated patients - SOB was considered the symptom most associated with severe levels of distress and severity of distress did not differ between vented and non-vented patients who noted SOB - ≥34% participants experienced delirium	- Not sure on the level of delirium in the patients used to test validity of these measures - Also, not sure inter-rater reliability measure is reliable to have both in the room at the same time then compare results within the room (should be independent assessment of each symptom) - Not sure consenting patient with mMAAS of -1 or +1 would be appropriate - Patients not given the option to say that the symptoms included in the study were absent - Majority of participants were unable to complete the survey and approximately 70% were unable to express severity of symptoms they noted to be present

Resilience in Survivors of Critical Illness in the Context of the Survivors' Experience and Recovery (Maley et al., 2016)	Identify facilitators and barriers to recovery for ICU survivors	2 site mixed method telephone survey -Included pts > 48 hr ICU stay -Excluded hospice DCs -43 participants completed telephone survey -Contacted participants median of 8-months post discharge	- Telephone interview - Cognitive questions (Health Utilities Index-HUI-3) - HADS - EuroQoL 5D-5L - PTSD-10 question questionnaire - Describe mental and physical health, and memory as better, worse, or same compared to before ICU stay - Open-ended ?s re-challenges experienced in ICU, transitioning to gen/med, and going home - Connor-Davidson Resiliency 10-item scale	-84% were discharged form hospital directly to home -Average hospital stay was 14 days -Physical debility, cognitive changes, mental health symptoms, dysphagia, difficulty communicating -Also, dependence on others and disease related symptoms -Limited ability to perform ADLs, scheduling/organizing follow-up - Family, community, and belief system support, provider encouragement, follow-up services, and optimistic outlook	- No time relation between ICU stay and gen/med stay prior to discharge - PICS identified by results of cognitive, mental health, and physical function questions – thus far, survey questions and self-reporting of PICS have proved unreliable - 84% direct discharge to home is a higher number than industry average and likely selection bias
Critical Care Pharmacists and Medication Management in an ICU Recovery Center. (Stollings et al., 2018)	Demonstrate potential for benefit from role of ICU recovery center (ICU-RC) critical care pharmacist	-ICU-RC Academic Tertiary care hospital - Vanderbilt University -Included patients with ICU stay and sepsis/septic shock, delirium, or respiratory failure requiring mechanical ventilator Excluded patients with terminal illness, <6-month life expectancy, hospice, preexisting cognitive issues, residence at SNF, outpatient follow-up already in place	-Prospective observational cohort study -Those that met inclusion criteria referred to ICU-RC where they were seen by: -Critical care pharmacist -ACNP -Pulmonary intensivist -Case management -Neuropsychologist - Included full med rec and med counseling	- 62 participants with 56 patients having full medication review - Medications stopped in 39% of visits - 23% of patients had 1 medication DCd while 9% had 2 and 4% had 3 DCd - 32% participants had 1 new medication started while 20% had 2 new Rx started and 7% had 3 new Rx started -Adverse drug effect (ADE) found in 14% by pharmacist	- Single center study - Small population - No comparison groups - Unknown whether PCP resumed the DCd meds

Table 2. Literature on PICS from patients' perspectives

AUTHOR & YEAR	**PURPOSE**	**SAMPLE/ SETTING**	**METHODS**	**RESULTS**	**DISCUSSION & LIMITATIONS**
Embracing the new vulnerable self: A grounded theory approach on critical care survivors' post-intensive care syndrome. (Kang & Jeong, 2018)	-Examine ICU survivors' experience of PICS	-13 participants -Interview location determined by participant as a place that they feel comfortable -Semi-structured interviews	-Open, axial, and selective coding -one on one detailed interviews -interviews transcribed verbatim and combined with field notes and memos to provide thorough description of ICU survivors' responses -participants interviewed up to 3 times	- Vulnerability was a key concept in the interviews - Vulnerability caused by new chronic symptoms including pain, depression, neurocognitive changes, and difficulty sleeping - Participants also lamented the loss of their independence as they were forced to rely on others for care and support - Causes of vulnerability related back to bad experience in the ICU, delirious memories, and apprehension surrounding dying - Differences depended on severity of illness and degree of family support - Coping methods typically focused on maintaining their previous social identities, acclimatizing to new functional limitations, and recovering mental/physical/emotional control	- Survivors had various constructive and deleterious approaches to dealing with their new limitations including developing tools, journaling, discussing their fears and concerns with family, support groups, and medical professionals, ignoring their issues and trying to forget the experience - Readmissions, monetary, and social difficulties were common barriers to recovery - Facilitating factors included internal (resilience, optimistic outlooks, and personal development) as well as external (social support, family, spiritual beliefs) - Study limited by small population and self-reported conditions/experiences - Limitations also include qualitative nature of the study and natural bias of authors
One patient amongst many': a qualitative analysis of	-Examine patient experience of transferring from ICU to	-ICU patients throughout United Kingdom -Interviews performed in patient homes after hospital	-Qualitative thematic analysis of audio/video recordings of interviews in participant homes	- Majority of participants felt that they did not receive the appropriate level of care or attention from the general ward - Participants ascribed this to an over-worked staff or under-staffed units	- Small participant pool - Qualitative analysis with limited number of patient settings relying on participant recall in the absence of available factors affecting their hospital stay, treatment, transfer timing, and discharge factors

intensive care unit patients' experiences of transferring to the general ward. (Field, Prinjha, & Rowan, 2008)	gen/med and factors related to stress	discharge with audio/video recordings	after hospital discharge -Utilized maximum variation sample -34 participants -Semi-structured 2-hour interviews -Interviews coded with modified grounded theory approach and thematic analysis using a priori themes	- Difficulties with ADLs and personal hygiene created distress - Difficulties with sleeping, weakness, and inadequate diet also contributed to participant distress - Participants also attributed differences in levels of care to breakdown in communication between ICU and gen/med floor staff - Timeliness of staff response also contributed to distress	

Results

A direct review of abstracts of the 50 articles revealed nine relevant publications using the search terms. Networking of professional peers and colleagues added to the collected data, giving additional face validity to the clinical perspective used to frame this work. All studies identified study aims with appropriate research designs. Most of the articles focused on a review of the symptoms affecting ICU survivors with PICS, management of individual symptoms related to PICS, PICS follow-up clinics, and prevention bundles available for implementation in an ICU setting. The research studies used in this manuscript are described in Table 1 by type of research, utility, and recommendations for future research. As can be seen in Table 2, only two manuscripts focused on patients' perspectives, their experiences with PICS after hospital discharge, and the difficulties they encountered with their recovery.

The nine articles most relevant to examining ICU survivors' experiences with PICS can be broken down into two categories: provider perspective studies (Table 1) and patient perspective studies (Table 2). Provider perspective studies typically focus on accepted measures to examine health related quality of life (HRQoL), physical function, anxiety, delirium, PTSD, cognitive function, provider defined symptoms, and illness severity scores. One of the difficulties shared with the many provider perspective studies is a lack of standardized measurements to assess quality of life in ICU survivors (Venni et al., 2018). HRQoL measures vary depending on author preference and geographic origin. The most common quality of life measures included in the nine examined articles were the Short form-12 and European Quality of Life Assessment (Euro-QoL EQ-5D-5L) scales (Haines et al., 2017; Maley et al., 2016; Venni et al., 2018). Researchers evaluating anxiety after hospital discharge mostly utilized the Hospital Anxiety and Depression scale (HADS) (Farley et al., 2016; Kerckhoffs et al., 2019). While these tests have validity within their original populations, there is little evidence that they provide representative information about ICU survivors with PICS in the outpatient setting. These measures may also be unable to account for normalization of symptoms and issues experienced after hospital discharge.

The two studies focused on patients' perspectives of PICS utilized semi-structured interviews with small numbers of participants (Field et al., 2008; Kang & Jeong, 2018). Field, Prinjha, and Rowan (2008) focused on patient experiences with transferring between ICU and general medicine wards within the hospital to examine the effects resulting from changes in level of care and degree of attention provided to each patient. However, this study took place in the participants' homes after hospital discharge and relied heavily on event recall. This study topic is also only relevant to a frequently small time period between the transition from ICU to general medicine wards and then to hospital discharge and does not reflect the level of support, or lack thereof, often experienced by ICU survivors as they transition back into the community (Field et al., 2008).

Discussion

Researcher/provider perspective studies

The nine studies included in this knowledge gap analysis examine PICS and ICU survivors. Those written from the researchers' perspectives utilize several surveys and Patient Reported Outcomes Measures (PROMs) designed to examine healthcare issues related to the patient perspective. The most common evaluation tools in this population are quality of life measures (QOL). These measures are historically poor at recognizing differences in quality of life between ICU survivors with PICS and patients treated in the hospital for similar issues who did not require ICU stays or develop PICS (Cuthbertson, Scott, Strachan, Kilonzo, & Vale, 2005;

Granja, Teixeira-Pinto, & Costa-Pereira, 2002; Oeyen, Vandijck, Benoit, Annemans, & Decruyenaere, 2010). While larger population sizes might increase sensitivity for these studies, enrolling that many ICU survivors may be difficult. QOL tools are designed to measure participant reported quality of life based on various aspects of physical, functional, and psychological factors. QOL measures may exclude those patients who are most debilitated by their ICU stay and would be unable to participate in a traditional survey. ICU survivors also normalize their symptoms and place different values on various aspects of their functional status making interpreting QOL measure results very difficult (Kerckhoffs et al., 2019).

Another commonly utilized PROM is the Hospital Anxiety and Depression Scale (HADS) that measures levels of anxiety and depression participants have experienced during the week prior to the administration of the survey (Snaith, 2003). While this is one of the more sensitive PROMs, it is restricted to measuring anxiety and depression during a very limited time frame and may not be applicable when trying to extrapolate the results to a longer period. Varying timeframes of validity, scales of measurement, and topics of focus make comparisons between results from different PROMs nearly impossible. QOL tools also address topics researchers and providers feel to be most relevant to the participant populations. Researchers examining quality of life for ICU survivors with PICS should develop a standardized QOL assessment tool or develop guidelines and agree on one tool to improve comparison and generalizability of results that incorporate quality of life measures validated by the patient population of interest.

The nature of ICU survivors as a study population also naturally limits the size of quantitative studies. The number of patients lost to follow up severely restricts the number of available research participants for large quantitative studies with ICU survivors (O. T. Ranzani, Zampieri, Besen, Azevedo, & Park, 2015). The population size is also limited by the 72% one year mortality rate (Needham, Feldman, & Kho, 2011). Other limitations to this population for quantitative studies include the degree of debilitation experienced by the most severely affected survivors. Variations and low prevalence of follow up modalities also limit the availability of multicenter participation.

Patient perspective studies

The two included studies that offer insights into PICS from the ICU survivors' perspectives utilize a qualitative approach with face-to-face interviews of participants providing rich data and information regarding the PICS and recovery experience of the study population. However, Field, Prinjha, and Rowan (2008) focused on participants as they transitioned out of the ICU into general medicine wards and step-down units rather than the recovery experience after hospital discharge. This study also focused on information provided by participant recall which may be severely affected by symptoms of PICS resulting in potentially unreliable data provided by the ICU survivors.

Kang and Jeong (2018) utilized a more traditional qualitative grounded theory approach with a small population size, face-to-face semi-structured interviews, in the outpatient setting after hospital discharge. This provided detailed information on the survivor experience with PICS and the participants' struggles to return to their levels of functional status. However, this study was also limited by population size and a single time point of data gathering for each participant.

Future research

Most recent studies focused on critical care and ICU patient populations rely on quantitative data to provide generalizable, statistically verified results. However, research on outcomes for ICU survivors as they return to their homes and their previous social settings is relatively new. The available PROMs focused on quality of life vary in their content, questions, and original population of development. Very few PROMs have been validated in the ICU survivor population. Varying utilization of QOL surveys also limits the comparability and generalizability these tools often provide in other settings. This approach also relies heavily on participant recall which can be severely affected by PICS. The few quantitative studies with ICU survivors utilize populations that are too small to provide reliable information utilizing the available PROMs. However, difficulties with accessing this population have also severely limited the availability of qualitative studies. The available qualitative research also focuses on a single interaction to provide all the data.

Future qualitative research should seek to expand on the available participant population, provide multiple points of interaction, and focus on survivor experiences in the process of recovery. With a more in-depth understanding of the ICU survivor experience with PICS, the available PROM tools could be adapted to provide more reliable data for this patient population. Accepted PROMs validated in ICU survivor population would allow other studies to utilize these tools and compare results across wider areas. However, the first step would be to better define the facilitators and barriers experienced by this population to facilitate selection of appropriate PROM tools to adapt to ICU survivors with PICS.

Limitations

The extant literature is limited by access to appropriate population, lack of organized follow-up, high post-discharge mortality, and severity of new neurologic/physical/cognitive limitations limiting patient participation in research studies. PICS is a relatively new area of research focus with many different research groups from various countries developing PROMs.

Other researchers apply previously tested HRQoL assessments to this population and currently utilizing various means to evaluate patient function related to recent hospitalizations. The nature of PICS also limits many research projects to patient-reported symptom severity and outcomes limiting the applicability of the research results depending on the participant population's reliability. As a recently developed designation for a sequela of symptoms, PICS research is also fragmented depending on researcher interest and specialty. Literature reviews are complicated by this disjointed body of knowledge requiring individual searches of each category and often specific symptoms related to PICS.

Conclusion

PICS is a sequelae of symptoms experienced by many ICU survivors that has a significant impact on their life after hospital discharge. As a recently defined syndrome, PICS requires standardized research approaches including assessment tools, PROMs, and evidence-based approaches to evaluating patient outcomes after hospital discharge. Much of the difficulty surrounding PICS research stems from limited access to participant population as well as a difficulty in accurately measuring significant differences in HRQoL related to relevant functional, neurocognitive, and psychologic changes associated with recent intensive care admission. With a growing focus on patient-reported outcomes, PICS research should focus on determining the participants' views surrounding after-hospital care, follow-up, and overall management of new debilities related to a recent critical illness and ICU admission.

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Chapter 4: Manuscript #2

The Journey to a "New Normal": The Process of Recovery for ICU Survivors with Self-Reported Symptoms of Post-Intensive Care Syndrome (PICS)

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Target Journal: ***American Journal of Critical Care (AJCC)***

Abstract

Background: In 2012, researchers defined Post Intensive Care Syndrome (PICS) based on clinical observations and assessment tools measuring changes to physical, functional, neurological, and cognitive functional changes related to prolonged Intensive Care Unit (ICU) stays. Research focused on patient-reported 0utcomes measures (PROMs) and patient-centered care suggests utility in engaging the affected patient population to determine targeted follow up and interventions.

Objectives: Identify facilitators and barriers to recovery for ICU survivors; and describe the process of transition from ICU discharge to a new functional status.

Methods: This qualitative study examined the process of recovery from the ICU survivor's perspective utilizing social media posts from patients with self-reported symptoms of PICS. A constructivist grounded theory approach was employed to analyze 20 primary posts and 325 response posts from May 2018 to April 2020. Posts were limited to English language, adults with self-reported recent admissions to an ICU, prolonged ICU stay, and reported symptoms of PICS.

Results: The major processes encountered by the participants included determining the consequences of survival, individualizing the process of recovery, and separating nightmares from reality.

Conclusions: The PROMs from ICU survivors are important measures of patient-centered care. Interprofessional teams and aftercare providers may need more education about PICS. Coordinated ICU follow up clinics with patient-centered care at the time of discharge are warranted. ICU survivors and their families should also receive education regarding PICS and various rehabilitation interventions to improve aftercare treatment and the journey to a new normal for newly-acquired chronic health issues.

Key words: ICU survivor, Intensive care survivor, Post Intensive Care Syndrome, PICS, qualitative, constructivist grounded theory

Purpose

Approximately 80% of ICU survivors experience decreased physical and cognitive abilities that persist years beyond their initial ICU stay (Harvey & Davidson, 2016). Recovery after ICU may require extensive rehabilitation. Many survivors experience a plateau in recovery where they function better than during their hospital stay but at a decreased state compared to their prior abilities. The length of time for recovery and reaching plateau may vary based on the severity of associated comorbidities, social support, rehabilitation, clinical follow up, and many other variables. This study explores the process of recovery for ICU survivors, with self-reported symptoms of post-intensive care syndrome (PICS), after hospital discharge. Data gathering focused on adult ICU survivors with symptoms of PICS who have posted about their recovery experience on freely accessible social media platforms. By examining patient social media posts, this study sought to describe the process of transition to a new functional status. With deeper insight into the needs of this population, the long-term goal of this program of research is to develop a patient-centric after-care approach to improve morbidity and quality of life for ICU survivors with PICS.

The specific aims of this study were to:

1. Identify facilitators and barriers to achieving the closest approximation to the ICU survivor’s previous functional status.
2. Describe the process of transition from ICU to a new functional status for ICU survivors.

Background and Significance

Critical care medicine researchers identify ICU survivors as people who have experienced a critical illness requiring admission to an intensive care unit having survived their hospital stay to discharge (Davidson, Hopkins, Louis, & Iwashyna, 2013). Changes in critical care medicine over the last 20 years have improved disease management with approximately 80% of patients admitted to intensive care units (ICU) surviving to discharge from the hospital (Garland, Olafson, Ramsey, Yogendran, & Fransoo, 2014). United States hospitals admit over five million people to ICUs each year (Barrett, Smith, Elixhauser, Honigman, & Pines, 2014). ICU survivors have 51% more healthcare expenses within five years after their initial hospital stay compared to matched patients with similar illnesses who did not require intensive care treatment (Lone et al., 2016). While we have data describing functional, neurological, and cognitive changes experienced by ICU survivors with PICS, much of the post-discharge research is disjointed and focused on specific, individual complications from a provider driven standpoint. Very few studies focus on the entire sequelae of issues, including the emotional and quality of life issues from the patient perspective. The available literature also lacks research examining how ICU survivors interact and deal with their new debilities.

A brief review of available literature regarding ICU survivors and PICS revealed 71 articles related to the search terms. Of these, only one study focused on patient experience with PICS after hospital discharge (Kang & Jeong, 2018). Other studies focused on 1-2 symptoms within PICS such as delirium, muscle weakness, post-traumatic stress symptoms, and Health Related Quality of Life (HRQOL) for ICU survivors with PICS (Abraham et al., 2014; Chaboyer & Grace, 2003; Jones et al., 2010). Kang & Jeong (2018) performed semi-structured interviews with 13 ICU survivors with PICS. These interviews resulted in a grounded theory framework that described the feelings of vulnerability experienced by many ICU survivors and their process of dealing with these new issues (Kang & Jeong, 2018). Kang & Jeong (2018) focused on coping mechanisms utilized by ICU survivors and their acceptance of new limitations related to their recent illnesses. Further research into the experiences with PICS will aid in developing patient-centered interventions to manage the sequelae of related symptoms. This study built on Kang & Jeong's (2018) results by examining the social interactions of ICU survivors with online support groups and their transition from ICU to their new functional state. Multiple posts from participants over time facilitated the development of a theoretical model for the process of recovery for ICU survivors.

Methods

Sampling and Data Sources

This study utilized 20 primary participant social media posts and respondent posts resulting in a total of 325 participant posts for examination. Purposive sampling provided an initial group of 16 participant posts based on self-reported recent intensive care unit admission for greater than 96 hours with symptoms consistent to PICS at hospital discharge. Theoretical sampling, examining varying levels of severity for initial illness and subsequent PICS symptoms, allowed for refinement through 4 additional participant posts, and provided greater depth for major theoretical categories. Data included any associated videos, pictures, and responses posted by ICU survivors, their family members, or primary caregivers on free-to-access websites. The posts for this study are available through Facebook or Google text searches with the terms "ICU survivor," "sepsis survivor," "post sepsis syndrome," "post ICU syndrome," and "post intensive care syndrome." Through multiple small group discussions (posts and responses) and participant self-identification, this study allowed for analysis of interactions, lingo adoption, common experiences, facilitators, barriers, participant-vouched remedies, and shared successes and frustrations of after care for PICS.

Participants included for analysis in this study consisted of adult authors over the age of 18, self-reporting a recent illness with more than 96-hour stay in intensive care, engaged in discussions of their experience of recovery after ICU stay, and posted statements consistent with symptoms of PICS. Posts written in languages other than English were excluded. Participants were excluded based on lack of description of ICU stay and recovery experience in their profile or posts, or with minimally detailed posts. The time period utilized for the purposes of this study included social media posts from May 2018 through April 2020 until a total of 20 primary participants were enrolled.

Analysis

This study utilized a constructivist grounded theory (GT) approach through analysis of freely available videos, blogs, and text content providing first-hand descriptions of ICU survivors during and after their hospital stay as they recover (Charmaz, 2014). The GT approach offered the development of a model to explain an observed process (Glaser & Strauss, 1967; Glaser & Holton, 2004). This provided a method of utilizing the input of the researcher, study participants, and target audience to co-construct frameworks that explain the subject of research (Charmaz, 2014). Constructivist GT accepts the subjective nature of qualitative research and all research in general as an interpretation of the researcher's conclusions from analysis of related data (Charmaz, 2014). Each ICU survivor has a different experience with their critical illness and subsequent hospital stay. Their recovery and interaction with PICS symptoms also differ depending on the degree of functionality loss, severity of symptoms, and the effect of those symptoms on their life. Each person's definition and understanding of these terms and experiences associated with PICS are their personal symbolic interactions. Overlaps of symbolic interactionism between ICU survivors and their experiences with PICS symptoms will offer insight into their recovery experience.

Participant posts were transcribed verbatim into Dedoose v 8.0.35 for coding and data abstraction (Dedoose development team, 2018). An in-depth review of the available participant interactions and experiences, combined with the primary author's professional experience, available literature, and expert input, facilitated a triangulated approach to the development of a framework to explain the process of transition to a "new normal" for ICU survivors. Initial coding entailed direct extraction of central ideas and context analysis to develop codes that are relevant to multiple participant posts. Medical definition of PICS provided an apriori framework for sorting issues previously described in the literature as associated with PICS and differentiating these from patient-centric, inductive codes less prevalent in previous studies. Theoretical sampling filled out evolving codes and categories of participant experiences by providing a detailed description of the consequences of an ICU admission. Comparative methods and inductive analysis provided categories based on relationships between initial and focused codes. Further theoretical sampling and selective coding facilitated additional data to refine emerging categories and their relationships. When no new ideas, properties, or interactions arose from further posts, it was determined that theoretical saturation was reached (Charmaz, 2014; Glaser & Strauss, 1967; Strauss & Corbin, 1998). At the point of saturation, several further posts were analyzed to confirm saturation and ensure that all ideas and categories are fully developed. This facilitated the development of a grounded theoretical model explaining the process of transition from ICU to home and a "new normal" state from the patients' perspective. Each post was read and reread multiple times after transcription. Initial, direct coding offered the foundation for categorization and eventual abstraction of the available data (Strauss & Corbin, 1998). Focused coding, in conjunction with further theoretical sampling highlighted the most salient emerging categories and fleshed out the related themes and relationships within the data (Charmaz, 2014). An explanatory matrix (EM) containing conditions, processes, and consequences was developed to provide a visual representation of the relationships between the most salient themes. The EM provided a framework to link concepts and their relationships based on symbolic interactionism (Charmaz, 2014; Strauss & Corbin, 1998). The framework organized the categories and configured the best fit for the data. The EM developed a description of the overarching social process experienced by the study participants (Kools, McCarthy, Durham, & Robrecht, 1996). This EM explains the shared experience of ICU survivors as they recover and progress to a new normal state.

Visual and audio data, including pictures, interviews, and sound clips, also contributed to the available wealth of data provided by participant posts. Like any observational data, videos and photographs were interpreted by the viewer's personal cultural and symbolic interactions (Ball & Smith, 1992). While inferences were drawn from images and video clips, reflexivity provided a contextual frame through which the target audience can understand any inherent biases reflected in the author's interpretation of the visual data. To provide more objective analysis of the available visual data, this study utilized three objective factors for each picture or video: content, referent, and context (Ball & Smith, 1992). The content of the visual data included any objects physically present in the picture or video. The researcher described the photographer's or videographer's expressed intent for the media. The context of the visual data included the photographer's or videographer's location of display and original purpose of the media. Ethnomethodology, procedures people use to contextualize their daily experiences, provided a framework for analysis of the visual media available in ICU survivors' social media posts (Ball & Smith, 1992). An examination of the ICU survivor's comments for each picture and corresponding responses offered social context for each picture or video and allowed for coding, categorization, and data abstraction from the visual media. The visual content provided context for corresponding text and proffered further background on the relevant participant. Coding for the visual content was included at the beginning of each respective participants' recorded entry and examined throughout the analysis to determine contextual relationship to each theme as they emerged.

The core category developed through this constructivist GT approach describes and explains the process of recovery and transition to a new state for ICU survivors with PICS as they leave the hospital and return to their lives (Charmaz, 2014). Efforts to ensure transferability included the use of constant comparative methods throughout the analysis phase. Literature review and consultation with clinical experts and an ICU survivor provided validation for the evolving categories and themes.

Results – The Journey to a New Normal

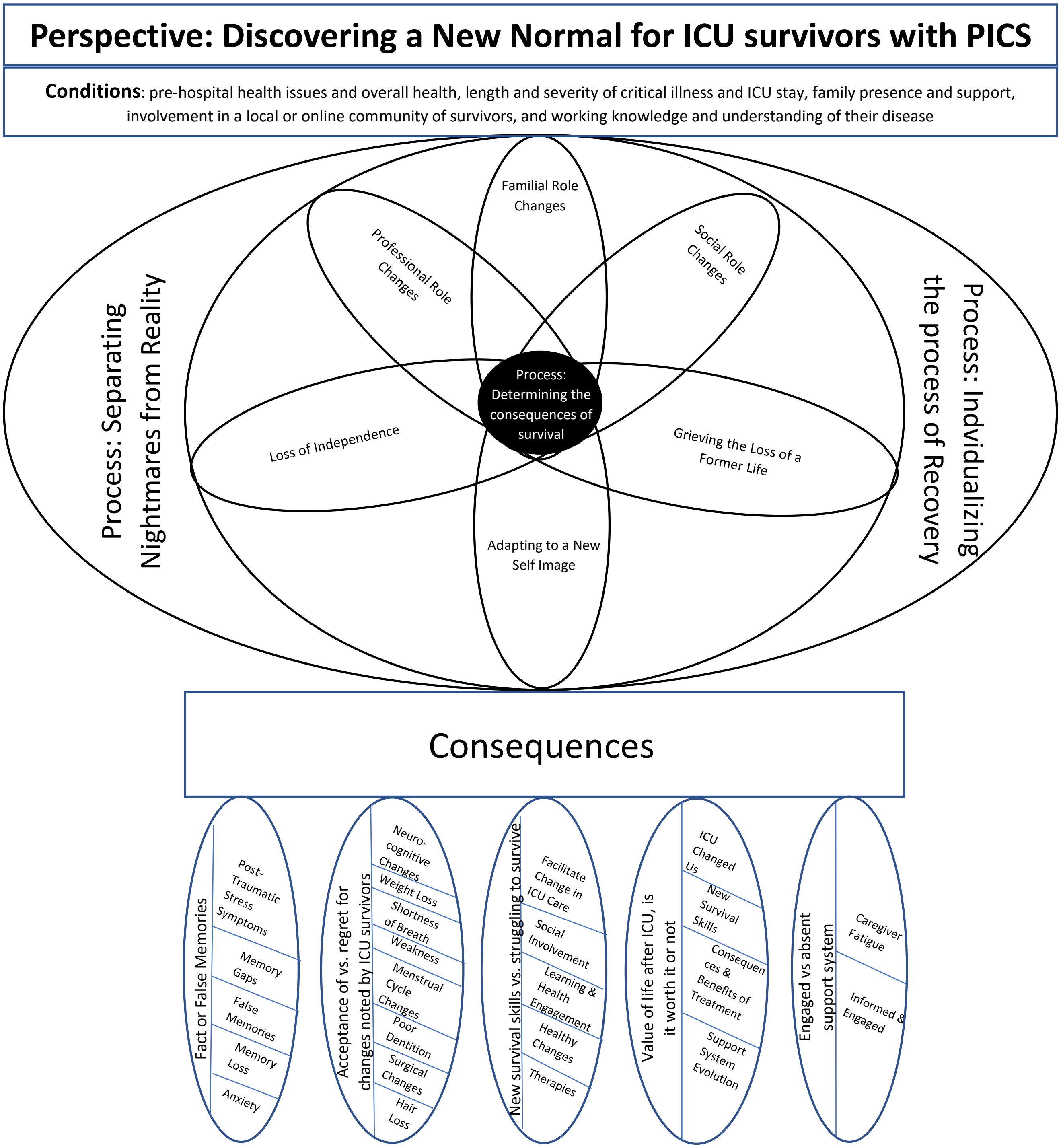
Analysis of the participant posts facilitated the development of an explanatory matrix through comparative methods and inductive analysis (figure 1). A dream catcher was chosen to represent the journey to a new normal because of the significant impact delirious dreams incorporated into memories have on survivor recovery demonstrated by the frequent posts from multiple participants describing their delirium and how it affected their recovery. The figure is also used in this context to represent dreams of future possibilities altered by a critical illness and ICU stay.

'Journey to a new normal' captures the theorizing generated from integrating the EM. For ICU survivors with PICS, this journey is their process of recovery after hospital discharge. The term 'new normal' appears multiple times in various survivor posts referring to a plateau in recovery that may be the closest approximation to that participant's previous functional status that they are able to achieve with their new physical, neurological, and neurocognitive abilities after their recent ICU stay.

> *It takes a long time to recover but you will, you may not be the same but its an ok new normal. Have patience and determination and then a new purpose in life. You may not ever be the same and thats ok…It took me a year and half to come to conclusion I was good as I was going to get. I struggle daily but life is good, don't give up, it will get better… (Participant 8754)*
>
> *…4 months of being bedfast damaged my body to the point that sitting turns me into a statue…I am still not as steady on my feet as I used to be [after 2.5 years of recovery]… (Participant 3054)*

The recurring phrase *'new normal'* describes the state at which an ICU survivor's recovery plateaus and is central to the overall process. It often represents the closest approximation to their previous functional status allowed for by their new chronic conditions accrued during their recent critical illness and ICU stay.

Figure 1. Model: The process of “Discovering a New Normal” for ICU survivors with PICS



Context

The journey to a new normal for ICU survivors occurs in the context of recovery after a prolonged stay in an intensive care or general medicine units as patients recover from recent critical illnesses. These settings may include interactions with nurses, physical and occupational therapists, physicians, pharmacists, and other healthcare workers seeking to optimize the survivor's recovery. The level of support from healthcare providers differs greatly between ICU and general wards and can often represent a traumatic transition for patients. Similarly, hospital discharge to various settings may also represent an anxiety-evoking shift in support availability that can greatly affect their journey to a new normal.

The survivor's interactions with healthcare providers, family, and social systems define the level of support as they enter the initial phases of recovery after hospital discharge. During their recovery, patients may move through rehabilitation and long-term care facilities and eventually be discharged home. The level of support and the individual's resiliency can greatly impact their ability to adapt to changes in their health resulting from the recent critical illness. While some survivors progress smoothly through their recovery, others may reach a point where they are unable to progress and become mired in recurrent healthcare visits and hospital readmissions.

Central Perspective: The Journey to a New Normal

The central perspective that evolved from the analysis is *the journey towards a new normal* as ICU survivors recover from their recent illness and ICU stay. As patients progress through their recovery, their central focus is the return to an approximation of their previous baseline physical, functional, and cognitive abilities. This process is individualized and varies depending on the following conditions.

Conditions

There are five main conditions that affect the journey to a new normal for ICU survivors. These conditions include pre-hospital health issues and overall health, length and severity of critical illness and ICU stay, family presence and support, involvement in a local or online community of survivors, and working knowledge and understanding of their disease. These factors affect the overall recovery trajectory for ICU survivors. The positive side of these conditions may facilitate a smooth, expedient, and more complete recovery while the negative side can result in setbacks, readmissions, and overall lesser degree of recovery.

Pre-hospital conditions and overall health

As with any ICU stay, preexisting comorbid conditions often complicate treatment and recovery after a new critical illness. Some patients note a gradual decline in their health with an increasing number of medical issues prior to a life-changing prolonged ICU stay.

> *…struggle with weird hospital stays prior to ending up in the ICU for "the big one"?...August 2011: 1 week in hospital due to Campylobacter jejuni infection resulting in myocarditis…March 2012: 1 week in hospital with VMRSA due to infection in a burn…August 2013: 1 week in hospital with thyroidectomy and compilations due to hypocalcemia…January 2014: Diagnosed with Celiac Disease…April 2014: 3 week ICU due to severe septic shock, traced to GABHS (Group A Beta Hemolytic Strep) infection (Participant 5604)*

Comorbid conditions add a layer of complexity to the recovery process that challenges ICU survivors and their support system. Their prior conditions may also increase their likelihood of developing ICU-delirium, worsening their chances of being discharged from a prolonged ICU and hospital stay with neurocognitive issues and other new comorbid conditions (van den Boogaard et al., 2012). ICU survivors with fewer complicating health factors are more likely to have a less complicated ICU stay and smoother, more expedient recovery.

Length and severity of critical illness and ICU stay

ICU visits vary greatly from patient to patient. However, more time in intensive care with a greater severity of illness may result in increased overall morbidity and mortality (Cuthbertson et al., 2005; Hirshberg et al., 2019; Hodgson et al., 2018). Patients with more complex healthcare maintenance needs after hospital discharge are likely to have a different recovery experience and trajectory compared to a patient with similar diagnoses who did not require an ICU admission (Hill et al., 2016).

> *I was on a ventilator for 2 weeks (2 years ago) and I still can't do simple math. Very frustrating. I just assume it's my new norm and will hopefully improve. (Participant 9854)*

> *...coma for 10 days due to severe sepsis, dr gave me less than 10% chance of making it and had to learn basically everything all over...left me with anxiety and memory problems, muscle fatigue etc! Trouble sleeping even more then before and a illiostomy bag... (Participant 1206)*

ICU illnesses can result in multiple hospital readmissions to manage issues associated with the survivor's initial diagnosis. These readmissions delay overall recovery and often represent serious setbacks in rehabilitation trajectory.

Family presence & support

Family support can often have a great impact on ICU survivors' recovery. Spouses and adult children may act as primary caregivers for patients during their initial rehabilitation after a severe critical illness. Having the family present during the hospital stay allows them to learn about the illness affecting their loved ones and appropriate interventions to improve care and rehabilitation after hospital discharge. Familial and social support presence is also important in providing support for roles that ICU survivors are no longer able to fill during their recovery period.

> *I did a medical advanced directive and proxy about 2 years before I got sick giving my sister and best friend medical power of attorney in the event I couldn't make decisions…Those two women along with my husband came together and made a network of support for my care…While I was in a coma, those women ran my care, and my husband*

> *was able to be supportive and loving to me but also take care of our children and keep our lives going outside the hospital. (Participant 7531)*

> *But [when you go home] carers [family members or primary caregivers] are the nurses, the nurses are your carers, and people keep saying to me and in Intensive Care literature information for patients is patients/relatives…this vision I have of Intensive Care is that if the patient representative is involved from the beginning, the patient representative can get to know the relatives, and friends, and carers, and supporters, whilst the patient is too ill to do anything and offer them help… (Interview #03)*

> *When I was so ill for over a year including numerous surgeries, hospitalizations, and an extended ICU stay I got used to people showing how much they cared…When I finally got well all of that care and attention ceased. I really struggled with that. I still felt so weak and at times depressed yet it seemed like everyone forgot about me. (Participant 3586)*

> *The first 2 or 3 weeks home I was recovering really quickly and my wife was super supportive and nurturing. Then my recovery plateaued and it seems my wife has pulled away from me. (Participant 5640)*

The absence of familial or social support may negatively impact the ICU survivor's recovery trajectory. Survivors often feel their social lives are passing them by and they are isolated because of their critical illness and its effect on their view of and place in the world.

A community of survivors

The process of recovery is often fraught with setbacks and can be difficult for anyone to navigate without support. Many survivors connect through social media and ICU survivor groups to share useful tools for recovery, express frustrations with a group of people who have experienced similar issues, and engender a feeling of belonging.

> *I know how you feel and it is frightening. Please let me know how it goes with discussing [your symptoms] with your dr., and if you ever need to talk I'm here. (Participant 1653)*

> *I hate that any of us are here at this place, but I feel less alone when I come here [to this chat group]. I owe everyone kind enough to share their experiences and thoughts a debt of gratitude…[My husband]'s not the same guy, I'm not the same person, but things get easier. That acceptance thing that 6405 is talking about goes a long way. (Participant 8456)*

Patients without such communities often express feelings of isolation and a lack of understanding from their families, social circles, and medical providers. In the absence of social support, survivors may feel alone and wonder at the purpose of their survival.

> *Worrying about such things just impedes your progress…I literally wasted years on being angry at everyone and everything that all I did was wait around for the next stroke so I could die…Finally I hit rock bottom and decided to quit waiting to die… (Participant 4258)*

> *Unless you have been through a prolonged period of critical illness, people just don't understand there are lingering and ongoing physical and psychological issues…I referred to it as 'sympathy fatigue', where there is a gradual decrease in compassion. (Participant 6357)*

Several survivors noted feelings of regret at survival, anger at the healthcare system that abandoned them, and severe depression.

Working knowledge and expertise of their disease process

ICU survivors often suffer setbacks during their recovery in the form of hospital or ICU readmissions. These issues may be related to their original admitting diagnosis, accrued during their ICU stay, or independent of their previous hospital visits.

> *It's been six years for me. I have been diagnosed with PTSD…My illness started with the flu and pneumonia…I too had relearn walk, relearn to use my hands, relearn to swallow, relearn to control my bowels…I have found therapy helpful. I tried a sleep doctor, but that was a bust. He didn't understand critical illness…didn't understand the aftermath of the critical illness. I did ease back into my volunteer activities…I had to find a new path…I did withdrawal from people and I know now that's ok. They will never understand what I went through. (Participant 3054)*

> *I was not expected to survive my illness on May 2018…I started rehab and P.I.C.S. therapy/treatment in July. IT IS HARD. The hardest and greatest thing I have learned since then is acceptance. (Participant 6405)*

A large part of recovery is learning how to manage their illnesses, accepting that there will be some setbacks, finding tools that help them maintain their independence and prevent readmissions, and accepting their new functional status.

ICU survivors with more time out of the hospital have greater experience dealing with their PICS associated health issues compared to patients recently discharged home. Hospital readmissions and mortality are relatively high for ICU survivors during the first year after their critical illness. Patients more experienced at managing their symptoms and new chronic illnesses often seek to share their knowledge with other survivors and critical care providers to improve ICU experiences for future patients.

Process: Determining the Consequences of Survival

One of the core processes involved in the journey to the new normal is determining the consequences of survival. It has several subprocesses or actions: losing independence, changing social, familial, and professional roles, grieving for the loss of former lives, and adapting to a new self-image. Debilitating physical, neurological, and cognitive changes often occur while the survivor is in an altered state of consciousness. Because they are unaware of the changes as they happen, patients must come to grips with the consequences of their survival.

Subprocess: Loss of independence

Through the changes wrought by their critical illness and subsequent ICU stay, many survivors lose some level of independence for varying periods of time. They come out of the ICU and hospital needing help with some of the most basic functions of life. Some of these changes will improve with time, but other changes may last for a prolonged period. In this case, the cost of survival may be some permanent loss of independence.

> *I was, so I understand, I was shaven, hair washed, nails cut and things like that. Things* that *you generally do and take for granted to do. And they all had to be done for me…If you don't do ill you don't accept it. And the fact that you're body is telling you, you can't do what you wanted to do or what you normally do, it's very hard to recollect* and respond. *(Interview #37)*

> *You lose, that's it, it's a loss of control. That's it encapsulated. You have no control over yourself any longer…I couldn't speak, I couldn't communicate, I couldn't write. I was*

> *alone…you have no control over anything…I'm a relatively young woman. I feel like eighty. (Interview #30)*

Physical rehabilitation and therapies facilitate regaining some level of independence for many ICU survivors. The cost of survival on the level of independence is often defined by physical, cognitive, or neurologic changes that remain permanent and limit the degree to which survivors can return to their previous lives.

Subprocess: Changes to social, familial, and professional roles

Survivors note their new debilities result in changes to many roles in their lives. With their new limitations to functional and neurocognitive abilities, many are unable to perform certain functions or process complex ideas.

> *…basing your self-esteem upon your intellectual capabilities. I was a lawyer for many years prior to the illness and emergency surgery which brought me to the ICU for 20 days…I was no longer able to ethically continue to practice law. Feeling "stupid" is not something I can ever get used to. (Participant 1058)*

> *…in my job…you need to be pretty quick-witted, work quickly, everything, it's a high level of stress...And I really seriously wonder whether I'd be able to function again…I work with younger people, you're always having to make certain that you are as good, as fast, as quick and as responsive as quickly as they are. And I didn't feel that I was…And I really lost huge confidence. (Interview #30)*

These changes may prevent them from returning to work, acting as the leader of the household, taking part in social situations, and various other facets often taken for granted by the general population.

Subprocess: Grieving for the loss of former lives

The loss of their previous lives and realization that they may never return to baseline functional status often results in a period of grieving. Survivors are sometimes forced to accept that life will never be the same and they will never be the same. They may feel like a completely different person and many of their social and familial contacts change as a result of new health issues acquired through their critical illness and ICU stay.

> *It has been about 2.5 years since I left a 4 month stay on ICU…still wondering if it was worth it…I am still only allowed to work part time until I find my physical limits without exceeding them…still not as steady on my feet. (Participant 3546)*

> *The biggest lesson I've learned on my 20 month journey is ACCEPTANCE. What I mean is learn to accept the disappointments and the struggle. BUT DON'T STOP trying to achieve the new life that is ahead of you. Allow yourself to grieve the loss of your past life and stay connected to others and you will make it through this valley (Participant 6405)*

ICU survivors may experience a loss of independence and changes in their social, familial, and professional roles as they come to grips with their new functional status. Many survivors also struggle with changes to their body image or are unable to return to work for an extended period after their illness.

Subprocess: Adapting to a new self-image

Critical illness can result in a need for various surgical procedures including tracheostomy, amputations, abdominal surgery resulting in ostomy bags, and many other surgical processes that significantly change body image for affected ICU survivors. Other patients experience substantial weight loss with decreased nutritional intake and increased caloric needs related to critical illnesses.

> *I had both legs amputated below the knee and lost my nose and four front teeth do to necrosis caused by septic shock…I had my nose rebuilt…I have come a long way and I'm so tired of worrying about my health. (Participant 3821)*

> *…I was in a coma for 10 days due to severe sepsis…left me with anxiety, and memory problems, muscle fatigue etc! Trouble sleeping…iliostomy bag…doing peritoneal dialysis…I have no desire to go anywhere or do any of the things I enjoyed before. This isn't me!!! (Participant 1206)*

Many ICU survivors also note hair loss, changes to dentition, and, in female survivors, alteration or cessation of menstrual cycle. These changes often occur in a short period of time while the survivor may be minimally conscious of themselves and their surroundings. Affected patients are forced to adapt to a new self-image.

Process: Separating the Nightmares from Reality

Delirium is a common occurrence that strongly impacts the degree of PICS for ICU survivors. Delirious episodes frequently haunt ICU survivors in recurrent dreams and false memories of their ICU stay. A second core process of recovery is focused on *separating nightmares from reality* and filling in the memory gaps.

> *I was in a coma for four weeks and trapped in a world of horrific nightmares…consisting of death, pain, and suffering…recurring…triggered by an external stimulus. I can still recall them with clarity nine years later…experiencing delirium…after 'waking up…with so many memories that I don't know whether they are real or imagined. (Participant 2958)*

> *The kidnapping and not being able to breathe are so bad…We've all had versions of those similar hallucinations and it's not something that you can just 'get over' so easily. One thing that has helped me (besides counseling) is going to the ICU with my Dr. who was able to show me everything I went through…It's emotional but I believe it has helped me a bit. (Participant 9054)*

Separating nightmares from reality is a long-term struggle for many ICU survivors. Participants mentioned several factors that may improve the anxiety and suffering related to delirium and false memories. Some methods for separating false memories from fact including counseling, cognitive behavioral therapy (CBT), eye movement desensitization therapy (EMDT), medications, ICU diaries, and immersion therapy focused on returning to the ICU and the scene of the traumatic experience. Other survivors note that family and social support are very important during this phase of recovery.

Process: Individualizing the Process of Recovery

Individualizing the process of recovery is a third core process; The recovery experience varies for each survivor. Some may view their recovery as a fight for survival where different tools can facilitate more complete and expedient successes. Family and social support play a big part in rehabilitation by facilitating the survivor's independence, assisting with care, acting as a source of support, and sharing in the experience. Finding a group of survivors who experienced similar ICU stays and health issues also facilitates recovery.

> *…side effects from prolonged ICU stay…all of us experienced the same…How far things improve is very much individual, as we are all affected in different ways with different outcomes, even if we had the same illness. (Participant 2958)*

> *One day at a time…I only had o2 [sic] early in my illness, had 3 liters of fluid drain from my lung, still short of breath. And I'm 2 yrs out. You will find your own pace, physical therapy will help, and do the breathing exercises if you can. Remember we are here (Participant 1257)*

Many survivors gain a sense of fulfillment from sharing their experiences and recommendations with newer survivors. This sharing also provides ICU survivors who are newer to their process of recovery with tools and guidance recommended by participants who were further along in their journey to recovery.

> *I [struggled with insomnia] for months [after ICU] …I started exercising hardcore (Participant 0785)*

> *I found this group…researching emotional effects after IC. I am only 20 days out of ICU…I quit smoking and have changed my eating habits…Tips on emotionally and physically bring okay during the first year out? (Participant 6345)*

ICU survivors may spend a significant amount of time becoming experts in their specific disease and symptom management.

> *[My ICU stay] was from exploded bowl and sepsis but this still has me having panic attacks…I too have many flashbacks even though it has been six years since my illness. (Participant 1206)*

> *My ICU stay was due to influenza and pneumonia. The current situation [with COVID-19] is doing my head in. I am constantly have flash backs and panic attacks…[My ICU stay] was 18 months ago. So still kinda fresh. (Participant 3839)*

However, despite common impressions, many ICU survivors experience long-term effects from their ICU stay and primary illness that develop into chronic health issues they struggle with for years after their initial ICU visit.

Consequences

The journey to a new normal for ICU survivors with PICS with all the processes and sub-processes has several consequences that the participants articulated in their posts. These consequences fall into five categories resulting from positive or negative results of the primary processes encompassed in the *journey to a new normal*. The results of these consequences affect the overall recovery trajectory of ICU survivors and the proximity of their *new normal* to their previous functional state.

Fact or false memories

Many patients describe episodes of delirium as if they are factual memories. ICU survivors can confuse true events with situations that they observed in their delirious states. Memory loss, memory gaps, and episodes of delirium incorporated into memory frequently cause anxiety and symptoms of post-traumatic stress in many ICU survivors.

> *I was in a coma for four weeks and trapped in a world of horrific nightmares throughout, usually consisting of death, pain and suffering, just complete mayhem. Some of them were recurring which must have been triggered by an external stimulus. I can still recall them with clarity nine years later. Then experiencing delirium for a couple of weeks after 'waking up'. Leaving me with so many memories that I don't know whether they are real or imagined. I endured eighteen months of weekly counselling and psychological treatment (CBT and EMDR) after hospital discharge. (Participant 2958)*

> *...i will list a few things I need to hit on that I hope will help me help you. things that im suffering from after time spent in icu. Severe flashbacks memory lossdreams that I can not explain nightmaresloss of timeconfustionive started sleep walking and laying objects on the floor ina order that I can not explain.fear of going outsidep.t.s.dweakness in my bodyacute anxiety and depression...I hope you can understand what ive written because memory loss and consentratjo has made it hard to do.to all the people who have spent time in icu keep your chin up and stay safe. (Participant 1023)*

They may suffer from newly developed agoraphobia, flashbacks, insomnia, and various other issues associated with their traumatic experience in the ICU. Patients who are successfully able to differentiate fact from delirious memory can gain some closure. Survivors who never separate reality from imagined horrors may suffer from prolonged anxiety, recurrent nightmares, and flashbacks when triggered.

Acceptance of vs. regret for changes noted by ICU survivors

Changes to social, familial, and professional roles as well as changes to self-image, independence, and overall quality of life are consequences of the process of survival. Survivors who were able to accept the factors of their life after ICU develop coping mechanisms and find support to aid them in their recovery and facilitate the greatest quality of life possible with their new limitations.

> *The hardest and greatest thing I have learned since [my ICU stay] is acceptance. Let go of expectations and find acceptance…You won't be as you were before but you can grieve your past life, accept where you are today, accept your limitations and CHOOSE the life you want and seek a way to achieve it. (Participant 6405)*

> *Sometimes I wish I hadn't survived. Tired of feeling like a burden and a wimp…Since the ICU I struggle with both short term and long term memory so I feel like a big part of me has been stolen…I'm tired of waking up every 203 hours in a panic from bad dreams, tired of hurting… (Participant 5640)*

> *It's very upsetting, who knows where I would be had I even known what actually happened to me! We were all just glad I survived and then when we realized that I am having severe difficulties stemming from my encounter with sepsis…no time, no clue, no idea what's wrong with me…Trying to get past this somehow, but it's beyond difficult…(Participant 3486)*

Whether from severity of debilitation, events during their ICU stay, lack of support after discharge, or other factors, some patients find themselves mired in the regret for the loss of their life from before the ICU and the potential that life entailed.

New survival skills vs. struggling to survive

Management of PICS and ICU survivorship is like chronic disease management. There is a learning period where high-functioning patients develop coping mechanisms and learn to maximize their functional abilities within the limitations of the disease itself.

> *…I would also suggest some box breathing… (Participant 2546)*
>
> *This may sound silly but do you knit: Your mind and hands keep busy…Learning to knit will keep your mind VERY busy. (Participant 0460)*
>
> *…physical therapy will help, and do the breathing exercises if you can. Remember we are here. (Participant 6345)*
>
> *Physically, rest as often as you need to. I switched to clean, organic eating, drinking 8-10 bottles of water a day. It was a long road and it took me years to do this and I wish I had done it sooner. (Participant 6547)*

Patients utilize tools learned through rehabilitation, social support group recommendations, individual ingenuity, and healthcare providers, to minimize the impact of the disease on their lives. With these tools, they can maintain their overall health and treat common symptoms.

Patients who are unable to adapt to new chronic debilitations have difficulty managing their recurrent symptoms, suffer hospital readmissions, and may note overall poor satisfaction with life after ICU.

> *…they do not educate the patient or family on what they may deal with after coming off intubation and sedation…Something needs to be done…They need more counselors or education on delirium and ptsd…we were left in complete confusion…thinking things happened to her that never did…I just can't wrap my head around why we were never told anything to watch out for… (Participant 5837)*
>
> *Most people are clueless as to how PICS affects survivors for the rest of their lives. They figure life is back to normal after being released from the hospital, when it's anything but. (Participant 9687)*

Survivors who struggle with adapting to their new health issues may feel they are unable to fully recover.

Value of life after ICU, is it worth it or not

ICU survivors often find themselves in a unique situation with first-hand experience of life-saving medical interventions. On arriving at a hospital with a critical illness, people without advance directives have a default "full code" designation. This means intubation and mechanical ventilation for respiratory failure as well as chest compressions and CPR for cardiac arrest. ICU survivors may experience these measures and the benefits as well as consequences associated with this care.

> *Worrying about such things just impedes your progress…you already beat the odds…I literally wasted years on being angry…But I'm not going to sit around waiting on it. I have things that I want to do…make the most out of every day and look forward to the future that the doctors said that you wouldn't have. (Participant 4258)*

> *I came home with a walker and very weak…I went to physical therapy 2 days a week and have continued to get stronger…I have had pain at different times in all different places…My stamina is still low but I'm taking care of my house with help…It's been slow and steady. Some days are harder than others…You will find everyone here is very supportive and at different stages of recovery. (Participant 7531)*

For some, this means new chronic issues that may include memory loss, shortness of breath, muscle weakness, neuromuscular issues, neurocognitive delays, anxiety, and symptoms of post-traumatic stress. Balancing the consequences of care with the benefit of survival is a long-term struggle for many patients. Some adapt and find new meaning in their lives and view further time with their family and friends as a gift.

Other ICU survivors decide they do not want to risk a repeat intensive care admission, intubation, or another round of CPR because of the consequences experienced from their previous critical illness. A prior intensive care unit hospitalization and the consequences of their critical illness may contribute the completion of an advance directive or durable do not resuscitate form requesting only conservative medical management for any future hospital admission.

> *It has now been 2.5 years since I left a 4 month stay on ICU &LTAC (Long-Term Acute Care), and I still wonder if it was all worth it…I am still only allowed to work part time until I find my physical limits without exceeding them – no more ICU's for me, thank you very much! (Participant 3546)*

> *I'm thinking about leaving a set of instructions for my BF/family for next time I'm in ICU…I'm not saying the Coronavirus has me anxious or anything…it was the flu last time. (Participant 9054)*

> *I told my family I don't EVER want to be on life support again! I don't think I can mentally handle it again, I'm still not over the first time and it's been one year ago since it happened… (Participant 3542)*

This is an important phenomenon with COVID-19 having caused protracted illnesses in many people and sometimes requiring prolonged intubation and ICU stays that often result in severe PICS.

Engaged vs. absent support system

ICU survivors frequently leave the hospital with new chronic health issues requiring additional support and assistance for rehabilitation and general health maintenance. Social, familial, and professional support systems can facilitate optimal recovery and independence for ICU survivors. Many patients seek out people in their support systems to act as their primary caregivers. Many patients feel isolated by their experience and changes to their familial, professional, or social role related to new functional limitations from their critical illness.

> *Healthy people are great support in an emergency, long term illnesses generally make them uncomfortable as they feel hopeless. Join more chronic illness support groups. Find some new people. And share any good news with the masses, they love good news. (Participant 4137)*

> *I see a psychiatrist and a therapist. They have made a huge impact on my life. Before seeing them I was depressed all the time, angry at everyone and everything and really didn't want to live. Now the Psychiatrist has me on the right medications and the therapist has helped me to accept the stroke and the things that I can't do anymore. (Participant 4258)*

Healthcare providers aware of the complications of PICS can make a great difference in the recovery trajectory of ICU survivors. Familial and social support from people with applicable healthcare experiences or understanding of PICS can greatly facilitate optimal independence and reintegration into general society for ICU survivors.

Other ICU survivors who are not connected to a well-informed familial, social, or professional support system may feel isolated and struggle in their recovery phase. Feeling isolated is a common sensation for some ICU survivors.

> *One year ago today my family was told to prepare themselves for the very real possibility I wouldn't be coming home, I did and although it's only been one whole year everyone seems to have forgotten how close I was to death and that it changed my life. Feeling alone (Participant 6524)*

> *It's been six years today for me. It will get better in time. My family got so they didn't want to talk about it. (Participant 3054)*

> *I experienced this as well prior to my first anniversary. When it came around, I could sense the ambivalence when I mentioned it and I refer to it as sympathy fatigue…There can be a perception that now we are out of hospital and back at home, then we must be better… (Participant 2958)*

Their hospital experiences and the consequences related to their illness separate them from their peers. Many patients feel frustrated with their interactions involving the healthcare system as well, noting that their primary providers and others may be dismissive of the symptoms related to PICS or poorly informed of the common consequences related to an ICU stay.

Discussion

This study utilized participant social media posts to develop a theoretical model that describes the process of recovery for ICU survivors. The resulting EM incorporates common themes and experiences, as well as facilitators and barriers encountered throughout the recovery phase after hospital discharge. This grounded theory study offers potential areas of intervention targeted at optimizing recovery and limiting long-term effects of PICS symptoms. This model also provides insight into positive and negative factors affecting ICU survivors' recovery.

There were several recurring themes associated with the journey to a new normal throughout the recovery phase. The central process that emerged through close examination of an extensive library of ICU survivor posts is *"The Journey to A New Normal".* While some ICU survivors can return to their previous functional state, many survivors note a plateau in their recovery after a certain amount of time. Some patients refer to this as their "new normal" state suggesting that they have recovered as much as possible. They often refer to acceptance of their "new normal" as being one of the most important lessons to learn. This is consistent with results from similar studies examining ICU survivors' experiences after hospital discharge (Kang & Jeong, 2018).

Available research focused on post-intensive care syndrome demonstrates that a large number of ICU survivors experience varying degrees of several common symptoms including muscle weakness, memory loss, depression, PTSD, and decreased neurocognitive abilities (Iwashyna et al., 2012). While many ICU follow up clinics and provider focus on these common symptoms when treating ICU survivors, the more humanistic factors experienced by patients in their *'journey to a new normal'* are often overlooked. Treating these symptoms is important, but only a part of aiding survivors in recovering from their PICS. Follow-up care for survivors should also focus on aiding them in adapting to long-term changes, teaching them to manage their complex medical issues, and assisting their primary caregivers in providing optimal aid to their loved ones. Clinics should also focus on providing education to primary care providers so they are aware of potential issues ICU survivors may encounter and have a better understanding of the complications of PICS.

Many of the patient social media posts discussed conditions that affected their overall recovery trajectory. Previous PICS research demonstrates that survivors are more likely to utilize healthcare resources than patients who did not require ICU care (Lone et al., 2016). However, the exact causes of increased utilization and rehabilitation setbacks have been difficult to elucidate in previously published PICS research. While causes for hospital readmission and increased clinic use seem to vary from patient to patient, participants who develop disease mastery, have engaged primary caregivers, and utilize social support systems seem to benefit greatly and express a stronger sense of control over their symptoms. Connecting patients with a community of ICU survivors early in their recovery period is also an important part of the rehabilitation process. Survivors and their primary caregivers frequently gain support, assistance, and helpful recommendations and may be aided in an expedient and full recovery by properly engaging a community of survivors who have experienced similar issues. By facilitating improved social support through connections to other ICU survivors with similar experiences, patient recovery in their physical, cognitive, and psychological functional realms may be positively influenced, increasing the likelihood of a more complete recovery (Tilburgs, Nijkamp, Bakker, & van der Hoeven, 2015).

Determining the consequences of survival was a key process in the journey to a new normal for many of the ICU survivors in this study. Physical and occupational therapy play an important role in maximizing patient’s independence and ability to return to their previous social, familial, and professional roles. However, a full return to each of these roles will not always be possible. In these cases, therapy sessions focused on managing these changes seem to be useful for many of the survivors who have sought out such assistance. Primary care and ICU follow up providers should be aware of these needs and encourage utilization of psychiatrists and therapists as indicated on an individual basis for each patient (Mehlhorn et al., 2014).

For many ICU survivors who experienced serious episodes of delirium, separating delirious nightmares from reality is an important process in their recovery. The patients in this study noted several interventions that had varying degrees of success in aiding them in separating fact from delirious memories. These include ICU diaries, revisiting the ICU where it all happened, EMDT, CBT, antidepressants, antipsychotics, and other various forms of cognitive and psychotherapy. Other efforts should be focused on further developing ICU survivor groups around through follow-up clinics and online to further facilitate the development of a survivor community. While many studies describe the benefit of ICU-diaries, the patient posts included in this study described how they can aid in separating fact from false memories and provide closure (Jones et al., 2010; Mehlhorn et al., 2014; Ullman et al., 2015). Offering psychiatric-focused follow-up to ICU survivors, providers would be able to offer focused treatment for PTSD, lingering delirium, depression, anxiety, and other related issues, could further patient recovery (Wang et al., 2018).

Limitations

The content of each post consisted of native language shared by ICU survivors and developed through common experiences. This approach precluded interaction with any of the participants and therefore, it was not possible to query for clarification or elaboration. The available information was limited to the topics naturally discussed by the participants. To minimize these limitations in this observational approach, an anonymous ICU survivor served as a consultant to review and verify concepts, categories, and conclusions throughout the analysis period. The research method for this study was also limited by selection bias. The data sources were restricted to online social media posts, reposts, responses, videos, and anonymous pictures. This selected for a certain level of education, desire to disclose personal experiences publicly, and access to the internet. While many ICU survivors have access to the internet, there is a population of ICU survivors who are generationally less likely to be computer literate. There are also patients who are homeless or marginally housed and do not have access to social media. The patients in these populations may have a different hospital and post-discharge experience than those observed in this study, so the transferability of findings in this study is limited to survivors who use social media to process their experiences. This study additionally included ICU survivors who were functionally able to write social media posts and excluded patients who suffered from the most debilitating illnesses and comorbidities. Further research could focus on the specific experiences and challenges experienced by other populations, using the more traditional approach of in-depth interviewing and participant observation. The participants also were at varying stages of their recovery and time out of the ICU resulting in variable reliability for recall of events. However, many of the participants were discussing symptoms they continued to experience despite sometimes extended time out of the ICU. This lends credence to statements of prolonged symptoms of PICS lasting sometimes several years after hospital discharge. Similarly, this study focused on English language social media posts available on internet servers in the United States and excluded discussions in other languages. Verification studies may be carried out to compare the experiences of ICU survivors in other countries or who do not speak the primary language of their home countries.

Implications for practice

Each ICU stay and critical illness affect survivors in different ways resulting in a need for an individualized approach to the process of recovery. As patients and their caregiver enter the hospital system for a severe critical illness, providers should seek to provide education surrounding the patient's illness, overall ICU stay, and begin the discussion of developing an advance directive. Those who are likely to experience prolonged ICU stays, sedation, mechanical ventilation, or other risky procedures and treatments should receive further education about post-intensive care syndrome. As patients approach hospital discharge, a holistic approach to PICS follow-up and planning may provide the best recovery outcomes. A patient and family driven plan for recovery, incorporating the patient's various healthcare providers would ensure a holistic approach. ICU follow-up plans should include primary care providers (PCP), referral to a Post-ICU follow- clinic, physical and occupational rehabilitation specialists, ICU survivor support groups, and a therapist or psychiatrist. The ICU after-care should be directed by an intensivist with understanding of critical care and common issues resulting from an ICU stay. Offering survivors the opportunity to volunteer in an ICU or assist in organizing a survivor support group also seemed to provide several participants in this study with a way to contribute to care of future ICU patients.

Implications for research

There are four time periods on which to focus research to minimize PICS and improve outcomes for ICU survivors. At the time of hospital admission and during the initial phase of evaluation, assessment, stabilization, and initiation of targeted treatment plans, it is often difficult to convey learning materials or facilitate thoughtful goals of care conversations. Studies focused on best methods to provide opportunities for discussions focused on advanced directives, goals of care, likely outcomes related to treatment and intensive care unit admission, and expectations for overall hospital stays would aid in directing care to patient desires. Efforts and interventions designed to incorporate patient and primary caregiver education throughout ICU and hospital stay would increase the overall understanding of new health issues and engage patients and their caregivers in facilitating optimal healthcare management. As patients near hospital discharge and prepare to transition to their next phase, interventions focused on removing barriers and facilitating attendance at follow-up clinics would improve aftercare treatment for new and ongoing health issues for ICU survivors. At discharge, studies focused on optimizing engagement of social support systems including online and local ICU survivor groups would improve development of these communities and facilitate survival tool development and sharing among survivors. Other studies could focus on potential benefits of engaging survivors in ICU quality improvement projects.

Conclusion

Post-intensive care syndrome is a serious consequence of a prolonged ICU stay and critical illness experience by many ICU patients. Until 2012, healthcare providers sought to address the sequelae of symptoms associated with PICS piecemeal as they were each recognized individually in the affected patient populations (Needham et al., 2012). SCCM's recommendation to group these symptoms together has facilitated improved evaluation on the affects that an extended ICU stay has on ICU survivors as a population. However, provider treatment of the symptoms associated with PICS usually physician-driven rather than patient-centered and focuses on managing common symptoms included in the definition of post-intensive care syndrome. Providers also frequently assume that PICS is a short-term syndrome that patients will get over with enough physical rehabilitation and treatment. By examining the PICS experience from the patients' perspectives, this study demonstrates several concerns commonly affecting the recovery of ICU survivors. While symptoms commonly associated with PICS such as anxiety, memory loss, weakness, fatigue, and symptoms of post-traumatic stress play a significant role in the recovery trajectory of this patient population, less recognized issues such as changes to body image, personal roles, feelings of isolation, caregiver fatigue, lack of provider education surrounding PICS, as well as overall duration of PICS are often overlooked.

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Chapter 5. Manuscript #3

Intensive Care Survivors' Perspectives of Post-Intensive Care Syndrome

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Target Journal: ***Annals of Thoracic Medicine Society***

Abstract:

Rationale: Management of post intensive care syndrome (PICS) is typically restricted to symptom and quality of life measures developed from provider perspectives. Many intensive care unit (ICU) survivors with PICS note an inability to return to their previous familial, social, and professional roles after their initial critical illness and ICU stay.

Objectives: Describe the quality of life and lived experience of intensive care unit (ICU) survivors and compare with the accepted medical definition of PICS.

Methods: Constructivist grounded theory was used in this qualitative study of ICU survivors with self-reported symptoms of PICS. Social media posts were analyzed for themes from patients' perspectives. The data was gathered during the period of May 2018 to April 2020.

Measurement and Main Results: This study compared patient perspectives and accepted medical definition of PICS. 20 primary and 325 response posts on social media platforms from ICU survivors with self-reported symptoms highlighted key differences between the current definition and first-hand experiences with PICS. ICU survivors noted difficulty in separating delirious memories from reality as well as inability to return to previous social, professional, and familial roles. Past ICU experiences and anxiety from media coverage of current events affected some participants' advance care planning.

Conclusions: Poorly organized follow up care severely impacted several participants' recovery. A concerted effort to involve ICU survivors in the expansion of the accepted definition of PICS would facilitate a more patient-focused education for providers as well as an improved organizational approach to treatment.

Keywords: post-intensive care syndrome, PICS, ICU survivors, ICU after care

Background and Significance

United States hospitals have more than 5 million patients treated in intensive care units yearly (Barrett et al., 2014; “SCCM: Critical Care Statistics,” n.d.). Researchers, practitioners, and educators have advanced critical care medicine in leaps and bounds in the first two decades of the 21st century. The improvements have resulted in a reduction in mortality rates, from more than 80% prior to 2000 to a mortality rate fewer than 20% before hospital discharge (Garland et al., 2014). With increasing success in managing critical illnesses, as measured by decreased overall morbidity and mortality for intensive care unit (ICU) patients (Garland et al., 2014), researchers, clinicians, and post-discharge ambulatory clinics are focused on improving outcomes, defined by primary and critical care providers, after ICU and hospital discharge (Elliott et al., 2014; Harvey & Davidson, 2016; Needham et al., 2012). The outcomes include improvements in health-related quality of life, physical, and cognitive abilities (Steenbergen et al., 2015; Venni et al., 2018). Positive outcomes during an ICU stay may result in hospital discharge of an “ICU survivor.” An ICU survivor is a patient who developed an illness severe enough to require admission to an intensive care unit and survived treatment of that illness through to hospital discharge (Davidson et al., 2013). A better than 80% survival rate for ICU patients means that there are over 4 million patients each year who fall into the group of ICU survivors. Approximately 66% of ICU survivors will experience prolonged functional, neurocognitive, or physical impairment up to three years and beyond their inciting critical illness (Iwashyna et al., 2012).

Traditionally, post-hospital discharge management of ICU survivors has been individualized based on the patient’s symptoms and the primary reason for the ICU admission. There is an increasing demand for organized follow-up care of ICU survivors based on a definition of common sequelae experienced by ICU survivors termed *post-intensive care syndrome (PICS)*. A team of researchers, critical care providers, and other members of the Society of Critical Care Medicine developed the definition for PICS to cluster symptoms associated with recent critical illness requiring prolonged ICU treatment (Needham et al., 2012). The group of symptoms in the definition are ones most frequently experienced by ICU survivors including muscle weakness, physical activity intolerance, memory loss, decreased cognitive and neurocognitive function, peripheral neuropathies, anxiety, sleep disturbances, traumatic flashbacks, and symptoms of post-traumatic stress among other shared symptoms (Needham et al., 2012). After the initial diagnosis of PICS, ICU survivors with symptoms consistent with the definition are increasingly invited to enroll in organized aftercare clinics; though this approach to follow-up care has not become widely adopted across the United States (Mehlhorn et al., 2014).

Despite advances in critical care medicine, ICU survivors have increased one- and five-year mortality rates compared to similar patients who did not require ICU admission (Lone et al., 2016). However, ICU survivors may develop new chronic comorbidities related to their inciting ICU stay that often affect their ability to return to their previous social and professional roles (Lone et al., 2016). ICU survivors with PICS can have a greater than 50% increase in healthcare utilization that is roughly $10,000 over the subsequent five years after their initial illness (Sjoding et al., 2016). Additionally, readmission rates are higher in ICU survivors with PICS with more than one-third of them requiring hospital readmission during the first six months after hospital discharge (Hua et al., 2015).

Awareness and management of PICS has become even more important during the 2020 COVID-19 pandemic. For example, ICU survivors who experienced prolonged episodes of deep sedation and mechanical ventilation during their ICU admissions have experienced flashback memories (Maramattom & Bhattacharjee, 2020). With up to five percent of COVID-19 cases requiring ICU admission and an estimated 65% survival rate for patients who required mechanical ventilation, greater numbers of COVID-19 survivors likely will suffer from PICS and be discharged from the hospital with PICS symptoms, including traumatic episodes of delirium (Auld et al., 2020). These episodes of delirium during an ICU stay may involve violent and horrific images sometimes leading to the increased likelihood of symptoms of post-traumatic stress (Belluck, 2020). Early anecdotal reports suggest that some ICU survivors of previous illnesses, who have not contracted COVID-19 yet, find themselves considering their own advance care plans should the worst happen and they contract the virus and require an ICU-admission (Belluck, 2020). Because of a renewed focus on advance care planning by ICU survivors, many primary and specialty medicine providers are finding themselves having palliative care conversations they feel poorly qualified to facilitate (White & Short, 2020). Facilitating better understanding of PICS, from the patient's perspective, and optimal prevention and management of the related symptoms is increasingly more important as healthcare providers are faced with ever-growing numbers of ICU survivors.

Current Study

There is limited first-hand information surrounding ICU survivors with PICS and their personal experience with recovery and rehabilitation. The purpose of the current study was to examine the differences between the medical definition of Post-Intensive Care Syndrome and the lived experience of PICS from the ICU survivor's perspective to determine variations between the accepted definition and the lived-experience. Grounded theory will be used to amplify or challenge current established medical beliefs about PICS.

Methods

Sampling and Data Sources

Social media posts written by ICU survivors 18 years or older, with self-reported recent critical illnesses requiring a stay in an intensive care unit for more than 96 hours with self-reported symptoms of PICS were collected over a two-year period from May 2018 through April 2020. The data library includes 20 primary participants social media posts with 325 respondent posts. These posts provided a patient-centered view of the recovery experiences for ICU survivors with self-reported symptoms of post-intensive care syndrome. The University of Virginia Institutional Review Board provided approval for the collection and development of this data library (Kelleher, Kools, Debnam, & White, under review). By applying constructivist grounded theory and symbolic interactionism, social media posts written by ICU survivors with PICS facilitated an examination of the process for their recovery and allowed a comparison between the provider definition and the patient experience for PICS (Blumer, 1969; Charmaz, 2014). A limitation of the source data utilized for this study excludes ICU survivors who were debilitated by PICS to the extent that they are unable to participate in social media, or who did not elect to share their experiences on these platforms. The content library also was limited to social media posts written in English. Participants younger than 18, or with hospital admissions without an ICU stay or fewer than 96 hours in an intensive care unit were also excluded.

Analysis

ICU survivor social media posts focused on PICS were transcribed verbatim utilizing Dedoose v 8.0.35 to facilitate coding and concept abstraction (team, 2018). Common emerging themes, resulting from grounded theory analysis, were compared to the current medical definition of PICS to highlight underrepresented symptoms and expand on the accepted group of symptoms including physical, neurocognitive, and psychiatric issues previously reported in related literature (Davidson et al., 2013; McPeake & Mikkelsen, 2018; Needham et al., 2012)

Results

Approximately 80% of participant posts were written prior to the current COVID-19 pandemic. Clinical discussions surrounding post-intensive care syndrome focus primarily on physical function, cognitive, and mental health changes related to recent critical illnesses and intensive care stays experienced by ICU survivors (McPeake & Mikkelsen, 2018; Needham et al., 2012). By focusing on these three topics, this paper highlights some issues associated with PICS that are consistent with patient-centered experiences. This paper then summarizes patient experiences and characteristics of PICS that are not fully elucidated in the extant literature. While COVID-19 references appeared to play a significant role in the most recent participant posts, because this was not relevant to the previous 80% of participant posts, any codes solely relating to COVID-19 were excluded from the following discussion. However, several of the themes and topics discussed by participants as relating to the COVID-19 pandemic were discussed, to a lesser degree, in previous posts and included in the discussion below due to their relevance to the larger percentage of the participant population.

Patient Perceptions of Issues Consistent with the Medical Definition

Survivor posts confirm several issues commonly noted in PICS literature. Seven major themes found in the ICU survivor posts can be broken down into the three major symptom groups used in the original definition of PICS. These themes include: persistent cognitive changes, sometimes long-term or permanent losses to familial, social, and professional roles, changes to family dynamics, insidious delirious memories more vivid than true-life memories, changes to desires for further critical care and end-of-life goals, loss of independence seriously affecting ability to comply with recommended medical therapies, and impact on family caregivers.

1. Cognitive changes

Decreased cognition can be an unfortunate result of severe critical illness with a prolonged ICU stay. Some patients enter the ICU as independent, high-functioning adults and leave the ICU barely able to perform simple arithmetic. Up to 50% of ICU survivors are unable to return to work for 12 months after discharge and approximately 20% may not return to work for more than five years (Collie et al., 2019; Herridge et al., 2003; Hodgson et al., 2018). However, most physical, and occupational rehabilitation prescriptions and plans of care only last for a few months to a year after hospital discharge. As a result of decreased cognitive abilities, many patients note an inability to perform their previous social, familial, and professional roles.

> *"I know exactly what you mean about basing your self-esteem upon your intellectual capabilities. I was a lawyer for many years prior to the illness and emergency surgery which brought me to the ICU for 20 days...I was no longer able to ethically continue to practice law...sitting at home is no place to try to regain self-esteem." (Participant 1058)*

These role changes may result in disruptions to the survivor's self-identity that go beyond their cognitive changes. Depending on the level of recovery, some of these changes may be permanent or at least lead to long-lasting alterations in their ability to return to previous roles after rehabilitation. These changes can disrupt the entire family of an ICU survivor depending on their role and responsibilities and the family dynamics. Not only do the family members experience the loss of someone who may have filled a leadership role, they often find themselves acting as primary caregivers for an ICU survivor who may need partial or total assistance with everything from feeding themselves and taking their medications, to toileting and dressing. Family members may also need to function as rehabilitation specialists throughout the day when the therapists are not present or between visits.

2. Mental health changes

Mental health issues represent a significant proportion of new symptoms experienced by ICU survivors with PICS. Patients who suffered significant and prolonged episodes of delirium during their hospital stay may experience memory loss, early onset dementia, anxiety, and symptoms of post-traumatic stress. Serious episodes of delirium also increase the likelihood that an ICU survivor will suffer decreased cognition related to that hospital stay (van den Boogaard et al., 2012). Separating real events from delirious episodes that have been incorporated into their memories as fact is a significant part of the mental health recovery for many ICU survivors.

> *"I was being cared for by Dog the Bounty Hunter in his house. He was paying for everything and the paparazzi wanted to know who he was helping so they kept trying to get pictures of me through the window. I also thought the staff was trying to kill me. I had an alarm on me which I disassembled, along with my feeding tube, etc and planned my escape. I thought if I could "blend in" no one would notice. So I went to the nurses desk and started answering the phone. I thought my room was in the basement of my doctor's office which is close by our house so I figured I could walk home. It was raining so I kept calling people to come get me. It was 4 am." (Participant 7832)*
>
> *"It's been years, and I still have issues believing those dreams were not real. I hope your aide, whether it be counseling, therapy, or medication. Therapy really helped me get the tools necessary to remember it was a dream and separate it from my real life experiences." (Participant 9374)*

Many of the delirious memories are violent or traumatic and contribute to anxiety and symptoms of post-traumatic stress experienced by ICU survivors. While there are various methods targeted at treating ICU-delirium and its consequences, including immersion, cognitive behavioral, eye movement desensitization, and others, the success of common psychiatric treatments tends to be anecdotal.

> *"...last time I almost needed ECMOS when ventilation wasn't working and the hospital I was at did not have that capability...I absolutely began verbally telling my husband a list of things that I wanted done/not done if I went to ICU again...I wanted him to keep a journal of the entire experience so I could fill in the memory gaps when I wake and not be so confused about lost time. Real vs. Non real." (Participant #4589)*

Several participants mentioned that ICU diaries or journals help to fill in the memory gaps and sort fact from delirium. Their experiences with delirium may be so severe that they develop or adjust their advance directive to ensure they will not be admitted to an ICU ever again. Other survivors feel the consequences of survival may outweigh the benefits and question the benefits of readmission.

3. Physical function and changes

Prolonged sedation and bedbound inactivity lead to significant changes in the physical abilities of ICU survivors. While these issues are well documented in ICU literature, the humanistic aspects related to these changes are less obviously relayed. Physical appearance is often tied closely to self-image and significantly affected for many ICU survivors with more profound alterations in their physical function and appearance. Many ICU survivors leave the hospital with significant weight and muscle loss, various surgical changes, and often a prolonged recovery period where they are unable to perform physical activities previously taken for granted. Many survivors are never able to return to work and forced to rely on their family for support where they were previously completely independent and fully functional.

> *"It's been six years for me. I have been diagnosed with PTSD which I wasn't surprised. My illness started with the flu and pneumonia, but then I had complication after complication... I too had relearn walk, relearn to use my hands, relearn to swallow, relearn to control my bowels..." (Participant 3054)*
>
> *"[I had] pneumonia, sepsis and they found an aortic aneurysm needing prompt attention...the fear and anxiety is overwhelming sometimes. Relearning all you described has been very challenging, the swallowing thing freaked me out, they said I might not be able to swallow again!, really! The physical aches and pains are now the new normal, walking with a limp, unable to bend over, but I keep plugging away at PT/exercise to get ready for the next episode." (Participant 8556)*

Some ICU survivors note that most of the changes to physical function improve with time and rehabilitation. However, some of the changes are permanent and become a part of the patient's *'new normal'* state.

> *"...we all live with the idealised notion that 'cheating death' is a noble undertaking. However, I have come to wonder whether survival in the face of critical illness is something that in all cases should be strived for...As someone who is facing his second round of cardiac bypass surgery...I am not certain that I want to undergo it again." (Participant 1058)*

These survivors may question the value of an ICU admission that saves their lives only to leave them a shadow of their former selves.

Patient Perceptions of Issues Expanding on the Medical Definition

There is an abundance of literature describing the individual symptoms that encompass PICS. There is much less information available regarding patient experiences with these symptoms, facilitators, and barriers experienced during the process of recovery for ICU survivors. The accepted medical definition of PICS relies heavily on the researchers' and providers' perspectives of expected symptoms, optimal treatment modalities, and symptom duration. However, examination of this library of ICU survivor social media posts demonstrates some lesser known aspects of issues related to PICS.

1. **Anxiety and flashbacks related to media coverage**

Some ICU survivors report flashbacks to their hospital stay as they watch news reports or read articles focused on experiences by other ICU survivors who suffered traumatic ICU stays. As they observe people describing prolonged ICU stays and survivors having serious functional and neurocognitive debilities, some participants noted increased anxiety levels and episodic flashbacks to their own critical illnesses.

> *"...the conversation my husband & I just had. He had pneumonia that turned into sepsis, this December. He just said if he gets sick again, he absolutely does not want to go back in (very aware of the Coronavirus) ...he wants to remain at home. He is terrified I will have him placed back in the hospital and let drs do whatever it takes to keep him alive (Participant 3148)*

> *"We all have dealt with and continue to deal with different issues, and it's good to have someplace to go and someone to talk about the experiences that understand them. Sleeping*

> *is a big issue for me, even though it has been 10 years since my coma. The nightmares are much less frequent now, but they still pop up, and with all going on in the world today I am sure many of us are in the same boat with worry and fear, along with our families.” (Participant 5640)*

Most ICU survivors note their anxiety and symptoms of post-traumatic stress improve over time. However, certain events may trigger memories of their illness and inciting hospital stay. The frequency and severity of these flashbacks can affect a survivors views on hospital readmission and further ICU care.

2. Re-evaluation of advance care plans and end-of-life goals

ICU survivors have a higher mortality rate at one and five years after hospital discharge compared to patients with similar diagnoses who did not require intensive care treatment during their hospital stay (Hill et al., 2016). Some participants expressed a desire to reevaluate their advance directives and goals of care for subsequent hospitalizations.

> *“I told my family I don’t EVER want to be on life support again! I don’t think I can mentally handle it again, I’m still not over the first time and it’s been one year ago since it happened…” (Participant 3542)*

Unfortunately, these conversations may occur with front-line providers who have limited palliative care training and are unfamiliar with end-of-life discussions and hospice options.

Considering the severity of illness many ICU patients experience, some survivors may decide to refuse ICU level treatment for subsequent hospital visits. Some patients have difficulties reconciling the benefits of their previous ICU stay with the long-term consequences of PICS from the same stay. Some of these patients, who previously wanted full care, may fill out advance directives and durable do-not-resuscitate wishes to prevent a potentially more serious form of PICS related to readmission to an ICU.

3. Challenges to follow-up care

Structured follow-up allows close monitoring and management of the multiple health issues related to PICS. The current healthcare climate has greatly affected outpatient clinic management, resulting in decreased availability of visit slots, and restricted waiting room space for ICU survivors who need close follow-up after a recent hospital stay.

> *"I see a therapist but have canceled my appointments with this virus at the moment. I have gone out only a few times...I wore gloves and a mask. I have been in my backyard, but I live in a rural area." (Participant 1206)*
>
> *"I was so unceremoniously discharged with ZERO follow up in place. They gave me referrals for all of the specialists I'm supposed to see. I can't get in with them until 6/21, three weeks post discharge. I'm so tired of making calls sucks bc my mouth is so damaged from the vent and it's hard to understand me." (Participant # 7596, posted 6/11/2018)*

ICU survivors may be reluctant to attend clinic appointments during infectious outbreaks and pandemics because of concern for being part of a high-risk population more likely to have negative outcomes if they contract the viral infection. Others may have poorly organized follow up or be unable to schedule their visits for various new health or logistical reasons. With many ICU follow-up clinics noting poor patient attendance, further reduction in patient visits related to concern over the highly publicized pandemic likely increases difficulty in providing these patients with appropriate follow-up (Lasiter, Oles, Mundell, London, & Khan, 2016; Williams & Leslie, 2008).

Discussion

The definition of PICS in the medical literature offers a provider-centric description of the clinical symptoms and comorbidities related to a prolonged stay in an intensive care unit (Needham et al., 2012). While this is important from a medical management perspective, an important source of evidence is missing—the patient's perspective. Some ICU survivors experience the after-effects of prolonged sedation and mechanical ventilation in the form of

PICS (Needham et al., 2012). This paper highlights the effect of PICS on ICU survivors and the patient-driven aspects less prevalent in the extant literature.

Some ICU survivors suffer from cognitive, psychological, and physical changes that prevent their return to previous social, familial, and professional roles. These symptoms can last more than five years and even prevent survivors from ever returning to work (Collie et al., 2019; Hodgson et al., 2018; Lone et al., 2016). The participant posts suggest that some survivors are unable to adapt to the cognitive changes from their ICU stay. Some survivors feel their healthcare providers are unable to understand their struggles and that the healthcare system has failed. Medicare and most insurance agencies only provide partial coverage of inpatient rehabilitation after hospital visits for up to 90 days and coverage of outpatient therapies varies greatly and may be limited by cost to the patient ("Medicare and You Handbook 2021," 2020). For survivors who experience enduring symptoms, more long-term therapy and support may be needed.

Anxiety flashbacks, and symptoms of post traumatic stress are also a common theme noted in previous PICS research (Jutte et al., 2015; Wolters et al., 2016). As with any traumatic event, ICU survivors are likely to find certain stimuli that trigger memories and flashbacks. They are also likely to experience anxiety related to new health changes and decreased control over their environment if they require assistance during rehabilitation or over an extended period (Mehlhorn et al., 2014). The participant social media posts utilized for this study demonstrate that anxiety and post traumatic stress symptoms related to PICS may last for years after the inciting illness. These feelings of anxiety may also affect ICU survivors' decisions to pursue subsequent care. Goals of care discussions and a palliative focus on symptoms that are unrelieved with rehabilitation exercises or time may benefit ICU survivors and facilitate a better understanding of their future wishes for further healthcare encounters.

There are many studies focused on components of PICS following hospital discharge and their impact on patient satisfaction and quality of life. However, very few of these studies ask the simple question of whether ICU survivors would want to do it all over again or be readmitted for another critical illness. Several participants included in this study discussed changes to their advance care plans and end-of-life goals related to their recent ICU stays. The degree of debility they experienced after hospital discharge and anxiety at considering readmission resulted in several of the participants filing advance directives with specific instructions for no further ICU care. This suggests that, while many quality of life indicators after ICU may be similar to pre-ICU status for survivors, something about their ICU stay or the resulting changes and PICS left these participants with serious concerns about receiving further critical care. This is something that should be discussed with survivors during follow up visits at ICU aftercare clinics or with their PCPs.

Several of the participants noted difficulty attending follow up appointments leading to limitations to rehabilitation and recovery. ICU survivor research validates these comments with attendance rates as poor as 50% in many cases (Lasiter et al., 2016). However, the ICU survivor perspective demonstrates several issues that affect this including poor symptom recognition by providers, functional status precluding travel to follow up clinics, depression, and a feeling that their follow up visits were not addressing their concerns with their overall health and PICS symptoms. Follow-up clinics should engage ICU survivors in active decision-making as they develop aftercare and treatment plans for issues of most importance to the patients.

Implications for education

Text book definitions, for syndromes affecting patients, can have a broad impact on the modality of treatment favored by providers. A definition that focuses on provider-driven descriptors that we assign to patients may miss factors in a disease that patients believe significantly affect their quality of life and ability to function in their accepted familial, social, and professional roles. In the last 20 years, the national healthcare focus has included more patient-centric approaches to managing healthcare issues (IOM, 2001, 2018). Adjusting the definition from a medical focus to a more patient-focused definition of the associated issues would be a collaborative approach to improving outcomes that have the greatest impact on ICU survivor recovery and quality of life.

In part, modifying the medical definition of PICS involves how educational institutions approach the topic as they prepare new professionals to treat the related issues. PICS may become a chronic, long-term sequelae to ICU hospitalization, and recognizing its many presentations is useful to recognize for effective treatment. Providing more emphasis on palliative care training for all providers, including emergency medicine, primary care, and critical care specialty practitioners would facilitate better symptom recognition and management as well as encourage an awareness of the importance of frequent and in-depth goals of care discussions at various levels of care. Education directly addressing PICS would also improve understanding and recognition of the various comorbidities that may result from a discharged ICU stay. Perhaps a patient-centric definition of PICS would include advance care planning and what about the previous ICU care would be “on the table” or not.

Implications for policy

A revised definition of PICS considering the patient’s perspective could be used to update national guidelines for best practices. Policy and procedure changes might include the development of medical and insurance codes that accurately represent PICS, revised patient care protocols and standardized work. Advance care planning for all ICU patients and frequent review of advance care directives with ICU survivors would inform healthcare teams about appropriate attention to ICU survivors with PICS. ICU survivors with PICS or who have a high likelihood of having any of the sequelae related to PICS may benefit from a palliative medicine professional and/or a complex care case manager during their initial hospital stay prior to discharge to manage expectations for post-discharge care and to follow up with advance care planning documents. ICU survivors who return to the hospital for subsequent admissions should continue to be connected to palliative care providers and case managers to provide continuity of care and facilitate continued discussions surrounding overall goals of care for each hospital visit and changing contexts.

Implications for practice

In addition to a greater emphasis on advance care planning and greater focus on primary palliative care, critical care providers should emphasize delirium and PICS prevention bundles like the ABCDEF bundle (Marra et al., 2017). The prevention focus would include minimized sedation, frequent checks for signs of delirium, daily sedation interruptions, early mobility, and other interventions targeted at minimizing the impact of PICS on future ICU survivors. ICU follow-up care should be offered to any patient with an ICU stay involving prolonged sedation, mechanical ventilation, immobility, and/or delirium. Inclusion of ICU diaries may facilitate improvement in memory retention and filing in memory gaps resulting from sedation and delirious episodes (Jones et al., 2010). The initial follow-up visit should be based on the gaps in care described in several of the referent social media posts from ICU survivors and designed to address issues relevant to the individual ICU survivor in addition to current tools utilized to evaluate the participants’ functional status: (1). consultation with a palliative care provider to evaluate symptoms and advance care planning goals; (2) patient education about possible signs and expectations in the ‘new normal’; (3) cognitive psychological evaluation; (4) physical and occupational rehabilitation assessment; and, (5) other health professionals as necessary to include chaplains and other professionals to determine the need for assistance with related issues and future follow-up plans. These follow-up visits should also include further in-depth discussions of overall goals of care and advance directives as the context changes. Referral to ICU survivor support groups would also provide great benefit to patients receiving post-discharge follow-up care.

Implications for future research

PICS is a complicated and multifaceted syndrome with much of the research focused on individual issues within the overall disease umbrella. Our findings bring to light several areas for further investigation. First, more knowledge is needed about the levels of competency, communication skill, and professional development needs for medical care providers to strengthen the recognition and treatment of PICS.

Second, there is an opportunity for development of evaluative and predictive tools to aid in assessment of the at-risk patients for PICS. There are several measures focused on determining the quality of life for patients at various levels of care. However, these tools historically have poor sensitivities for differentiating between changes in quality of life related to PICS (Granja et al., 2002; Rosenthal et al., 2016). Inviting ICU survivors to help develop or augment preexisting quality of life tools would provide better measures to evaluate the impact of PICS. Accurate evaluation of the effect of PICS on quality of life would also facilitate the development and testing of education and aid bundles targeted to optimize ICU survivor rehabilitation and support through their primary caregivers and family members. These bundles could be introduced to the primary family caregiver and survivor prior to hospital discharge and emphasized at each follow-up visit.

Finally, larger scale research is needed to examine not only the thoughts and perspectives of patients or their surrogates who post their experiences on social media outlets, but to include of a wider array of diverse perspectives to receive input on patients' experiences. Face-to-face interviews would also facilitate a more in-depth examination of the survivor experience in the process of recovery from PICS. Funding opportunities are needed to carry out such research. Research is also needed to correlate experiences with actual post-discharge assessments and outcomes related to quality of life and the physical, psychological, spiritual, and emotional elements of well-being.

In conclusion, continual advancements in medicine and critical care are resulting in ever greater numbers of ICU survivors. With up to 10% of these survivors experiencing some level of PICS, it is imperative to facilitate the development and expansion of ICU follow-up services offered to this population (Davidson et al., 2013). The numbers will continue to grow as medical professionals are educated about the presenting signs and symptoms and as more patients require and are discharged from ICU care. Deep sedation and prolonged intubation are precursors to underscore the importance of improving awareness and knowledge, prevention, and management of PICS for all levels of healthcare providers. Providing a more patient-centric definition of PICS will facilitate meaningful treatment of this syndrome that affects a growing population of ICU survivors.

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Chapter 6. Discussion and Conclusion

Post-intensive care syndrome (PICS) can be a serious complication of a critical illness requiring prolonged treatment in an intensive care unit. While the treatments for individual symptoms and debilities related to PICS are well described, there are patients' perspectives of this syndrome that have not been fully investigated. The purpose of the dissertation research was to explore patients' lived experiences of ICU survival and to learn more about their process of recovery. Through this examination, the research sought to determine facilitators and barriers encountered during the process of recovery to improve patient follow up care and optimize overall ICU survivor rehabilitation. The knowledge gap review demonstrated a paucity of literature focused on patients' perspectives of PICS. Most research for PICS focuses on siloed symptoms dependent on the researcher's disease focus or organ specialty. This study attempted to elicit variations between the accepted medical description and the patient described experience with PICS. One manuscript (Chapter 3) resulted from the initial qualitative, grounded theory study utilizing ICU survivor social media posts. The third manuscript (Chapter 5) examined the conclusions from the initial study, and compared patient centric definition of PICS with the accepted medical definition of this syndrome to determine gaps in the current understanding of this syndrome.

Key Findings and Contributions

There are several key findings that result from exploring the research questions for the study. First, there remains an opportunity to further examine patient-derived issues that affect ICU survivor rehabilitation. Second, quality of life measures developed in collaboration with ICU survivors targeted at measuring variations in outcomes specific to this population after hospital discharge would provide more sensitive measures for further research. Third, there remains a general lack of awareness of PICS from patients, family members, and even primary care providers (PCPs).

Patient-Derived Assessment of Issues Affecting ICU Survivor Rehabilitation

The review of accepted evidence and knowledge gaps from the extant literature on ICU survivors with self-reported symptoms of PICS demonstrated a need for further research on patient-derived issues that affect the degree and quality of rehabilitation. Follow up clinics for ICU survivors are gradually becoming more common throughout the country. These follow up clinics vary widely in the therapy provided, quality of life (QOL) measures utilized, and duration of therapy provided for their patients. The most common intervention for PICS is implementation of a preventive bundle such as the ABCDE bundle (Balas et al., 2014; Barr et al., 2013). This bundle focuses on awakening, breathing, coordination, delirium, and early exercise. This bundle minimizes time on sedation, coordinates sedation wean with spontaneous breathing trials, utilizes optimization of sleep/wake cycles for delirium prevention, and encourages patients to start early mobility and physical therapy (Balas et al., 2014; Carrothers et al., 2013). While these bundles minimize the development of symptoms related to PICS, they do not address patients who are affected by PICS.

Collaboratively Developed Quality of Life Measures

Various specialty groups from several countries have developed quality of life (QOL) assessments commonly used in healthcare research including Health Related Quality of Life (HRQoL), Short Form (SF36), European Quality of Life (Euro-QoL), and Neurological Quality of Life (Neuro-QoL) assessments (Cella et al., 2012; Chrispin, Scotton, Rogers, Lloyd, & Ridley, 1997; Granja et al., 2002; Kerckhoffs et al., 2019). While these PROMs provide information on the quality of life of the individuals, they do not account for accommodation and patient tolerance of symptoms (Kerckhoffs et al., 2019). Similarly, the Hospital Anxiety and Depression Scale (HADS) is sensitive for situational anxiety and depression, but may not detect unrelated symptoms. The available assessment tools utilized in follow up clinics require greater sensitivity and specificity to detect changes to quality of life related to PICS. Standardization of QOL assessments and interventions would allow a better understanding of the overall benefit afforded to patients attending these clinics. One way to improve the utility of these assessment tools would be to include more patient-driven subjects in the assessment scores. A focused examination of the process of recovery for ICU survivors with PICS would facilitate the inclusion of more patient-driven measures in QOL assessments.

PICS Awareness and Quality of Life

Current measures for quality of life have difficulty detecting variation between ICU survivors and patients who did not require an ICU visit for similar primary diagnoses. Despite a lack of statistical significance in QOL indicators, many ICU patients note difficulty returning to previous social, familial, or professional roles after hospital discharge. These patients may be unable to return to their previous lives and roles for months to years after their inciting illness. Educational material provided to PCPs, patients, and family members would increase awareness and understanding of PICS. This could also improve follow up attendance for ICU survivors. However, these clinics unfortunately report approximately 50% attendance rates (Lasiter et al., 2016; Williams et al., 2008). Many PCPs, primary caregivers, and family members are unaware of PICS and how it affects ICU survivors. This is a challenge for healthcare workers during hospitalization and after discharge but also represents an opportunity for improvement from the providers standpoint. By providing better education about PICS and the recovery process, healthcare workers could assist patients and their family members in optimizing the process of recovery from PICS.

The primary study focused on expanding previous research for PICS and ICU survivor rehabilitation. This research provided a grounded theory explaining the process of recovery for ICU survivors with self-reported symptoms of PICS through the examination of 20 primary ICU survivor social media posts and a total of 325 subsequent response posts. The study provided a better understanding of the themes and experiences encountered through the process of recovery for ICU survivors with symptoms of PICS. It also emphasized facilitators and barriers encountered by patients during the recovery process. This allowed for a comparison between the patient-focused experience and the provider-driven definition of PICS. Finally, through examining variations in patient-focused experience and provider-driven definition of PICS, this study highlights opportunities to improve education of ICU survivors, patient family members, and involved healthcare workers; optimize patient follow up, and facilitate advance care planning for patients affected by symptoms of PICS.

Summary of results. The explanatory matrix (EM) developed through the initial study evolved from common themes and experiences encountered by ICU survivors with PICS during their recovery after hospital discharge. The matrix demonstrates areas to optimize ICU survivor recovery and minimize the long-term effects of PICS symptoms. The EM also provides insight into facilitators and barriers to recovery for ICU survivors. The central process of this study was *"The Journey to A New Normal"*.

The Journey to a New Normal. A new normal state is the plateau in recovery many ICU survivors reach that is the closest approximation to their previous functional state attainable due to new chronic health issues related to PICS. One of the most difficult aspects of their recovery is acceptance of their new limitations. This is consistent with previous research on ICU survivors' experiences after hospital discharge (Kang & Jeong, 2018). ICU survivors may struggle to with new physical, neurocognitive, or psychological limitations. Follow up clinics should focus on optimizing recovery as well as facilitating adaptation to new chronic health issues related to PICS. ICU after care groups should coordinate patient care with PCPs and ensure primary physicians receive education regarding PICS. Previous research demonstrated that ICU survivors utilize more healthcare resources than similar patients who never required ICU treatment for their health issues (Lone et al., 2016). The increased need for healthcare utilization may be related to a variety of issues not yet identified by current research. However, ICU survivors who develop disease mastery, engage their primary caregivers, and employ social support systems expressed a feeling of empowerment over their symptoms. Follow up clinics that encourage networking among ICU survivors and facilitate social support networks could aid in optimizing rehabilitation for their patients. Patients with active involvement in social support networks noted positive influences in physical, psychological, and neurocognitive recovery, similar to results from previous research (Tilburgs et al., 2015).

The cost of survival was another key concept for *"the journey to a new normal"* state for ICU survivors. Many patients experience a loss of independence and inability to return to previous familial, social, or professional roles due to new debilities related to PICS. The role of physical and occupational rehab in maximizing patient function and aiding in adaptation to new limitations is of great importance to the process of recovery. Psychiatrists and therapists may play a significant role in addition to PCPs and after care clinics to facilitate optimal recover for ICU survivors (Mehlhorn et al., 2014). Many ICU survivors suffer from delirium and delirious memories that make it difficult to separate nightmares from factual events that occurred during their hospital stay. These delirious memories and memory gaps may lead to depression, anxiety, and various other psychological issues and may benefit from psychiatric follow up. Several participants mentioned the benefit the experienced from ICU diaries of events that occurred during their hospital stay. This is consistent with previous research into the benefit of ICU diaries in providing closure for survivors with PICS (Jones et al., 2010; Mehlhorn et al., 2014; Ullman et al., 2015). Expanded utilization of ICU diaries could facilitate closure for an increased number of patients. Survivors attending follow up clinics should be given these diaries and be evaluated for signs and symptoms of persistent delirium, depression, anxiety, and other issues and referred to a psychiatrist as needed.

A more patient-centric definition of PICS. Symptoms and new health issues related to PICS are described in the literature (Colbenson et al., 2019; Davidson et al., 2013; Needham et al., 2012). Some ICU survivors suffer from decreased cognitive abilities and are unable to return to their previous professional, familial, or social roles after hospital discharge. The extant literature emphasizes this issue by indicating that up to 50% of ICU survivors are unable to return to work for 12 months after discharge, and around 20% are unable to return to work for up to five years after their initial ICU stay (Collie et al., 2019; Herridge et al., 2003; Hodgson et al., 2018). However, physical therapy, occupational therapy, and most follow up clinics only provide care for up to a year after the inciting illness. With many survivors suffering debilities beyond the 12-month recovery period, ICU follow up clinics should offer support for as long as necessary and focus on rehabilitation as well as reintegration and adaptation to new chronic limitations.

Neurocognitive changes may be some of the more significant and severe debilities related to a recent ICU stay. With up to 70% of ICU patients having experienced episodes of delirium during their hospital stay, many survivors are at risk of suffering decreased cognition, memory loss, and early onset dementia (van den Boogaard et al., 2012). However, recent literature regarding PICS seldom mentions that many ICU survivors experience such traumatic delirious episodes during their hospital stay that they develop or adjust advance directives to ensure they will never be admitted to an ICU again. This further emphasizes that the general public has a limited understanding of the consequences of an ICU stay and would benefit from PICS education at the outset of a hospital admission.

Physical function changes are another significant consequence of an ICU stay for many survivors. Available literature seldom addresses the more humanistic aspect f these changes. Many ICU survivors have serious issues related to their self-image that is significantly affected by the profound alterations to their physical function and appearance because of events they experienced during their hospital stay. They may return home having lost significant muscle mass, suffering from various surgical changes, and experience a prolonged recovery where they must rely heavily on others to perform even the most basic activities of daily living (ADLs). While some of these changes improve with time, other issues may be permanent and become part of the ICU survivors *'new normal'* state. This can lead to survivors questioning the value of their ICU admission if it saves their lives only to leave them a shadow of their former selves.

These issues are compounded in the current COVID-19 pandemic. With a higher number of ICU patients than any time during recent history, many of whom require prolonged mechanical ventilation and significant amounts of sedation during their hospital stay, the impact of PICS on this patient population may be even more significant. As a result of the prevalence of these patient stories in the news articles and media, ICU survivors who have experienced previous critical illnesses may note increased levels of anxiety and episodic flashbacks to their own hospital experiences. This increase in anxiety and frequency of flashbacks may result in many ICU survivors reevaluating their advance care plans and end-of-life goals. These patients will seek to address these concerns with whatever healthcare professional they most frequently interact with resulting in many PCPs and other providers having goals of care and palliative conversations.

The COVID-19 pandemic has also decreased the availability of access to follow up clinics for many patients. ICU survivors may also be reluctant to attend clinic visits because of their concerns of being exposed to the COVID-19 virus. Follow up clinic attendance, already limited by the nature of the ICU survivor population, now face further reduction in appointment attendance resulting in further difficulties in providing this population with much needed after care (Lasiter et al., 2016; Williams & Leslie, 2008).

Implications for practice and education

ICU stays and resulting PICS vary for each patient. At the time of ICU and hospital admission, providers should provide education focused on the patient's illness, ICU stay, PICS, and initiate discussions of advance directives. Hospital discharge provides an additional time to address education and further advance directive planning. Patients with prolonged ICU stays requiring mechanical ventilation, sedation, or prolonged immobility, should be referred to an ICU follow up clinic.

The current definition for PICS focuses on provider-driven descriptors assigned to patients based on various assessment tools including HADS, QoL assessments, 6-minute walk, and pulmonary function tests. These may not produce results that are meaningful to individual patients. There are many holistic factors that influence the degree of recovery and the *'journey to a new normal state'* for ICU survivors. In the first two decades of the 21st century, national healthcare has shifted focus to include more patient-centric approaches to managing medical issues (National Academy of Medicine [previously IOM], 2001; 2018). Adapting the definition of PICS to include more patient-driven descriptors of the associated issues would offer an augmented context to include in educational approaches taken by healthcare training programs. The expanded PICS definition could allow greater emphasis on communication with the patient about their goals of care and early recognition of comorbidities associated with PICS. .

A patient-driven definition of PICS would also facilitate policy change and improve development of national guidelines for best practices. This would allow for inclusion of PICS and related issues in medical diagnoses and coding practices for improved reimbursement of follow up and treatment plans. More standardized guidelines would also encourage providers across the country to adopt PICS prevention bundles like the ABCDEF bundle (Marra et al., 2017). This shift to a patient-focused definition of PICS would also emphasize the importance of primary palliative care discussions and advance care planning discussions. ICU follow up clinics would additionally benefit from these changes, gaining a standardized approach to after care, including early palliative care consultation, improved patient and family education, extensive cognitive psychological evaluations, and further physical and occupational rehabilitation involvement. The initial ICU follow up clinic visit would be the most important for care planning with subsequent visits determined by individual patient needs. In addition to evaluation indicated by each patient’s primary cause of ICU admission, the first visit may include: (1). consultation with a palliative care provider to evaluate symptoms and advance care planning goals; (2) patient education about possible signs and expectations in the ‘new normal’; (3) cognitive psychological evaluation; (4) physical and occupational rehabilitation assessment; and,

(5) other health professionals as necessary to include chaplains and other professionals to determine the need for assistance with related issues and future follow-up plans.

Implications for future research

There are several implications for future research which are summarized in four themes: (1). Best practices for introducing PICS farther upstream; (2.) Variation in patients' experiences of PICS and quality of life (i.e., COVID-19 vs. non-COVID-19 patients); (3.) Larger studies to obtain more information about the patient's lived experience (including patients who do not use social media); and, (4.) the relationships between principal ICU diagnosis, duration of stay, patient characteristics, provider characteristics, and small area variation in patient outcomes. Each of these implications are will be elucidated below.

Best practices. PICS has many interconnected symptoms that can affect ICU survivors sometimes for years after their inciting critical illness. During the inpatient ICU stay for all patients who could develop post-discharge symptoms related to PICS, research is needed to determine the best timing and method for introducing education about PICS, what to expect regarding symptom management and examples of feelings, fears, and issues they may encounter (based on what other ICU survivors have expressed), advance care planning, and goals of care conversations with the patient and their primary caregivers. Further research into patient-reported outcomes as methods to develop quality of life measures and improve QOL assessment sensitivity in the ICU survivor population, as well as standardization of QOL measures across research groups, would improve generalizability and comparability of future studies on PICS.

Variation in patient experience with quality of life. Historically, quality of life assessment tools are limited in determining quality limiting changes related to PICS (Granja et al., 2002; Rosenthal et al., 2016).Tailored assessment tools are needed to determine the severity and duration of PICS. Engaging ICU survivors in developing a quality of life assessment tool specifically focused on their feelings, fears, goals, and decision-making autonomy, is needed. Severe critical illnesses that require prolonged hospital stays, can result in changes to physical, functional, and cognitive abilities, and affect survivors' capability of fulfilling previous social, familial, and professional roles that defined their lives prior to their inciting illness. However, many patients go through a process of normalization and may not report significant health changes as affecting their quality of life (Kerckhoffs et al., 2019). Further research on patient-reported quality of life indicators affected by symptoms of PICS would improve sensitivity of quality of life assessment scales in this population.

Larger studies. Many PICS studies have very small patient populations. The ICU survivor population is difficult to engage in research studies. This patient population generally has poor follow up clinic attendance that increases difficulty with research engagement (Lasiter et al., 2016). However, population studies would increase the power and reliability of study results and improve the sensitivity of measures developed through these studies. Increased population size and improved patient follow up will allow for more extensive quantitative studies with this patient population.

Relationship between patient and provider variables on outcomes. Patient-reported outcomes measures (PROMs) are increasing in prevalence in recent research designs. However, these measures commonly used to determine quality of life and outcomes measures for ICU survivors are primarily provider-driven. By merging these provider-driven measures with PROMs, and standardizing which measures to use for the ICU survivor population, researchers could better measure effects of prevention and treatment measures targeted at improving recovery for patients with symptoms of PICS.

Conclusion

This dissertation adds to the evolving body of research surrounding PICS and ICU survivors. The study examined the first-person experience with recovery of ICU survivors with self-reported PICS. While the accepted definition of PICS is relevant to the physical, cognitive, and psychological issues experienced by many patients, it is important to consider the "lived experience" of intensive care patients to add to the definition of PICS described by Needham et al. (2012) and is accepted as the current practice. By examining ICU survivor social media posts, the study expanded on the previous understanding of PICS to offer a patient-focused description of the journey to recovery for ICU survivors with PICS. The results of this study offer practice and education opportunities to improve evidence-based practice guidelines and approaches to managing PICS and ICU survivor follow up care. The research also includes survivors' experiences to allow for expansion of the current definition of PICS to include more patient-centered descriptors of the experience. Future research on the association of PICS and all diagnoses and patient populations discharged from intensive care units will allow for a better understanding of optimal follow up and management of the syndrome as well as provide insight into successful prevention bundles and their impact on ICU survivors.

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